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**CARING FOR A RELATIVE
WITH DEMENTIA:
Anticipatory Grief and
Social Death
VOLUME ONE
(Of Two Volumes)**

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**Submitted for the degree of Ph.D.
University of Glasgow
Faculty of Medicine
March 1991**

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DECLARATION

I declare this thesis and the research upon which it is based to be my own work, and testify that it has not been accepted in any previous application for a degree, that all verbatim extracts have been distinguished by quotation marks, and that all sources of information have been specifically acknowledged.

Signed HELEN N. SWEETING

Date 15th March 1991

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SUMMARY

This exploratory study has as its background the effects of dementia, not only on the sufferers themselves, but also on those who love them. The end-result of dementia may be a sufferer who is completely unable to exist independently, unable to communicate meaningfully, or to recognise once familiar persons.

The first area of investigation was whether the reactions experienced by caregiving relatives constitute "Anticipatory Grief" in response to the "loss" of the person of the dementia sufferer. The study examined the nature of the emotional and behavioural reactions of caregiving relatives, the possibility that they may emerge in some sort of predictable stage-like sequence, and the ways in which different types of reaction may be associated with different characteristics of the carer, the sufferer, or their relationship. The second main area of interest in the study was the possibility that dementia sufferers may become "Socially Dead". That is, that they may in some senses be discounted as persons by their caregiving relatives. The study examined whether the relatives of dementia sufferers did perceive them in a way that could be described as "socially dead", and it investigated variables associated with the social death of dementia sufferers. The third main area within the study was to investigate the impact which carer "anticipatory grief" and sufferer "social death" might have on carer well-being and their preference for institutional care for the sufferer.

The study derived its data from semi-structured interviews with 100 relatives of patients with a

primary diagnosis of dementia. At the time of the interview, the dementia sufferer lived with the carer in 61 cases, in their own home in 16 cases, and in long-term institutional care in 23 cases. The interviews were based on a "Carers' Questionnaire" which had evolved via preliminary unstructured exploratory interviews with carers, followed by a pilot study employing an initial draft of the questionnaire.

The study demonstrated that caregiving relatives generally acknowledged dementia to be, an illness which would result in continued deterioration and death in the sufferer; that is, as a terminal illness, bringing both current and future losses.

The emotional and behavioural reactions which previous studies have labelled "anticipatory grief" were experienced - to varying degrees - by the caregiving relatives of dementia sufferers. While partly simply a response to the burdens of the caregiving situation, they could also be attributed in part as the response to the loss of the person of the dementia sufferer. The majority of carers believed they had experienced grief, and the underlying structure of their reactions was similar to that of conventional grief. The results of the study showed that taken as whole, there was considerable stability in the emotional and behavioural reactions of the caregiving relatives of dementia sufferers over time. Against this background, there was a sub-group of approximately one-third of the sample of carers whose shock, or disbelief, or hope was greater earlier on in the process of their relatives' dementia, and whose acceptance of the illness and the future had increased over time. There was, however, no evidence of a phasic emergence of a variety of discrete stages in the carers' reactions, nor of an end-point of

resolution or acceptance. The different components of the emotional and behavioural reactions of caregiving relatives were associated with different caregiver and sufferer characteristics. Initial shock was associated with learning the diagnosis and prognosis suddenly. Current carer shock, denial or hope were associated with sufferers who were younger, were spouses or siblings, and were demanding, with carers who were older, and with less time since onset of the dementia. Protest, questioning and guilt were more likely in younger carers, those who perceived dementia as a horrible/worst illness, and those reporting a poor relationship with the sufferer. Reactions of yearning or preoccupation were more likely in carers who perceived dementia as a horrible/worst illness, and who were not helped by a religious or other belief. Carer depression was associated with demanding sufferer behaviour, perceiving dementia as a horrible/worst illness, and reporting a poor relationship with the sufferer. Finally, carer acceptance was more likely when they perceived dementia as the consequence of aging or as just an illness, and when they had greater general knowledge regarding dementia.

While not labelling it as such, some carers did perceive their dementing relative in terms which could be regarded as "socially dead". Three factors comprised the underlying structure of social death. Factor One, "Anticipate Death", relating to thinking in a variety of ways about the sufferer's death, had occurred for between half and three-quarters of the sample. "Anticipate Death" was associated with variables suggesting that the dementia sufferer had lived too long, and that the carer was fed up (angry or depressed) with the situation. Factor Two, "Life Pointless", relating to elements of social death such

as believing that the sufferer's death would be a blessing, had occurred - to varying degrees - for at least half the sample. This was the only social death factor to be associated with a carer's belief that they had experienced grief. It was also related to a lack of carer hope or bargaining behaviours (perhaps representing the acceptance of the inevitability of the sufferer's decline), with increased sufferer dependency, with the carer's perception of dementia as a horrible/worst illness, and their reporting a poor relationship with the sufferer. Social Death Factor Three, "Sufferer Unaware", relating to sufferer lack of awareness of, and response to, their environment, was endorsed by the vast majority of the caregiver sample. It was associated with increased impairment in the sufferer (perhaps representing "loss of the person".)

Those carer emotional and behavioural reactions most clearly representing distress were associated with increased subjective burden. Belief that they had experienced grief was associated with a reduction in a carer's perceived coping ability. None of the social death factors was linked to carer subjective burden or coping. Finally, with regard to institutionalisation, there was no evidence that placement in long-term care triggered either the social death of dementia sufferers or anticipatory grief in their relatives. Among community carers, preference for institutional care was not directly related to any of the anticipatory grief reactions. It was, however, associated with social death factor "Life Pointless". This suggests that if a carer perceives the continuation of their dementing relative's life as meaningless, then the removal of the physical presence of the sufferer to institutional care may be more acceptable, or even welcomed.

PART ONE

INTRODUCTION

AND

LITERATURE REVIEW

CHAPTER ONE

PREAMBLE

"... I'm president of the Alzheimer's Disease Society, and when I talk to public meetings about it I talk about it as an uncollected corpse; there is this terrible thing which is walking around which the undertaker has cruelly forgotten to collect."

["Goodbye to All This", Jonathan Miller in conversation, Independent on Sunday Review, 15.4.90.]

How is dementia, or the diseases which cause it, generally perceived? The answer is conveyed in the following headlines: "Death of a Mind: A Study in Disintegration" [Anonymous, 1950]; "A Never-Ending Funeral: One Family's Struggle" [Glaze, 1982]; "Slow, Steady and Heartbreaking" [Wallis, 1983]; "Alzheimer's: Slow Death in Dickensian Squalor" [Forster, 1989]; "My Husband the Stranger" [Forsythe, 1990].

The dementias are thus perceived as relentless diseases with nightmare results not only for the sufferers but also for those who love them. While the progression is generally slow, sufferers who reach the stage of very severe dementia become completely unable to exist independently, needing others to do their feeding and watering, their bathing, toileting and mopping-up, even their moving. They are generally unable to communicate meaningfully or to recognise once familiar persons. Coupled with this picture are the statistics which testify to the rising numbers of dementia sufferers. The condition is generally described in "epidemic" proportions.

Media or non-academic attention is usually focussed on the end-results of dementia. Glaze [1982] describes her husband, once a loving, gentle man, as "no longer there", and herself as physically and emotionally exhausted: "We have already lost a loved one in this slow devastating process that diminishes one to a shell that simply breathes" [p.52]. "Pain and incapacity and disfigurement can be faced with fortitude, but the sight of a disease which seems to rot the self is hard to bear" [Anonymous, 1950, p.1014]. Wallis [1983] refers to the "haunting sense of loss" felt by family members, although the person is still with them in body. Forster [1989] speaks of her mother-in-law as having been dying for five years, the time since she was diagnosed as having Alzheimer's disease. This elderly patient lived in "the twilight world" of the National Health Service. On her ward were "six women sitting so still you might think they were corpses but, alas, they are not". They are "wrecks of human beings", often not recognising their relative: "someone there but not there". Forsythe's [1990] husband looked "like a living corpse". During the long car journey to a private nursing home she frequently checked to make sure he was still breathing. Turner [1979] reports staff in an old people's home as referring to a room full of people with severe dementia as "the babies' room", and walking through it as if it was empty of people.

What are the effects of this slow, "living death" on relatives? They may be burdened not only with the physical aspects of caring for the dementia sufferer, but also by the emotional effects of seeing the person they love becoming increasingly incapacitated. Family reactions to this loss have been described in terms of grief. Glaze [1982] says "I can tell you that it is

like a funeral that never ends". The relative of one dementia sufferer is quoted by Wallis [1983] as saying "It's not guilt I feel, it's heartbreak". One of the carers who appeared in the Channel 4 TV documentary programme "Thief in the Night" [March 1990] said "I try to put a smile on my face because I think people don't want to listen to you moan ... no-one sees me going to bed at night with my tears, I keep that to myself". Forsythe [1990] describes herself as using the time shortly before her husband's death (when she fed him, dressed him, or just sat holding his hand) in order to sort out her own confused feelings.

This is the area of the present study. It focuses on the emotional and behavioural reactions of the relatives of dementia sufferers in response to the actual or anticipated stage of a person who is "there but not there". The study investigates firstly whether the reactions experienced by caregiving relatives are those of grief in response to the "loss" of the person of the dementia sufferer. The study examines the nature of these reactions, the possibility that they emerge in some sort of predictable stage-like sequence, and the ways in which different types of reaction may be associated with different characteristics of the carer or the dementia sufferer. The second main concern of the present study is the possibility that dementia sufferers may become "socially dead"; that is, that they may in some senses be discounted as people by their caregiving relatives or by others. Variables associated with the social death of dementia sufferers are investigated. The final area of interest within the present study is the relationship which carer reactions and sufferer social death may have with carer well-being or burden and preference for institutional care.

The thesis is in three sections. The introductory first section consists of a review of the background literature and closes with a list of the aims of the study. The literature review is exceptionally long because it brings together diverse areas, only one of which, to the author's knowledge has hitherto been reviewed. The second section of the thesis describes the administration of a questionnaire to the relatives of dementia sufferers, and the analysis of the data which emerged. The final section is the longest, presenting and discussing the results of the study.

With regard to the introductory first part, the background literature review is divided into a number of different sections, each of which forms the basis for a separate chapter. These chapters cover the topics of "The Caregivers of Dementia Sufferers", "Grief", "Anticipatory Grief", "Social Death", and finally, "Social death of Dementia Sufferers and Anticipatory Grief in their Relatives". It may appear to the reader of this first part that there are certain topics which need not have been discussed. For example, why labour the questions of grief and anticipatory grief as stage-like processes? Why discuss whether religious beliefs or practices have a mitigating effect on grief? The reason should become clear with further reading: issues which may initially appear irrelevant are taken up and discussed again in later sections of the thesis.

CHAPTER TWO

DEMENTIA: SYNDROME, SUFFERERS AND CAREGIVERS

"The sixth age shifts
Into the lean and slipper'd pantaloon,
With spectacles on nose and pouch on side,
His youthful hose well sav'd a world too wide
For his shrunk shank; and his big manly voice,
Turning again towards childish treble, pipes
And whistles in his sound. Last scene of all,
That ends this strange eventful history,
Is second childishness, and mere oblivion,
Sans teeth, sans eyes, sans taste, sans everything."

[Shakespeare, "As You Like It", II.vii.]

I. INTRODUCTION

The subject of dementia has received increasing interest over the past 20 or so years, as evidenced by the amount of available literature on the topic, not only within the academic field, but also within the more popular media. Discussions or documentaries which touch on the issue, particularly with regard to the family caregivers of dementia sufferers are now not uncommon on the radio or television, and within the academic literature a recent article was entitled "Do we need another 'stress and caregiving' study?" [Zarit, 1989]. This growing interest reflects not only the increasing numbers of people with dementia (and by implication, also the increasing numbers of their family caregivers), but also an increasing awareness of the problems which these carers face, most pertinent in the current climate of community care.

This chapter will focus upon the effects of dementia on the caregiver ("the hidden patients" [Fengler and Goodrich, 1979]) rather than the sufferer. It is divided into several sections. First, an introduction to the syndrome of dementia, which describes its clinical features, its most common causes, its prevalence, and those factors which have been suggested might influence its onset. This is followed by a section which examines the characteristics of the caregivers of dementia sufferers. The third section examines the objective problems faced by these carers, after which studies of their subjective burden (well-being) are reviewed. The fifth section links these two areas together with a presentation of the way in which the various different objective problems are related to amount of carer subjective burden. Finally, the factors which have been suggested might contribute to a breakdown of community caregiving and the subsequent institutionalisation of the dementia sufferer are reviewed.

II. THE SYNDROME OF DEMENTIA

1. What is Dementia?

dementia - n. a state of serious emotional and mental deterioration, of organic or functional origin. (C19: from Latin: madness; see DEMENT)

[Collins English Dictionary, Hanks, Long and Urdang (Eds.), 1979]

"Dementia" is a word which the majority of the population would probably feel able to discuss - their definitions focussing around the notions of increasing forgetfulness, madness, becoming "senile" or

"wandered", and associated with old age. They would not be far from the truth, although "dementia" covers a wide range of disorders, has more wide-ranging effects, and affects a wider age range than is commonly assumed.

Gilleard [1984] describes the clinical manifestations of dementia under the following three headings:

COGNITIVE CHANGES:

The most obvious failure, and often the first to be noticed, is memory failure, particularly the loss of ability with recent information. This probably results from deficits in both the storage and retrieval of information. Jolley [1981] notes that (contrary to popular belief) recall from distant memory stores is also faulty. Numerous secondary problems arise from this increasing memory failure, including disorientation, forgetting what one is doing, lack of purpose or initiative, distractibility and repetitiveness. In addition, there is a reduction in more general intellectual performance, most particularly in those areas which require the development of new knowledge and problem solving strategies, as opposed to the application of existing knowledge and strategies. Some people with dementia also suffer from "focal" cognitive deficits, for example, problems in spatial and bodily orientation, or in expressive speech and writing.

EMOTIONAL CHANGES:

Gilleard notes that depression or anxiety is not uncommon, particularly early on in the process of dementia. Such disorders may be viewed as the emotional reaction to the recognition of forgetfulness and inability to perform everyday tasks as easily as previously. He also describes the "catastrophic

reaction" characterized by extreme anxiety and agitation which can occur in some people in the face of a failure of competence. Emotional lability is also seen quite frequently in people with dementia. The opposite side of the coin to all this is the apparent emotional indifference and apathy exhibited by some people with dementia; the "frontal lobe syndrome". Jolley [1981] writes of a persistence of the mood which has prevailed throughout life, but with less flexibility; for example, the timid become fearful, or the miserable crabby. This is often characterized by the, on the face of it, peculiar description of people with dementia as having become "more like themselves".

BEHAVIOURAL CHANGES:

This is the final group of changes mentioned by Gilleard. Obviously the cognitive and emotional deficits will have a number of behavioural results for the person with dementia, accounting for problems such as becoming lost in unfamiliar surroundings, burning the pots, flooding the bathroom, not bothering with the garden, and so on. However, there are several other behaviours which often cause considerable problems for persons with dementia and/or their carers, and whose development, as Gilleard points out, seems to bear no relationship to degree of dementia. These are wandering and restlessness, incontinence, and aggression and hostility. Levin, Sinclair and Gorbach [1984] also discuss this lack of association between the level of dementia in the sufferer and some of the behaviours which supporters find particularly difficult to cope with.

Dementia is a progressive illness. The initial presentation is usually one of forgetfulness with its associated problems but often also with preserved

social skills and ability to cope independently with daily life so long as there is no disruption to long-established routine. Gradually however, cognitive deficits and confusion become obvious to the observer - although the sufferer may experience a progressive lack of insight. This is despite clear disorientation, gaps in knowledge of past and present life experiences and inability to perform tasks such as dressing, cooking, or organised shopping trips with complete independence. Finally, impairment is such as to render independent existence impossible, with lack of awareness of surroundings and often also of previously familiar persons, inability to perform basic self care tasks, grossly impaired communication abilities and frequent personality changes.

Despite the unremitting decline which characterizes dementia, the term will not be found on death certificates. Robertson and Kennedy [1983] outline the usual fatal course, "as the patient becomes more helpless she is prey to infection, particularly bronchopneumonia, which is the commonest cause of death" [p.261].

2. Types of Dementia

So far, "dementia" has been described as though it is a single disease process. In fact, as is well known, this is not the case. "Dementia" is a general clinical syndrome resulting from a number of different causes. This can make for some confusion among the uninitiated as they read the literature, particularly as a result of the frequent interchange of the terms "Alzheimer's Disease" and "Senile Dementia", and "Dementia" and "Senile Dementia". A brief description of the most frequent causes of dementia will now be presented.

Alzheimer's Disease was first described in 1907 by the German physician who gave his name to the disorder. At autopsy of a woman who had died of dementia at an early age, he discovered the now characteristic pathological forms of brain atrophy associated with the disease; neurofibrillary tangles (spaghetti-like jumbles of abnormal protein fibres) and plaques (patches of degenerated nerve endings). [Butler and Emr, 1982]

Senile Dementia is defined by Gruenberg [1978] as "a particular clinical syndrome characterized by unremitting progressive deterioration of cognitive functioning and ability for self care not attributable to progressive brain disease other than senile brain disease" [p.437]. This gradual progressive loss of cognitive and personality function in elderly persons is a disorder which has been recognised for a very long time: "Literary descriptions of the decay of the mind in senility can be found from early times and certainly are clearly described in the works of Shakespeare and Swift" [Bergmann, 1969, p.727]. In fact, the myth that "senility" is the lot of all elderly people still prevails in some areas, particularly among the elderly themselves, who often expect to become forgetful with increasing age. The distinctive senile plaques and neurofibrillary tangles which have been described in Alzheimer's disease are also found in a large proportion of cases of senile dementia. This, as Gruenberg [1978] points out, has led to the following question: "Are Alzheimer's disease and senile dementia the same disorder but starting at different ages?" For this reason, senile dementia is often now termed "Senile Dementia of the Alzheimer's Type" [SDAT]. A further complicating factor is that the "pathological" histological changes of Alzheimer's/Senile Dementia are also found in the normal elderly brain, although as

Butler and Emr [1982] point out, research has demonstrated a much greater loss of large neurons in the cerebral cortex of SDAT sufferers than in the normal aged cortex.

Multi-Infarct Dementia (Arteriosclerotic Dementia) is the term used to describe dementia associated with arteriosclerosis of cerebral vessels and multiple (usually "mini") infarcts in a person who is usually also suffering from hypertension. Because of its different causation, multi-infarct dementia usually has a somewhat different clinical course to SDAT, being characterized by a stepwise deterioration of function and often also focal neurological signs, caused by the successive infarcts. "In this condition fair sized chunks of brain tissue may be killed off, leaving the rest of the otherwise normal brain to compensate as best it may" [Jolley, 1981, p.77].

These diseases are by far the most common causes of dementia. Katzman [1982] quotes the following figures to account for the production of dementia: Alzheimer (ie. Alzheimer's disease plus SDAT), 54%; multi-infarct dementia, 12%; Alzheimer plus multi-infarct, 12%. There are a wide variety of other, much rarer causes of dementia. These include other degenerative diseases of the brain such as Huntington's Chorea, Parkinson's Disease, and Pick's Disease; the results of alcoholism (Korsakoff's Psychosis); infections such as Creutzfeldt-Jakob Disease; and some potentially treatable disorders, for example, drug toxicity.

3. What is the Prevalence of Dementia?

Ineichen [1987] refers to the fact that despite the long standing acknowledgement of dementia as a disorder, there are still a number of problems which make it difficult to count the number of dementia sufferers. These can be detailed as follows.

(1) The fact that there is no universally agreed criterion for what constitutes a case (and as Pollit, O'Connor and Anderson [1989] point out, this will be particularly difficult at the beginnings of dementia, the "grey area" where normal and abnormal aging overlap).

(2) Since dementia is age-related any demographic changes will influence the measurement of prevalence.

(3) Studies of prevalence often have doubtful methodology, for example, measuring only those in receipt of those services, or employing an inadequate sample size.

(4) Since dementia may be influenced by sociocultural factors, any variation in these may influence the measurement of prevalence.

Following a review of numerous studies Ineichen suggests "a simple rule of thumb" for the prevalence of dementia, namely 1% of people aged 65-74 and 10% of those aged 75 or over. If we take the estimates of population change in Britain between 1961 and 2001 [O.P.C.S. 1983, cited by Gillear, 1984] it is possible to calculate figures for the prevalence of dementia in Britain, based on Ineichen's estimates. (See Figure 2.1, over page.)

It is this increase in the numbers of people suffering from dementia which has led a number of authors to describe the syndrome in epidemic terms, for example,

Table 2.1
Estimated Prevalence of Dementia in Britain 1961-2001

	Total number of people		Estimated number of people with dementia		Increase in number with dementia 1961 - 2001
	1961	2001	1961	2001	
Age (yrs) 65 - 74	4.0m	4.5m	40,000	45,000	5,000
Age (yrs) 75 +	2.1m	3.7m	210,000	370,000	160,000
TOTAL	6.1m	8.2m	250,000	415,000	165,000

"the rising tide" [Ineichen, 1987], and "The frightening statistics of psychogeriatric practice are well known" [Argyle, Jestice and Brook, 1985, p.355].

4. What Factors Might Influence the Onset of SDAT?

To answer this question would also allow us to decide which group(s) of people are at most risk. Unfortunately, in the case of SDAT, neither of these questions has an easy answer. In contrast, the association of multi-infarct dementia with hypertension means that some causal factors (for example, smoking) can be identified. The influence of the following factors on SDAT has been examined in reviews by Bergmann [1969], Gilhooly and Birren [1986] and Ineichen [1987].

AGE:

There is a well established, clear and positive relationship between both the prevalence and the incidence of dementia with age.

GENDER:

The evidence for one or other sex as having a greater risk for dementia is not clear cut. Although all

studies indicate greater overall numbers of female dementia sufferers, the consensus seems to be that this is entirely because women live longer than men on average, and so have more chance of succumbing to dementia.

SOCIOECONOMIC FACTORS:

The evidence is largely lacking, and is complicated by the fact that if psychological tests are used to assess dementia their results may be confounded by factors such as the amount of education, 'class, or race. Similarly, the fact that social isolation is associated with dementia does not allow us to implicate social isolation as a causal factor for the onset of dementia - the relationship may be in the reverse direction.

GENETIC FACTORS:

Early studies which found the morbidity risk for senile dementia to be greatly increased in the first degree relatives of persons with the disease have more recently been criticised with regard to methodology. Despite this, there are some suggestions for an increased risk in the relatives of persons with early onset (under 65 years) Alzheimer's disease.

PERSONALITY OR LIFE EVENT FACTORS:

Once again, this is an area for which evidence is lacking, since early studies which might have demonstrated a relationship between factors such as life crises, social isolation, or obsessional personality have been criticised on the basis that their data on such factors was gathered retrospectively. As such, they may have resulted from the recognised early stages of the dementia itself.

5. How Long do Dementia Patients Live?

All reviews note the rarity of studies which examine the survival times of individuals suffering from dementia [Gilleard, 1984; Gilhooly and Birren, 1986; Ineichen, 1987]. In addition, there are problems with dating the start of dementia because its onset is generally so insidious, and so may not be recognized initially by those close to the patient.

There is evidence that people with dementia live longer now than they would have done in the past. For example, Gruenberg [1978] refers to data collected between 1947 and 1967 in the Lundby population in southern Sweden. This shows that whereas until about 1949 episodes of senile dementia lasted less than three years on average, episodes beginning after that date had a much longer duration, and indeed, some of the cases present in 1957 were still alive 10 years later. He attributes this extension to life to the reduction in fatal infections, particularly pneumonia, in this group.

Despite this, the majority of studies and reviews note an association between dementia and premature death. It would thus be correct to regard dementia as a "terminal illness". For example, Bergmann [1969] cites a study by Kay [1962] which demonstrated significant reductions in survival time for people with dementia as compared with the mean expectation of life among the general population. Jolley describes one of the features of dementia as "progressive deterioration to early death" [1981, p.75]. He notes that this has been demonstrated in both hospital patients and community studies. Robertson and Kennedy [1983] speak of the relentless decline of dementia towards helplessness and death, most commonly due to infection, particularly pneumonia.

There is evidence that in comparison with mean life expectancy, later-onset dementia is associated with a lower mortality rate. "In other words, excess mortality associated with dementia decreases with age" [Gilhooly and Birren, 1986, p.4]. Ineichen [1987] indicates a number of studies which demonstrate that although increased mortality is associated with early onset of dementia, this is not the case for onset over 80 years of age.

Gilleard [1984] also notes that enhanced mortality, relative to expected survival, decreases with increasing age of onset of the dementia. He follows this with data which suggests that once an elderly person develops dementia, his or her relatives have on average about 6 or 8 years of coping with ever-increasing problems, and that "such extended caregiving may involve a gradually increasing burden for family members that may extend beyond their limits to maintain care over such a prolonged period" [p.44]. It is these family caregivers who form the focus of the next section of this chapter.

III. WHO CARES FOR THE DEMENTIA SUFFERERS?

Possibly the recent media interest in what is generally portrayed as the plight of dementia sufferers and their family supporters is going some way to dispel any public myth of family neglect of elders. Professionals have been aware of the evidence which dispels the myth of family neglect for many years. Over 20 years ago, Grad and Sainsbury [1968] described the "currently favoured practice of community care". In the U.K. in 1970 the estimated number of people with dementia living in the community far exceeded the total number

of elderly in institutional care, not all of whom would have had dementia [Bergmann, Foster, and Justice et. al, 1978]. Gilleard [1984] cites Kay and Bergmann [1980] as suggesting that between one fifth and one quarter of the moderately and severely demented are living in institutional care in the U.K.

What, then of all the people with mild cases of dementia, and the remaining 75-80% of moderately and severely demented in the U.K.?

Bergmann, Foster and Justice et. al. [1978] found that from a sample of 83 consecutive patients with organic mental disorder studied on their first admission to a psychiatric day hospital assessment unit, 34% were living alone (which does not necessarily mean they were without some degree of family support), 23% with their spouse, 29% with relatives, and 14% in residential care. Eliminating those who came from residential care this gives statistics from the community sample of 39% living alone, 27% with their spouse, and 34% with relatives. Unfortunately this may well not represent the distribution of people with dementia in the community, since day hospital referral may be prompted by factors such as living alone which would then be over-represented in the sample - and in fact the conclusion of this study was that family support was the most important factor in maintaining a dementia sufferer outwith an institution. In their study of the supporters of confused elderly persons at home, Levin, Sinclair and Gorbach [1984] found 41% of these supporters were spouses and 44% were children, and in the majority of cases where sufferer and supporter lived together, this relationship was extremely long-standing.

Thus we have the situation where the bulk of care given to people with dementia is provided by the "informal" support system of family and friends as opposed to the "formal" institutions of hospital, local authority, private and voluntary long-term, respite and day care. Cicerelli [1986] presents a series of arguments which favour this situation. Firstly, the influence which cultural tradition exerts on the family to provide the care-giving function for its members. Secondly, the strong motivating factor provided by affection and bonds of attachment within the family. Thirdly, the family may be the only practical alternative if formal services are unavailable or prohibitively expensive. Fourthly, certainly until the very late stages of dementia the family can probably provide the highest quality of care. Finally, as a result, families do tend to assume the care-giving role fairly readily. Jolley [1981] adds another feature which favours family caregiving, particularly for spouses, namely that the slow progression of dementia allows the spouse to gradually accommodate to the escalating demands of the sufferer. Whittick [1987] also adds the suspicion and distaste with which the alternative of institutionalisation is viewed by family caregivers, and in addition the sense of duty or reciprocity felt by many carers - in other words, that they married "for better or for worse", or that the sufferer cared for them at some point in the past thus it is only fair that they now care for the sufferer. This traditional acceptance of the care-giving role continues despite recent changes in family characteristics (for example, increased geographic mobility, smaller family size, fewer unmarried children, and increased participation of women in the work force) which might be assumed to make taking on such a role more difficult [Archbold, 1981].

Scott, Roberto and Hutton [1986] have stated that for every one person who suffers from Alzheimer's disease there are many other persons in the individual's social network who are affected. However, their own study of 23 primary caregivers of Alzheimer patients demonstrated that the major tasks of caregiving were the primary caregiver's responsibility, while the rest of the family gave very little support, either financial or physical. In line with this, the majority of writers agree that there is usually only one person who assumes the real burden of care. For example, in a discussion of child carers: "There is consensus in the literature that one member usually assumes the role of primary caregiver and provides the bulk of help given to the parent" [Brody, Hoffman, and Kleban et. al., 1989, p.530]. Jones and Arie [1982] also describe the common phenomenon of one or two family members providing the care while other relatives stand on the sidelines and make criticisms of the care being provided.

Archbold [1981], Cohen [1983], and Whittick [1987] point out that as with any group of carers, by far the majority of the informal caregivers of dementia sufferers are women. Whittick suggests a number of reasons why this might be the case. First, the belief that women adopt the caring role more naturally and traditionally are the "homemakers". Second, the possibility that women feel stronger kinship ties and are emotionally closer to their relatives. Third, on a practical level, there is usually less financial loss if it is the female member of a couple who gives up her job in order to care for a relative. Tobin and Kulys [1981] paint the usual caregiving scenario: "The spouse, particularly the wife because women outlive men, is the primary caregiver to the impaired.

Daughters are expected to assume responsibility for mothers, but elderly women are the caregivers for ailing husbands" [p.146]. An additional finding of relevance here is that elderly females may look after their dementing husbands for longer than men look after their dementing wives [Bergmann, Foster, and Justice et. al., 1978].

Several writers also point out another feature of the family caregivers of dementia sufferers, namely their age. Since dementia is primarily a disease of the "old-old", any spouse caregiver is also likely to be "old-old", and a great many child caregivers are "young-old". Levin, Sinclair and Gorbach [1984] found the average age of supporters to the confused elderly at home (ie. spouses and children taken together) as 61 years. Cohen [1983] points out that as a result even the "young-old" child supporters are likely to be coping with their own aging process, including the possibility of deteriorating physical health, loss of financial resources and changing roles.

IV. OBJECTIVE BURDEN - PROBLEMS FACED BY THE FAMILY CAREGIVERS OF DEMENTIA SUFFERERS

Two aspects to the burden which may fall on the family carers of dementia sufferers can be distinguished. These are the "objective" burden and the "subjective" burden. The former refers to those factors which would be apparent to an observer, such as the behavioural changes of the dementia sufferer, changes in the caregiver's daily routine, health, or status, or financial loss. The latter is the extent to which the relatives feel they carry a burden; that is, their emotional reactions [Fadden, Bebbington and Kuipers,

1987; Morris, Morris and Britton, 1988a]. This section will examine those factors which might constitute a caregiver's objective burden. These include the behaviour of the dementia sufferer, changes in caregiver role or lifestyle, caregiver financial and physical health burdens. The following two sections will discuss their subjective burden, together with those factors which have been found to influence the degree of subjective burden.

1. Behaviour of the Dementia Sufferer

The most obvious problem faced by family caregivers is that of the behavioural changes or disturbances of the sufferer. A number of studies have examined these behaviours and these will now be reviewed. It should be noted that at this stage the focus is simply on the presence of certain behaviours and not on which of these behaviours might be particularly stressful for caregivers. That is an area which will be examined later.

Machin [1980] interviewed 47 supporters of dependant elderly people who had been admitted for holiday relief. She used the Shortened Stockton Geriatric Rating Scale to assess the elderly person's dependency level and behavioural characteristics. Her sample was not limited exclusively to the families of dementia sufferers. The commonest problems were the inability to leave home unaided, inability to walk, and inability to dress. Bizarre or difficult behaviours (for example, hoarding meaningless items) were not common.

In order to determine the impact of dementia on the family, Rabins, Mace and Lucas [1982] interviewed the primary caregivers of 55 patients suffering from

(irreversible) dementia. Their results demonstrated both the large number of problems which families can face in relation to the patient's behaviour and mood (22 different main problems were identified) and the differences between individual patients and families (3 families denied having any problems). Over 50% of families reported the occurrence of the following problems (in descending order of frequency): memory disturbance, catastrophic reactions, demanding/critical behaviour, night waking, hiding things, communication difficulties, suspiciousness, making accusations, requiring assistance at mealtimes, daytime wandering, and requiring assistance with bathing. The authors go on to discuss the limitations to this study, which they believe might have led to an over-reporting of problems in their group of caregivers. Firstly, the interviewed families were already seeking medical help and thus might have been experiencing more problems than those who do not seek help. Secondly, their use of a standardized structured interview may have elicited more complaints than would have resulted spontaneously.

Gilleard [1984] reports on the development of a 34-item Problem Checklist which would allow the supporters of the elderly mentally infirm to indicate both the frequency of occurrence of a deficit or disturbing behaviour and also its perceived severity. This system was devised because it had become apparent that many supporters distinguished between noticing their dependant's disabilities and reporting them as problems. Over a series of studies of the occurrence of "problem" behaviours the following were consistently endorsed by over 50% of supporters (in descending order of frequency): sits around doing nothing, unable to occupy self doing useful things, forgets things that have happened, not safe outside alone, unsteady on

feet, unable to read newspapers and magazines, disrupts personal/social life, unable to hold a sensible conversation, unable to take part in family conversation, unable to follow TV or radio, unable to dress without help, demands attention, no interest in news of friends or family, unable to wash without help, always asking questions, careless about own appearance, temper outbursts, cannot be left alone for even one hour, falling, no concern for personal hygiene, unable to manage stairs, unable to walk outside the house, and wanders about the house at night: Gilleard also discusses the use of a checklist to report disabilities rather than relying on spontaneous suggestions from supporters. Checklists will result in the production of a more lengthy problem list because unless a supporter regards a particular behaviour or disability as an actual problem they are unlikely to report it spontaneously. Thus problem checklists are more likely to result in the objective recording of disabilities whereas spontaneous suggestions will result in a subjective report.

Argyle, Jestice and Brook [1985] studied the main supporters of 62 patients who had been admitted to a psychogeriatric ward because their relatives could no longer cope at home. They were given a structured interview covering problems in three areas: the patient's behaviour or limitations; the relative's own problems; the relative's social problems associated with the patient's care. They found a high number of problems were reported, with the patient's behavioural problems most prominent. The commonest problems tended to be of the "simple nursing" type, for example, requiring help with dressing or washing.

In the most recent study available, O'Connor, Pollitt, and Roth et. al. [1989] present the problems reported by relatives in a community study of dementia in Cambridge. They used Gilleard's [1984] Problem Checklist and grouped the items into three categories, namely, physical dependency, disturbed behaviour and forgetfulness-inertia. They found that for moderately and severely demented people physical dependency and forgetfulness-inertia problems occurred relatively commonly, while disturbed behaviours (apart from demanding attention, temper outbursts and disruption of supporters' lives) were relatively infrequent. Mildly demented elderly people exhibited relatively few problem behaviours in comparison, and were broadly similar to a control group of cognitively intact elderly people.

2. Changes in Caregiver Role or Lifestyle

As Zarit [1982] points out, a dementing illness causes a gradual shift in tasks from the patient to the caregiver. We can assume that the result of this will also be a gradual change in that caregiver's role and life-style. Cicerelli [1986] refers to the fact that this will be more difficult the greater the degree of role change involved; for example, as a spouse takes over unfamiliar gender-specific roles or an adult child takes over former parent roles.

In their study of the impact of dementia on the family, Rabins, Mace and Lucas [1982] found that 29% of primary caregivers cited "difficulty assuming new roles and responsibilities" as a problem. O'Connor, Pollitt and Roth et. al. [1989] felt both that women carers in their study took on the role of "nurse" earlier than husbands and that they were expected to do so by their

husbands. However, husband carers, who were more likely to be taking on novel tasks around the home and revolving around the physical care of their dementing wives, seemed to enjoy their work and took pride in their new accomplishments. In contrast, wives tended to view caring for their husbands as "an unremitting trial" [p.15]. Boutselis [1983] cites a study by Johnson [1983] as finding that in general, children are more negatively affected by the experience of caregiving, with the implication that this results from the different expectations and norms for children versus spouses.

Having the responsibility for a person with moderate or severe dementia can be incredibly time consuming. Gilhooly [1990] describes most caregiving tasks as involving "surveillance". Gilleard [1984] presents the results of those "Edinburgh" research studies which have employed the Problem Checklist with informal caregivers looking after dementia patients. The item "Cannot be left alone for even one hour" came "nearest to being universally described as a problem by supporters" [p.71]. Problem items which presented the greatest difficulties to supporters were the need for constant supervision, proneness to falls, incontinence, night time wandering, and the inability of the dementia sufferers to occupy themselves.

Such problems will most certainly disrupt the previous routine or life-style of a caregiver, and the following studies give some indication of the extent to which this is the case. Grad and Sainsbury [1968] examined the effects of a large number of mentally ill patients (not limited to dementia sufferers) on their families by sampling the families of approximately one in three of all the patients referred to the Chichester and

Salisbury (UK) psychiatric services during the year 1960-61. They found that one third of families suffered a restriction in social and leisure activities, and 29% had their domestic routine upset. Domestic upset (for example, difficulty in getting away on holiday, change in social life, or upset to household routine) was, not unexpectedly, found by Greene, Smith, and Gardiner et.al. [1982] to be associated with poor physical self maintenance of the dementia patient. Rabins, Mace and Lucas [1982] found family conflict to be a problem for 56% of the caregivers they interviewed; and the loss of friends and hobbies - no time for themselves, to be a problem for 55%. In their study of the problems faced by the supporters of psychogeriatric patients, Argyle, Jestice and Brook [1985], found several social problems to be associated with patient care. The most frequent was decreased social life, reported by 74% of relatives. The authors describe the high tolerance of such personal and social problems which they attribute to resignation to a life of self-sacrifice in these caregivers.

O'Connor, Pollitt and Roth et. al. [1989] found that children living with a demented parent were under greater strain than spouses and non-resident children. They suggest the possibility that this is because of the multitude of problems arising not just from their dementing parent, but also their own families. Cicerelli [1986] describes the strain which can result between the caregiver and other family members, either because of the time and energy which a caregiver has to invest in someone with dementia, or because of family conflicts about how care should be provided.

In her study of the supporters of dependent elderly people at home, Machin [1980] comments that some

supporters had found the first few months of caring most difficult. This may be related to a gradual getting used to their new role and lifestyle as caregivers with time. This point is taken up by Gilhooly [1984] who suggests that her result of a positive association between both the morale and mental health of the supporters of a dementing relative in the community and the duration of care-giving could be attributed to an improvement in caregiver wellbeing with an increasing time in which to learn to cope and adjust. Her alternative suggestion is that it is only those who have high morale and good mental health who "survive" as carers for a long time.

3. Financial Burdens in the Supporters of Dementia Sufferers

Whittick [1987] lists some of the additional expenditures which may be required in order to care for a disabled person: fuel, transport, bedding, incontinence equipment, laundry, house alterations, etc. The financial burden will be increased if the carer has to give up or reduce paid employment in order to look after a relative.

In their study Grad and Sainsbury [1968] found a reduction of income by at least 10% in a quarter of families caring for a person with mental illness in the community, while there was a reduction by at least 50% from normal income in 10% of families. In contrast to this, only 6% of the relatives of patients being admitted to a psychogeriatric ward reported a financial burden in the study by Argyle, Jestice and Brook [1985]. This may reflect a difference between actual loss of income and the reporting of a financial burden. Another possibility is that there has been an

increase in the amount of financial assistance (attendance allowance and invalid care allowance) available to carers over the 20 years between these two studies. However, Gilhooly [1990] comments that the carers of dementia sufferers whom she interviewed described the amount of financial assistance they received as being too small to make a real difference in terms of day-to-day activities.

The way in which the financial resources of the family may determine the fashion in which that family gives care is discussed by Cicerelli [1986]. Families with less money are more likely to look after the dementia sufferer at home with very little formal support, whereas those with more money will buy in care-givers and companions in order to maintain the dementing person. This difference may be more prevalent in the U.S. where there is less state support to carers. However, the distinction is also noted by Archbold [1981] in her discussion of the impact of parent caring on women. She identifies two caregiving roles: the "care-provider", who performs the services needed by the parent herself, and the "care-manager", who organises the provision of these services by others. Archbold found socio-economic status to be the major factor influencing a woman's choice of caregiving modality, with care-managers coming from a higher socio-economic background than care-providers.

4. Physical Health Burdens in the Supporters of Dementia Sufferers

As noted previously, the majority of family caregivers to people with dementia are themselves either "young-old" or "old-old". It has also been noted that many of the tasks of caring are such as to require an increased

level of daily physical exertion, with extra lifting and carrying, bathing and dressing, toileting and changing, cooking and feeding. Thus, it might be expected that family carers of dementia sufferers would report a deterioration of physical health as a result of their care-giving role.

Sixty-four percent of the supporters of dependent elderly persons interviewed by Machin [1980] felt that their physical health had suffered to some extent through caring. Levin, Sinclair and Gorbach [1984] found that only one third of their sample of supporters of confused elderly persons rated their health as having been good over the year before they were interviewed, and about half had activity-limiting disabilities themselves. Of the 62 supporters of patients admitted to a psychogeriatric ward who were interviewed by Argyle, Jestice and Brook [1985], 16% reported arthritis, 15% shortness of breath, and 13% other illness. Whittick [1985] reports one of the "Edinburgh" studies (129 supporters of first time admissions to a psychogeriatric day hospital) as finding that 65% of subjects felt their own health to have been seriously affected by having to care for an elderly mentally infirm person.

George and Gwyther [1986] criticise previous studies of caregiver well-being and burden because of their use of instruments designed specifically to measure caregiver burden. As such, they cannot be administered to comparison groups of non-caregivers. They therefore assessed caregiver physical health via doctors' visits over the past 6 months and self rated health (poor, fair, or excellent). Their results gave no evidence of increased use of medical services, or poorer ratings of physical health by the caregivers of dementia sufferers

when compared with random community samples: "In terms of physical health, the caregivers appear similar to other populations" [p.256].

Following this lead, Pruchno and Potashnik [1989] assessed the physical health of those caring for a spouse with Alzheimer's disease or a related disorder by using measures which could be compared with the general population means. They found that in comparison with the general population, caregivers, regardless of age and gender, spent less time sick in bed, reported fewer visits to the doctor, and spent fewer days in hospital if they were admitted. Despite this, caregivers also rated their own health as "excellent" less frequently, and reported higher rates of diabetes, arthritis, ulcers, and anaemia than the general population. The authors explain this apparent discrepancy between the actual health and the caregivers' use of health services by attributing it to their inability to allocate time to their own health needs.

It thus appears that caregivers are correct when they estimate their physical health to have deteriorated as a result of caring for a person with dementia, since the results hold when they are compared with the general population. However, the situation of caring means that they are unable to do anything much about it.

V. SUBJECTIVE BURDEN - THE WELL-BEING OF FAMILY CAREGIVERS OF DEMENTIA SUFFERERS

As noted at the start of the previous section, "subjective burden" refers to the emotional reactions

of the caregiver. Thus it includes measures of perceived strain, reduced morale, anxiety and depression. As Morris, Morris and Britton [1988a] observe, there are far fewer studies which simply measure the subjective burden than there are those which attempt to relate subjective burden to other aspects of the caregiving situation. This section limits itself to a review of the former studies.

A problem arises with the use of "strain scales" (for example, Machin, 1980; Gilleard, 1984) to measure subjective burden. This is because these scales include items which are actually measuring objective burden (for example, "Has your household routine been upset in caring for the elderly relative?" "Do the problems of caring prevent you from getting away on holiday?" [Gilleard, 1984, p.123]) as well as items which measure subjective burden (for example, "Do you get depressed about the situation?"). This means that they are really composite measures of both objective and subjective burden: "The presumed stressor and its outcomes become intertwined such that one cannot independently relate caregiving to its impact" [George and Gwyther, 1986, p.254]. This section therefore limits itself to those studies which employ instruments designed specifically to assess well-being or mental health and which have been sufficiently tested to have population norms. This has a double advantage. Firstly, it eliminates any confounding of subjective burden measures by the addition of objective burden items. Secondly, it also answers George and Gwyther's [1986] criticism of the use of specially designed instruments which make comparisons between the care-givers and the general population impossible (also noted in previous section).

1. Studies of the Subjective Burden of Caregivers Which Employ the GHQ

The General Health Questionnaire (GHQ) of Goldberg [1978] has been the most popular assessment instrument of subjective burden in the caregivers of dementia sufferers in Britain. This is a self-administered screening test aimed at detecting psychiatric disorders among respondents in community settings. It focuses on changes in normal function rather than on lifelong traits by asking respondents how they have felt over the past few weeks, for example "Have you recently been feeling run down and out of sorts?". The instrument has been well validated and permits direct comparisons between levels of distress in the supporters versus the community at large. There are several versions, named according to the number of questions which they contain (for example, the GHQ-60 has 60 items). Responses to each item are (usually) scored either 0 or 1. The GHQ scales each have a threshold score for "caseness". Persons scoring above this count as "cases" in that they can be said to be suffering from a degree of clinical disturbance.

The "Edinburgh" studies conducted by Gilleard and his colleagues have used the GHQ-30 to measure the level of emotional distress in supporters of elderly mentally infirm people. Gilleard, Belford and Gilleard et. al. [1984] report the results of 3 separate studies which employed the GHQ-30 with the supporters of the elderly mentally infirm. The first study was of 53 supporters with a dependant attending a day hospital in Edinburgh. The second study was of the supporters of a series of 129 consecutive referrals to psychogeriatric day hospital care in the Lothian region. The third study was of 45 supporters of a person with dementia who had

either attended a psychogeriatric day hospital for 3 months or was on the waiting list. The proportions of supporters found to exceed Goldberg's threshold score for caseness were 62% in the first study, 73.5% in the second study, and 57% in the third study (this difference between studies did not reach statistical significance). In the third study the authors validated this high degree of caseness among supporters by the use of a clinical interview. They write "It would seem reasonable to conclude that there will be no gross over-classification of psychiatric disturbance through using the GHQ in this population .." [p.174]. They compare this with estimated GHQ prevalence rates of between 16% and 23% in other community samples. Turning from prevalence of "caseness" to the average GHQ-30 score of supporters of people with dementia, Gilleard [1984], in a prospective study, quotes scores of 10.3 for supporters who were still looking after the dementia sufferer 6 months later and 13.6 for supporters of a dementia sufferer who was receiving long term institutional care 6 months later. (The "caseness" cut-off of the GHQ-30 is a score of 4/5.)

Toner [1987] reports very similar results to those of Gilleard: a mean GHQ-28 (cut-off threshold also 4/5) score of 10.7 for a group of 18 relatives looking after a dementia sufferer at home.

Whittick [1988] compared the GHQ-30 scores of 37 daughters caring for a dementing parent, 63 mothers caring for a mentally handicapped child, and 45 mothers caring for a mentally handicapped adult. Her results are again very similar: the mean GHQ-30 score for daughters with a dementing parent was 10.4. Whittick also found that this group of carers had a

significantly higher mean GHQ score than either of her groups of mothers.

Eagles, Beattie and Blackwood et. al. [1987] included the GHQ-60 (cut-off 11/12) among several measures of mental health in their community study of 274 elderly married couples (ie. 548 subjects) only 31 of whom (7%) were categorised as "demented" by their score on the Mental Status Questionnaire (MSQ). In addition to the GHQ they assessed mental health via the Leeds General Depression Scale and the Leeds General Anxiety Scale. The prevalence of caseness as assessed by the GHQ-60 was 9.7% in the spouses of demented subjects, as compared to 8.5% in the spouses of non-demented subjects. Similarly, the authors found no significant differences in degree of caseness for the spouses of demented versus non-demented subjects for either of the Leeds scales. In fact the only positive relationship between cognitive impairment in one partner and psychological distress in the other was a very small one between degree of wives' impairment (as measured on the MSQ) and husbands' depression (Leeds Depression Scale). The authors comment on this finding - described as "surprising" both in view of common sense as well as the findings of other studies in the same area. They suggest six possible reasons for why it may have occurred. Firstly, the subjects of previous studies were the relatives of elderly patients who had been referred to the psychiatric services, whereas this was a community survey. Secondly, their use of the MSQ to classify the demented group might have resulted in the inclusion of people with such a mild degree of dementia that they would not be expected to cause psychological distress in their relatives. Thirdly, the MSQ only measures cognitive decline and not difficult-to-cope-with behaviours. Fourthly, and as a result of the

similarity of these results to those of Gilhooly [1984, see the following page in this review] who studied family carers in the same geographical area (Aberdeen, Scotland), there is the possibility that there is something unusual about this locality (the authors note low geographical mobility, high community cohesiveness and high standards of primary medical care). Fifthly, the GHQ and Leeds scales may not be suitable instruments with which to screen for psychiatric morbidity in an elderly population. Finally, in contrast with other studies of carer well-being or burden, which usually have a varied subject sample in terms of caregiver age and relationship with the dementia sufferer, their subjects were all elderly spouses.

A similar result has recently been reported by O'Connor, Pollitt and Roth et. al. [1989] who compared the GHQ-28 scores of the family supporters of non-institutionalised demented elderly people with those caring for cognitively intact elderly people, a proportion of whom were frail and physically disabled. They divided their demented population into "mild", "moderate" and "severe" groups on the basis of Mini-Mental State and CAMDEX (Cambridge Mental Disorders of the Elderly Examination) results. The mean GHQ-28 score for the supporters of cognitively intact elderly people was 2.4, of mildly demented subjects was 3.2, of moderately demented subjects was 3.4, and of severely demented subjects was 2.6. The difference in GHQ-28 scores for the supporters of cognitively intact versus demented elderly people was not significant.

2. Studies of the Subjective Burden of Caregivers Which Do Not Employ the GHQ

In her study of the impact of care-giving on caregivers Gilhooly [1984] used two measures of supporters' psychological well-being. Morale was examined via the Kutner Morale Scale, and mental health via the OARS Multidimensional Functional Assessment Questionnaire's "Mental Health" scale. She found that morale in her sample of 37 supporters of people with senile dementia living in the community was fairly low. However, their mental health scores indicated either "good mental health" or only "mildly mentally impaired". There was no evidence of severe psychiatric symptoms or intellectual impairment in this group of supporters. Gilhooly suggests the possibility that it is only those supporters who are able to cope with caring for a dementing relative who "survive"; for the rest the demented person will be institutionalised. Thus this fairly good mental health may reflect the "survival effect".

George and Gwyther [1986] used four measures to assess the mental health of 510 family caregivers of a memory-impaired adult: firstly, a checklist of symptoms (The Short Psychiatric Evaluation Schedule); secondly, a measure of affect (The Affect Balance Scale - ABS); thirdly, a single item measure of life satisfaction; and finally, psychotropic drug use over the past 6 months. Comparison normative data collected via random community samples was available for all these measures. George and Gwyther's results "exhibit large discrepancies between the caregiver and comparison samples" in terms of mental health [p.256]. Caregivers reported almost 3 times as many stress symptoms as the comparison sample, considerably lower levels of affect

balance and life satisfaction, and higher psychotropic drug use.

Two measures of subjective burden in 20 spouse caregivers of dementia sufferers were employed by Morris, Morris and Britton [1988b]. They were a single item 7-point strain scale (I feel no strain - I feel severe strain because of the way my partner is nowadays), and the Beck Depression Inventory (BDI). Only the BDI had been validated on an elderly population. Although only three subjects (ie. 15%) scored above 14 - the cut-off point for clinical depression, the mean BDI score in these subjects was 7.5, which is higher than normal in the elderly.

Pruchno and Potashnik [1989] have also assessed the mental health of persons caring for a spouse with Alzheimer's or a related disorder. They compared the mental health of 315 spouse carers with general population norms, employing measures of psychotropic drug use, the Center for Epidemiologic Studies Depression Index (CES-D), and the Affect Balance Scale (ABS). They found that in comparison with population norms these caregivers reported higher psychotropic drug use, higher depression scores and lower (ie. more negative) affect scores.

Thus it is evident that the majority of studies have found caring to create a subjective burden for the caregivers. Which particular aspects of the role and tasks of caring might be the most important in terms of their negative impact on supporter well-being or mental health will be examined in the next section.

VI CORRELATES OF SUBJECTIVE BURDEN IN THE CAREGIVERS OF DEMENTIA SUFFERERS

It is most particularly in this area that the number of research reports has proliferated over recent years, and most evidently following the publication of reports demonstrating that caring does create a subjective burden in supporters. Some tie their results in with the suggestion that knowledge of the effects of such factors may allow the design of interventions to alleviate subjective burden. However, as will emerge, the majority of these factors are not such as would be amenable to manipulation. Thus, the main value of these studies has been in suggesting those variables within the caregiving situation which might allow for the identification of the "at risk" carer.

In a review of the impact of functional psychiatric illness on the patient's family, Fadden, Bebbington and Kuipers [1987] criticise the "scatter-shot" approach on the part of "researchers who have failed to follow through on promising leads in their own data" [p.290]. To some extent, the same can be said of the body of literature to be reviewed here. The vast number of these reports, all of which examine the effects of at least one or two different factors can leave the reader with the feeling of having been swamped with information, but without having learned anything. This review will examine reports of the impact of the following factors on caregiver subjective burden: the behaviours/impairment of the dementia sufferer; age and sex of the dementia sufferer; age and sex of the caregiver; individual caregiver characteristics; blood/role relationship of sufferer and caregiver; quality of relationship between sufferer and caregiver; living

arrangements of sufferer and caregiver; and finally, informal and formal support received by the caregiver.

Unlike the previous section, studies employing measures of subjective burden which may have been specially designed and/or which do not have general population norms are included. There are two reasons for this. Firstly, because not to do so would eliminate a large number of studies in this area. Secondly, because the aim here is not to compare carers with the general population but to look at factors that may differ within the caregiving situation, thus measures designed specifically to examine caregiver strain are adequate.

1. Effect of Behaviours/Impairment of Dementia Sufferer on Subjective Burden of the Carer

The majority of studies in this area find a relationship between the behaviour of the sufferer and caregiver burden.

In their study of the effects of psychiatric illness on the family, Grad and Sainsbury [1968] found that at first referral the presence of the following five symptoms were significantly related to whether or not they caused a severe burden: aggression, delusions, hallucinations, confusion and the inability to care for self. While their survey was not restricted to the families of dementia sufferers, they found that it was the demented and bedfast patients who needed constant attention and interfered drastically with home life that affected the family most severely.

In an interview study of the primary caregivers of 55 dementia patients, Rabins, Mace and Lucas [1982] found the following behaviours to be cited by caregivers as

causing serious problems: physical violence, memory disturbance, incontinence, catastrophic reactions, hitting, making accusations and suspiciousness.

A factor analytic study of the behavioural disturbance shown by elderly dementia patients at home and the effects of this behaviour on their caregivers was reported by Greene, Smith and Gardiner et. al. [1982]. They obtained ratings from 38 relatives of both the behaviour and mood of the patient plus the degree of stress and impact which they felt from having to care for the patient. Both the scales were made up of items which the authors had "culled from the literature". On the basis of their factor analysis, two scales were constructed, each made up of 3 subscales. These were the Behaviour and Mood Disturbance Scale (BMD - with Apathetic-Withdrawn; Active-Disturbed; and Mood Disturbance subscales), and the Relatives' Stress Scale (RSS - with Personal Distress; Life Upset; and Negative Feelings subscales). The authors found that personal distress in the relative was associated with the amount of apathetic and withdrawn behaviour in the patient, whereas negative feelings in the relative were associated with the degree of disturbance of the patient's mood.

Gilleard, Boyd and Watt [1982] also report on a factor analytic study of the behaviour of dementia sufferers at home. They administered an early version of the Problem Checklist (25 items, no apathy-withdrawal type problems included) to 112 primary supporters of patients attending psychogeriatric day hospitals. Principal components analysis yielded five meaningful dimensions of behaviour, which they labelled "dependency", "disturbance", "disability", "demand" and "wandering". The authors then examined the relationship

between each of the problem domains and the supporter's rating of strain. Strain was assessed by summing carer ratings of burden ("none" = 0, "intolerable" = 3) and ratings of ability to cope ("able to cope indefinitely" = 0, "unable to cope at all" = 3). Results clearly demonstrated that it was the "demand" problems which most contributed to supporter strain. Low supporter mood (assessed via a 20-item Mood Checklist) was associated with high demand and dependency problems in the sufferer. There was also a strong association between the patient continuing to be cared for in the community 12 months later, and the supporter reporting a lower than average number of demand problems.

Gilleard [1984] discusses the apparent discrepancy in the results of the above two factor analytic studies. Firstly, a different selection of items used by the two studies has produced a lack of common problem domains. (Most importantly, the Gilleard et. al. study did not include any of the Apathy-Withdrawal type of problems which Greene et. al. found to be important determinants of caregiver burden.) Secondly, both apathetic and demanding behaviours, when viewed within the context of the family as a whole "may be seen as reflecting an increasing ego-centredness and lack of concern on the part of the dementing person" [p.66]. The result is a one-sided and unrewarding relationship between sufferer and carer. Gilleard has obtained similar results in further studies. The number of problems relating to the elderly mentally infirm person's disturbance and demand was found by Gilleard, Belford and Gilleard et. al. [1984] to be significantly and positively associated with the supporter's GHQ score. Overall number of problems obtained via the Problem Checklist correlated closely with both supporter Strain Scale score and GHQ score [Gilleard, 1987].

Levin, Sinclair and Gorbach [1984] obtained significant associations between strain in the supporters of the confused elderly at home as measured by GHQ scores and a number of the problems they faced in looking after their relatives. These included: heavy incontinence, "trying behaviours", disturbance during the night and inability to have an ordinary conversation.

Argyle, Jestice and Brook [1985] found that the most common behavioural problems displayed by 62 patients who had been admitted to a psychogeriatric ward were not necessarily the least well tolerated. Their relatives reported the latter to be aggression, verbal abuse, wandering, faecal smearing and urination in appropriate places.

Although they found little evidence of raised psychiatric morbidity (as measured by the GHQ-60) in the co-resident supporters of elderly demented patients when compared to those living with a non-demented elderly person, Eagles, Craig and Rawlinson et. al. [1987] did find a positive relationship between the level of a dementia sufferer's behavioural disturbance and supporter strain, mood and GHQ scores. They point out however, that since it was the supporters themselves who made the ratings of sufferer behavioural disturbance it is possible that more distressed supporters rated sufferer behaviour as more disturbed, rather than the opposite causal relationship.

Similar results are reported by O'Connor, Pollitt and Roth et. al. [1989] in their community study of 120 relatives of a dementia sufferer and 107 relatives of a cognitively intact elderly person. While GHQ-28 scores did not differ between the two groups of supporters, strain scores correlated strongly with total problem

frequency and severity scores (as assessed by the 34-item Problem Checklist). It was the physical dependency and disturbed types of behaviours which they found to be associated with strain in the relatives, while apathy-inertia problems were tolerated well.

Two more recent studies also report a relationship between sufferer behaviours and supporter burden. Barusch and Spaid [1989] interviewed 131 spouse caregivers. They found that the patient's cognitive and behavioural difficulties were the most important predictors of caregiver burden. Pruchno and Resch [1989] report from a sample of 262 subjects, that asocial and disorientated ("aberrant") behaviours in patients with Alzheimer's disease are related to burden. The more frequent these behaviours are, the more stress is experienced by the caregiver. The authors believe that these behaviours are stress-provoking because of their unpredictability and their social unacceptability. Forgetful behaviours, on the other hand, have a different relationship with caregiver stress. Patients with very few forgetful behaviours are generally those with very mild dementia for whom caregiving is relatively easy. Patients with very many forgetful behaviours are generally those with very severe dementia, often vegetative, requiring only basic nursing care. Caregiving is thus relatively easy for this group also. It is the patients with a moderate number of forgetful behaviours, corresponding to moderate dementia who are more likely to exhibit "difficult" behaviours and for whom caregiving is a hard job. Thus, mild and severe forgetfulness are both associated with low caregiver burden, while moderate forgetfulness is associated with raised burden.

Although the majority of studies report a significant association between dementia sufferer behaviour and caregiver burden, there are a number which do not. Zarit, Reever and Bach-Peterson [1980] interviewed primary caregivers (18 spouses and 11 daughters) of senile dementia sufferers. Degree of burden as determined by a 29-item self-report inventory was not associated with any of their sufferer behaviour variables (frequency of memory and behaviour problems, extent of cognitive impairment, level of functional impairment, or duration of dementia). The authors comment that this finding was "contrary to expectations". Similarly, Gilhooly [1984] writes that although the dependent's cognitive functioning and impairment level was expected to be significantly associated with poor mental health in the 37 supporters whom she interviewed, this was not found to be the case. She comments that this result may have arisen because her use of general measures of dementia and impairment may have masked any relationship between specific features of the sufferers' behaviour and caregiver burden. Finally, George and Gwyther [1986] also comment on the unexpected nature of their findings of "little evidence that patient illness characteristics are important factors in understanding caregiver well-being" [p.258]. Patient illness characteristics were only minimally related to caregiver well-being, and not at all to illness duration. Again, however, they used a single measure for severity of dementia rather than examining the association between specific behaviours or behaviour types and caregiver burden.

The evidence thus strongly supports the notion of a positive association between caregiver subjective burden and the presence of certain behaviour

characteristics in the dementia sufferer. These behaviours tend to be "aberrant" or of the type which vastly reduce the chances of any sort of rewarding relationship between sufferer and caregiver. This relationship may be masked if more overall measures of dementia are employed, since these behaviours may come and go throughout the illness (particularly during the "moderate" stage), rather than following a predictable course.

2. Effect of the Age and Gender of the Dementia Sufferer on Subjective Burden of the Carer

Only two studies have been found which examine these factors. There are several more which examine the effects of the caregiver's age and gender on caregiver subjective burden (see following sub-section), and to some extent the results of these may be related to the effects of sufferer gender. This is because in an examination of spouse caregivers, the sufferer is by definition of the opposite gender - thus the effects of both carer and sufferer sex will be confounded.

Zarit, Reever and Bach-Peterson [1980] found no relationship between any caregiver or dementia sufferer demographic data and carer burden. Gilhooly [1984] however, reports that sufferer gender was significantly correlated with supporter morale. In her study care of a female was associated with higher morale. There was no relationship between sufferer age and supporter morale.

3. Effect of the Age and Gender of the Carer on Subjective Burden of that Carer

In addition to the confounding effects of sufferer gender on these variables (mentioned above), the blood/role relationship will also be a confusing factor since while the majority of male carers are spouses, female carers are both spouses or daughters of sufferers.

Most studies report a relationship between the gender, although not the age, of the carer and the subjective burden of that carer. Two of the available studies do not. As noted in the previous sub-section, Zarit, Reeve and Bach-Peterson [1980] found no relationship between any caregiver demographic data (age, sex, income, education) and carer burden. Argyle, Jestice and Brook [1985] were surprised to find no differences in the number of problems reported by male or female relatives of patients entering a psychogeriatric ward. Nor was the age of the sufferer significant.

In those studies which do report a relationship between carer gender and subjective burden, the results are unanimous in suggesting a positive association between female carers and higher burden.

Boutsellis [1983] discusses the study by Zarit [1982] which found women carers to report more burden than men. This was despite the fact that men endorsed a higher frequency of sufferer memory and behaviour problems and both male and female carers reported equal tolerance for such problems. It is suggested that this is because male carers use more paid help than women, and also that a husband caring for a wife with dementia

may receive informal support from his wife's former friends.

Gilhooly [1984] offers similar explanations for her finding that male carers had significantly higher morale than females. Firstly, she suggests that men were less likely to be emotionally involved with the sufferer's illness than were female supporters. Secondly, men were more willing to leave the sufferer alone in the house, and were thus less socially isolated. The third reason suggested by Gilhooly for higher morale in male carers is simply that they are less willing to admit distress than are females.

In each of the three studies of supporters of the elderly mentally infirm described by Gilleard, Belford and Gilleard et. al. [1984] the proportion of high GHQ-30 scores was considerably greater amongst women than men. This finding held irrespective of age and of the type of relationship to the dependent. The authors conclude that female supporters either find giving care to the elderly mentally infirm more distressing than men, or else that they are more willing to report their distress.

O'Connor, Pollitt and Roth et. al. [1989] suggest three possible explanations for their finding that the wives of moderately demented men reported more problems and strain than did husbands. One reason may be that women find the physical tasks of caring more of a strain than men. The second may be that, as suggested by Gilhooly, male supporters might find it easier to leave their dependent spouse unattended in order to continue their own social lives. The third reason may be that a male is more likely than a female supporter to be taking on

a new role as carer, and as such may actually find it gives him some rewards and interest.

Barusch and Spaid [1989] found that caregiver age was significantly associated with caregiver burden, with young carers reporting greater subjective burden. They also note that even among spouse caregivers males tend to be older than females. They conclude from this that "women experience greater stress in part because they are younger than men who become caregivers" [p.674]. However, two further studies (those of Gilhooly [1984] and Gilleard, Belford and Gilleard et. al. [1984]) find no relationship between caregiver age and subjective burden.

4. Effect of Individual Carer Characteristics on the Subjective Burden of that Carer

Zarit, Todd and Zarit [1986] assessed the burden of 64 carers of dementia sufferers using a 20-item Burden Interview based on their definition of burden as "the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative" [p.261]. They found that burden was more highly associated with the sum of the cross product of frequency and tolerance ratings from their 28-item Memory and Behaviour Checklist than with either scale alone. This means that caregivers feel burdened when the patient manifests deficits in behaviour AND they have difficulty tolerating those behaviours. The authors point out that this result demonstrates how individual caregivers react differently to problem behaviours. They also note that not all caregivers find the same problems to be troublesome.

Individual differences were also highlighted by Morris, Morris and Britton [1989] who investigated a sample of 20 spouse caregivers of dementia sufferers. They assessed caregiver depression via the Beck Depression Inventory (BDI) and strain via a 7-point scale ("I feel no strain ..." = 0, "I feel severe strain because of the way my partner is nowadays" = 7). The authors found that caregiver depression and strain were significantly correlated with perceived ability both to cope with their own emotional reactions and to cope with the behaviour of the dementia sufferer.⁴ Thus, individual coping cognitions predict both depression and strain.

5. Effect of Blood/Role Relationship with the Dementia Sufferer on Subjective Burden of the Carer

Once again, in reviewing studies of blood/role relationship with the dementia sufferer and degree of subjective burden in the carer the problem of confounding variables arises. Spouse caregivers will not only be older on average than child carers, but will also be co-resident, whereas children may take a parent into their own home or look after them as non-resident carers.

There appears to be a fairly equal balance between studies which find that blood/role relationship is associated with carer burden and those which do not.

No relation was found in the following four reports. Zarit, Reever and Bach-Peterson [1980] report no association between the relationship of caregiver to sufferer and carer burden when they compared 18 spouses versus 11 daughters using a 29-item burden inventory. In none of the three studies reported by Gilleard, Belford and Gilleard et. al. [1984] was supporter/

dependent relationship (spouse, child, other) found to be associated with supporter emotional distress as measured by the GHQ-30. Eagles, Rawlinson and Restall et. al. [1987] compared 41 spouse carers and 25 child carers and found no significant differences in psychological morbidity or strain (as measured by the GHQ-60, Relatives' Mood Scale and Relatives' Stress Scale). In a study which controlled for household arrangement, Diemling, Bass and Townsend et. al. [1989] found that within the shared residential setting, relationship (spouse versus child) of carer to elderly person (only some of whom were dementia sufferers) was not associated with carer stress: "spouse caregivers, in spite of their advanced age, are not significantly more likely to report health decline, relationship strain, or activity restriction compared to adult children who live with and care for a parent" [p.79].

A similar number of the available studies have found an association between carer-sufferer blood/role relationship and carer subjective burden; however, their results vary with regard to which relationship is associated with most stress. Boutselis [1983] cites a study by Johnson [1983] which found children to be more negatively affected by the experience of caregiving. Various suggestions are made as to the reasons for this, including the different norms and expectations for a child versus a spouse with regard to caregiving, and the increased likelihood of role conflict which a child caregiver is likely to experience since they are more likely to have their own spouse and family to care for in addition to their parent. Quite the opposite result was found by Gilhooly [1984] who reports a negative correlation between the distance in the blood/role relationship and the supporter's mental health. Thus she found spouses to have worse mental health than

child carers, and both these groups to have worse mental health than "other" carers (for example, daughters-in-law). Gilhooly explains this as probably reflecting the extent of emotional involvement of the supporter with the dependent and their illness. George and Gwyther [1986] report similar results. Even controlling for the age differences between spouse and child caregivers, spouses were found to score more poorly on their measures of well-being than were either children or other relatives.

6. Effect of Quality of Relationship with the Dementia Sufferer on Subjective Burden of the Carer

Studies have examined the effects of the quality of both premorbid and current relationship on caregiver subjective burden. This sub-section will review studies of the effects of quality of premorbid relationship first, followed by studies of the effects of the quality of the current relationship between carer and dementia sufferer.

Gilhooly [1984] rated the quality of the premorbid relationship between supporter and dementing relative using a 5-point scale, based on a number of questions about the relationship at various points during the supporter's life; quality of premorbid relationship rating was not related to any of her measures of supporter well-being. (Morris, Morris and Britton [1988a] suggest this might be accounted for by the relatively high morale and low incidence of poor mental health in her sample of supporters.) Wheatley [1979], however, describes a close and lengthy premorbid relationship as resulting in a continued affectual bond between the supporter and the dementia sufferer which in turn acted as a source of both motivation for care

and satisfaction in the carer: "The closer the relationship, the more emphasis there was on the happiness of the elderly person him/herself and this emphasis in itself appeared to be a source of both motivation and satisfaction" [p.196]. The carer's view of the quality of past relationship was also found by Gilleard, Belford and Gilleard et. al. [1984] to be positively associated with that carer's subjective burden as measured by GHQ-30 score. (It is possible that current carer distress may colour their ratings of premorbid relationship.)

Morris, Morris and Britton [1988b] have examined the effects of both premorbid and current relationship (as measured by a marital intimacy questionnaire) and the subjective burden of 20 spouse caregivers of dementia sufferers (measured using a 7-point single item strain scale and the Beck Depression Inventory). They found the highest levels of perceived strain and depression amongst caregivers who reported lower levels of both premorbid and current marital intimacy. Loss of intimacy was significantly correlated with supporter depression, but not with supporter strain. In addition, scores on the Problem Checklist were significantly negatively correlated with levels of present intimacy and positively correlated with loss of intimacy, while the association between loss of intimacy and depression ceased to be significant after partialling out scores on the Problem Checklist. In the discussion of their results, the authors suggest that people with high premorbid intimacy may take on the caregiving role for positive, loving reasons, whereas those with a lower premorbid intimacy may take on the caregiving role out of a sense of duty. Another possibility is that low premorbid intimacy acts as a vulnerability factor for high subjective burden. Finally, they attribute the

depression of supporters associated with loss of intimacy with the dementia sufferer to be the result of a sense of loss as the sufferer exhibits an increasing number of behavioural problems and thus becomes more difficult to relate to.

In another recent study, Motenko [1989] has also examined premorbid and current marital intimacy (measured using the Lopata Emotional Support Systems of Widows Scale) and the gratification and well-being of 50 women caring for a husband with dementia. She found that wives who reported a decrease in marital closeness since the onset of dementia received less gratification from caring than wives who reported no change in marital closeness: "Change in the closeness of the marital relationship appears to be more critical to lower gratification from caregiving than the actual closeness of the marriage" [p.169]. She suggests that it is continuity of relationship, whether good or bad, which explains carer gratification and well-being.

7. Effect of Living Arrangement on Subjective Burden of the Carer

Only a few studies have examined this factor. For example, in her survey of 47 supporters caring for elderly people who had been admitted for holiday relief, Machin [1980] found non-resident supporters reported lower levels of subjective burden and higher levels of life satisfaction than co-resident supporters. Machin believed that this was probably associated with the fact that non-resident supporters also received significantly more relief from caring, devoted less time to caring and suffered fewer restrictions in their social lives than did co-resident supporters. Gilhooly [1984] also found co-resident

supporters to have slightly lower morale and poorer mental health than non-resident supporters, however the correlations did not reach significance levels. In her discussion Gilhooly points out that these relationships have many confounding variables, for example, co-resident supporters are more likely to be older, spouses, or males. Similarly, O'Connor, Pollitt and Roth et. al. [1989] identified co-resident children looking after a demented parent as being the supporters who were under most strain. They suggest that this group of carers may have a large number of problems arising from not only from their parent but also from their own family, and that because of their living arrangements they have no refuge from the situation.

Finally, although Diemling, Bass and Townsend et. al. [1989] also found non-resident adult children reported far less health decline than those sharing a residence with an elderly dependent, when they controlled for the effects of elder impairment, carer age and social supports, this relationship was not significant. The authors conclude that: "This indicates that health decline in adult children is not a function of the care setting" [p.77].

8. Effect of Support on Subjective Burden of the Carer

Studies have examined the effects of both informal (family/friends) support and formal services on the subjective burden of the caregivers of dementia sufferers. The majority have focussed on the effects of formal services. One reason for this may be because they are often easier to measure (more likely to be either present or not present, whereas informal support is generally available but at varying degrees). A second reason may be because this is the area of

support which professionals may be in a position to manipulate, with the possibility which this brings of having an effect on caregiver subjective burden. This review will commence with the few available studies of the effects of informal support.

INFORMAL SUPPORT

The only factor which Zarit, Reeve and Bach-Peterson [1980] found to contribute to levels of burden in 29 primary caregivers of a dementia sufferer was the frequency of family visits. Those subjects who received more visits reported less burden. The authors discuss the importance of providing support "as a critical step in the community care of elderly persons with dementia" [p.649].

Scott, Roberto and Hutton [1986] examined the support provided by families to 25 primary caregivers of Alzheimer's disease patients. 33% of carers were rated as receiving more than enough support, 48% enough support and 19% not enough support from their families. When functional impairment of the dementia sufferer was controlled for, they found that greatest burden (measured using the same burden as that of Zarit et. al. [1980] - above) was reported by those carers who had been rated as not receiving enough family support. However, the authors were surprised to find that almost as much burden was reported by carers who had been rated as receiving more than enough family support, while least burden was associated with the receipt of enough support. They suggest this arises because large amounts of family support are given to some carers as a result of their high levels of burden.

In a rather complicated study, Brody, Hoffman and Kleban et. al. [1989] report on the relationships between caregiving daughters and their local siblings. The primary caregivers were looking after widowed, non-institutionalised elderly mothers, many of whom were severely disabled, but not all of whom were dementia sufferers. The authors point out that sibling interaction is not necessarily always supportive and positive - however, the primary caregivers did feel rewarded when siblings gave them emotional support. Those caregivers who reported most strain from hassles had weaker feelings of family and sibling closeness, felt strain from inter-sibling problems, did not feel close to their families and had few local siblings.

FORMAL SUPPORT SERVICES

Within the area of formal support a variety of different services may be available to community carers of people with dementia - although it should be said that due to financial or other constraints (or their own wishes), the majority of carers will receive only a small ration of these. Gilhooly [1990] has categorized these formal services in the following terms: Information and counselling to the caregivers; Substitution services (for example, home helps, bathing services, meals on wheels); Respite care (day care or holiday admission); Financial help; and Dementia therapies. The first three of these categories of community support will be considered in this review.

A written self-help and information guide was given to 18 primary carers of dementia sufferers by Toner [1987]. Half received it at the start of the study and the rest (control group) after a 6 week delay. The GHQ scores of the group which had received the booklet

first decreased significantly over the 6 week period in comparison with those to whom it had not yet been given. Level of behavioural problems presented by the dementia sufferers did not change over this period, allowing Toner to conclude: "much of the real change in stress levels arose from the provision of information, both in terms of carers' increased knowledge about dementia and it's problems and the consequent reduction in feelings of uncertainty" [p.26]. Chiverton and Caine report the pilot study results of a "brief educational program" conducted with 20 spouse caregivers of Alzheimer's disease sufferers. A further 20 carers acted as a control group. The educational programme consisted of three 2-hour, small-group (3 - 6 spouses) sessions. The first half of each session consisted of a didactic presentation of information, and the rest allowed for discussion. The authors report improved coping ability (measured on the Health Specific Family Coping Index) for those who had completed the programme. In addition, they had significantly greater scores in the domains of "Therapeutic Competence" (for example, ability to give medications), "Knowledge" (of the illness and treatment) and "Emotional Competence" (coping resources). They also note the support which participants received simply from being part of a group. This theme is also raised by Schmidt and Keyes [1989] in a discussion of group psychotherapy with family caregivers of demented patients, however these authors do not provide any objective measures of change in the subjective burden of those carers who attended the group.

With regard to substitution services, Gilhooly [1984] found that the home help service was associated with significantly increased supporter morale and better mental health. Frequency of visits by a community nurse

was also significantly correlated with supporter morale. Receipt of meals on wheels was not associated with supporter morale or well-being. Gilleard, Belford and Gilleard et. al.[1984] found no association between any "input" variables (for example, professional help received, family support) and supporter GHQ scores. They suggest this could be because more distressed supporters may receive more support, which in turn serves to reduce their distress to a level similar to those supporters who needed less help in the first place. In her survey of the emotional' distress in three groups of carers (daughters caring for a dementing parent, mothers caring for a mentally handicapped child and mothers caring for a mentally handicapped adult), Whittick [1988] found that although those caring for dementia sufferers received significantly more home help services than either of the other two groups, there were no significant correlations between carer well-being and the overall level of services received for any of the groups. Barusch and Spaid [1989] also report no association between caregiver burden and either number of formal services received or receipt of home-delivered meals by their group of 131 older spouse caregivers.

With regard to respite care, Gilleard [1987] points out: "One of the most frequently cited goals of psychogeriatric day hospitals is the relief of strain amongst relatives caring for the elderly patient" [p.219]. In his study of 129 community referrals for psychogeriatric day hospital he found that 3 months after initial attendance the GHQ-30 scores of the carers was significantly reduced, however there had been no significant changes in either the number of problems presented by the patients or the relatives' strain. Day care thus reduced reported distress in

supporting relatives, but not the actual problems or strain of caring. Gilhooly [1984] on the other hand, found no association between day hospital attendance and either morale or mental health in her sample of community caregivers. In-patient respite care has similar aims to day care: "The theory behind respite services suggested that unrelenting caregiving demands may have unfavourable outcomes for the caregiver and the impaired person. Periodic relief of such external stress is therefore seen as directly therapeutic for the caregiver and indirectly for the patient" [Powell-Lawton, Brody and Saperstein, 1989, p.14]. These authors found that although respite care did not affect levels of either caregiver burden or mental health, satisfaction was very high. Families in receipt of respite care managed to maintain the dementia sufferer in the community for a few weeks longer on average.

The results of these studies suggest that - contrary to "common sense" expectations - there is no clear and direct relationship between level of carer subjective burden and the receipt of formal support services. One reason for this is suggested by Horowitz [1981 - cited in Gilleard, 1984]. She also found no relationship between carer strain and absolute level of formal services received. However, expressed satisfaction with services was associated with lower reported strain. Horowitz argues that this means that what is important is not the absolute level of services, but whether services match a carer's level of need. Gilleard [1984] points out that the direction of causality may run the opposite way, with greater strain leading a carer to express the need for greater formal service provision.

Plainly, the topic of the correlates of subjective burden in the caregivers of dementia sufferers is both

complex and difficult to unravel because of the way in which different factors may be associated and thus confound the issue. The majority of reports conclude with recommendations for further research. Morris, Morris and Britton [1988a] describe the currently predominant cross-sectional correlational research strategy as "preliminary even if it is supplemented with multivariate statistics, giving some insight into the causative factors determining the caregiver's emotional well-being" [p.154]. They identify the need for both longitudinal and intervention studies of caregiver strain, in order to provide data upon which decisions can be based in clinical practice.

VII. INSTITUTIONALISATION

Jolley [1981] cites two reasons for institutional care. the first is when special investigations or expertise are required in order to care for the patient. This is of more relevance to patients with acute physical or mental illnesses than to the majority of dementia sufferers. The second reason, which is of far more relevance to the admission of dementia sufferers is the need for supervision which for some reason cannot be continued in the community.

This section will attempt to answer the question of why does community care break down? Which factors have been found to be predictors of the institutionalisation of a dementia sufferer? To be considered are the following: Lack of available family caregiver; Behaviour of the sufferer; Caregiver characteristics and well-being; Bonds between sufferer and caregiver; Support available to the caregiver.

1. Lack of Available Family Caregiver

The presence of family support to the dementia sufferer was found by Bergmann, Foster, and Justice et. al. [1978] to be the most important factor determining continued life in the community. Brody, Poulshock and Masciocchi [1978] also found that the lack of spouse and/or child carers were critical factors in the decision of whether or not to place a chronically ill or disabled (but not necessarily dementing) elderly person into an institution. Tobin and Kulys [1981] confirm this when they suggest that institutionalisation of elderly impaired people is precipitated by the death of family caregivers or by their moving away from the locality.

2. Behaviour of the Sufferer

While it might be assumed that the behaviour of the dementia sufferer would influence the decision of whether or not they should be institutionalised, findings in this area are equivocal.

Brody, Poulshock and Masciocchi [1978] found that differential levels of functional ability did not predict the placement of chronically ill or disabled elderly into institutional care. Although their sample was not limited to dementia sufferers, Gilhooly [1986a] reports similar results in a study of the factors associated with preference for institutional care in 48 community supporters of a dementia sufferer. Following intensive semi-structured interviews she rated supporter "preference for institutional care" on a 7-point scale, based on the answers to direct questions in this topic area. (Gilleard [1984] reports that attitudes and expectations about continuing the caring

role are indeed predictive of future behaviour as a carer.) Gilhooly found no relationship between this rating and either supporter or day hospital staff ratings of degree of impairment in the sufferer. In a longitudinal study of the predictors of institutionalisation of Alzheimer's disease patients, Colerick and George [1986] also found no relationship with patient variables such as severity or frequency of symptoms or illness duration.

A greater number of studies have found sufferer behaviour variables to be predictors of institutionalisation. Wilder, Teresi and Bennett [1983] suggest that it is not the presence of dementia itself but rather the presence of "noxious" behaviours (for example, aggressiveness, anger, hostility, or making demands) which create unwillingness to continue providing care. Levin, Sinclair and Gorbach [1984] describe family supporters as becoming "gradually worn down" such that institutionalisation becomes necessary because of the strain resulting from problems such as incontinence or "trying behaviours" in the dementia sufferer. In an examination of those factors which predicted institutionalisation within 6 months, Gilleard [1984] reports that it was number of problems faced rather than supporter strain or distress which most closely influenced subsequent outcome. Morycz [1985] identifies the need for a high degree of physical labour (for example, toileting, bathing or feeding) in the care of the dementia sufferer as increasing the desire of a supporter to institutionalise that person.

3. Caregiver Characteristics and Well-Being

Caregiver characteristics and well-being have also been identified as as important predictors of the institutionalisation of the dementia sufferer.

Levin, Sinclair and Gorbach [1984] found that high levels of supporter strain (assessed via the GHQ) were strongly associated with the placement of confused elderly persons into permanent institutional care within the following year. While she did not find carer morale or mental health to be significantly related to preference for institutional care, Gilhooly [1986a] did identify a number of other caregiver characteristics which were so related. Caregivers who received a high preference for institutional care rating were more likely to be younger, have other commitments (employment or another dependant), have more contact with friends but less satisfaction with help from relatives. Broadly similar results are reported by Colerick and George [1986] who found that caregivers who institutionalised Alzheimer's patients were more likely to be female, younger, children rather than spouses, employed, in higher income brackets, reporting high levels of stress and dissatisfaction with time spent in recreational pursuits. Morycz [1985] also reports caregiver subjective burden to be highly predictive of desire to institutionalise a relative with Alzheimer's disease.

4. Bonds Between Sufferer and Caregiver

If you have lived with a person for a very long time and your affectional ties are strong it may be very difficult for you to allow the institutionalisation of that person. This is found in a number of studies.

Close blood/role relationship, high quality of premorbid relationship and living with the sufferer (rather than in separate houses) were all found by Gilhooly [1986a] to be strongly predictive of a low preference for institutional care by the supporters of dementia sufferers. Both Gilleard [1984] and Colerick and George [1986] point out that spouse caregivers are far less likely to relinquish the care of a dementia sufferer to an institution than are other relatives. The latter authors describe spouses as both accepting their role as caregivers and in addition as feeling that the sufferer continues to occupy a central role in their lives. Hirschfeld [1981] identifies current relationship as the crucial variable in determining a family's ability to continue caring for a dementia sufferer at home. She defines current relationship in terms of "mutuality". "Mutuality was defined as the caregiver's ability to find gratification in the relationship with the impaired person and meaning from the caregiving situation. Another important component to mutuality was the caregiver's ability to perceive the impaired person as reciprocating within the relationship by virtue of his/her existence" [p.160]. High mutuality was very strongly related to a negative caregiver attitude toward institutionalisation.

5. Support available to the Caregiver

With regard to informal (family/friends) support, Gilhooly [1986a] reports that those carers who have more contact with friends but less satisfaction with help from relatives (which is not necessarily equivalent to actually receiving less help from relatives) expressed a higher preference for institutional care of the dementia sufferer. Morycz [1985], however, did not find that frequency of family

interaction or that availability of back-up help were related to caregiver desire to institutionalise elderly patients with Alzheimer's disease.

Turning to formal service provision, as Gilhooly [1990] indicates, the current ideology surrounding the provision of services to community caregivers is that they will slow patient decline and/or alleviate carer burden, with the result that institutionalisation will be delayed or prevented, thus reducing public expenditure. However, as has been noted earlier (section on "Effect of Support on Subjective Burden of the Carer"), there is little evidence that formal support of any kind has a strong impact in reducing caregiver burden. We might assume from this, then, that formal support will have a less than significant impact on the decision to institutionalise a dementia sufferer. The results of the available studies are certainly neither unequivocal nor particularly impressive in terms of the effectiveness of formal services in the prevention of institutionalisation.

Neither day hospital care, the receipt of home help, community psychiatric nurse visits, or meals on wheels were found by Gilhooly [1986a] to significantly influence preference for institutional care. She suggests that this result may have arisen from the lack of variation in the provision of services in the locality which she studied. Contrary to what might be expected, Colerick and George [1986] found that caregivers who subsequently institutionalised a dementia sufferer reported more support than those who kept the sufferer in the community. They suggest that this perhaps reflects "an effort to investigate all potential relief sources before making a final placement decision" [p.497]. Day care provision was

found by Gilleard [1987] to significantly reduce distress and allow some supporters to continue giving care. However there were other supporters whose distress was not alleviated by day care and whose relative was institutionalised fairly rapidly. Finally, as reported earlier, Powell Lawton, and Brody et. al. [1989] report that respite care can delay institutionalisation, although this was found to be only by a few weeks on average.

Cicerelli [1986] sums up those factors which increase the likelihood of institutionalisation of a dementia sufferer as follows: little feeling of attachment or sense of obligation to the sufferer, low coping ability or intolerance of the problems of caring, insufficient support of all kinds, and competing demands on the primary caregiver.

VIII. SUMMARY

This chapter has examined the effects of the increasingly prevalent syndrome of dementia, not only upon the sufferers themselves, but more particularly upon their caregivers. By far the majority of these caregivers are "informal", usually the spouses or children of the sufferers. Most are women.

Carers are burdened not only by the behavioural disturbance or deficits in the sufferer, but also by the changes they may have to make to accommodate caregiving into their lives, the financial implications of caring and the impairment which caring can produce in their own physical health. The result of this is "subjective burden" - that is, a deterioration in carer mental health and well-being. Although the confounding

factors among studies of the correlates of subjective burden can make their results difficult to untangle, increased burden would appear to be related to the following factors: disturbed or "noxious" behaviours in the sufferer (as opposed to simply needing to be "nursed"); a female caregiver; poor quality of premorbid or current relationship; possibly living with the sufferer; lack of family support and possibly also lack of formal support services. It is not really surprising that the presence of similar factors have been found to increase the likelihood of institutionalisation of the dementia sufferer.

How caregivers face the process of institutionalisation is an issue which will be examined later in this thesis. (See Chapter Six.)

CHAPTER THREE

GRIEF

"Numerous other correspondents counselled patience and endurance; time, they told me with maddening unanimity, would heal. I resented the suggestion bitterly; I could not believe it, and did not even want it to be true. If time did heal I should not have kept faith with Roland, I thought, clinging assiduously to my pain, for I did not then know that if the living are to be of any use, in this world, they must always break faith with the dead."

[Following the death of her fiance, in France, Christmas 1915. From "A Testament of Youth", Vera Brittain, Virago, 1987, p.247.]

I. INTRODUCTION

It is now 35 years since Gorer first raised the issue of "The Pornography of Death" [reprinted in Gorer, 1965], which discussed a shift in prudery such that it was now the topic of death rather than sex which had become an unmentionable in western societies. Rando [1984] also refers to this public attitude towards death, describing our culture as "death denying". Most people are now shielded from contact with dying people since death rarely happens at home and in public any more, and there are few prescribed rituals for recognizing death. Similarly, phrases like "pass on" or "at rest" are favoured, as though the word "dead" causes too much discomfort when mentioned.

Despite this cultural attitude of denial, over this same period there has been a steadily increasing number of research reports and academic literature on the topics of death and grief. Parkes [1986] in the

introduction to his book "Bereavement" points out that "when the first edition of this book was published in 1972, it was possible to mention most of the scientific studies which had been carried out in the field of bereavement. Now it is not" [p.15].

Osterweis, Solomon and Green [1984] suggest that this widening interest in bereavement by health professionals may be related to two recent social developments. The first of these is the way that achievements in medical science 'have shifted the location of death from the home to the institution, and the cause of death from the acute infection to the chronic disease. The second is the lack of traditional social supports (either institutions or face to face contact with members of the extended family) for the provision of help to the bereaved.

This chapter will review the consequences of this widening interest in bereavement and grief. It is in four sections: firstly, descriptions of normal uncomplicated adult grief; secondly, a discussion of the notion of grief as a process of "phases" or "stages"; thirdly, an examination of the question of whether grief constitutes a health risk; finally, a survey of some of those factors which may make an individual more at risk for a poor outcome to their grief.

It is recognized that this review does not even touch upon certain very important aspects of grief, for example, forms of "pathological grieving". It also needs to be recognized that "normal" adult grief is itself an enormous topic. It forms the subject of numerous books, for example, Parkes [1986], Raphael [1984], Stedeford [1984], Osterweis, Solomon and Green

[1984], Rando [1984]. Not only that, but volumes have even been written about particular aspects of post-death adult grief, for example, Worden [1983], Stroebe and Stroebe [1987]. Given this, the following chapter cannot attempt to present an exhaustive review of the academic literature in it's entirety. In particular the third and fourth sections (grief as a health risk, individuals at risk for a poor grief outcome) refer at several points to review articles or volumes rather than individual source reports.

To finalise this introductory section, a note on the definitions of the three terms "bereavement", "grief" and "mourning" as they are used in this review.

Bereavement is the state of having suffered a loss by death. Thus, all the examples in this chapter are of individuals who have lost a loved one through death, as distinguished from becoming separated or divorced from that person.

Grief is the normal response to the loss of a valued object. Although normally only considered in the context of a loss by death, it can occur after many types of loss: loved person, cherished possession, job, status, home, country, an idea, a part of the body - in fact anything to which a bond or relationship has been formed. The grief reaction has emotional, behavioural, physical and social components.

Mourning is the cultural response to grief. For example, rituals surrounding the funeral, wearing "mourning dress", and in some societies, but increasingly denied in western culture, the ritual display of emotion. Thus, a bereaved individual is very likely to attempt to follow the culturally prescribed course of mourning whatever the course of their grief. [Engel, 1961; Gorer, 1965; Rando, 1986].

II. DESCRIPTIONS OF NORMAL ADULT GRIEF

Over the past 20 years a large number of published descriptions of normal adult grief have appeared, based on a rather smaller number of research reports. Prior to that, virtually the only report was that by Lindemann, titled "The Symptomatology and Management of Acute Grief". Despite its having been published in 1944, in 1961 Bowlby was still able to write that among attempts to conceptualise the processes of grief and mourning in the psycho-analytic literature, "Lindemann appears to be alone in making the first-hand study of acute grief his main concern" [p.318]. Similarly, in 1965, twenty-one years after its publication, Gorer described Lindemann's account as "to the best of my knowledge, the first and still the most complete analysis of the behaviour of recently bereaved persons" [p.122].

In this section, five of the "classic" descriptive studies of the emotional, behavioural and physical aspects of normal adult grief will be reviewed. These are followed by a review of the social aspects of bereavement.

1. Lindemann's Observations

Lindemann [1944] published his observations on acute grief following a series of interviews with 101 subjects. A criticism which has been made of his study [Clayton, Desmaris and Winokur, 1968; Clayton, Halikas and Maurice, 1971], is that his subjects comprised four very different groups: (1) psychoneurotic patients who lost a relative during the course of treatment; (2) relatives of patients who had died in hospital; (3) bereaved disaster victims and their close relatives

from the thus immortalised "Coconut Grove" fire; and (4) relatives of members of the armed forces.

Despite this variety of subjects, Lindemann reports that "the picture shown by persons in acute grief is remarkably uniform". He identified the following five features which "seem to be pathognomic for grief" [p.142].

Somatic distress, occurring as waves of discomfort, with sighing respiration, tight throat, choking and shortness of breath, emptiness in the abdomen, and lack of muscular power.

Preoccupation with the image of the deceased and a feeling of increased emotional distance from other people.

Guilt, as the bereaved accuses him or herself of negligence towards the lost one, and exaggerates minor omissions.

Hostility and loss of warmth in relationships with other people, often surprising to the bereaved, and handled by a stilted social formality.

Change in patterns of behaviour. For example, pressure of speech, particularly concerning the deceased, restlessness and searching for something to do, but coupled with a lack of zest and inability to initiate and maintain organised patterns of activity with the realisation that so much of their activity was done in relationship to the deceased and as such is now meaningless.

Lindemann also described a sixth characteristic, which he believed to be displayed by people bordering on pathological grief reactions. This feature is the appearance of traits of the deceased in the behaviour of the bereaved; for example, the symptoms of their final illness, or their interests, or their mannerisms. Lindemann believed that this represented some sort of

transformation of preoccupation with the image of the deceased in this group of people.

A further criticism of Lindemann's work is the absence of information concerning not only the time perspective with regard to how frequently or how long after bereavement his interviews were conducted, but also with regard to the frequency of occurrence of the reactions which he describes, and how they might vary over time [Parkes 1970; Epstein, Weitz and Robach et. al., 1975]. Despite this, all subsequent authors agree that not only was Lindemann's an important study in the pioneering sense, but also that his results were very valuable and can be regarded "as a useful account of symptoms of normal bereavement" [Ball 1975].

2. Parkes' Descriptions of Grief in London Widows

In his longitudinal, interview-based study of the reaction of 22 London widows to the death of their husbands, Parkes [1970] attempted to improve upon Lindemann's descriptions by providing information about the timing of his interviews, and the relative frequencies of the reactions which he described, along with their variation over time. Parkes conducted lengthy semi-structured interviews with the widows at 1, 3, 6, 9 and 13 months after bereavement.

Parkes described the most frequent reaction immediately after the husband's death as a state of numbness, with difficulty in accepting the fact - a denial of the full reality of what had happened, and sometimes accompanied by a restless busyness. Alternating with this emotional numbness were brief outbursts of distress, manifested by crying, aggression, or panic attacks. This numb period generally lasted about a week and was followed

by a rise in the level of affective disturbance - such that there was "a significant negative correlation between overall affect in the first week after bereavement and that in the third month" [p.450]. Parkes groups the reactions during this period under two major headings; firstly, search for the lost object; secondly, anger, guilt and associated features.

Searching, or pining for the dead person is manifested by the following features:

Preoccupation with thoughts of the deceased, with very clear memories and visualisations of the person, both happy and disturbing (such as memories of the way they were during the final illness).

Direction of attention to places and objects associated with the deceased, for example, feeling drawn to old haunts, visiting the grave, or treasuring their possessions.

Perceptual set for the deceased, so that the bereaved may misperceive auditory or perceptual stimuli as signs of the deceased, for example, a creaking floorboard might indicate the presence of the dead husband in the house. Sometimes this amounted to transient hallucinations, but these were always recognised as such.

Parkes described the above three features as "each components of a single process, and it is my contention that they all reflect the urge to look for and, in some sense to find the lost person" [p.453]. They were also correlated with a fourth feature, crying for the lost person.

Parkes found anger, usually expressed as general irritability or bitterness, was described at some point during the first year of bereavement by the majority of widows interviewed, although it was rarely continuous.

If directed at an object at all, it was directed at people - the deceased who had abandoned his widow, doctors, or family members. Guilt was less of a problem than anger but was apparent in approximately half the widows interviewed; self reproach over generally trivial omissions or commissions in their relationship with the deceased, or during the events of the death. Parkes describes his general impression as "of an intense impulse to action, generally aggressive, which was being rigidly controlled" [p.456].

This distress was not continuous. Parkes outlines forms of mitigation, ranging from the involuntary initial numbness to various strategies which were under voluntary control. These include avoiding those reminders of the deceased which they knew would trigger distress, "selective forgetting" of painful memories together with the evocation of pleasant thoughts and idealisation of the deceased, or deliberate attempts to distract themselves.

Parkes details three further aspects of the bereavement reaction. Firstly, identification phenomena, very similar to the characteristic which Lindemann believed to be bordering on the pathological, namely that of the appearance of traits of the deceased in the behaviour of the bereaved. Parkes describes about half the widows interviewed as tending to behave or think more like their dead spouse, while a fewer number described symptoms similar to those suffered by their husband while he was dying, or feeling as if their dead spouse was inside them or one of their children. Parkes suggests that such identification phenomena may represent a similar response to that of the sense of the presence of the deceased. This may also be true of a second further aspect of the bereavement reaction

which is outlined by Parkes, namely clear and realistic dreams about the deceased. The final aspect of grief which Parkes describes here is the "inhibition of other appetites and activities"; the widow is so involved with grieving that she is unable to engage fully in other areas of life, such as eating, sleeping, or relationships with others.

By the time of the final interview, 13 months after bereavement, the majority of widows still demonstrated some degree of disturbance and were easily upset. However, guilt and tearfulness were now rare, as was the avoidance of painful reminders of the deceased. The general health and appetite of the majority had returned to normal, although some still experienced restlessness. The majority still spent time thinking of their dead husband and had a clear visual memory, while many still had a sense of his presence and continued to find it hard to believe he was dead. In fact, only 3 of the 22 widows could be described as having adjusted sufficiently well to widowhood as to be able to regard thinking of both the past and the future as pleasurable. 19 of the 22 widows continued to live in the house they had shared with their husbands. Over half were working - 7 of whom had taken a job for the first time - and they appeared to value their work and the social contacts it gave them. Despite this, the majority were financially less well off than previously, and several had money worries. Their social life was limited, and loneliness was described as a common problem. As Parkes points out, at this time "the process of grieving was still going on and although the principal features were all past their peak there was no sense in which grief could be said to have finished" [p.464].

3. Maddison and Colleagues - the Health of Widows

Following a series of studies, Maddison and Viola [1968] describe the use of a questionnaire to gather data on the health of 132 widows in the Boston (USA) area during the year following the death of their husband, and its replication with a sample of 243 widows in the Sydney (Australia) area.

The widows recorded many more complaints about their health during the year following bereavement than a comparison group of matched controls over the same time period. Psychological symptoms discriminated between the widows and the controls best of all, in particular depression, but also insomnia, "nervousness", and "reduced work capacity". There was also a marked increase in sedative and tranquilizer use by the widowed group. Although symptoms such as headaches, indigestion, and palpitations were very common among the widowed group, there was no significant difference in major diseases (for example, peptic ulcer, cancer), between the bereaved and the control groups. The authors conclude that these women were "unquestionably sick".

4. Clayton and Colleagues - the Depression of Grief

Clayton and her colleagues have also described normal bereavement, in a series of papers.

Clayton, Desmaris and Winokur [1968], outline the results of a study which interviewed 40 relatives of a series of hospital patients who had died, two to twenty-six days after the death. They found only 3 symptoms - depressed mood, sleep disturbance, and crying, occurred in more than half these subjects.

Guilt and hostility were rarely voiced - but were not systematically inquired about. Twenty-seven of these 40 subjects were given a follow-up interview two to four months later, by which time approximately 80% had improved, only 4% were worse, and only one relative had sought psychiatric assistance during the bereavement period. The authors note that their findings differed from those of Lindemann in that the majority of their subjects did not experience severe episodes of somatic distress, and preoccupation with the image of the deceased, guilt and hostility were also rare. Those subjects who were taking psychotropic medication or were drinking heavily had also tended to do so prior to bereavement.

In their discussion of their results, Clayton, Desmaris and Winokur [1968] remark that they tend to corroborate Freud's beliefs about grief, in that although it may represent a serious departure from the normal attitude of life, grief is not pathological and is generally self limiting.

Clayton, Halikas and Maurice [1971] published the first of a series of papers relating to a prospective study of the bereavement of a randomly selected group of 109 widows and widowers. This was a description of the first month of conjugal bereavement, obtained via a systematic interview comprising questions about the physical and mental health of the survivor, their social network, and their marriage. Their results were generally in agreement with their previous study. Crying, depressed mood and sleep disturbance were the primary features of the first month of bereavement. Poor concentration or memory, anorexia or weight loss, and the use of tranquilizing medication of some form or another was also common. Approximately 20% of these

subjects expressed guilt, as found by Parkes [1970], over trivial aspects of their behaviour either during the illness or at the death, or else more generally during their marriage. Restlessness was present in 45% of the subjects. Anger, or blaming others was usual, as were anxiety attacks. Clayton, Halikas and Maurice's discussion of these results is very similar to that of their earlier study. This is unsurprising in light of the similarity of the results.

Clayton, Halikas and Maurice [1972] followed the previous study with a further examination of their interview data from the 109 widows and widowers, but this time concentrating solely on evidence for depression. They drew up a series of criteria for a diagnosis of depression (for example, low mood, loss of appetite/weight loss, sleep difficulties, suicidal thoughts). Thirty-five percent of their subjects satisfied these criteria and thus received a diagnosis of depression. Thirteen months later, a large percentage of both the depressed and the non-depressed groups had "become well throughout the entire period of follow-up", however, "a subject depressed at one month after the death had a significantly higher risk of being depressed at one year" [Bornstein, Clayton and Halikas et. al., 1973, p.562]. On the other hand, when defined purely on the grounds of the onset of depression at follow-up of a subject who had not been depressed at one month after the death, the risk of "delayed grief" was estimated to be only two percent.

5. Harvard Bereavement Study

The largest study of grief thus far is the "Harvard Bereavement Study", with results published in two books

[Glick, Weiss and Parkes, 1974; Parkes and Weiss, 1983].

Between 1965 and 1970, 43 widows and 17 widowers all aged less than 45 years were interviewed on four occasions each. Firstly, within about three weeks of the death of their spouse - as near as possible to bereavement. Secondly, approximately eight weeks after the death - by which time the authors expected the immediate reaction to loss to have subsided. Thirdly, approximately thirteen months after the death - after a year of bereavement, but hopefully avoiding any "anniversary reactions". (Jacobs, Schaefer and Ostfeld et. al, [1987] note that the majority of bereaved persons observe the first anniversary of the death of a close family member, and they found this period to be associated with health or psychological changes, for example, depressed mood, nervousness, sleep or appetite disturbance, in about half the bereaved spouses whom they investigated). The final, follow-up interview in the Harvard Bereavement Study took place two to four years after the death. Slightly greater numbers of subjects participated in fewer than all four interviews.

Glick, Weiss and Parkes [1974] report that the reaction simply to the loss of their spouse was similar for widows and widowers, although the way the two groups reacted to the traumatic disruption to their lives was different.

The early reactions to death of a spouse were immediate disbelief, shock, or both. Crying was very common, coupled with sadness and despair. Impaired sleep, appetite, energy, and a general disorganisation appeared in some bereaved. "In the early weeks of

bereavement, shock, physical distress, bewilderment, and deep despair dominated the picture" [1974, p.52].

The feelings of shock and unreality generally only lasted a few days, coming to an end around the time of the funeral. As it dwindled the sorrow emerged, although by three weeks after the death about half their sample were crying less than they had earlier on, and as time went by crying tended to occur only in private - described by Glick, Weiss and Parkes as "solitary mourning" [1974, p.137].¹ The authors report that some self-blame and guilt was evident, but anger was much more commonly expressed - at either the spouse or at others (for example, doctors), who were perceived as having failed or misused the deceased. During this period, which the authors describe as "intense mourning" [1974, p.125], the bereaved engaged in frequent compulsive thoughts, reviewing the events up to and surrounding the death of their spouse, as though searching for the meaning of their loss. The authors believe that this activity could serve the useful function of allowing the bereaved to take in the loss both cognitively and emotionally. Anxiety, and disorganisation were also prominent, as the bereaved faced the prospect of coping alone. This was particularly the case for widows, who frequently expressed the feeling of having been abandoned by their husband. The majority of their subjects managed to cope with these reactions without resorting to professional help. Glick, Weiss and Parkes suggest that this was perhaps because of a belief that grief was without remedy, and that doctors would only prescribe pills which they may start to rely on; as such they must try to cope independently. By about two months after the death, the majority of their subjects were beginning to feel more like themselves again; "they had essentially

mastered the psychological shock brought on by the death of their husband and were beginning to direct their energies to life without him" [1974, p.141].

Throughout the first year of bereavement most subjects would think frequently of their dead spouse. However, as time went by their memories would become more realistic - as opposed to the earlier idealistic images. These memories were often comforting, as was the very commonly expressed sense of the spouse's presence. As the reality of the death of their spouse was accepted, the obsessional review of the circumstances surrounding the death ended. It was often around this time that activities such as sorting through the clothes of the deceased could be faced; a symbolic breaking of the ties.

By the end of the first year, some sort of new life had often been established. For widowers this recovery of normal roles and functions usually occurred sooner than for widows. Glick, Weiss and Parkes [1974] suggest that this results from their generally different social situations; men were more likely to have to hold down a job, and possibly the competing demands of work and family life pushed them into considering remarriage in order to re-establish an orderly life. In comparison, widows were more likely to remain alone with their children, sometimes out of continued loyalty to their dead husband, sometimes because they assessed the risks of a further loss as outweighing the benefits of another relationship. By follow-up, approximately one third of the widows and about half the widowers were moving towards remarriage.

6. Social Aspects of Bereavement

The majority of descriptions of bereavement note that not only does it mean loss of the loved one, but also loss of the roles and the life built up around that person - thus it is a social as well as an emotional process. For example, Parkes [1986] writes that the loss of a husband "may or may not mean the loss of a sexual partner, companion, accountant, gardener, baby-minder, audience, bed-warmer, and so on, depending upon the particular roles normally performed by the husband" [p.27]. There are also what Parkes terms "secondary losses", for example, a possible reduction in family finances.

As Bowling and Cartwright [1982] note, the fact that a bereaved spouse has to take on new roles at the same time as adjusting emotionally to their loss will tend to magnify the enormity of these changes. However, if the deceased had a long and disabling terminal illness, the survivor may have assumed many of their traditional roles before their actual death. Some bereaved spouses seem to regard the taking on of new roles as a challenge, whereas others resent having to learn new tasks.

Ball [1977] notes that "widows are unique in that they experience not only object loss but role loss as well" [p.309], and it is likely to be particularly so for a widow who previously defined her identity solely in terms of "wife". Glick, Weiss and Parkes [1974] list some of these roles in their description of "The Widow as Mother and Provider" as follows: informing her children of their father's death; deciding how to handle her own grief in front of her children; coping alone with, and setting rules for, often troublesome or

disturbed children; organising family budgets, including the provision of income; possibly taking up paid employment for the first time in their lives; and simply having to make decisions alone.

Osterweiss, Solomon and Green [1984] refer to the fact that in modern western societies there is generally less traditional support for the bereaved person, for example, extended families or religious rituals. Similarly, there is conflict in these societies between treatment of bereaved persons as though their loss is trifling (for example, negligible/no official leave from work granted in the event of a death in the family, societal discomfort if a bereaved person expresses their grief in public), and the expectation that they will conduct themselves in a manner regarded as respectful to the deceased (for example, the often subtle censure of the widow who begins to socialise "too soon" after her husband's death). Gorer [1965] points out that it is usually only the initial period of "shock" which is given social recognition in western societies. Once the funeral is over, most bereaved are left to face the period of "intense mourning" without either support or guidance.

The majority of authors note the isolation of the bereaved spouse, in particular widows. Gorer [1965], for instance, describes the avoidance of his widowed sister-in-law by her friends: "they treated her, she said, as though she were a leper" [p.15]. Only 4 of the 22 widows studied by Parkes [1970] could claim more social contacts thirteen months after bereavement than when their spouses were still alive. As has already been described, early in the grief process the majority of the bereaved are still so involved with resolving their relationship with the deceased that they have no

wish to enter into social situations, becoming isolated and withdrawn. But as Raphael [1984] points out, however willing a bereaved person may later be to re-enter society, the structure of modern western societies can make this difficult: society is oriented to couples, a single person is thus the odd one out. Glick, Weiss and Parkes [1974] quote a widow who described herself as feeling like a "fifth wheel" socially, believing that others did not feel comfortable in her presence. This is particularly the case for widows due to their greater numbers in society, whereas widowers, particularly younger ones, may actually be regarded as quite eligible. The result of this is that widows in particular may seek out the less threatening society of others in a similar position to themselves. Glick, Weiss and Parkes point out that the bereaved will continue to express great loneliness unless they are able to find a partner who can take the place of their spouse. It is not surprising then, to discover that Bowling and Cartwright [1982] found loneliness to be the most common problem identified by the elderly widowed in their study: 33% of their subjects replied "loneliness" when asked "Thinking about your life now, is there anything that you feel is a particular problem?"

III. GRIEF AS A PROCESS

Because some of the features of grief appear to be characteristic of certain stages of the bereavement period, the majority of authors describe grief as consisting of "phases" or "stages", each with differing characteristics. For example, Parkes writes as follows:

".. grief is a process and not a state. Grief is not a set of symptoms which start after a loss and then gradually fade away. It involves a succession of clinical pictures which blend into and replace one another. ... each of these stages of grieving has its own characteristics and there are considerable differences from one person to another as regards both the duration and the form of each stage. Nevertheless, there is a common pattern whose features can be observed without difficulty in nearly every case, and this justifies our regarding grief as a distinct psychological process." [1986, p.27].

As Stroebe and Stroebe [1987] point out, although there are differences in opinion over exactly how many phases of grief a bereaved person experiences, and over the terminology used to describe these phases, there does seem to be a general consensus about the nature of the process.

Bowlby [1961] initially described three phases of mourning: "In old and young, human and sub-human, loss of loved object leads to a behavioural sequence which, varied though it be, is in some degree predictable" [p.351]. These are: Phase One - "Urge to Recover Lost Object"; Phase Two - "Disorganisation"; and Phase Three - "Reorganisation". Parkes [1970], also describes three phases of grief: firstly, "numbing"; secondly, "yearning and protest"; and thirdly, "disorganisation". Parkes [1986], and Bowlby [1980], each acknowledge their close working relationship and their sharing of ideas, so it is perhaps not surprising that by 1980 Bowlby acknowledges that his initial description of three phases of mourning omits an important though brief first phase, that of numbing. This notion of a four phase process will now be used as a framework to describe grief.

1. Phase One - Numbing

This is variously described as "numbness" [Parkes, 1970; Bowlby, 1980], "numbness and disbelief" [Stedeford, 1984], "shock" [Gorer, 1965; DeVaul, Zisook and Faschingbaur, 1979], "shock and disbelief" [Engel, 1961], "shock, numbness and disbelief" [Raphael, 1984], "acute shock" followed by a "controlled phase" [Pincus, 1976], and, rather disconcertingly by Rando [1984], "avoidance".

Immediately after the death of a loved one, and before the onset of acute grief, the newly bereaved person may experience an emotional numbness. Intellectually they accept what has happened, but even so, the majority of the time they feel nothing. Breaking through this calm there may be sudden outbursts of intense emotion or panic attacks. Disbelief is expressed, with a sense of unreality and distance, as though what has happened cannot be true and must be happening to someone else. It is as if the newly bereaved is "in a dream or a nightmare from which he will awake" [Raphael, 1984, p.34], but while saying "I just can't believe it", the majority will realise the incongruity of this statement.

Raphael [1984] notes that although this shock and numbness is most severe when the death is unexpected, it occurs to some extent even when a death is anticipated. Similarly, "mourners often complain that they were not prepared for what it would be like" [Pincus, 1976].

Stedeford [1984] suggests that this phase has a protective function, allowing the bereaved to gradually take in the implications of the loss over a period of

time. Similarly, Rando [1984] describes this phase as representing a desire to avoid the terrible acknowledgement that that which was loved is now lost; denial functions as a buffer, "emotional anaesthesia" [p.29], allowing the bereaved person to gradually take in the reality of the loss.

Most authors agree that this stage usually lasts only a few days, and a maximum of two weeks in normal uncomplicated grief. Often it ends around the time of the funeral - when the sight of the coffin or sympathy from relatives and friends mean the reality of the loss cannot be denied any more.

2. Phase Two - Yearning and Searching: Urge to Recover Lost Object

Described as "yearning and protest" [Parkes, 1970]; "urge to recover lost object" [Bowlby, 1961]; "yearning and searching for the lost figure: anger" [Bowlby, 1980]; "searching" [Pincus, 1976]; "developing awareness of the loss" [Engel, 1961]; "intense mourning" [Gorer, 1965]; "acute mourning" [DeVaul, Zisook and Faschingbaur, 1979]; "acute grief" [Stedeford, 1984]; "separation pain" [Raphael, 1984]; "mental anguish" [Ball, 1977]; and "confrontation - angry sadness" [Rando, 1984].

As the numbness and denial fade away, the real pain and misery of grief are felt most intensely. Waves of distress break over the bereaved person. There is intense pining for the dead person, sobbing, and a high level of psychological arousal manifested by restlessness, agitation and insomnia. Grievers often experience panic and anxiety at this stage, stemming from having to face the unknown: "bereavement

invalidates a host of assumptions about the world" [Parkes, 1985].

Two other important features also tend to distinguish this phase. The first is a sense of the presence of the deceased. This manifests itself as preoccupation with thoughts of the deceased, for example, ruminating about their death, dreaming about them, and also misinterpreting signals such as a noise or a view of a person across the street as meaning the deceased is returning. The second feature is anger, and sometimes also guilt. Stedeford points out that "to bereave" can be literally interpreted as "to rob" or "to dispossess", and as such the bereaved person will experience a sense of outrage: he or she has been robbed not only of someone precious, but also of many hopes for the future. She believes that if this anger is acknowledged and either borne alone or shared, it will be gradually dissipated. However, if not acknowledged, it may be displaced or suppressed. Suppression of anger may result in depression or psychosomatic illness. Displacement of anger and blame can occur in any of several directions: onto the self, when it results in guilt over instances when the bereaved might have done or said something differently; onto those around them, when it results in alienation or irritability and accusations that no-one cares or understands what they are going through; onto the professionals who cared for the deceased, when it results in complaints of negligence and possibly litigation; and finally, onto God, with a resulting loss of faith.

The majority of authors follow Bowlby [1961, 1980] and Parkes [1970, 1986] in regarding this stage as representing an attempt to recover the lost one; a

biologically adaptive mechanism in social animals. When infants miss their mothers, their first response is usually to cry. This is adaptive because it will usually hurry the mother's return. Other social animals also have "lost calls" designed to provoke reunion; other social animals also engage in anxious searching for lost mates or pack members. Again this is adaptive because such a search may lead to reunion with the lost companions. It is thus not surprising that a bereaved individual will engage in crying or calling the dead person's name, thinking intensely about them, restlessly moving about and scanning their environment, developing a perceptual set for the lost person with the result that they are misperceived as present, and directing their attention to those parts of the environment which are associated with the deceased. Similarly, a demonstration of anger and aggression can be useful in achieving the return of a temporarily missing mother or partner - and in demonstrating displeasure at their disappearance, thus ensuring that it is less likely to occur again. Anger, then, can also be understood as an expression of the urge to recover the lost object. The problem is that in the case of bereavement the loss is permanent. Neither searching, crying, or anger will recover the deceased person. The result will be a deep sadness in the bereaved person.

3. Phase Three - Disorganisation and Despair

Once again, variously described: "disorganisation" [Parkes, 1970]; disorganisation and despair" [Bowlby, 1961, 1980; Parkes, 1986]; "depression and despair" [Stedeford, 1984]; "finality and mourning" [Raphael, 1984]. However, several authors regard this as a further part of the previous phase [Engel, 1961; Gorer,

1965; Pincus, 1976; Ball, 1977; DeVaul, Zisook and Faschingbaur 1979; Rando, 1984].

As noted above, all longing, searching, and other attempts to retrieve the deceased must in the end be fruitless. Eventually therefore, they dwindle and extinguish due to lack of positive reinforcement [Averill, 1968]. This is followed by a period of uncertainty, aimlessness and apathy, characterized by depression and withdrawal. The depression of the bereaved may be distinguished from a depressive illness in that it is rarely associated with fear of losing one's mind, is not retarded, rarely results in self deprecatory cognitions or suicide, and is not so commonly associated with a family history of psychiatric illness. Thus "grief is grief and is not a model for psychotic depression" [Bornstein, Clayton and Halikas et. al., 1973].

This phase is one of review and undoing the bonds that went into building the relationship. The bereaved person goes over the memories, thoughts and feelings associated with the dead person, both on their own and when talking with others. Sadness for all that has been lost is the predominant emotion. The bereaved may become so preoccupied with focussing on the dead person that their current day-to-day life seems meaningless and becomes disorganised. Life without the deceased may seem purposeless, and the bereaved may rely on other people to organise his or her daily activities.

This stage is often regarded as representing the gradual "emancipation from the bondage of the deceased" [Lindemann, 1944, p.143] - necessary before the bereaved can continue with their life or invest in further emotional relationships. Pincus [1976] and

Worden [1983] both discuss this as akin to the healing process following a physical wound. After a loss the bereaved individual will become healed not by simply forgetting the deceased but by "internalizing" them so that gradually the dependence on the external presence of the deceased is diminished. Stedeford [1984] describes this "healing" process to her clients as a smoothing off of the raw surfaces created by bereavement so that "you become a rounded person again", but "bigger than when you began. You will take into yourself some of his characteristics" [p.154].

4. Phase Four - Reorganisation

This final phase is also given a variety of different titles by different authors: "reorganisation" [Bowlby, 1961; 1980], "recovery" [Parkes, 1986], "restitution and recovery" [Engel, 1961], "resolution" [Ball, 1977; DeVaul, Zisook and Faschingbaur 1979; Stedeford, 1984], "adaptation" [Pincus, 1976], "re-establishment" [Rando, 1984].

Gradually the attention of the bereaved person shifts away from the deceased and towards their world without that person. They begin to build up new behaviours in place of those which were discarded as meaningless following the loss of the dead person. They begin to realise that life can go on without the deceased and indeed that new relationships may be possible - "the beginning of the emotional and social reentry back into the everyday world" [Rando, 1984, p.35]. This may be accompanied by a sense of achievement and new independence as the bereaved realises that they are capable of filling some of the roles previously occupied by the deceased. Although they cannot forget the lost person, their memories at this stage are

generally realistic and not associated with pining or sadness, However, a continued, often acute loneliness is common.

How long it takes to reach this stage has been variously estimated by different authors. As Worden [1983] points out, there can be no prescriptions for the duration of grief: "In some cases grief goes on for a relatively brief period of time, while in others it seems to go on for ever" [p.29]. The earlier studies generally estimated grief to be a fairly brief process: Lindemann [1944] wrote that with a psychiatrist to share the grief work, the normal adult grief reaction should settle within four to six weeks. Clayton, Desmaris and Winokur [1968] found that the bereavement symptoms in 81% of subjects followed up 2-4 months after the death of a relative had improved, and that those who had done so dated their improvement to 6-10 weeks after the death. Parkes [1986] however, described the process of grieving as still going on 13 months after bereavement in the widows whom he interviewed. The Harvard Bereavement Study concluded that most widowed would probably have accepted their loss and accomplished most of the work of review within a year of bereavement, but that it might take 2 or 3 additional years to firmly establish a new identity [Parkes and Weiss, 1983]. Bowlby [1980] discusses the bias in the earlier studies towards underestimating not only the intensity of distress and disablement of grief, but also the speed at which a normal healthy person should be able to completely get over a bereavement. He supposes that this denial of the effects of grief results from the impotence which we feel when faced with a bereaved person to whom no-one can bring true comfort.

5. Grief - "Phases" and "Stages", or Simply "Reactions" and "Components"?

It has been emphasised by many authors that the description of grief as a process of "phases" or "stages" should not be interpreted too literally. Even while first delineating his "Three Phases of Mourning", Bowlby [1961, p.331] points out that the sequence does not run a smooth, unvarying course, and that although there is a plainly discernible trend through the phases, both behaviour and feeling may oscillate violently, particularly soon after bereavement. Again, Bowlby [1980] describes his (by now) four phases of mourning as not clear cut, although an overall sequence can be described. Raphael [1984] notes that as well as passing backwards and forwards among the phases of grief, an individual may become stuck in one or another (which, should it be long lasting would represent a form of pathological grief). Both Osterweiss, Solomon and Green [1984] and Rando [1984] warn against the temptation to regard grief as a series of neat, individual stages, since such a simplification "might lead people to expect the bereaved to proceed from one clearly identifiable reaction to another in a more orderly fashion than usually occurs" [Osterweiss, Solomon and Green, 1984, p.48]. The result of this can be an attempt to understand an individual grief reaction by forcing it into one or other stage as outlined by the theory, rather than relating it to the individual's experiences and personality. Rando [1984] therefore rejects the use of the terms "stage" or "phase" to describe grief and instead opts for presenting "reactions", which she warns may not all be experienced by every griever and on the other hand may not be all that every griever experiences.

To complete this discussion, it should also be noted that this description of grief as a process of "stages" or "phases" would not be endorsed by every single author on the topic. In his discussion of "grief work" (emancipation from the bondage of the deceased, readjustment to the environment in which the deceased is missing, and the formation of new relationships), Lindemann [1944, p.143], describes the bereaved as having to yield to the grief process, but in this context Lindemann seems to be simply referring to the discomfort of bereavement, rather than grief as a serial, stage-like process. Bugen [1977], while acknowledging that the prevalent approach to the process of mourning is that of stages of bereavement, suggests instead "a theoretical conception that is not tied to a fixed order of emotional states" [p.196]. He criticises the writings of those who subscribe to a "stage" concept of grieving for the following five "theoretical weaknesses and inconsistencies". Firstly, the authors generally acknowledge that the stages they describe are not separate entities but blend into one another. Secondly, Bugen notes that the stages may not always succeed each other in the prescribed order. Thirdly, not every stage need be experienced by every individual. Fourthly, different individuals will experience differing intensities and durations of any one stage. Finally, while these authors write about grieving as "staged", they present little empirical evidence to back up this assertion. Bugen therefore presents a model which suggests "that stages, in the strictest sense, do not exist in the grieving process. Instead ... the existence of a variety of emotional states is the essential point, and not the need to order them" [p.197]. His model suggests that the intensity and duration of human grief can be predicted by two factors, the closeness of the relationship and

the mourner's perception of the preventability of the death. Ramsay [1979] agrees with Bugen "that the muddle of stages and components has caused theoretical and practical difficulties" [p.220]. He attempts to impose order onto the confusion by proposing a scheme of phases or components of grief. These include shock, disorganisation, searching behaviour, emotional components (subsuming pining, despair, guilt, anxiety, jealousy, shame and protest), resolution, acceptance and reintegration. Ramsay acknowledges individual differences in suggesting that one person does not have to experience all components. Most importantly, he suggests that the emotional components "can appear in any order, with varying intensity and importance for different persons ... they ebb and flow" [p.222]. He notes that denial plays a part throughout the process, while reintegration, at the end of his list of grief components is a long, difficult process which suffers interruptions and setbacks, particularly at anniversaries and festive occasions. Ramsay presents this scheme within the context of treatment for pathological grief. He suggests simply that the therapist should know which phases and components can exist, so that explorations can be made to check if one component is causing problems. He does not suggest that each grieving person should experience each component in a predetermined stage-like fashion.

IV. IS GRIEF A HEALTH RISK?

Engel [1961], asked the question "Is Grief a Disease?" He concluded that indeed grief did fulfil all the criteria of a discrete syndrome with relatively predictable symptomatology and course: firstly, grief involves suffering and impaired capacity to function;

secondly, we can identify a consistent etiologic factor - that of loss; thirdly, the grieving person is often obviously and objectively distressed and disabled.

Since then, the majority of authors have concentrated not so much on whether grief itself can be regarded as a disease, but whether it might cause illness and death, in other words, whether grief is a health risk. This section will examine the relationship of grief to mental and to physical health, and to mortality rates. It will conclude with a survey of the reasons which have been put forward to explain the relationship between bereavement and health and mortality. The aim of this section is to demonstrate that grief may have considerable effects on health, and if only for this reason is worthy of concern.

1. Does Grief Affect Mental Health?

Given that the central features of grief are emotional distress and long-term sadness, it is perhaps not surprising that bereavement is associated with an increase in psychiatric morbidity.

As noted previously, Clayton and her colleagues have focused on depression following bereavement. They report depressed mood, sleep disturbance, and crying in more than half a series of 40 bereaved people within the first month after the death of a relative [Clayton, Desmaris and Winokur, 1968]. Thirty-five percent of a group of 109 randomly selected widows and widowers had a collection of depressive symptoms similar to those common in psychiatric depressed patients [Clayton, Halikas and Maurice, 1971]. A year later 17% of these 109 subjects could be diagnosed as depressed [Bornstein, Clayton and Halikas et. al., 1973]. Also

noted earlier were Maddison and Viola's [1968], findings that when comparing matched controls with a group of 375 unselected widows thirteen months after bereavement, it was psychological symptoms (nervousness, depression, fear of nervous breakdown, panic, fears, repeated peculiar thoughts, nightmares, insomnia, trembling), which differentiated most consistently between the groups.

Parkes [1970], assessed the psychological state of 9 out of the 22 widows whom he interviewed as "definitely worse" 13 months after bereavement than prior to the terminal illness of their spouse. Of the rest, 7 were probably worse, 3 unchanged, and only 3 better. The Harvard Bereavement Study compared their group of widows and widowers 13 months after bereavement with a matched group of married controls [Parkes and Weiss, 1983]. They found their bereaved sample were especially likely to report more symptoms associated with the functioning of the autonomic nervous system - that is, symptoms of "tension" (for example, twitching, sweating, palpitations). They also displayed a greater incidence of emotional distress (for example, restlessness, finding life a strain, depression, insomnia, and changes in appetite). Finally, the bereaved group reported increased use of psychotropic medication, alcohol and smoking.

With regard to the incidence of other psychiatric disorders following bereavement, Stroebe and Stroebe [1987], and Osterweis, Solomon and Green [1984], review reports of an over-representation of the widowed relative to the married for incidence of mental disorder and psychiatric admission - certainly within the first year following bereavement. The conclusion,

then, is that the newly widowed are at risk for psychiatric illness and hospital admission.

2. Does Grief Affect Physical Health?

Although Maddison and Viola [1968], report a high frequency of symptoms such as headache, aching, fatigue, indigestion, palpitations and chest pain in their widowed group when compared with controls, this excess of physical complaints did not extend to increased frequency of severe diseases in the bereaved. Parkes [1970], described the physical health of 6 of the 22 widows interviewed as definitely worse 13 months after bereavement than before the illness and death of their husbands. Their symptoms included headaches, digestive disturbances and aching limbs - but again no severe diseases.

Parkes and Weiss [1983], compared the hospital admissions of their group of widows and widowers with their group of matched controls over the year following the bereavement or the interview. More bereaved subjects had been admitted and it appeared to the authors that the conditions which had precipitated their admission were more serious than those precipitating admission in the controls. They conclude that even if bereavement did not actually produce the disability reported it is likely that it had exacerbated it.

Osterweis, Solomon and Green [1984], review the evidence linking certain medical disorders to bereavement. They present reports of associations between bereavement and hyperthyroidism, diabetes, some cancers and cardiovascular disease. Nevertheless, their

overall conclusion is that apart from cardiovascular disease, any evidence for an association is meagre.

3. Does Grief Affect Mortality Rates?

Lieberman and Jacobs [1987], describe the two methods which can be used to assess the mortality of bereavement. One is to conduct a cross-sectional comparison of death rates in bereaved as compared to non-bereaved groups. The second is to conduct a longitudinal prospective examination of groups of bereaved persons. They conclude their review: "Both types of study consistently demonstrate an elevated risk of mortality in acutely grieved individuals" [p.28].

The old concept that bereavement is associated with an increased mortality rate for close relatives was examined in a cross-sectional study by Rees and Lutkins [1967]. During a six year survey in a small Welsh market town they found a seven-fold increase in risk of death for bereaved close relatives (spouse, child, parent or sibling) as compared with a matched control group of non-bereaved. The increase in risk was found to be greater for male than for female relatives, and for widowed people as opposed to those whose parent had died.

In their review of "The Mortality of Bereavement", Jacobs and Ostfeld [1977], note the association between widowhood and suicide, particularly for men. They describe reports demonstrating higher mortality in non-married groups when compared with married, and among the non-married in particular in the widowed rather than the single, divorced, or separated. They refer to the increased mortality rate for widowers within the

first 6 months of bereavement - whereas for widows the second year after bereavement may represent the period of highest risk. They note the over-representation of cardiovascular diseases as a cause of death in the bereaved.

Similarly, Osterweis, Solomon and Green [1984], conclude from their review of the mortality studies that bereavement is associated with a statistically significant increase in mortality for men under 75 years of age, most particularly in the first year, but possibly for as long as six years if they remain unmarried. The evidence is less clear for women. Older widowers and single men whose mothers have died are at increased risk from suicide. Again, the evidence for suicide is weaker for women. Widowers are more likely to die as a result of accidents, cardiovascular disease and some infectious diseases than married men. Widows are more likely to die from cirrhosis than married women.

Finally, following their review of the mortality literature, Strobe and Stroebe [1987], conclude that "with the exception of a few studies which employed small samples, findings from longitudinal studies substantiated the evidence from cross-sectional research indicating significant increases in mortality following marital bereavement" [p.161].

4. Why Does Grief Affect Health?

In fact the question here should still be, "Does grief affect health?" The reason for this is that the evidence reviewed above does not allow us to distinguish between two major hypotheses with regard to the association between bereavement and ill health or

death. These are: firstly, that grief itself can produce illness or death; secondly, that bereavement can result not only in grief but also "the event of conjugal loss identifies a group that has an excessive risk of mortality for other reasons" [Jacobs and Ostfeld, 1977].

With regard to the hypothesis that it is grief itself which produces illness or death, two possible causal mechanisms have been identified. The first of these is suicide. In their review Stroebe and Stroebe [1987], note that the rate of suicide is considerably higher among the widowed than among the married, certainly among men, and most especially in the period very soon after a death, as would be expected if suicide is taken as a behavioural indicator of the despair of grief. The second causal mechanism is what has been described as "the classical broken heart" [Parkes, 1985]. It has been noted that among the bereaved there is an over-representation of cardiovascular diseases. Parkes [1985, 1986], hypothesises that given the well known effects of emotion on the coronary arteries, it is possible that the physiological accompaniments of severe grief exacerbate heart disease in those people for whom it is already present at a considerable level. Until this mechanism is further researched, however, other causes of heart disease following bereavement cannot be ruled out, for example, increased smoking or alterations in the diet.

With regard to the hypothesis that it is not grief per se which produces an elevated risk of mortality, several causal mechanisms have been postulated [Epstein, Weitz and Roback et. al., 1975; Jacobs and Ostfeld, 1977; Jacobs and Douglas, 1979].

The selection hypothesis states that those widowed who are in good health tend to remarry quickly and select themselves out so that only those of the widowed population who have a high risk of illness and mortality remain.

The homogamy hypothesis states that knowingly or unknowingly the unfit marry the unfit, thus increasing the likelihood that both partners will die around the same time.

The joint unfavourable environment hypothesis states that both partners may have shared common unfavourable environments thus again increasing the likelihood that both will die around the same time. An extreme example of this would be that if a married couple had a car crash in which one partner died immediately and the second a few hours later, that second partner would count among the bereaved in the mortality statistics.

The behaviour change hypothesis states that because the deceased is not available to encourage or support adaptive behaviours, the bereaved person may cease activities such as visiting the doctor, taking medication as prescribed, or eating sensibly.

Although it is still not entirely clear which of the above mechanisms best accounts for the mortality of bereavement (other than by suicide), Epstein, Weitz and Roback et. al., [1975], state that physiological effects of grief (the broken heart) plus the behaviour change and the joint unfavourable environment hypothesis seem to account for the data more adequately than either the selection or the homogamy hypotheses.

V. ARE SOME PEOPLE AT GREATER RISK FOR SEVERE GRIEF?

Not every bereaved individual suffers grief to the same extent. Indeed, as Parkes [1985] points out, not every loss is necessarily even harmful, and many individuals "come through the stress of bereavement stronger and more mature than they were beforehand" [p.11].

A great many factors have been postulated as placing an individual at greater risk for an adverse outcome following bereavement, either in the form of a more severe grief reaction, or adverse health consequences. A brief review of these factors follows. The characteristics of the bereaved subject will be considered first, followed by the relationship of the bereaved to the deceased, and finally those factors which appear after the death. The effect of the circumstances surrounding the death will not be considered in this section.

1. Characteristics of the Bereaved Subject

AGE:

Maddison and Walker [1967] found that out of various social and personal characteristics of the 132 Boston widows who completed a health questionnaire, "only age of widow and age of husband were found to have a statistically significant relationship to illness score, with younger widows and/or widows of younger husbands reporting greater deterioration in health following bereavement" [p.1065]. Similarly Ball [1977] found that middle and old age widows had a significantly lower level of grief responses as measured by a self-report questionnaire, than did young widows. Parkes [1986] describes finding that widows under 65 years of age were much more likely to consult

their GP for help with emotional problems, and to increase their consumption of sedatives following bereavement than were older widows. In view of the evidence linking more intense grief reactions with younger age, the Harvard Bereavement Study decided to only select subjects under 45 years old, in order to maximise the likelihood of encountering troubled recoveries [Parkes and Weiss, 1983].

Thus the evidence is that grief intensity - certainly for women - is significantly inversely related to age. Stroebe and Stroebe [1987] sum this up: "... the majority of the studies on age and bereavement outcome documented the relatively good adjustment of older widowed compared with younger ..." [p.187]. However, they warn against assuming from this that the older widowed might not suffer severe grief.

GENDER:

It is actually quite difficult to begin to determine the effects of gender on bereavement outcome, because the majority of studies only have female subjects. This is because they are relatively so much more common, for as Gorer [1965] points out: "widowhood is the likely lot of every British married woman, for women are longer lived than men, and usually, younger than their husbands" [p.91].

Osterweis, Solomon and Green [1984] report a disagreement in the results of studies which examine the effects of gender, with some finding men do better and others that they do worse. Parkes [1986] concludes that "one way and another women usually come out of bereavement worse than men" [p.142]. He cites studies which demonstrate more obvious distress among bereaved women than men. However, he goes on to say that the

findings of the Harvard Bereavement Study demonstrated that when compared to married controls, widowed women actually showed no greater decline in adjustment than widowed men - and by follow-up the men seemed to have taken longer to recover than the women. Glick, Weiss and Parkes [1974] also discuss this gender difference in grief, commenting that from the outset men tended to be more realistic about the death, but also that they found it more difficult to display their grief openly. Culturally it is more acceptable for an open display of grief from women. It is interesting then, that Stroebe and Stroebe [1987] state that although any evidence of a gender difference for bereavement outcome is somewhat inconclusive, if there is a difference then it is men who are at a higher risk. Jacobs and Ostfeld [1977] are more definite: "men are consistently at greater risk at all ages than women" [p.352].

From the above evidence the only conclusion can be that it is virtually impossible to draw firm conclusions on the effect of gender as a risk factor for grief.

RELIGIOUS BELIEFS:

Parkes [1986] reports that 13 of the 18 London widows who expressed a belief in God believed that their faith had helped them - possibly their belief allowed these widows to place the bereavement into some sort of meaningful perspective. However, he also notes that several regular churchgoers did not cope well with their bereavement. In their consideration of the depression of the widowed 13 months after bereavement, Bornstein, Clayton and Halikas et. al. [1973] found that 50% of those who were still depressed had never attended church before the death, compared with 17% of the non-depressed. This difference was statistically significant. Almost all the elderly widowed subjects

investigated by Bowling and Cartwright [1982] said they had a religion, and about half that they had some sort of belief or philosophy or practise which had helped them adjust to bereavement. Despite this, there were no significant differences on either an adjustment scale or in the amount of loneliness reported by those who felt they had a helpful philosophy when compared with those who did not.

Turning from the effects of a religious belief on grief or adjustment to the effects of bereavement on religious beliefs, 73% of Glick, Weiss and Parkes' [1974] sample of widows said the death had not affected their religious beliefs. Of course, this means that the beliefs of a quarter of these subjects had been shaken. Some found it helpful to give their bereavement some sort of religious explanation ("God must have wanted him very much").

Stroebe and Stroebe [1987] close their review of the impact of religious beliefs on bereavement outcome by concluding that if religion is a predictor at all, it is a very weak one. They also point out a confounding factor, in that "religion" has both social and spiritual components, and any mitigating effects of these two aspects are difficult to separate.

SOCIOECONOMIC STATUS:

Maddison and Walker [1967] report no significant relationship between illness score and socioeconomic status in the 132 Boston widows who completed their health questionnaire. This disagrees with the findings of the Harvard Bereavement Study that low social class did correlate significantly with poor outcome 13 months following bereavement. However, as Parkes and Weiss [1983] point out, their results are somewhat confusing

since this relationship did not hold for the grief reactions of their respondents at the time of their first and second interviews (about 3 and 8 weeks after bereavement).

The majority of reviews [for example, Jacobs and Ostfeld, 1977; Shackleton, 1984; Osterweis, Solomon and Green, 1984], conclude that the association between socioeconomic status and bereavement outcomes has not been adequately studied.

PERSONALITY:

Lindemann [1944] believed that although people "with obsessive personality make-up and with a history of former depressions are likely to develop an agitated depression", social factors were more important predictors of the type and severity of the grief reaction than "a tendency to react with neurotic symptoms in previous life" [p.146-7]. Maddison and Walker [1967] did not find that "overt neurosis itself" was a predictor of outcome. Parkes [1986], however points out that we might expect personality variables to be an important factor in determining the magnitude of grief and "that a person may be grief-prone I do not doubt" [p.153]. He describes studies which lead him to conclude that previous severe grief reactions, or a history of depression, might predict poor outcome. He speculates that this might be due to "clinging" or "dependent" personalities resulting from early losses in the lives of these individuals.

2. Relationship of the Bereaved to the Deceased

BLOOD/ROLE RELATIONSHIP:

By far the majority of bereavement studies have concentrated solely on the effects following death of a

spouse. One study which does compare the intensities of grief across bereavement situations is that of Sanders [1980] who used the Grief Experience Inventory and MMPI to compare adult bereavement following the death of a spouse, child and parent. Interviews were conducted by Sanders with 102 bereaved adults an average of 2.2 months following the death, and with 107 controls who had not experienced a bereavement in the previous five years. Her results demonstrated the highest intensities of bereavement and the widest range of reactions following the death of a child, while the death of a parent generated the lowest intensities of bereavement. Sanders explains these results in terms of the low expectation of losing a child compared with that of losing a parent during one's lifetime. Similarly Gorer [1965] describes the loss of a grown child as "the most distressing and long-lasting of all griefs" [p.106]. He speculates on two reasons for this: firstly, as put forward by Sanders, that it goes against the order of nature for a child to die before his or her parents; secondly, that the death of a child represents a destruction of the self image (as "mother" or "father") of the parents.

QUALITY OF RELATIONSHIP:

While noting that there was no general evidence of a clear one-to-one relationship between a poor marital relationship and an unsatisfactory outcome following bereavement, Maddison [1968] does identify a particular group of widows in whom this was the case, namely where their marriage "had shown unequivocal sado-masochistic aspects" [p.225]. He points out that culturally it would have been very difficult for the Boston widows whom he studied to express any hostility to their dead spouse. The Harvard Bereavement Study found that although the survivors of conflicted marriages seemed

less likely to be affected by the loss of their spouse early in the bereavement process (at the 3 and 8 week interviews). By follow-up 13 months later, it was those widows and widowers whose marriages had been low in conflict who were most likely to have returned to effective functioning [Parkes and Weiss, 1983]. As Bowling and Cartwright [1982] point out, people who have had a good relationship with their spouse may feel a greater sense of deprivation when they are widowed, however if feelings within the marriage were mixed or unhappy then the surviving partner may be more likely to harbour bitterness, resentment and guilt and perhaps be less able to come to terms with their emotions.

3. Factors Following the Death

DOMESTIC SITUATION:

While Maddison [1968] describes his study as suggesting that widows with dependent children tend to do badly, the Harvard Bereavement Study found that having children at home resulted in a somewhat better outcome, but this result was not statistically significant [Parkes and Weiss, 1983]. They did not find any relationship between proximity of siblings and outcome, nor for poor financial status or low income.

SOCIAL SUPPORT:

Maddison and Walker [1967] report that a bad outcome for bereavement (as assessed by poor health status at 13 months), occurred in widows who tended to perceive their social environment as actively unhelpful in terms of coping with their grief: social exchanges were more likely to be hostile, to prevent the widow expressing her feelings, and to attempt to make her think about the future. Parkes and Weiss [1983] report that it is not so much the number of people who might act as

supports to the bereaved person, but whether their support was utilized as time went on that was important.

EARLY GRIEF REACTION AS A PREDICTOR OF OUTCOME:

As previously reported, Bornstein, Clayton, and Halikas et. al. [1973] found that depression at one month following bereavement was a significant predictor of depression thirteen months later. Similarly, two out of the three major determinants of pathological grief in the Harvard Bereavement Study were earlier reactions of anger and/or self reproach, and reactions of intense yearning. Thus we can conclude that a severe early grief reaction does appear to predict poor outcome.

4. The Circumstances Surrounding the Death

This is another area where the reports yield conflicting data. However, since the topic forms much of the next two chapters (on "Anticipatory Grief" and "Social Death"), it will not be discussed further here.

VI. SUMMARY

This section has discussed the increase of academic and professional interest in bereavement and grief over recent years, and has presented several descriptions of "normal" adult grief. It has pointed out that grief has not only psychological but also social aspects. These descriptions have then been placed within the context of grief as a process of identifiable phases (numbing; yearning and protest; disorganisation and despair; reorganisation), together with a warning against taking such a stage-like notion of grief too literally.

The notion of grief as a significant risk in terms of mental health, physical health or death, has been presented - either as a direct result of the grief per se or else because bereavement identifies a group of "at risk" individuals.

Finally, those factors which may increase the likelihood of a poor long term outcome to a grief reaction have been discussed. Although much of the data in this area is conflicting, it appeared that the following may predict a "bad" grief: young age; possibly being male; possibly a "clinging" or "dependent" personality; an unhappy relationship; death of a child (rather than a parent); the prevention of the expression of emotion or review of the past by those supporting the bereaved; a severe early grief reaction.

Whether the circumstances surrounding the death affect the post-death grief reaction belongs to the following chapters.

CHAPTER FOUR

ANTICIPATORY GRIEF

"This autumn I learned from experience that a man can cross the threshold of death even when his body is still not dead. Your blood still circulates and your stomach digests, while you yourself have gone through the whole psychological preparation for death - and lived through death itself. Everything around you you see as if from the grave."

[Solzhenitsyn, "Cancer Ward", Penguin, 1971, p.41.]

I. INTRODUCTION

"Anticipatory Grief" is defined by Aldrich [1974] as "any grief occurring prior to a loss, as distinguished from the grief which occurs at or after a loss" [p.4]. As Siegel and Weinstein [1983] point out, it is a concept which, despite "surprisingly little empirical study" has received considerable attention in the academic and professional literature on dying, grief and mourning - it has been the subject of 3 review articles [Fulton and Gottesman, 1980; Siegel and Weinstein, 1983; Sweeting and Gilhooly, 1990], and 2 books [Schoenberg, Carr and Peretz et. al., 1974; Rando, 1986].

The majority of papers refer to the fact that the term was first coined by Lindemann [1944]. Writing during the second world war, he described his initial surprise at the reactions of some of the relatives of members of the armed forces - players in a situation in which the threat of death was ever present. Lindemann observed that commonly those left behind were so concerned with

their adjustment should their father/son/husband/boy-friend be killed that they "went through all the phases of grief - depression, heightened preoccupation with the departed, a review of all the forms of death which might befall him, and anticipation of the modes of readjustment which might be necessitated by it" [pp.147-8]. Although this might serve to safeguard the relative should there be news of sudden death, it could also be a disadvantage should the soldier, sailor or airman return, since in some cases the relatives had resolved their grief so thoroughly by this time that it was hard to accept him back into their lives.

Since then, anticipatory grief has most usually been applied to patients and families facing a lengthy terminal illness, such as cancer. It has often been assumed that, just as with Lindemann's relatives of members of the armed forces, the relatives of dying patients are so concerned with their adjustment in the face of the potential loss that they slowly experience all the phases of normal grief as they cope with the illness or endure separations prior to death. As a result of this emotional preparation it has also often been assumed that after the death their experience of grief will be less intense.

The aim of this chapter is to examine these two assumptions in detail. The first section reviews the nature of anticipatory grief. This is done by first presenting the evidence, in the form of descriptive studies of the reactions of those involved with dying people, followed by discussions of this evidence. The discussion is both in terms of whether these reactions can be said to constitute grief in anticipation, and also whether they can be described as a sequential or staged process. The second section asks whether

emotional preparation really does result in the experience of reduced grief after a death. Again this is done by first presenting the evidence available from research studies, followed by a discussion of the results which have been obtained.

II. ANTICIPATORY GRIEF - WHAT IS IT REALLY?

1. Descriptive Studies of "Anticipatory Grief" Reactions

Rando [1986] refers to anticipatory grief as "multidimensional". She describes it as having two perspectives and three time foci. The perspectives are those of the dying patient and those of the people who are emotionally involved with that patient, which includes both family and professional caregivers. The three time foci are the past, the present and the future. She points out that the term "anticipatory grief" may be something of a misnomer, since once someone becomes a dying person they have already lost certain things (for example, their health, their role as worker, their ability to play 18 holes of golf), they are currently losing things (for example, through increasing debility and reduced control over their own life), and they will lose more in the future.

The presentation of the descriptive evidence for the concept of anticipatory grief will use the perspectives suggested by Rando - namely patient, family and professional caregivers - as a framework. However, the emphasis is most heavily directed towards the reactions of the relatives of dying patients. Within each subsection the studies are presented in largely chronological order.

STUDIES OF THE REACTIONS OF DYING PATIENTS THEMSELVES

Hinton, a psychiatrist, first published his book entitled "Dying" in 1967. It presents not only medical and social facts about death and dying in the middle of the twentieth century, but also a discussion of emotional distress in terminal illness, based on conversations with, and observations of dying patients. He describes the mixture of emotions with which adults may meet their death: "Mingled with the courage and the varying degrees of acceptance of the inevitable are a host of other emotions, pleasant and unpleasant, some concealed and some plain for all to see" [p.79]. Anxiety was plainly obvious in some patients, related to fears of death, fears of severe physical discomfort, or fears of separation from loved ones. Although Hinton found that the anxieties of dying people tended to fluctuate from time to time, he could discern no definite trend of either increasing or decreasing fear as the illness progressed. He describes depression as more commonly occurring than anxiety: he observed sadness and melancholy which were not simply the results of physical exhaustion. Some terminal patients consider - or succeed - in a suicide attempt. Hinton noted depression to increase as the illness lengthens and physical discomfort increases. It is miserable to have to endure so much pain and exhaustion. A greater degree of depression was also associated with the lack of availability of love and companionship, thoughts of the injustice of the situation and of personal and future losses, and with previous personality characteristics. Hinton refers to a controversy over the extent to which dying people are aware of their approaching end, pointing out that professional findings may relate more to professional opinions rather than to objective facts. Thus those who give the

dying a chance to talk about such things find that they are generally relieved to do so, while those professionals who believe their patients do not wish to discuss the matter will, by their own behaviour probably also have their opinions confirmed. Hinton himself found that during his bedside visits to a number of patients only 5% seemed confident of recovery, 8% anticipated partial recovery, 49% quickly demonstrated they knew their illness might be fatal and 38% did not speak of their future outlook, apart from the use of vague terms such as "taking it steady". "Considered as a group ... those patients who remained and died in the hospital came to know more and more certainly that death was approaching" [p.98]. Despite this, there were some patients who used denial - and Hinton found that denial and acceptance could occur in the same patient; people are unlikely to want to think constantly of their death, and it can be a comfort to dream about the future. He also describes a group (about 25%) of patients who while aware of the fact of dying, struggle against it - exhibiting distress and discontent with themselves or the professionals. Finally, Hinton refers to the quarter of patients in hospital whom he found to exhibit acceptance and positive composure, often referring to themselves as having had "a good life". He believes that acceptance need not be a slow process, although it often is, and can be associated with making practical preparations for approaching death and even showing "a quiet enjoyment of their relaxation, now that the struggles of life are over" [p.107].

Hinton's work was completely overtaken in the popularity stakes by the next book to tackle the emotional reactions of dying patients - Kubler-Ross' [1970] "On Death and Dying". It is interesting to

speculate on the reasons for this. Kubler-Ross includes lengthy transcripts of her conversations with dying patients which certainly add to the "human interest" aspect of the work. She also presents their reactions as a clear process of defined stages. By doing this she conveys the impression of something which is fairly simple to understand and she also provides what often seems to have been regarded as the therapeutic key - if dying patients and their families can be "helped" through this process towards mutual acceptance then the death will be a "good" one in the sense that the emotional distress which follows it should be minimised. The study was written after 2½ years of listening to, and learning from, the stories of over 200 dying patients in America. The stages through which Kubler-Ross observed these patients to pass form the titles of chapters in the book. The first stage is "Denial and Isolation". Initial denial of the diagnosis or prognosis was described by the majority of patients, and accompanied by behaviours such as insisting a mistake had occurred in the diagnostic tests, "shopping around" for alternative diagnoses, or isolating themselves so as not to have to discuss their health with others. Kubler-Ross points out that denial is not only used at the beginning but also from time to time throughout the illness. She regards this as a healthy way of coping providing it does not reach excessive levels. This is followed by the second stage, "Anger". While denial is associated with thoughts of, "No - it's not me" , anger is associated with thoughts of, "Why me?". The patient may experience anger, rage, envy and resentment. If these feelings are projected onto their doctors or their family it can be particularly difficult to cope with: "Wherever the patient looks at this time, he will find grievances" [p.45]. The third stage is "Bargaining", often with God, and associated

with "If I do ... then ...", and a belief in rewards for good behaviour. It is an attempt to postpone: patients may become involved in the church, or promise to donate their body to science. This is followed by the fourth stage, "Depression". When denial cannot be continued, and as the patient becomes weaker and sicker, he or she is faced with a sense of loss. Kubler-Ross refers here not only to loss of life, but also to loss of body parts, role, finances, etc. - with a resulting reactive depression. At the same time, patients are described as engaging in "preparatory grieving", that is, grieving for their future loss of life and separation. She points out that this is "tremendously sad" and that patients should therefore be allowed to express this legitimate sorrow rather than just encouraged to cheer up. The fifth and final stage is that of "Acceptance". Kubler-Ross believes that it will only occur if the patient has had enough time and has been given help in working through the previous stages. Having expressed his or her anger and mourning the patient can now accept fate. Kubler-Ross describes this stage as neither one of having hopelessly given up, nor of happiness, but rather as almost devoid of feelings. Throughout each of these stages the common thread is hope, which she describes as evident in even the most accepting patients. Hope for a new cure or some other miracle can maintain the patient who would otherwise be unable to cope with the strain of their illness and its treatment.

Sanders and Kardinal [1977] identified the following adaptive coping mechanisms in 6 adult leukaemia patients who were in remission and receiving maintenance chemotherapy: denial of being sick, identification with fellow patients, and anticipatory grief. Denial was manifested by the desire of the

patients to remain in a normal "well" role within the family. Their families on the other hand tended to treat them as continuously "sick", and very little communication occurred with regard to their diagnosis, treatment or prognosis. Denial was also evident in the delaying of return visits to hospital by these patients - hospital is for sick people. When patients did return to hospital, denial was difficult to maintain and they commonly coped by becoming part of the "hospital family". Group identity was very strong, with high status being related to lengthy survival or periods of remission. The impact of the death of one member on the rest of the group was enormous. Sanders and Kardinal believe that by mourning the loss of another, the patients were also engaged by proxy in their own anticipatory grieving.

STUDIES OF THE REACTIONS OF THE RELATIVES OF DYING PATIENTS

The earliest descriptions (described by Rando as forming the "backbone of research on the topic" [1983, p.4] are of the reactions of parents whose children were dying of malignant diseases. Possibly this group of subjects was focussed upon because although in previous centuries the death of a child might have been just part of everyday life, recently, with the increase in life expectations, childhood and death have become so antithetical that the impact of the death of a child has correspondingly increased [Gourevitch, 1973]. A further point of note is that in the 30 or so years which have passed since the publication of the earliest of the studies to be cited here, the treatment of these diseases has further advanced. Bozeman, Orbach and Sutherland [195] compared the average survival period of children with leukaemia treated at Memorial Center

for Cancer, New York between 1926-48 (when it was 19.3 weeks) with the fact that by 1955, 50% of children with acute leukaemia could expect to survive more than 12 months after the onset of the disease. But at that time, "Despite remarkable advances in treatment, leukaemia (was) invariably fatal" [p.1]. Now it is not. Van Dongen-Melman and Sanders -Woudstra [1986] describe childhood cancer, once regarded as an acute fatal illness as now a chronic life-threatening disease. The reactions of the parents of current day children diagnosed with cancer are therefore likely to be somewhat different from those of 30 years ago. That makes the poignant studies to be described here even more interesting.

Richmond and Waisman [1955] report observations made during their management of "48 children with leukaemia and many children with other malignant lesions" [p.42]. They document several features of what they describe as part of the "mourning process" which the parents of these children experienced. These included parental withdrawal, feelings of unworthiness, preoccupation with thoughts of earlier times, initial anxiety and guilt about the possibility of their having been responsible for the development of the illness, together with feelings of concern, loss and emptiness as they realise they are to be separated from their child. Richmond and Waisman discuss the advantages of a prolonged fatal illness since it allows a substantial part of the relative's mourning process to occur prior to the death of the patient, facilitated by the physical separation which results from their hospitalization: "parents are often enabled to traverse this difficult emotional experience with much less difficulty in this way" [p.45]. They found parental adaptation to be facilitated by personal participation

in the care of their own child, since it both served to relieve guilt because of the feeling that they had done everything possible for their child, including the relief of pain and discomfort, and it also allowed them to spend as much time as possible with their child. After a time in which involvement was solely with their own child, parents tended to develop a desire to help in the care for other children. Richmond and Waisman believed that this "marked a turning point in parental adjustment which reflected acceptance of the child's illness and ultimate death" [p.45]. Energies which had been previously directed towards mourning could now be directed elsewhere.

Bozeman, Orbach and Sutherland [1955] describe the way in which 20 mothers reacted to leukaemia in their young children. At that date the usual course of this illness was fluctuating but inevitably fatal. Once the child had been hospitalized, mothers were seen by the authors as frequently as possible; between 2 and 5 formal focussed interviews were conducted, plus informal chats and observations. Initial reactions to the diagnosis included disbelief and sensations of physical injury, quickly followed by efforts to prove that the diagnosis was incorrect with the demand for second or third professional opinions. Often hospitalization was welcomed at this stage, as representing a chance for professional contact and possible recovery. With time, if the diagnosis could not be denied, the mother would attempt to deny its hopeless prognostic implications. Bozeman et. al. also report feelings of guilt and the assumption of personal responsibility (due to some sort of failings) by these mothers soon after the receipt of the diagnosis. The authors describe anger and hostility focussed on the physicians which they believe represented a fight to reverse the diagnosis, since in

making the diagnosis the doctors become the perpetrators of the injury. Because of this, the way in which the physician breaks the news of the fatal diagnosis, and any optimism which he demonstrates is regarded as a key determinant of the mother's subsequent adaptation. Although hospitalization was generally regarded as positive in that it was associated with the possibilities of alternative diagnosis or cure, Bozeman et. al. also comment on the way in which it represents a rehearsal of the permanent separation which will come at the child's death. In what they regard as an attempt to prevent this, mothers were observed to physically cling onto their children and to ask when they would be discharged from hospital. The authors present the start of the leukaemia treatment as representing the time at which the diagnosis could not be denied further. It was associated with a redirection of the mothers' energies towards gathering information about the illness in a further attempt to prove the doctors wrong. The failure of this strategy was associated with the intellectual acceptance of the diagnosis and fatal outcome. However, the mothers still exhibited hope, demonstrated by their own child's immediate condition and treatment, and their delight and triumph if remission allowed for a temporary discharge from hospital.

Following their observations of 33 mothers of children who were fatally ill with leukaemia or a related disorder, Natterson and Knudson [1960; Natterson, 1973] described a triphasic response in those whose child survived more than four months from the time of the fatal prognosis. Initially denial and guilt were predominant. Most of the mothers were tense, anxious, withdrawn and weepy, reacting with disbelief to either the diagnosis or the prognosis which they had been

given. The needs of the rest of their family were subsumed by their need to be with the sick child. Hope for new treatments was expressed, along with guilt about what they might have done to cause their child's illness. In the intermediate phase the mothers tended to accept the reality and to direct their interest toward realistic measures that gave hope of saving, or at least comforting their child. The authors describe this phase as representing the beginning of the mourning process as described by Richmond and Waisman. In the final "terminal" phase, (which usually only occurred if the time between diagnosis and death was longer than 4 months), the mothers tended to direct their energies away from their own children. Over half demonstrated a "calm acceptance" of the fatal outcome. Wishes for the death of the child might be expressed openly and without guilt. They were able to separate from their own child and its immediate concerns and move towards providing aid and comfort for all the children on the ward, or expressing interest in leukaemia generally. When their child died they expressed "calm sorrow and relief". In their 1960 report, Natterson and Knudson imply that these mothers had almost finished their grief work, but Natterson [1973] amends this somewhat by remarking that his subsequent clinical experience "definitely indicates that grief work is far from complete at this time" [p.124].

Chodoff, Stanford and Friedman et. al. [1964] present their observations on the adaptational techniques and coping strategies of a group of 46 parents of fatally ill children (suffering from neoplastic diseases). Despite the enormous stress of watching and caring for a dying child, the authors describe most parents as able to function effectively during this period of

illness, and in their paper they describe this "'natural history' of adaptation to the situation, an almost orderly and predictable sequence of events through which the parents passed" [p.744]. Even before the diagnosis most parents felt vaguely uneasy. Despite this, the diagnosis is received as a physical blow and with an insulating feeling of unreality. With admission of their child to hospital these parents generally experienced a split between intellectual acceptance and emotional non-acceptance of the grim diagnosis and prognosis. Chodoff et. al. note, a variety of fairly persistent patterns of coping which appeared at this time. These included internal "defensive" behaviours, the most common being isolation of affect, denial (ie. failure to accept either the diagnosis or its consequential grim prognosis), and motor activity. Coping also included the ability of the parent to continue caring for their sick child as well as fulfilling their other responsibilities. The authors also describe the urgent "search for meaning" which the parents engaged in, both on the specific "Why did it happen to my child?" level, and the more general level demonstrated by an intellectual interest in the disease itself. With time, as their child became more obviously sick, the parents became more emotional: "As denial waned and reality enforced its claim, there appeared the phenomenon of 'anticipatory mourning' as first described by Lindemann and applied by Richmond and Waisman ..." [p.744]. In agreement with Natterson and Knudson's [1960] findings, these authors describe the process of anticipatory mourning as occurring most clearly if the child's illness lasted longer than about 4 months. It was associated with a facing of reality and diminution of hope. The parents displayed somatic changes characteristic of grief, and were preoccupied with thoughts of their child. With time, and increasing

resignation, these thoughts changed as though the child was becoming less of a real object to the parents and more a memory. Parents described a feeling of detachment and when the child's death occurred they usually took it with calmness and relief. The authors note an inverse relationship between anticipatory mourning and denial, with increased denial during the terminal illness associated with greater distress once the death had actually occurred.

Similar results were again reported by Binger, Ablin and Feurstein et. al., [1969] in a study of the emotional impact of child leukaemia on the patient's family following lengthy interviews with 20 families after the death of their child. Many parents described the diagnosis as the hardest blow they had to face, with reactions ranging from loss of control to calm resignation. Although more distant relatives might deny the diagnosis, the parents did not, and from the time of the diagnosis they experienced what the authors describe as the "anticipatory grief reaction", manifested by intellectualization, frenzied activity, depression, irritability, anger, hostility and guilt.

"The actual death was not always the most important event in the parents recollection of the child's illness. Often, the time of initial diagnosis was equated with death, and it was then that grieving began. The parents of 10 children expressed a sense of relief as well as grief at the time of the child's death. Some were relieved that the child's suffering was at an end; others felt relieved from long-standing worry over when and how the child would die" [p.417].

Despite this apparent relief, in 11 of the 20 families at least one member suffered such severe emotional disturbances after as to the death as to need psychiatric help.

In what must be the most well-read description of the emotional reactions of dying patients, Kubler-Ross [1970] also includes a brief description of the "stages of adjustment" of their relatives, which she speaks of as similar to those of the dying patients. In contrast to the earlier descriptions cited here, the subjects of her study were adult patients and their families. The reactions of these families are described as follows. Initial disbelief, with denial, "shopping around" for an alternative diagnosis or secrecy about the illness. Secondly, anger projected at those involved in the professional diagnosis and management of the patient and guilt at missed opportunities. Thirdly, "preparatory grief" which if it can be expressed openly and with the patient before their death allows for a gradual and mutual facing of the reality of the impending separation which Kubler-Ross states will make it less unbearable after the actual death. She presents the idea of a "working through" and open communication by both patient and family of each stage of adjustment towards acceptance of the death.

To return to the emotional reactions of the families of fatally ill children, Futterman, Hoffman and Shabsin [1972] and Futterman and Hoffman [1973] present parental anticipatory mourning as "a set of processes that are directly related to the adaptive mechanisms whereby emotional attachment to the dying child is relinquished over time" [1972, p.251]. Data obtained from extensive open-ended interviews conducted with the families of 23 leukaemic children plus informal contact with over 100 additional families lead them to suggest the following sequential emergence of the processes of anticipatory mourning. First comes a progressive acknowledgement of the inevitability of the child's death. Secondly comes grieving, that is the experience

and expression of the emotional impact of the anticipated loss. This is followed by reconciliation to the child's anticipated death, but preserving a sense of the worth of the life it has left. Fourthly comes detachment, the withdrawal of emotional investment from the child as a person with a future. The final phase is memorialization, during which the parents develop a fixed representation of the child (either abstract/generalised traits, or idealised) which will endure after the child's death. The authors also describe a set of processes which serve to maintain the parents' confidence during this period. Futterman and Hoffman present them as evolving in sequential order of prominence (in the same way as the anticipatory mourning processes), as follows. Firstly, mastery operations, most prominent soon after the onset of leukaemia. These include searching for information about the disease (seen as an effort by the parents to gain some control over it and to exonerate themselves of any blame for its onset) and participating in the care of their child (seen as a means of reducing helplessness and increasing their sense of importance in the well-being of the child). Secondly, maintenance of equilibrium, manifested by sticking to regular patterns of behaviour as regards family routines or interactions. This is followed by affirmation of life by which the authors mean that despite the seeming injustice of their child's death, these parents tended to reject bitterness or cynicism and continued to emphasise the good things in life, such as the quality of medical care on offer or positive relationships with family or friends. Finally comes reorganisation, the revision of parental values and goals often associated with an awareness of personal growth as a result of the sickness and death of their child. This represents a mastery of their loss and the authors comment that it

was generally strongest after the acute post-bereavement period. Maladaptive outcome was rare for this group of parents.

In their discussion of a therapeutic group to help parents of children newly diagnosed with leukaemia, Knapp and Hansen [1973] present the process of their anticipatory mourning using the framework of stages suggested by Kubler-Ross [1970]. They describe shock immediately after the diagnosis, and denial. Following this the parents started to experience at the "feeling level" and a great deal of anger and hostility was expressed, generally directed towards God or the staff involved professionally with their child. After the expression of this, the next stage was bargaining, for example, by donating blood for research purposes or becoming involved in church activities. Hope was strong during this period. During the fourth stage, the depression which occurs as the illness progresses and death appears inevitable, is less easily relieved by encouragement and reassurance from others. Finally comes a resigned, sad acceptance. Knapp and Hansen state that "After the child dies, the nature of the actual mourning can vary from intense grief to a feeling of relief, depending on the course of the illness and the duration of anticipatory mourning" [p.71]. Very similar observations, also based on Kubler-Ross' stage theory can be found in Kartha and Ertel's [1976] paper on short term group therapy for mothers of leukaemic children.

The same sort of support programme for the parents of children with leukaemia is described by Lascari and Stehbens [1973; Stehbens and Lascari, 1974]. The authors describe the emotional reactions of 20 families over a series of three time periods, namely, at

diagnosis, the interim period and the terminal period. The initial reactions to hearing the diagnosis were shock, disbelief and numbing, followed by a search for explanations as to the cause of the disease, and guilt feelings with regard to their possible role in this. The interim period is described as relatively calm, as the parents accepted the need for the professional care and hospitalisation of their child. The terminal phase represents not only the few weeks prior to the child's death (when it became obvious that "the end" was near), but also a "variable" period afterwards. During this stage impaired sleep and appetite were common, as was preoccupation with thoughts of the child, and some parents found it difficult to maintain their regular routines. However, no consistent pattern of symptomatology could be discerned.

In the final available study of the reactions of the families of children with leukaemia, Kaplan, Smith and Grobstein et. al. [1977] divide them into two groups: those who exhibit adaptive coping and those who exhibit maladaptive coping. In families that achieve "adaptive coping", parents understand both the nature and the prognosis of leukaemia within a few days of the diagnosis. Self-blame or hostility with regard to the onset of the illness does not occur. These families engage in shared mourning and mutual consolation - grief involves the whole family, including the leukaemic child. These authors report, however, that of the more than 50 families studied, 87% engaged in "maladaptive coping", failing to resolve successfully even the initial coping tasks associated with confirmation of the diagnosis. A variety of means of denial are described, including avoiding the use of the word "leukaemia", isolating the child so as to avoid the danger of it hearing the diagnosis, or seeking

further medical opinions. Despite this, they rarely deny the treatment offered their child, although they may display hostility towards medical staff. Some families, while accepting the diagnosis, refuse to believe the prognosis and resort to such alternatives as faith healers or special diets. In yet another group, both the diagnosis and prognosis may be accepted, but yet the parents fail to cope by refusing to participate in the care of the child. Parents may actively avoid their grief or attempt to at least postpone it by "flights into activity", for example, deciding to move house.

Similar observations are made by Vachon, Formo and Rogers et. al., [1977] in a paper describing the experiences of a group of 73 women during their husband's final episode of cancer, The authors describe the "idealised picture", often found in the literature, of mutually open and supportive communication during a terminal illness. Their results do not confirm this. Although 66% of the women had been told that their husband was dying, 40% had refused to accept the warning, and 20% said their husband had not been told. The authors discuss the use of denial by these women. Sixty-one percent had never discussed death with their husbands - with the result that conversations during the final illness became tense and stilted for fear of what might slip out. These findings agree with previous comments by Parkes [1970] who found that out of 22 London widows interviewed, although 19 said they had been told of the seriousness of their husband's condition, only 6 of these felt they had fully accepted it. The rest denied either the diagnosis or the prognosis. This strategy allowed them to continue to interact with their dying husband without breaking down. Similarly, Powers [1979] describes her own

reactions during the period in which her infant son was dying. While confused and intensely anxious, she carried on a "vast pretending game" of denial. She believes that she never engaged in anticipatory grief, partly as a result of this denial, but partly also because she was "never helped or given permission to grieve" by the professional staff involved in her son's care. Vachon et. al. found that a woman whose husband had a lengthy final illness with many ups and downs (perceived as "lingering") might become so used to the situation that she "came to ignore the physicians' warnings and began to regard her husband as almost immortal" [1977, p.1153]. The husband had been ill for so long that the wife's health had also begun to deteriorate. The couple were isolated because family and friends had given up visiting. Similarly, Silverman [1974] comments that although many of the women participating in a widow-to-widow programme had been aware of their husbands' terminal state, they did not grieve in advance but rather they learned to live with the illness and modified their lives as necessary: "Only when the door was finally closed did they in fact begin to mourn" [p.321]. In contrast to this sort of situation, Vachon et. al. found some wives perceived their husband's final illness as definitely "terminal", in which case, time was at a premium and was sometimes used to achieve a "remarkable" intimacy between the couple, as well as the settling of business affairs etc. Vachon et. al. also compared the experiences of the women whose husbands had died of cancer with the experiences of 51 women whose husbands had died of chronic cardiovascular disease. Results showed that cancer was associated with a more stressful and distressing final illness, perceptions of loss of control, wishing that death would occur, anxiety, denial, anger and guilt. They conclude that it is the

negative social attitudes towards cancer which make the final illness and the bereavement period particularly difficult for this group of widows.

While leukaemia is the illness which by far the majority of researchers have focussed on in the examination of the reactions of families to fatal illness in a child, it is not the only one.

Cystic fibrosis has also created interest, not only because of its chronic but generally fatal course, but also because since it is an inherited illness, many parents may have more than one child to suffer and die from it. Burton [1975] notes that in such circumstances parents may hope that if the later born cystic fibrosis child was to die then it should happen quickly, while the child was still a baby, thus reducing their anticipated distress. In addition, "some parents admitted to deliberately endeavouring at the outset to diminish their bond with the later born sick child. When hospitalised, especially as an infant, they declined to visit" [p.216]. Leiken and Hassakis [1973] describe a very small scale study (four families) of the parents of children with cystic fibrosis. They report how each of these families would think of the death of their child only very rarely because of the distress brought about by such images. While some denial (manifested most frequently by the "doing defence") could be helpful to both patient and parents, massive amounts of it did not reduce parental anxiety and could actually interfere with medical care, since parents might fail to present the child for clinics. Tropauer, Franz and Dilgard [1977] report on the patterns of defence and adaptation seen in 23 mothers of children with cystic fibrosis. Three of the 23 were clinically depressed, while a further 8 exhibited

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frequent periods of dejection and discouragement, usually related to clinical exacerbations. While encouraged to treat them "normally", these parents are faced with the fact that their child's lifespan is limited no matter how assiduously they stick to the daily therapy routines. The key role of the parents in the maintenance of the health of a child with cystic fibrosis means that clinical exacerbations are highly likely to be associated with self-blame and guilt. The authors present various means of handling the guilt, anxiety or depression seen in these mothers: both overprotective and rejecting behaviours were exhibited; the transfer of anger or resentment to unsupportive husbands or other somehow less deserving parents of healthy children; consciously not allowing themselves to dwell on their child's condition; denial of the gravity of the illness; and finally, believing themselves to have been specially "chosen" to carry the burden of care.

In one of the few available studies to attempt to explore the experience of anticipatory grief in the family members of dying patients by the use of a recognised questionnaire, Welch [1982] administered a 12-item revision of the Texas Inventory of Grief [Faschingbaur, Devaul and Zisook, 1977] to 41 relatives of adult cancer patients. Examples of the items used include "I still cry when I think of my family member having cancer", and "I seem to be preoccupied with thoughts about my ill family member". These relatives were coping with all stages of the illness, as well as a variety of treatment modalities. She found significantly higher mean grief scores (which she regarded as indicative of more problems coping with unrelieved grief responses) to be associated with the following. Firstly, the patient being treated in a

specialised oncology unit (possibly due to the salience of the diagnosis in these units). Secondly, feeling panicky about the possibility that something might happen to the patient while they were at home. Thirdly, crying about the diagnosis. Lower mean grief scores were associated with having previously lost a relative to cancer and with having an elderly patient. Welch concludes that "anticipatory grief is very much a normal and expected process in coping with the anticipated death of a loved one" [p.156]. An issue which she did not report on was the relationship of the grief scores to the time since the relative received news of the diagnosis.

In the final available study of the reactions of the relatives of a person known to have a fatal illness, Jacobs, Kasl and Ostfeld et. al. [1986a] compared 150 acutely bereaved widows and widowers with 68 persons whose spouse was hospitalised with a life-threatening illness. Since they wished to systematically assess the psychological manifestations of grief using the framework of attachment theory, items were developed to measure the following: Numbness-Disbelief, for example, "In the past week, did you feel stunned or dazed?"; Separation Anxiety, for example, "In the past week did you dream of your husband/wife?"; and Sadness-Despair, for which they used the Center for Epidemiologic Studies Depression Scale (CES-D). These items were incorporated into a structured interview with their subjects. On the Numbness-Disbelief scale the most recently bereaved group of people scored the highest and the non-bereaved group the lowest. Bereaved persons also scored higher than the non-bereaved on the Separation Anxiety scale, although the scores of those of the non-bereaved who were threatened with imminent loss were moderately high, and particularly so for

those items that characterised the pangs of grief. The non-bereaved group also received lower scores on the depression scale. It would appear from these results that, apart from pangs of distress, having a spouse who is threatened with a life-threatening illness does not spark of a reaction equivalent to that which occurs after the death of a spouse.

STUDIES OF THE REACTIONS OF PROFESSIONAL CAREGIVERS

This is an issue which has received far less concern in the literature than the emotional reactions of the dying patient or their family; for example, it does not receive a mention in a recent 35-page review of the psychosocial aspects of childhood cancer [Van Dongen-Melman and Sanders-Woudstra, 1986].

Rando [1986] points out that in western societies there is commonly a transfer of the care of dying patients from their family members to professional caregivers in institutions. These professional staff can themselves become caught up emotionally and socially with their patients. The result of this may be a grief response associated with the death of certain patients. She indicates that this may be problematic, for the following reasons. Firstly, death of a patient is not generally viewed by society as an appropriate cause for grief. Secondly, professional staff have to fulfil the role of "emotionally strong" person. Thirdly, there is rarely any support, either formal or informal, for grieving staff. Fourthly, their grief may be complicated by guilt at having failed in yet another of the prescribed roles of professional caregiver - that of curing patients. Finally, professional losses may spark off grief over previous personal losses. Certain groups of professional caregivers, for example those

working on oncology units may be subject to an overload of patient deaths. Rando believes that the result of this can be accumulated unresolved grief, helplessness and professional burnout. She presents a "stage model" of the way in which caregiving staff learn to cope most effectively with their role of caring for dying people. It can be viewed as representing a somewhat idealised and increasing professional maturity in the caregiver. First comes intellectualisation, as the staff member attempts to deal with their anxieties about dying by focussing on facts, policies and procedures. Next, once the staff member confronts the reality that patients cannot all be saved, come distress and depression. This is followed by the ability to deal with dying patients without excessive pain or identification, and finally a stage of "deep compassion" and appropriate interaction with the patients.

Quint-Benoliel [1974] also describes the effect of anticipatory grief in professional staff. She believes that many staff are traumatized by the syndrome of anticipatory grief early on in their careers and thus seek to insulate themselves from its further occurrence by employing "a general stance of maintaining considerable social distance in interaction with their clientele, and markedly so where the threat of death is readily apparent" [p.226]. This observation is also made by Binger, Ablin and Feuerstein et.al. [1969] in their study of the emotional impact of childhood leukaemia on patient and family. Six of the 20 families they studied believed that as death approached, their child became increasingly isolated by professional staff, not only because of isolation precautions against infection, but also because they were actively avoided by staff. However, the opposite coping technique of over-involvement by the professional staff

dealing with dying children is described by Richmond and Waisman [1955].

2. Are These Reactions Grief in Anticipation of Loss?

These descriptive studies demonstrate that certainly some sort of reaction occurs in patients, their relatives and probably also their professional caregivers once a terminal diagnosis has been given.

The fact that such a reaction has been labelled "Anticipatory Grief" leads to the assumption that it is exactly the same as post-death grief, however a few authors have observed that this cannot be the case. Aldrich [1974] notes several important differences between "conventional" and "anticipatory" grief. Firstly, while anticipatory grief can be experienced by both patient and family, conventional grief can, of course, only be experienced by the survivors. Secondly, while conventional grief can be infinitely prolonged, anticipatory grief has a definite endpoint, the occurrence of the anticipated loss. Thirdly, while uncomplicated conventional grief generally decreases with time, anticipatory grief should theoretically increase as the anticipated loss becomes imminent. Aldrich attributes the fact that it may not actually do so to the effects of denial. Fourthly, should ambivalence be present, the potentially dangerous impact this may have on the vulnerable dying patient may lead anticipatory grief to be more easily denied than conventional grief. Finally, while hope can accompany anticipatory grief, of course it cannot be part of conventional grief. Further differences between conventional and anticipatory grief have been documented. Fulton and Gottesman [1980] point out that society has a set of norms for the appropriate

behaviour of truly bereaved people. In comparison, there is no set of rules for the anticipatory griever. Similarly, Weisman [1979] mentions that "It is strange that we have no widely accepted commonly used term for people who are soon to be widows, widowers or orphans ... Surely, before-death survivors have a set of attributes and roles, just as they have after death, when someone closely related dies" [p.95]. A final distinction between anticipatory and conventional grief is made by Rando [1986] when she notes that the endpoint of anticipatory emotional reactions is not necessarily detachment from the dying person. Continued involvement by both family and professional caregivers has been described in several of the studies reviewed here.

These issues lead Siegel and Weinstein [1983] to suggest that the concept of anticipatory grief has simply become a self-fulfilling prophecy. By this they mean that the more widely it became accepted, the more that acceptance was taken as evidence of its existence, thus it became even more widely accepted, and so on. Clinicians who expect to see anticipatory grief in the relatives of dying patients will be rewarded.

It was pointed out earlier that Rando [1986] regards the term "anticipatory grief" as a misnomer. Other authors have also made this assertion. Gerber [1974] suggests that the term "anticipatory grief" is too narrow in scope to describe the experiences of those anticipating a loss. Instead he proposes the term "anticipatory bereavement". Bourke [1984] chooses the term "pre-death" or "pre-bereavement" in order to convey the notion that bereavement need not begin with death but is rather a continuum with death as a stage in it. This idea is also suggested by Weisman [1974]

who presents anticipatory grief as the first stage of bereavement, followed by the stages of mourning, resolution and finally, restitution.

Following up Gerber's [1974] point with regard to reactions prior to death being broader in scope than might be implied by the term "anticipatory grief", it is clear that for by far the majority of dying patients and those close to them, their reactions do not occur in some sort of vacuum. Several of the studies which have been reviewed here discuss not only emotional reactions, but also what tend to be termed "adaptational tasks" or "coping skills" - engaged in by the patient and those surrounding him or her. A patient may be dying, but while doing so, he or she must also continue to cope with living. This means getting used to limitations, new roles or experiences resulting either from the illness or their "dying" status. Relatives must also deal with the fact of a dying family member within the context of their own living. This means coping not only with the patient, but also the rest of their family, housework, employment, finances, social roles, etc. Fulton and Gottesman [1980] have therefore approached the analysis of anticipatory grief on three levels. First is the psychological level, that is, the individual emotional reactions (and the only level which Gerber [1974] would wish to term anticipatory grief). Second is the interpersonal level, that is, the way in which the patient and those around him or her interact during the terminal period. The third level is the socio-cultural level, that is, the role or position which anticipatory grievers hold in society. It is while focussing on this level that Gerber defines "Anticipatory bereavement as a period of socialisation into the bereaved role" [1974, p.29], in order to take account of the life

style and social changes which may be made in advance of the death.

It was noted in several of the studies reviewed here that both dying patients, and perhaps more particularly their relatives may deny the future loss. The assumption is that in such cases little or no anticipatory grief in the sense of emotional reactions can have occurred prior to the patient's death. However, these families may have experienced separations due to hospitalization, the taking on of new roles which the dying patient has had to relinquish, the need to attend a social engagement alone because the patient was unable to accompany them, or disappointment because a family holiday had to be cancelled. (Described as "training for independence" by Geyman [1983].) The point is that even these relatives have had some sort of preparation for life following the death of the patient, even if it was largely not on an emotional level. "Anticipatory grief" may well not be the most appropriate term for this. Possibly terms such as Gerber's "anticipatory bereavement", or simply "anticipatory preparation" would be better choices. However, "anticipatory grief" will continue to be used here because not to do so would be inconsistent with the other literature in this area.

3. Is Anticipatory Grief a Staged Process?

Sweeting and Gilhooly [1990] refer to the interesting pattern which is evident when the literature describing what has usually been termed anticipatory grief reactions is presented, as it has been here, in chronological order. The early descriptions which concern themselves with the reactions of parents of dying children are "remarkably consistent, so much so

that it is almost as if one is reading the same study over and over again" [p.1075]. While later studies seem to be describing similar reactions, the way in which these reactions are documented gradually changes, such as to appear like an increasingly orderly progression through a number of stages.

The point in the chronology at which this change occurs is around 1960-70. It is perhaps not so much of a coincidence to find that in 1961 Bowlby published "Processes of Mourning" with a description of the way in which "loss of loved object leads to a behavioural sequence which, varied though it be, is in some degree predictable" [p.331]. As documented in the previous chapter, he presented the following three phases of mourning. Firstly, "Urge to Recover Lost Object", characterised by yearning, searching behaviour and frequent anger. Secondly, "Disorganisation and Despair", characterised by aimless or restless behaviour, depression and apathy. Thirdly, "Reorganisation", resumption of life directed towards a new object. In 1970 Parkes presented data confirming this notion of grief as a phasic process "although the transitions from one phase to another are seldom distinct and features from one phase of grief often persist into the next" [p.465]. He described four phases: Numbness; Yearning and Protest; Disorganisation; and finally, the return to effective functioning.

Probably of more importance to the anticipatory grief literature is the fact that at this stage in the chronology Kubler-Ross [1970] also published her description of the stages in the reactions of dying people and their families. As previously noted, these are: "Denial and Isolation"; "Anger"; "Bargaining";

"Depression"; and "Acceptance". (Despite the somewhat different terminology, these stages can be seen as not dissimilar from the phases of conventional grief as described by Bowlby and Parkes.) Although she points out that "these stages do not replace each other but can exist next to each other and overlap at times" [p.236], Kubler-Ross's presentation is very much of a neat orderly process and it appears that this was immediately adopted by researchers and professionals working with terminal patients and their families during the 1970s. For example, "There is often the belief that memorising the five stages is equivalent to knowing what the dying process is all about and, therefore, what should and should not be done" [Kastenbaum, 1977, p.209]. Some of the subsequent criticisms levelled at Kubler-Ross should therefore perhaps have been directed at those who stepped onto the "staging" bandwagon in too simplistic a fashion. Some of these criticisms or suggested modifications to the stage theory of anticipatory grief follow.

Schulz and Aderman [1974] review data collected during five other investigations of the psychological reactions of terminal patients which they claim "call into question the validity of Kubler-Ross's observations" [p.142]. The findings of these studies were that although the patients may exhibit depression, denial, anger, anxiety and acceptance, these emotional reactions did not follow an orderly sequence. The most consistent finding - in agreement with Kubler-Ross - was of depression shortly before death in most terminal patients. While acknowledging the value of Kubler-Ross's work in improving the sensitivity to the needs of dying people, Kastenbaum [1977] lists a series of points which counter the stage theory of dying. First, and as noted by Schulz and Aderman, the existence of

the stages as such has not been demonstrated. What objective criteria are used to define a "stage"? Dying people engage in a greater number of emotions than those discussed by Kubler-Ross - how do they fit into the stage theory? Should they each be assigned a stage? Secondly, although she describes different people in different stages, Kubler-Ross does not present evidence of individual people moving along from "denial" through each intervening stage to "acceptance". Thirdly, the validity of Kubler-Ross's methodology, in particular that she is collecting her own data using the psychiatric interview, and therefore this material might be influenced by her own professional orientation. Fourthly, the notion of all terminal patients as having the potential to pass through the same stages removes the possibility of individual differences in either their personality characteristics or the rest of their lives.

These criticisms suggest that further, more objective examination of anticipatory grief should have been undertaken before the hasty and uncritical application of Kubler-Ross' theory to both dying patients and their families.

III. THE IMPACT OF ANTICIPATORY GRIEF OR PREPARATION ON POST-BEREAVEMENT ADJUSTMENT

As was suggested earlier, it has often been assumed that as a result of their emotional preparation during the terminal stages of a loved one's life, bereaved survivors will experience less grief once the death actually occurs. For example, Pine comments that "Our notions about anticipatory grief suggest that people who work through the grief of a loss while it is still

potential are better able to cope with death because, in effect, they have resolved their grief in advance" [1974, p.33]. Similarly, Kutscher writes that "The contention here, requiring intensive study, is that there is a kind of symmetry and replication of effects: the more the anticipatory grief reaction before the loss, the less the bereavement effects following it; the less the anticipatory grief reaction before the loss ... the more the bereavement effects after the loss" [1973, p.15]. Presumably these assumptions were based upon both the "hydraulic or cathartic model" [Shackleton, 1984] of grief work, in which the important thing is for the subject to go through a certain quantity of the pain of grief, and also upon the descriptions of so many of the parents in the earlier studies as exhibiting "calm relief" by the time their children died.

A number of studies have set out to investigate this contention. Sweeting and Gilhooly [1990] note that they differ from those describing the nature of the "putative anticipatory grief process" in the families of dying patients on several counts. Firstly, while the subjects of the majority of the descriptive accounts are relatives of a dying child, most of the studies of the impact of anticipatory grief concentrate on those bereaved of a spouse. Secondly, while the majority of the descriptive accounts are simply that - descriptive accounts of subjective observations - the studies of the impact of anticipatory grief base their conclusions on empirical data. Thirdly, while some of the descriptive accounts were published in the 1950s and 1960s, almost all the studies of the impact of anticipatory grief have been conducted since 1970, "rather as if this was the date at which anticipatory

grief came into existence as a real concept whose effects could then be studied" [p.1076].

These studies will now be presented. First are those which have found anticipatory grief to have either no impact or a negative impact on post-bereavement adjustment. This is followed by those studies which have found anticipatory grief to have some sort of positive impact on post-bereavement adjustment, although not necessarily to globally reduce the experience of "conventional" grief. As in the previous section, the studies are presented in chronological order. Finally, the results of these studies are discussed.

1. Studies in which Anticipatory Grief/Preparation Appears to have No Impact or a Negative Impact on Post-Bereavement Outcome

In his study of the effects of conjugal bereavement on the physical and mental health of 132 young and middle aged women, Maddison [1968] reports "contrary to popular belief" that he found those whose husbands had died with no or very little warning were not more prone to a bad outcome than those who had had lengthy foreknowledge of the death. Indeed, the evidence was that an extended period of dying might increase any pre-existing ambivalence and thus lead to guilt and inadequacy following the death, and/or strain due to the need for physical nursing, hospital visiting, or coping with deformity or distress in the dying spouse.

In their study of "The Bereavement of the Widowed", Clayton, Halikas and Maurice [1971] found that only 2 out of their list of 26 bereavement symptoms distinguished the 74 whose spouse had died after an

illness lasting 6 months or less from the 35 whose spouses had died after an illness lasting longer than 6 months. The "prolonged illness" group were significantly more likely to report loss of interest (in TV, news, or friends) and irritability than the former group. The same subject group was used by Clayton, Halikas and Maurice et. al. [1973] to investigate the effects of anticipatory grief on bereavement outcome, however this time they dropped 28 subjects whose spouse had died in less than 5 days because these were counted as "sudden deaths". The two comparison groups were now 46 bereaved in the "shorter illness" and 35 bereaved in the "prolonged illness" groups (average age of all subjects was 61 years). The only symptom to now distinguish between the groups was significantly greater irritability in the prolonged illness group (ie. there was remarkable similarity between the groups). The authors defined "an anticipatory grief reaction" as having occurred if subjects (retrospectively) confirmed the presence of a constellation of depressive symptoms during the terminal illness. The same symptoms were defined as "a normal depressive reaction" if present following the death of the spouse. Results showed that those who had experienced "anticipatory grief" were more likely to have a post-mortem depression one month after bereavement, but by the following year were no more nor less likely to be depressed than those who were defined as not having experienced anticipatory grief.

Gerber, Rusalem and Hannon et. al. [1975] divided 81 bereaved widows and widowers (mean age 67 years) into two groups. The "acute illness death" group (whose spouse had died without warning and prior knowledge or else within 2 months of the onset of a medical condition) were assumed to have had little or no

opportunity for anticipatory grief. The "chronic illness death" group (whose spouse had died following a severe life-threatening illness of greater than 2 months duration) were assumed to have engaged in anticipatory grief. The medical adjustment of the two groups was compared on three variables: (1) number of visits to the doctor; (2) number of illnesses without calling the doctor; (3) use of psychotropic medication. They found that 6 months following bereavement there were no significant differences between the acute and chronic illness death groups on any of these variables, thus "We tentatively conclude that exposure to anticipatory grief has no appreciable impact on aged survivors' medical adjustment 6 months after their loss" [p.227]. However, the authors go on to report that those who were bereaved following a chronic fatal illness that had lasted longer than 6 months reported significantly more visits to the doctor and more occasions of illness when they had not called the doctor than those whose spouses had died of a shorter chronic illness. Gerber et. al. therefore suggest that it is lengthy experience with anticipatory grief (described as "an extended death watch") which accounts for poor subsequent medical adjustment rather than the phenomenon itself - possibly because of the emotional pressure, plus neglect of the survivor's own health while their spouse was dying.

Sanders [1980] conducted the first available study to attempt to assess post-mortem grief directly rather than assuming adaptation from other variables (such as depression or visits to the doctor). She administered the Grief Experience Inventory (GEI - Sanders, Mauger and Strong, 1979] to 102 bereaved subjects, identified by newspaper obituary columns and visited an average of 2.2 months following the death. To the best of her

knowledge "the GEI is the only psychological inventory developed especially for use in assessing the grief experience" [p.308]. (In fact the Texas Inventory of Grief was also available at that time - Faschingbaur, Devaul and Zisook [1977].) When Sanders divided her subjects into a "sudden illness death" group (whose relatives died within 7 days of onset of illness or accident) and a "chronic illness death" group she found no significant differences between any of the GEI scale scores. Nor did the length of illness at home make any difference in reducing bereavement intensities. In her discussion, Sanders suggests the possibility that follow-up would be valuable in order to determine long-range effects of length of illness on the survivors.

Similarly, in their study of the elderly widowed, Bowling and Cartwright [1982] found no association between their index of adjustment and the length of time their spouse had been ill, the place of death, whether they had known their spouse was likely to die or described the death as expected. Nor did they find loneliness to be associated with duration of the illness, knowledge of prognosis, or expectation of the death.

Jacobs, Kasl and Ostfeld et. al. [1986b] conducted a structured interview incorporating items designed to measure Numbness-Disbelief, Separation Anxiety, and Depression (discussed earlier in this chapter) with 114 persons one month after bereavement. They hypothesized that the intensity of grief would attenuate with increasing age. This was based on the assumption that for the elderly (defined as over 60 years old), death of a marital partner is more expected and less untimely and thus "anticipatory preparation" will have occurred. However, they found few significant differences between

the grief of elderly by comparison with middle aged persons, and thus concluded that their findings did not support "the idea that anticipatory grief, assuming that this has taken place among our older spouses threatened with a loss, attenuates the intensity of the actual distress after a loss occurs" [p.310].

The final available study which does not support the hypothesis of anticipatory grief or preparation having a positive impact on post-mortem grief is that of Dessonville Hill, Thompson and Gallagher [1988]. They interviewed 95 widows (all over 55 years old, average age 66 years) at 2 months, 6 months and one year following bereavement. Their adjustment to widowhood was assessed according to psychological health (Beck Depression Inventory and Brief Symptom Inventory), physical health (number of reported illnesses and self rating of physical health), and grief reaction (Texas Revised Inventory of Grief). The sample was divided into subgroups depending on whether they said they had expected the death of their spouse, and also whether they had engaged in rehearsal for the role of widowhood (based on questions about the extent to which they had thought ahead to the funeral, being on their own, etc.). Results suggested that neither expectancy of death nor rehearsal for the role of widowhood were related to the subsequent adjustment to bereavement in this group of women. Indeed, those who had engaged in spontaneous rehearsal rated themselves as being in significantly poorer physical health than those who had not, and also had a tendency (non-significant) to higher depression as assessed by the BDI.

2. Studies in which Anticipatory Grief/Preparation Appears to have Positive Impact on Post-Bereavement Outcome

The earliest available study to examine this is that of Rees and Lutkins [1967]. In their report of "The Mortality of Bereavement" over a 6 year period in the small market town of Llanidloes, Wales, the authors found a 5 times increased risk of death in bereaved survivors when the original death had occurred somewhere other than home or hospital - for example, a road or field. They point out that deaths in these places tend always to be sudden and unexpected, thus associated with increased shock to the bereaved.

Ball [1977] assessed widows' grief symptoms and adjustment via an anonymous postal questionnaire. She divided the 80 widows (ages 18-73, mean age 54 years) in her sample into two groups. Widows in the "sudden death" group (less than 5 days between symptom onset and death) were assumed not to have experienced anticipatory grief. Those in the "prolonged death" group (6 or more days of illness) were assumed to have experienced anticipatory grief. Results showed sudden death to be associated with a more intense grief reaction, regardless of age. For younger widows (18-46 years) sudden death was also associated with less direct measures of grief, including experiencing a greater number of grief symptoms, a greater severity of symptoms and various individual symptom measures (for example, greater irritability). Ball's conclusion is that "anticipatory grief is a mitigating influence on the post-death grief of the young bereaved person" [p.330]. However, she found age to be more predictive of post-bereavement grief response than mode of death.

The study by Vachon, Freedman and Formo et. al. [1977] which was described earlier in this chapter presents not only the experiences of widows during the final illness but also during the bereavement period. Their results are equivocal as to any mitigating effect of anticipatory grief on post-bereavement adjustment. They found that 81% of the women who had discussed their husband's impending death with him felt that their shared grief had made it easier to face bereavement. Of those who had not talked, 36% believed that this had made bereavement more difficult ; however 59% felt that it had made no difference in their bereavement adjustment. Those women who had used the clearly perceived "terminal" illness period to achieve great intimacy with their husbands were often left with a big lonely gap in their lives when he died; however, those who perceived the illness as "lingering" and their husbands as "immortal" were completely shocked by the death.

The main aim of the Harvard Bereavement Study [Glick, Weiss and Parkes, 1974; Parkes and Weiss, 1983] was the identification of those factors which determine the course of grief over the first years of bereavement. Interviews were conducted with 43 widows and 16 widowers at 3 weeks, 8 weeks, 13 months and 2-4 years following bereavement. (Larger numbers of subjects completed fewer than all four interviews.) Because of the influence of age on bereavement outcome, all subjects were under 46 years old. The authors examined the effects of forewarning of death by dividing the subjects into two groups. The "Brief or No Forewarning Group" comprised subjects who said they had had less than 2 weeks warning that their spouses were fatally ill and less than 3 days warning that they were about to die. The "Long Forewarning Group" comprised subjects

who had had over 2 weeks to prepare for bereavement. They found that forewarning of loss had a major impact on the nature of later recovery. In particular, 3 weeks after bereavement the "Brief or No Forewarning Group" were significantly more likely to be reacting with disbelief, to appear upset or disturbed, anxious, self reproachful, to perceive themselves as having been abandoned and to agree that "I wouldn't care if I died tomorrow". Eight weeks after the bereavement this group were significantly more likely to appear severely anxious or depressed and less likely to have visited the grave or engaged in any social activity. By 13 months after the bereavement they were more likely to be tearful and self reproachful and less likely to have made regular visits to the grave, to have increased their social activity, or to be working outside the home. They were far less likely to have received a "good outcome" rating. These differences remained even at the 2-4 year follow-up. At this stage the "Brief or No Forewarning Group" were less likely to have accepted the death (for example, sensing the presence of the deceased, feeling as if it was all a dream, wondering why the death had happened), were more emotionally distressed (for example, more anxious, upset, depressed, self reproachful or lonely), were less likely to be socially recovered (for example, refusing to consider dating, concerned about their functioning, concerned about finances), their attitude towards the future was less often good, and very few were rated as "things going well/very well". The explanation which the authors give for these results is not in terms of the effects of anticipatory grief. (Indeed, Glick et. al. note that although most of those who had had significant forewarning believed that they had begun to grieve prior to the death, and were often relieved when it eventually occurred, this had not reduced their

subsequent grieving.) The authors point out the way in which any conjugal bereavement invalidates numerous assumptions about the world. Plans, routines and interactions which had involved the spouse become senseless and must all now be modified. That group of subjects who had a period of forewarning have been given time to gradually modify their "my husband/wife and I ..." assumptions, while those without significant forewarning are brought up short by conjugal bereavement. "Unexpected loss shows the world to be unpredictable" [p.72]. If one disaster can occur, why not another? In response, those bereaved without significant forewarning are more likely to insulate themselves from further risk by withdrawing from the world as it is and devoting themselves to the safer past, continuing to reminisce and grieve over their dead spouses. Glick et. al. point out a critical difference between those widows who did and did not anticipate their husband's death. Those who did not anticipate bereavement were far less likely to consider re-marriage - rather as if they feared the trauma of a further loss to themselves or their children. The authors suggest that in this group, marriage itself has become feared, whereas for those who had significant forewarning there was the understanding that their loss was caused by disease, and thereafter it was that disease rather than marriage itself which was associated with fear. This finding was less common in widowers, possibly because of the greater pressures which they may be under to re-marry. Parkes and Weiss term the reaction which occurs following bereavement in the absence of forewarning the "Unexpected Loss Syndrome", characterised by disbelief, avoidance, self reproach and despair, social withdrawal and continued ties to the deceased, loneliness, anxiety and

depression. They believe it is likely to occur in the face of an unexpected and untimely major loss.

Rando [1983] in the only available study of post-bereavement adjustment in subjects whose children (rather than spouses) had died, collected data via a structured interview with 54 parents whose child had died from cancer 2 months to 3 years previously. During structured interviews with the parents she collected information on their grief (using the Grief Experience Inventory - GEI, Sanders, Mauger, and Strong [1979]) and their experiences during their child's illness (using a Parental Experience Assessment Form - PEAFF, which she had designed herself). Rando's results were as follows. Firstly, with regard to the effect of the length of the child's illness on subsequent parental grief experience, there seemed to be an optimum duration of illness which was between 6 and 18 months. Both shorter and longer illnesses were associated with low parental preparedness for the child's death and low subsequent adjustment. The longer the illness continued, the angrier and more disturbed the parents appeared to be following the death. Rando suggests that, as had been suggested many times previously, illnesses that are too short do not give the parents adequate time to prepare, but in addition, illnesses that are too long may encourage parents to believe that their child is never actually going to die, in addition to wearing them down both emotionally and physically, thus they are neither prepared for the death nor able to adjust well subsequently. In order to investigate the effects of anticipatory grief, Rando attempted to operationalise the concept as the numerical sum of 8 behaviours engaged in during the child's terminal illness (for example, discussing with someone the possibility that their child would die). She found anticipatory grief

was positively associated with preparedness at death, and inversely associated with abnormal grief (atypical responses following the death). In addition, there also appeared to be an optimum amount of anticipatory grief since parents who engaged in either very few or a great number of anticipatory grief behaviours were found to have participated less in the care of their child during hospitalisations. Rando's conclusion is that although "appropriate" amounts of anticipatory grief may be associated with improved coping during the illness and following bereavement, there can be "too much of a good thing" [p.17].

Cameron and Parkes [1983] describe the effects of hospice type care on subsequent adjustment. Twenty close relatives of people who had died in a Palliative Care Unit (PCU) were matched with 20 relatives of people who had died in other parts of the same hospital. Relatives of patients on the PCU were encouraged to express their own anticipatory grief and to communicate openly with the patient, and in addition, to be present at and following the death. The dying patients in this unit received a high degree of care and symptom control. One or two weeks after the death, the bereaved PCU relatives were contacted and received informal counselling via visits and phone calls. None of the controls received these services. One year and two weeks after the death, all subjects were interviewed by telephone, during which a 32-item "Health Adjustment Inventory" (covering psychological aspects of bereavement and mental health) was administered. Results showed that the PCU relatives had adjusted better to bereavement than had the controls, and that regardless of where the patient had died, relatives who had been aware of the imminent death had a better overall outcome than those who had not. While

it is difficult to separate out which aspects of the PCU package of care explain this better outcome for bereaved relatives, Cameron and Parkes believe the two most important aspects were the provision of adequate pain relief for the patient and advance knowledge of the imminent death by the relatives.

Lundin has examined both the immediate and long term effects of sudden unexpected bereavement. Sudden and unexpected death was operationalised as occurring when the deceased was under 65 years old, without prior chronic illness, fatal illness lasting under 2 hours and news of the death given without any preparation. Lundin [1984a] compared a group of 32 close relatives who had experienced sudden and unexpected bereavement with 55 matched controls for whom the death of a relative had been expected. The health status of his subjects was examined in terms of days of sickness for two years before and two years following the death. He found an increase in both physical but more especially psychiatric illness after sudden unexpected bereavements. Although the amount of sickness in the control group was high overall, it did not change significantly following the (expected) bereavement. Lundin therefore concludes that "persons exposed to sudden and unexpected loss are subject to increased psychiatric morbidity, and constitute a high-risk group" [p.88]. In a follow-up study, Lundin [1984b] used the Expanded Texas Inventory of Grief to compare the reactions of the sudden and unexpected bereavement group of relatives with the expected bereavement group eight years after the death. He found that relatives in the sudden and unexpected bereavement group had a significantly greater degree of mourning, more guilt feelings, numbness, feelings of missing the deceased, need for crying and greater difficulty in trying to

stop thinking about the deceased. Lundin comments that this more pronounced grief reaction in his sudden and unexpected bereavement group is similar to the "unexpected loss syndrome" described by Parkes and Weiss [1983].

In a study which examined the effects of prior expectation of death together with participation by the bereaved in making funeral arrangements on grief adjustment 12-18 months following the death, Doka [1984] conducted interviews with 50 primary survivors. (He defined "primary survivor" as the person who had primary responsibility for arranging the funeral.) He found that expectation of death was the only one of his variables to be associated with grief adjustment a year later: expectation was positively related to better adjustment. Further, Doka points out that, as has been noted earlier, neither the nature of the condition nor length of the illness of the deceased can necessarily be assumed to be the same thing as expectation of death.

3. Explanations for these Conflicting Results

On the face of it, these results which appear to show the impact of a period of anticipatory "grief" or preparation on post-bereavement adjustment to be sometimes positive, sometimes insignificant, and sometimes negative, are simply confusing. However, a number of explanations for their contradictory findings have been offered in reviews by Fulton and Gottesman [1980], Siegel and Weinstein [1983], Rando [1986], and Sweeting and Gilhooly [1990].

Firstly, "anticipatory grief" has not been subject to a consistent operational definition. The majority of

studies define it by the length of time between onset of disease/knowledge of fatal prognosis and the death. The variation in these time periods between studies is vast, for example, 2 hours [Lundin, 1984a,b], 5 days [Ball, 1977], 7 days [Sanders, 1980], 2 weeks [Glick, Weiss and Parkes, 1974; Parkes and Weiss, 1983], 2 months [Gerber, Rusalem and Hannon et. al. 1975], 6 months [Clayton, Halikas and Maurice, 1971]. Anticipatory grief has often been assumed by these researchers to have occurred simply because the death was anticipated. This issue was discussed earlier (previous section) when it was pointed out that anticipatory preparation did not necessarily mean that relatives would have experienced the emotional reactions of grief. Some studies have attempted to overcome these difficulties. For example, Clayton, Halikas and Maurice et. al. [1973] defined anticipatory grief as occurring when subjects (retrospectively) identified a cluster of depressive symptoms as having been present during the terminal phase. Rando [1983] defined anticipatory grief as a set of behaviours engaged in by parents before their child's death. It could be argued that anticipatory grief constitutes more than either depression or behaviours such as discussing the possibility of the death of the child. It could be said even more strongly that reaching the age of 60 years is not necessarily the same as engaging in emotional preparation for the death of a spouse - but this was the criterion assumed by Jacobs, Kasl and Ostfeld et. al. [1986b] to indicate that anticipatory grief might have occurred in their bereaved subjects.

Secondly, the operational definitions of "post bereavement adjustment" or "grief" employed in these studies have not been any more consistent than have those of anticipatory grief. Measures used have

included the following: degree of depression [Clayton, Halikas and Maurice et. al., 1973], medical adjustment [Gerber, Rusalem and Hannon et. al., 1975], sick days [Lundin, 1984a,b], mortality [Rees and Lutkins, 1967], specially constructed questionnaires [Glick, Weiss and Parkes, 1974; Parkes and Weiss, 1983; Jacobs, Kasl and Ostfeld, 1986b], self ratings of adjustment [Vachon, Freedman and Formo et. al., 1977], the Grief Experience Inventory [Sanders, 1980; Rando, 1986] and the Texas Inventory of Grief [Dessonville, Hill and Thompson et. al., 1988]. While noting that this difficulty has arisen because until recently there were no widely available validated measures with which to assess grief, and that more recent studies have moved towards the use of such inventories, the difficulty still remains when trying to make comparisons between the bulk of the studies on the impact of anticipation on post-bereavement adjustment.

Thirdly, not only do the studies differ in their definitions of both anticipatory grief and post-bereavement adjustment, they also differ in methodology. For example, the ages of the subjects studied vary from widowed women aged 18 years and over [Ball, 1977] to "aged widows and widowers" mean age 67 years [Gerber, Rusalem and Hannon, 1975]. Subjects have included parents [Rando, 1983], widows [for example, Maddison, 1968], and both widows and widowers [for example, Jacobs, Kasl and Ostfeld et. al., 1986b]. This is unfortunate, since both gender of the bereaved and blood/role relationship with the deceased have themselves been demonstrated to influence the risk of a poor outcome for grief. Studies also vary in relation to the nature of the data collected, the number of interviews conducted, and the ways in which the data was analysed.

In view of these issues, Fulton and Gottesman conclude that "The methodological difficulties and differences reviewed here raise compelling questions as to the reliability, comparability and validity of the studies, and cast serious doubts upon the conclusions reached" [1980, p.9].

But there are still other dimensions which confound the anticipatory grief literature. Siegel and Weinstein [1983] point out that however beneficial a period of emotional anticipation may theoretically be for the future survivor, this may be cancelled out in practise by the effects of coping with a protracted terminal illness in a loved one. These include the stress of a long death-watch, financial worries, social isolation and physical exhaustion. Rando [1986] refers to the fact that sudden deaths are far more likely to be both "untimely" in that they usually occur to younger people, and traumatic in that they usually follow accidents or violence. This is really the point made by Parkes and Weiss [1983] when they describe the differences observed in the survivors of deaths with or without forewarning as resulting from the "unexpected loss syndrome". It can also be related to Fulton and Fulton's [1971] distinction between a "high grief potential" death (the sudden accidental death of a man or woman upon whom others depend for their physical and/or psychological well-being) and a "low grief potential" death.

A further issue which is not discussed in the studies of the impact of anticipatory grief on post-bereavement adjustment is that of individual differences. It is raised by Bourke [1984] in his presentation of grief as a single process which is interrupted by the event of death ("the continuum of pre- and post-bereavement

grieving"). He points out that it is likely that people who experience a complicated pre-death period will have a similarly complicated post-death period, while those with uncomplicated grief in the pre-death period may be expected to continue in the same way after the death. The result might thus be a positive rather than an inverse association between pre- and post-death grieving when studied on an individual basis. However, in studies which investigate the impact of anticipatory grief on post-bereavement adjustment across groups these individual differences could tend to cancel themselves out.

IV. SUMMARY

This chapter has discussed the changing ways in which the concept of "anticipatory grief" has been described and studied since it was first defined almost 50 years ago.

The background to the twin notions of anticipatory grief as being necessarily the same thing as conventional grief and as proceeding in an orderly sequence of stages was presented, and the validity of these beliefs was discussed. It was suggested that the term anticipatory grief may convey an unnecessarily narrow definition of the ways in which future survivors may become prepared for bereavement. Studies of the impact of anticipatory grief or anticipatory preparation on post-bereavement adjustment have been presented, together with a discussion of the explanations for their conflicting results.

Although anticipatory grief has received a great deal of attention over recent years, this chapter has highlighted the gaps in our knowledge of the concept. There is a need firstly for more objective descriptions of the emotional, behavioural and social effects of foreknowledge of death. Secondly, there is a need for studies of how these effects may vary both with increasing time periods between terminal diagnosis and death, and with the nature of the terminal illness in question. (For example, can we assume that any anticipatory grief reaction will be identical in the face of such a variety of "terminal" illnesses as cancer, cardiac disorders, and dementia?) Finally, there is a need for studies of the relationship between this objectively defined concept and post-bereavement adjustment.

CHAPTER FIVE

SOCIAL DEATH

"They were just forgotten really - it's like they'd just not existed - they'd been there for twelve years."

[Alonish Dmitri speaking of her family after their release from a Somalian prison camp. "An Ethiopian Odyssey", BBC Radio 4, Monday 6th August, 1990.]

I. INTRODUCTION

"Until recently, death was something you could put your finger on, so to speak" [Fulton, 1981, p.241].

Now it is not so easy. Death can be defined on a variety of different levels. The majority of people are likely to define death in a "physical", "clinical" or "biological" sense - the area of most interest to undertakers or those in the medical profession. However, the definition of death which may have a greater impact upon a large number of people today is their own, or their relatives' "social death". That is, the point at which a person "dies" in the social sense.

This chapter begins with a survey of the ways in which social death has been defined by authors with a range of different backgrounds (sociology, thanatology and nursing). The width or restriction of usages applied to the concept are found to vary greatly. Having examined what it is to be socially dead, or a "non-person", attention is directed to the opposite side of the coin: the second section of the chapter asks what it is that makes an individual into a "person"? What is it that

allows us to say that an individual has a "worthwhile life"? The third section investigates whether there may be a relationship between the onset of an individual's social death and the anticipatory grief of those close to him or her - those people who one might normally expect to contribute to the individual's "social life". The final section examines two groups who might be regarded as particularly vulnerable to the onset of social death prior to their physical death. These are those suffering from a chronic terminal illness ("lingering" deaths) and those who are very old.

II. DEFINITIONS OF "SOCIAL DEATH" AND ALLIED CONCEPTS

The majority of writers in this area refer to the work of Goffman, and this section therefore opens with a review of his use of the concepts of "mortification" and "non-person" treatment. It is the thanatologists, however, who have shown most interest in definitions of "social death" per se. The notion generally presented is that social death is merely one of a series of levels of death, and it is this literature which is reviewed here. A brief review of the nursing literature in the area follows. This is interesting because although clearly addressing the concept of social death, it is termed "dehumanisation" and in line with the nursing ethos it is usually bracketed with discussions of how it might be banished.

1. Goffman's Descriptions of "Mortification" and "Non-Person" Treatment

Goffman [1961] described the central features of the "total institution" (for example, a prison, mental hospital, boarding school or monastery) as being a

breakdown of the barriers which normally separate sleep from play from work. Unlike the outside world, in an institution these three aspects of life occur, firstly, in the same physical place and under a single authority, secondly, along with a batch of other people all doing the same thing, and thirdly, according to a tight schedule which has been imposed by the higher authority.

Goffman uses an intriguing term to describe the process which can occur to a person who enters such a total institution. He calls it "mortification". By this, Goffman means the removal of the roles and possessions which the person held in the outside world: "Upon entrance (to the establishment) he begins a series of abasements, degradations, humiliations and profanations of self. His self is systematically, if often unintentionally mortified" [p.24]. Goffman [1963] later describes the personal attributes and roles of a human being as their "social identity". Thus, the mortification which occurs upon admission to the total institution can be seen as the removal of a person's social identity. Goffman gives examples of the admission procedures which can be used to "trim" a person so that he or she fits easily into the administrative machinery of the institution: taking a life history, searching, listing and removing personal possessions, undressing, bathing, disinfecting, haircutting, issuing institutional clothing, etc. Perhaps the most significant removal can be one's own name, to be replaced by an impersonal number. Individuality is removed and replaced by standard issue institutional attributes. The person has become simply "... a member of the largest and most abstract categories, that of human beings. Action taken on the

basis of such attributes necessarily ignores most of his previous bases of self-identification" [1961,p.26].

Jones [1972], writing 10 years after Goffman first outlined these ideas, comments on the wide audience which they had reached, not only among social scientists, but also among those administratively responsible for institutional admission procedures. However, this interest in Goffman's ideas had not lead to any obvious changes in practice at that time. Jones cites a study which had recently taken place in 7 psychiatric hospitals in the UK and which found that despite the efforts of senior staff these routine practices (the "ritual dance" of admission) continued.

Following admission, Goffman notes that violation of the boundary between the individual and his or her environment may occur via the publication of information about the inmate's past life, physical exposure during bathing or examinations, the exhibition of their personal possessions, etc.

Goffman points out that many of the inmates of total institutions regard their time spent "inside" as time wasted or taken away from their lives. They have been exiled from living. His description of many total institutions as seeming "to function merely as storage dumps for inmates" [1961, p.73] has been quoted frequently since. He directs attention to the way in which people can be worked upon in almost the same way as inanimate objects. They can be treated as a "non-person" - that is, as someone to whom no ritual notice has to be taken. The examples which Goffman gives of this kind of treatment within institutions include the following: surgeons who prefer thin rather than fat patients because they have fewer layers to cut through

and the instruments don't get so slippery; and inmates who are followed round the institutional system by chains of informative receipts, which may not even cease after their death. According to this formulation, in an institution one may be bureaucratically or administratively alive, even when physically dead. Staff within the institution generally find it easiest to maintain a socially distant role from the inmates. This is typified in Goffman's description of "the wonderful brand of 'non-person treatment' found in the medical world" [1963, p.298]. The doctor treats the patient as a person for the civil "hello" and "goodbye" rituals, but in-between behaves as though they weren't a person at all, for example, discussing their diagnosis with other staff in the patient's presence as if they were simply an inanimate object.

2. Definitions of "Social Death" in the Thanatological Literature

The first available presentation of social death is that of Glaser and Strauss [1966]. During a discussion of "hopelessly comatose" patients these authors describe their receipt of "non-person" treatment from hospital personnel - for example, talking freely about things which would matter to the sentient patient. "Socially he is already dead, though his body remains biologically alive" [p.108]. They also describe some "senile patients" as "socially dead as if they were hopelessly comatose" [p.110] in the eyes of the families who consign them to institutions and thereafter fail to visit.

In his study of the social organization of death, Sudnow [1967, 1970] distinguishes between "clinical death", "biological death" and "social death", which he

defines as follows. Clinical death is the appearance of death signs upon physical examination. Biological death is the cessation of cellular activity. Social death is marked by that point at which a patient is treated essentially as a corpse, though perhaps clinically and biologically still alive. (It should be noted that Sudnow attributes his own interest in the notion of social death to Goffman's observations of the pre-death treatments of patients in a mental institution. Unfortunately Sudnow does not cite a reference to this particular aspect of Goffman's writings in either his PhD thesis nor the [1967] publication which resulted from it. A careful reading of Goffman's [1963] description of "Asylums" does not find mention of the term "social death".)

Sudnow comments that although it may be tempting to apply the term social death to any radically asocial treatment of a person (such as desertion by one's family or "non-person" treatment), he chooses to restrict his use of it, in keeping with the literal sense of death. (In this, Sudnow clearly diverges from what it must be assumed was Goffman's wider interest in the notion.) Thus, Sudnow regards social death as occurring once a (live) person is regarded as already dead and is being treated by society as a body. It is the end of his or her social existence. Ryder and Ross [1981] comment that when social death precedes biological death, the needs of the dying patient become secondary to institutional routine. Sudnow observed a nurse attempting to force the eyelids of a dying woman patient shut. Although the woman was still alive the nurse was doing this because a person's eyes should be closed after death, but it is much easier to achieve this while a patient is still alive and while the muscles and skin are more elastic. He points out that

social death does not always lead to biological death, and nor is it such a definite concept. Rather like a disease, social death can occur in mild, moderate or severe forms. Milder social death is exemplified by activities such as filling out the autopsy permit prior to death, disposing of personal effects, or preparing obituary notices, and severe social death by activities such as the cessation of administration of standing-order medications, inspecting the changing condition of the eyes, talking in their presence, or moving them in ways which would normally be reserved for the treatment of corpses. These more severe social death treatments are reserved for patients in a coma: "A patient 'dies' in some important organizational respects, once he enters what is taken to be a terminal coma; and death itself is not radically marked by a special attitude toward the body ..." [1967, p89]. Sudnow describes the physician as "symbolically" signing the patient's social death warrant whenever he decides that nothing else can be done to preserve life. However, a patient would not necessarily have to pass through the hands of a doctor to be regarded as socially dead. This is exemplified by Sudnow's observation that patients admitted to the hospital in what is regarded as a near death state might be left on a stretcher overnight on the assumption that they were about to die and thus it would be a waste to allow them to mess up a bed. However, if they were still alive in the morning, such patients would be hastily assigned a bed before doctors or visitors could spot them. Sudnow discusses the way in which such treatment as dead may become a self-fulfilling prophecy in that it may speed actual physical death.

Kalish discusses the "continuum of subjectively perceived death" [1966a] and the indivisible division

between life and death [1968]. Since neither he nor Sudnow cite each other's publications it must be assumed that each worked independently of the other. He presents the following series of levels of life and death. The first level is physical, which he subdivides into biological and clinical. The second level is psychological (self awareness). The third level is social, sub-divided into self-perceived and other-perceived. The final level is sociological (the status of the individual in the community).

Physical death is the area of most interest to physicians, who can define it on two levels: biological death, which occurs when the organs cease to function, and clinical death, which occurs when the organism ceases to function as an organism (and which Kalish notes to be closest to the legal definition of death).

Psychological death occurs when the individual ceases to be aware of his or her existence - neither knowing who he is, nor that he is. Although for most people this may occur at the same time as physical death, Kalish cites some examples when it may precede it (the fully comatose, completely drugged or hopelessly senile). Kalish points out that an individual's psychological death can be regarded as a continuum in two dimensions: firstly with regard to the amount of psychological death at any one time, and secondly with regard to the length of time over which psychological death occurs. The presence of a degree of psychological death is generally disturbing to those close to the patient. It is often associated with the belief that the patient might as well be dead and therefore should either not be kept alive by heroic measures or in some cases should be helped to die (euthanasia). Kalish suggests that the presence of psychological death may

actually influence physical death; for example, a comatose patient may elicit different (and by implication less effective) responses than the alert patient. Related to this is Kalish's [1965] question of "At what point do 'you' cease to become 'yours'"? In other words, when does a person's responsibility for their body and their thinking cease? If "you" are demonstrably unable to take the responsibility, then responsibility for "you" will cease before death - with the result that "you" can be medicated, sedated, operated on, or performed upon, in other ways without having given permission yourself.

Self-perceived social death occurs, in Kalish's analysis, when an individual accepts the notion that they are "as good as dead". It differs from psychological death in the presence of self-awareness. Various events may precipitate social death, for example, being given a terminal diagnosis, suffering a disabling illness, or severe grief. The state of self-perceived social death can be reversed in some cases. Kalish maintains that the more common form of social death is other-perceived social death, which occurs when people who once knew an individual as alive "now think of him as being, for all practical purposes, dead or non-existent" [1968, p254]. Obviously this is also reversible and can vary as a function of the perceiver - not everyone will necessarily regard an individual as socially dead, and it is more likely to occur when people lose contact with the individual. Kalish points out that social death is also more likely to occur to a psychologically dead individual who has become merely a shell of what they once were.

Finally comes the level of sociological death, occurring when the individual loses all social status

in their community. Kalish's examples of this include the traitor who is cut off from his community, whose writings are burned, possessions destroyed and name unmentionable. He also discusses the status of individuals who become legally dead, for example, soldiers who go missing in combat.

A further variation on the theme of definitions of death is given by Kastenbaum [1969, 1977]. Kastenbaum [1969] discusses three varieties of "psychological death". First among these is thanatomimesis - which could be defined as mimicking death. This occurs when something which at first appears dead subsequently proves to be alive, for example, some spiders mimic death when intimidated. Although this may not appear at first sight to have much relevance in modern western societies, Kastenbaum points out that in fact it may do, since the result of some of the new medical technologies is that a person who would once have been pronounced dead may not now be regarded as such. The second of the varieties of psychological death discussed by Kastenbaum is what he terms phenomenological death, occurring when the organism is definitely alive although the observer would doubt it. Included in this category are persons whose feeble expressions of life are only maintained by medical heroics. "The person inside the body gives absolutely no indication of his continued existence ... we feel unable to classify this body as dead, but also unable to classify this person as alive" [1969, p.9]. It is an "in-between condition" and as such tends to generate medical ,administrative, legal, ethical, psychological and social problems. This is also a state which is both reversible and in addition dependent upon the criteria which different observers may employ for its presence. Kastenbaum lists the "unfortunate effects" of false

judgements of phenomenological death - errors of both omission and commission from caregiving personnel or families. Social death is the final area of psychological death defined by Kastenbaum: "Social death must be defined situationally. In particular it is a situation in which there is absence of those behaviours which we would expect to be directed toward a living person and the presence of behaviours we would expect when dealing with a deceased or non-existent person" [1969, p15 and 1977, p.31]. Thus, although the individual may be animated and, potentially responsive, indeed even desperately seeking recognition and interaction, that individual will by this definition be socially dead if others cease to acknowledge his or her continued existence. Kastenbaum lists several potential causes of social death. These include the violation of social taboos which may result in being "cut dead", "sent to Coventry" or, more seriously, excommunicated; changes in the individual (for example growing old or contracting a feared disease such as AIDS) which may result in loss of live person status; or becoming a dying person which may result in treatment as though already dead. Related to this final example is Kastenbaum's comment that "a person may come to be classified as socially dead precisely because he has not died" [1969, p17]. Such individuals are regarded as have lived well beyond their prime.

Pattison [1987] suggests four different kinds of death. These are firstly social death: the person is treated as if dead as others withdraw and separate themselves from him or her. Secondly is psychic death which occurs when an individual accepts their own death and regresses into him or herself. Next comes biological death, by which Pattison means that the biological organism as a self-sustaining entity is dead, although

the heart and lungs may function with artificial support. Finally is physiological death when none of the vital organs continue to function. In view of the number of definitions of death given by previous authors, Pattison's addition to the list might seem like just another semantic exercise, however he then goes on to point out that the importance of these four kinds of death is that they can occur out of phase with each other. He diagrams the "ideal" death sequence as follows: commencing with knowledge of death there is "expectational hope". This is followed by "giving up", at which point "desirability hope" begins. Next comes "social death" quickly followed by "psychic death", "biological death" and finally "physiological death". If the time interval between "social death" and "psychic death" becomes extended, this can be regarded as "social rejection of the patient". If "social", "psychic" and "biological death" occur together, a significant time after knowledge of death, this is "social and patient rejection of death". If "psychic death" precedes "social" and "biological death", this is "patient rejection of life". Finally, if the situation of "social rejection of death with artificial maintenance" should happen, this means that "psychic" and "biological death" have occurred together, a significant time before "social" and "physiological death". Pattison believes that "our task" is to synchronise each of these dimensions of death, so that they converge together rather than occurring out of phase with each other.

3. "Dehumanisation" - Social Death in the Nursing Literature

Vail [1964] also refers to Goffman's work in his own discussion of the danger of dehumanisation in

institutions such as "public mental hospitals". He defines dehumanisation as "divesting a person of human capacities and functions until he becomes less of a man" [p.599]. (This, of course, is very close to Goffman's concept of "mortification".) Vail believes that dehumanisation can occur in any situation where one person or group is responsible for daily decisions with regard to the comfort and welfare of other people. While the occurrence of dehumanisation is not restricted to psychiatric hospitals, this is the area on which Vail concentrates. He points out that the rationale of the total institution is to produce a different kind of person. In the case of a psychiatric hospital, treatment is supposed to produce a "better person", but what is often produced is a "career mental patient". Vail gives examples of mortification and also of the complex reward and punishment systems that are often so entrenched within the institution of the psychiatric hospital as to go un-noticed. He refers to the ways in which patients can feel degraded and as though they are being handled as units within a batch. Vail asks what we can do to reverse dehumanisation. Unfortunately, he does not answer the question, apart from suggesting that staff at every level get together and decide what they could do. It is interesting that while indicating the effects of dehumanisation upon the patients in psychiatric hospitals, he does not go on to suggest that they join in the decision making process.

Travelbee [1964] defines the process of dehumanisation as occurring when "the 'patient' becomes an abstraction, a set of expectations represented by tasks to be performed, treatments to be carried out, a specific illness, perhaps just a room number" [p.71]. At a later date she speaks of the same process as "human reduction"; that is, "the diminishing capacity

to perceive ill persons as human beings accompanied by an increasing proclivity to perceive ill persons as an illness, or as a task to be performed" [1971, p.34]. She points out that no-one can feel warmth or compassion for a "patient" or an "illness" or a "task", and that to perceive a person in such a way is to ignore his or her humanity, instead regarding them as "a set of stereotyped characteristics". Examples of this include the beliefs that "all patients" are helpless and dependent, or "all patients" are not too bright. As a result, nurses may feel sympathy or pity ("you poor thing") for their patients, but they will not feel empathy. (This phenomenon is termed "identity spread" by Strauss [1984], who comments on the way in which some - usually visible - symptoms of illness cause other people to assume that the sufferer cannot act, work, or be like ordinary mortals. He gives the example of blind or physically handicapped people who continuously "have to cope with people rushing up to help them do what they are quite capable of doing or being treated in other ways as only blind or physically handicapped" [p.81]. Their visible symptoms dominate their interactions with other people.) To return to Travelbee's thesis, her belief is that the professional nurse must establish a human-to-human relationship with the ill person in order to help them and their family to cope with their illness and suffering. She cites a number of the capacities which might be regarded as defining a "human being": they are unique, thinking, able to communicate and relate with other people, they can evolve and change, they can remember the past, live in the now, and anticipate the future. She believes that communication is the key to the establishment of a human-to-human relationship between nurse and ill person. She describes such communication as reciprocal and mutually significant: "Each participant in the

relationship perceives and responds to the human-ness of the other ..." [1971, p.124]. The very obvious difficulty with this somewhat idealised picture of the relationship between nurse and ill person (whom we dare not now call "patient") is that there are some ill people for whom behaviours such as remembering the past, anticipating the future or reciprocating in a mutually significant way with others may be impossible. Travelbee does not suggest how the professional nurse can maintain a human-to-human relationship with such individuals.

In their description of "residential institutions for incurables" (by which they mean younger, chronically disabled people, suffering from conditions such as cerebral palsy, muscular dystrophy or arthritis), Miller and Gwynne [1973] describe two quite distinct approaches to residential care. They term these "the warehousing ideology" and "the horticultural ideology". The warehousing approach is exemplified by the following: patients sleep in wards which contain few personal possessions and are out of bounds during the day; patients spend most of the day just sitting around; conversation and mobility are minimal, the prevailing mode of behaviour being withdrawal, apathy and depression; visiting is strictly regulated; not only is the intake of food and drink regulated, but so is excretion (via suppositories); staff do the thinking for the patients. The task of the warehousing approach is simply to prolong physical life and it does this by processing the patient as necessary. The "good" patient accepts and acts according to the wishes of the staff. In contrast, in units which exemplify the horticultural approach, inmates have bed-sitting rooms, full of personal belongings and with no restrictions upon their use; inmates are seen to be busy and more full of

purpose and conversation; sophisticated wheelchairs allow inmates to move around freely; visitors can come and go as the inmates wish. The task of the horticultural approach (hence its name) is to develop the unsatisfied drives and unfulfilled capacities of people who are constrained by their need for physical care. In complete contrast to warehousing, the horticultural approach aims to develop independence. Miller and Gwynne comment that such an approach is often much more difficult for staff to accept, since their status is diminished, as is their usual protective role. While the horticultural approach appears to be "such a welcome contrast", Miller and Gwynne point out that perhaps it is not ideal in every way. People who enter such institutions are not only by definition so physically disabled that they cannot look after themselves, but they are also socially rejected: "by crossing the boundary into the institution they have demonstrated that they lack any role which is socially valued in the outside world. ... by the very fact of committing them to institutions of this type, society is in effect defining them as socially dead, and ... they will stay in an institution until they are physically dead" [p.140]. The authors believe that the seemingly ideal horticultural approach to care for such individuals denies the reality of differences between disabled and able-bodied people - it serves a defensive function, preserving "the fantasy of rehabilitation". Rehabilitation rarely occurs to socially dead people. They suggest a model for an appropriate caring organization which provides for both the disabled person's dependency and independency needs, and at the same time provides interpersonal support for those who have to cope with "all the pain of being a cripple".

III. A "PERSON" WITH A "WORTHWHILE LIFE"

Knutson [1970] points out that the most important feature of any of the definitions of death which one can discuss is the fact that once such a definition is applied to an individual, the behaviour of others towards that person can be expected to change. He concludes a discussion of a variety of these definitions (the termination of vital functioning, brain death, Sudnow's distinctions of clinical, biological and social death and Kalish's definition of psychological death) with the comment that "the above definitions all emphasise the degree to which the individual concerned is treated by observers as human" [p.4]. He refers to the way in which such definitions parallel (perhaps mirror would be a better term) those of the qualities that at the beginning of life turn a human life into a human being.

This section therefore considers accounts of the attributes of, firstly, a "person", and secondly, a "worthwhile life". If an individual ceases to possess the characteristics which we recognise as being those of a person, or if a life ceases to be recognised as worthwhile, then that individual may be more susceptible to social death.

1. What Makes "A Person"?

Harris [1985] starts by asking what is it that makes human life so valuable? In particular, what makes it more valuable than that of animals, fish or plants? This question raises a number of moral issues, one of which is "When does life begin to have that special value we believe attaches to human life and when does it cease to have that value?" [p.8]. Harris believes

that this is a far more important question than simply asking "When does life begin?" or "When does life end?". Whatever the features are which make human life valuable, they will therefore have moral relevance, justifying the belief that it is right to treat people as equals of one another and as the superiors of other creatures. Harris decides to define humans who possess such features as "persons". He recommends John Locke's account of what it is that distinguishes between persons and other creatures. This account combines rationality (a person is "... a thinking intelligent being, that has reason and reflection ...") and self-consciousness (a person "... can consider itself, the same thinking thing, in different times and places"). Harris' own concept of the person is very simple: "a person will be any being capable of valuing its own existence" [p.18]. He describes such a definition as being both value- and species-neutral. It also enables us to both understand why persons are valuable (ie. the reason for the moral difference between persons and other beings) and to tell persons from non-persons: creatures which cannot value their own existence will be robbed of nothing by death. The next problem for Harris is "How do we recognize persons?". The answer is simple if a creature has language because it will be able to say whether or not it values life. Polden [1989] criticises this notion on the basis that it does not allow for the possibility of poor communication between persons such that "it is not clear what happens if the wrong conclusions are drawn about the capacity of an individual to value life, nor what is to be done with, or to, those individuals who apparently cease to be persons because they do not express in an intelligible way their sense of valuing life" [p. 175]. However, Polden does not seem to have taken on board two further observations by Harris. The first of these

is that if beings of the kind we know to be capable of valuing their own lives exhibit some self awareness then we should take this as evidence of self-consciousness and the ability to value their own existence. The second important point is that irrespective of whether or not a being SAYS they value their existence, what is important is the CAPACITY to value it.

Harris goes on to ask "Once a person always a person?". If humans become persons when they develop the capacity to value their own lives it follows that they will cease to be persons if they lose that capacity. Harris believes that "If I am permanently unconscious, where 'permanently' means that there is zero probability of my ever regaining consciousness, it seems fair to say that I have ceased to be a person, for there can be no self-consciousness and so no ability to value my existence if I am permanently unaware of my existence" [p.26]. In such circumstances, Harris would argue that personhood is lost and even if the body is still technically alive, it has lost its moral significance - it has ceased to matter whether it is allowed to die or preserved alive.

Downie and Telfer [1969] also give the notion of "person" a more restricted use than the term human being in their discussion of "Respect for Persons". Two features make up the distinctive endowment of persons. First of these is the ability to be self determining, comprising both the ability to choose for oneself, to formulate purposes, plans, and policies, as well as the ability to carry out one's decisions, plans or policies in reasonable independence. Thus, "to impair a person's abilities to formulate and carry out aims and policies of his own devising is to that extent to destroy him as

a person" [p.21] - being too helpful or kind to someone with a disability can be regarded as eroding their personhood. The second feature of persons, according to Downie and Telfer, is the ability to adopt rules which govern one's conduct. Since these features are both present in normal adult persons, ipso facto these individuals are respected. However, Downie and Telfer are left with some cases which are more difficult to explain since according to their formulation, they are "not persons in the full sense". While the attitude of respect for persons may not be appropriately applied to "children, the senile, lunatics and animals", nor can we treat them with complete indifference. Children and "senile" people are human beings but may not be persons as defined by Downie and Telfer. They describe children as "potential persons" and senile people as "lapsed persons". While not necessarily able to show agape to such beings, they are cared for out of a sense of affection or pity.

Englehardt [1987] points out that there are bound to be a variety of different definitions of death since they reflect the variety of different human purposes - medical, legal, religious, or whatever. Definitions of death should seek to characterise those states in which there is no further sense in being termed "alive". Again though, this leads to the philosophical question of what it means to be a person: "In order to decide when we will be dead, we must to some extent reflect on what we are" [p.16]. If minimal sentience and minimal consciousness are necessary conditions of personhood, the problem of the definition of "minimal" arises. Differing definitions of death can therefore be regarded as different specifications for what constitutes "minimal" experience and doing in this world. In parallel with recent developments which

distinguish human personal (conscious) life from "mere" biological life, have come the definitions of brain death: if being a person requires a minimal level of sentience, and sentience is embodied in the brain, then destruction of the brain is equivalent to destruction of the person. Englehardt notes that in this view, life itself has no intrinsic value: "When the person living the life is no longer capable of being conscious, that life ceases to be of any direct value to him or her .. and, he or she is dead" [p.19]. He argues that it is possible to move even further and to define persons as humans who can interact within a social context. To lose the capacity to do this would then count as "death". The problem with pushing definitions of death too far which is outlined by Englehardt, is that it may result in too many false positives, and "being falsely labelled dead is, quite obviously, of great significance" [p.20].

2. What Makes "A Worthwhile Life"?

Within western cultures two views have become very important with regard to their influence on the conduct of laymen, and more particularly of medical personnel who have to make decisions concerning dying persons. They are discussed by Crane [1970]. The first revolves around the notion of "the sanctity of life". This notion has as its basis Christian beliefs, and it results in the attempt by medical personnel to prolong life for as long as they possibly can. However, some individuals, such as the irreversibly comatose can seem to be exempted from this: "When life continues after its peculiarly human qualities have been lost, it frequently but not always loses its sanctity" [p.307]. The second notion is that of "humanitarianism", that is the belief that suffering should be alleviated, if not

prevented. Crane points out that although both of these norms are part of the medical ethos, over recent years they have begun to contradict each other: the prolongation of life may add up to a high cost in the suffering it causes. Once again, we see from another author the idea that there are some cases in which the norms of the sanctity of life or humanitarianism are not necessarily applied. In these cases a number of more general social norms may take precedence. These include the notion of "social differentiation" - the idea that certain classes of individuals are more important and thus more worthy of saving. A significant dimension on which people can be valued is their stage on the life cycle. Death of the young or middle-aged entails a break in the life cycle. Such persons may thus be deemed of greater value and thus more worthy of saving than those who are regarded as being at the end of their life cycle. Another of the more general social norms which may come into play is "utilitarianism" - the idea that those who are regarded as contributing more to society (ie. as benefiting society) are more worthy of the receipt of costly medical resources.

This utilitarian notion of the economic and social costs of death is discussed more fully by Bailey [1970]. Since humans are no longer sold on the marketplace in western societies, economists have to estimate the value of a human life indirectly. This is done via a person's role as a producer. Clearly in the adult years (ages 21-65) most people are engaged in some form of productive work - in fact they often produce more than they consume. It would therefore be an economic cost to lose such a valuable person by death. But what about those outwith this range of the age spectrum? Children consume more than they produce, however it is still worthwhile investing in their lives since they

can be regarded as valuable in that they will be producers in the future. The elderly, on the other hand, also consume more than they produce, but can be regarded as having no value as an economic investment for the future. "Just as physical capital is viewed as having a limited life and is destined for the scrapheap when its value in production becomes zero, so also does human capital depreciate to the point where it can no longer be supported on economic grounds" [p.283]. At this stage, Bailey comments, the economist must give way to a value system that looks at life with different criteria. These different criteria are surveyed by Morison [1977]. He notes the intangibles of the complexity or richness of a person's life; the love, affection and respect commanded by the person from those who know him or her; the "sanctity of life". These parameters will all bulk up the "benefit" side of the value-of-life equation. The costs may be degradations, pain or suffering.

Foot [1978] suggests that there is no direct relationship between life and "good". She points out that sometimes life can seem a "good" even when it brings more bad than good things. For example, there are some quite severely physically or mentally disabled whose lives we can still see as good and as worth having, even if they embrace a degree of suffering. On the other hand there are some lives which seem to break the connection between life and good. Foot gives the example of "senility". While at a mild degree we might count someone as better off having their life than not having it and as being benefited by the doctor who is able to prolong life, this may not be the case for someone with very severe dementia: "There are some in geriatric wards who are barely conscious, though they can move a little and swallow food put in their mouths.

To prolong such a state, whether in the old or in the very severely handicapped is not to do them a service or confer a benefit" [p.93]. Foot suggests it is not the mere state of being alive that can count as a good. Rather, life has to come up to some standard of normality to count as a good. Even very hard human lives are worth maintaining if they contain a minimum of basic goods. However, when these are missing, the question arises of whether life is worth preserving. Evils only become relevant if they destroy the ordinary goods of life, or else invade a life in which these goods are already missing. "So, for instance, the connection between life and good may be broken because consciousness has sunk to a very low level, as in extreme senility or brain damage. In itself this kind of life seems to be neither good nor evil, but if suffering sets in one would hope for a speedy end" [p.94].

Kohl [1978] discusses what it is that makes a span of life meaningful. He cites three criteria. First, that the individual has some dominant goal(s) which give direction to their life. Second, that the individual believes that these goals are attainable. Finally, that these goals are sufficient to thwart depression and perhaps even add spice to the individual's life. Kohl comments that according to this viewpoint "a span of life becomes devoid of meaning roughly when, or to the extent to which, an individual believes he cannot possess goals or when, if he can and does have goals, they are impossible of being achieved" [p.126].

3. "Social Death" and "A Person With A Worthwhile Life": Opposite Sides of the Same Coin?

"Social death" or allied terms such as "dehumanisation" or "non-person" treatment can be applied to those situations in which the behaviour adopted towards one or more individuals is such as might be adopted if that person or group of persons had died. There is divergence in the range of behaviours to which this definition of social death is extended. The sociologist, Goffman, applies the concept in its widest sense when he discusses removing a person's individuality and treating them as just another human being. Kastenbaum's definitions of social death which range from being "cut dead" or excommunicated are also wide in their remit. Kalish would term this area sociological death. The use of dehumanisation in the nursing literature comes closest to Kalish's definition of other-perceived social death and Pattison's social death. The narrowest application of the term social death is that of Sudnow, who limits it to behaviours which would normally only be performed following the physical death of a patient. This range of definitions is summarised in Figure 5.1. (over page).

The characteristics of a "person" and a "worthwhile life" can be viewed as complementary to the point at which an individual becomes socially dead. The most inclusive standpoint is that of those who argue that life per se is worthwhile, that is, the "sanctity of life" argument. This comes close to the nursing view as represented by Travelbee - that it is important to strive towards the maintenance of a relationship which recognises the human-ness of the individual, however impaired they may be. The majority of definitions of personhood and a worthwhile life require the presence

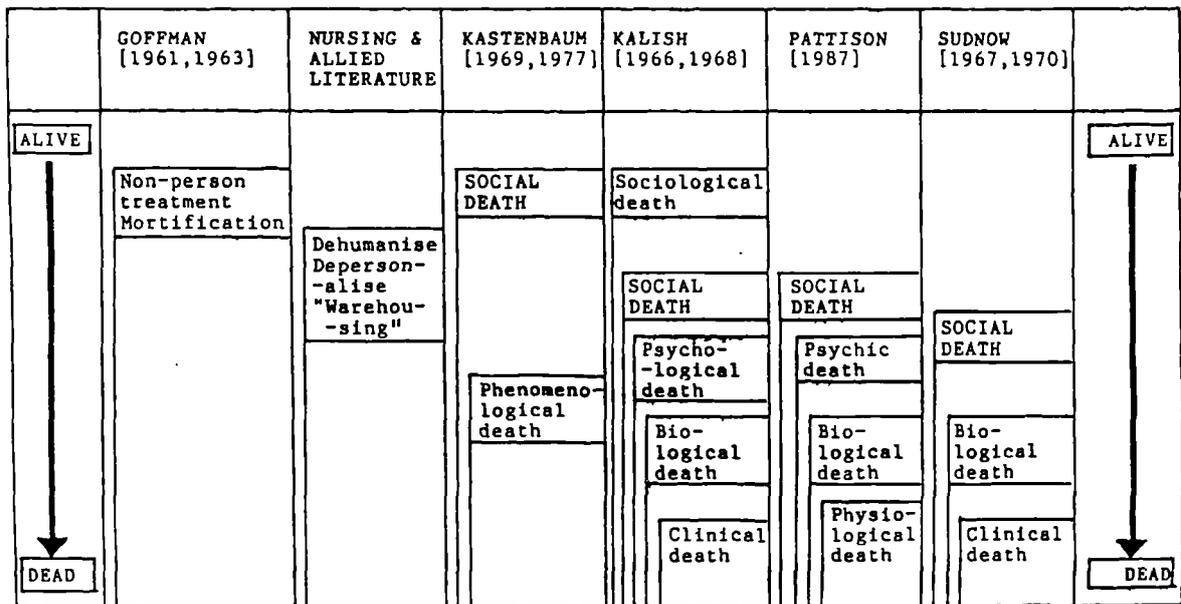


Figure 5.1 Definitions of Social Death Within the Transition from Life to Death

of characteristics which are not present in certain groups, for example, the irreversibly comatose, or those very severely impaired by mental handicap or dementia. While still physically alive, they have lost their individual characteristics and that which made them persons. Such groups come close to the view of the socially dead as presented by authors such as Sudnow, Glaser and Strauss, Kalish or Pattison. Yet another viewpoint is that which defines a worthwhile life via some more positive, often socially-based criterion, such as quality of life or level of mental health. Individuals who have been institutionalised, dispossessed of roles or subject to non-person treatment may not fulfil such criteria. In a way they can be regarded as having had their individual characteristics and that which made them persons forcibly removed.

IV. ANTICIPATORY GRIEF - A MAIN ROAD TO SOCIAL DEATH?

In the first analysis of anticipatory grief, with military personnel and their families during the Second World War as subjects, Lindemann [1944] highlighted a possible disadvantage of such a reaction. It will be recalled from the previous chapter that Lindemann's description of anticipatory grief was that the family members of those in the armed forces might be so concerned with their adjustment after the death of the soldier as to go "through all the phases of grief" once he went off to war. Lindemann observed "several instances" where a soldier who returned home alive was met by rejection on the part of his family. He believed the reason for this to have been that "the grief work had been done so effectively that the patient has emancipated herself" [p.148]. This observation is also made by Rando [1984] who notes the high divorce rates in the marriages of American POW soldiers returning home after Vietnam: "Their families had apparently grieved their absence to such an extent that when they did return the emotional investment was no longer present" [p.39]. On a similar note, Fulton and Fulton [1970] point out that it is not only those who are released from military service, but also those returning home from jails or from hospitals who may find it difficult to reintegrate themselves into their families. These authors suggest that "their significant others are no longer emotionally capable of incorporating them into the family or friendship circle" [p.94].

Does the same thing happen with dying patients? Might their relatives also go "through all the phases of grief", reaching a stage of decathexis and resolution before the patient's physical death?

Perhaps it does. The previous chapter referred to Natterson and Knudson's [1960; Natterson's 1973] descriptions of the reactions of mothers of fatally ill children as following a triphasic pattern. During the initial phase denial and guilt were prominent. During the intermediate phase, energies were directed towards the possibility of saving the child. The terminal phase (usually reached about 4 months after diagnosis) was characterised by calm acceptance: separation from the child became easier, wishes for the death of the child could be expressed, and the actual death was received with calm sorrow and relief. These authors believed that if given long enough to do her grief work, the mother of a fatally ill child could achieve emotional separation from her child before its death. Similar results are described by other studies of the reactions of the parents of fatally ill children.

What might be the consequences of emotional separation from the patient prior to their physical death?

Fulton and Fulton [1971] believe the most significant implications are for the patient him or herself. Not only are they having to cope with their own emotional reactions in the face of illness and imminent death (assuming they have been given their prognosis), but at the same time it may appear to them that their survivors are neither concerned nor saddened by the situation. Emotional separation may lead to physical withdrawal by relatives. Fulton and Fulton note observations of a gradual reduction in both the number and length of visits made by relatives to chronically ill or dying patients in hospitals or nursing homes. The impression of the patients may be that they have lost the love of their family. Caroff and Dobroff [1974] speak of "disturbing consequences" should family

members be emotionally or physically unavailable at a time when the dying patient is most in need of their interest, care and affection.

The patient may not be the only one to suffer in this situation, however. The ideal scenario of calm, accepting relatives described by Natterson and Knudson [1960] may not be entirely correct. Pine [1986] simply describes "problems" as arising when a terminally ill person hangs onto life while significant others have already let go. Rush [1974] refers to family members "exhausting" their emotional resources and wishing the patient would die in order that they could return to their normal lives. The result of this was an enormous amount of guilt on the part of the survivors when the death eventually occurred. Rando [1984] mentions the possibility of frustration, anger and resentment in family members. Caroff and Dobroff [1974] describe the "critical attitude" of staff members should they perceive the behaviour of relatives as inappropriate, indifferent or callous at the same time as they are investing heavily in their work with the dying patient. (For example, Fulton [1987], cites an incident in which a nurse apparently said with great emotion, "If family survivors can't behave more fittingly following a death, they should stay away from the hospital and from the funeral!" [p.253].) Similarly, Fulton and Fulton [1971] comment on our cultural expectations for mourning following a death: "Joyful, casual, or business-as-usual behaviour is considered both inappropriate and disrespectful" [p.94]. Survivors who do not display behaviours considered appropriate for bereaved people may receive censure not only from society in general but also those professionals who have been involved in their relative's terminal care. The survivors of a long drawn out death may feel the

traditional funeral ceremony to be somewhat redundant. However, such bereaved people would also be dismissing themselves of the possibility of any social or community support following the death.

A variety of inventive terms have been applied to the situation of an excessively long anticipatory grief period. Gosling [1980] discusses the effect of "blocked anticipatory grief" on survivors whom she calls the "NOBs" (not-officially-bereaved). She suggests that being a NOB is increasingly common nowadays as a result of the progress in resuscitation techniques and heroic medical interventions. She describes the products of these interventions as patients who are often "a mutilated caricature of their previous whole person" and relatives who may have to go through the processes of anticipatory grief repeatedly. These anticipatory grief processes may be practical and legal as well as emotional, and when the patient fails to die these relatives must try to pick up the threads of their relationship again. David [1980] discusses the same phenomenon but calls it "The Resurrection-of-the-Dead Syndrome". The reason for this choice of term is to suggest the notion of the psychological restoration of a person who continues to be perceived as dead, even when the threat of their physical death is over. David believes that in such situations "the personality of the sick member never quite manages to be perceived as very 'alive' even though the patient becomes physically reasonably well" [p.120]. He describes this as anticipatory grief at its most maladaptive. Finally, the same situation, of families who are unable to re-invest in the patient who has failed to die at the expected time is described as the "Lazarus Syndrome" by Rando [1984].

It thus appears that the outcome of extended or repetitious anticipatory grief processes in the relatives of a patient with a lengthy terminal illness (possibly also with remissions and exacerbations) may lead to their psychological and/or physical withdrawal from the patient. In other words, while the patient is still alive these relatives start to normalize their lives without the patient in the way that they would have done if the patient had died. In the most extreme cases it is possible that to all intents and purposes the patient would be dead in the eyes of their relatives. This, of course, is the definition of social death.

It should be noted here that this formulation of social death resulting from extended anticipatory grief does not receive unanimous support. Vachon, Freedman and Formo et. al. [1977] note that for some, the limited time left together during a terminal illness is used to achieve greater intimacy and to settle any unfinished business. Similarly, Parkes and Weiss [1983] comment that a lengthy terminal illness may allow spouses to round off their relationships. Rando [1986] asserts that one of the misconceptions about anticipatory grief has been that it must result in withdrawal from the dying individual.

V. PRIME CANDIDATES FOR SOCIAL DEATH

1. Social Death in Patients Suffering from a Chronic Fatal Illness

The notion of death as a taboo subject has been discussed previously (Chapter Three). If we avoid

discussing or thinking about death nowadays, do we also avoid dying people physically?

Kalish [1966] describes a study designed to investigate the social distance that people place between themselves and the dying, relative to the social distance desired from other avoidance-producing groups (such as gamblers, drug addicts, alcoholics, convicts, patients from a mental hospital, etc.). He asked 203 students to rate the various avoidance-producing groups using a social distance scale (asking questions such as "Would willingly admit to my street to live within a few doors of me", "Would willingly go out on a date"). Results showed the dying person to be generally more highly avoided than ethnic groups such as Mexicans or Jews (but less so than addicts, gamblers, etc.). Over one third of the sample would not willingly allow a dying person to live in the immediate neighbourhood. While there are obviously problems in generalising from how people say they would behave to the way they actually do behave, Kalish concludes that if taken at face value, "the social isolation of the dying is a very real occurrence".

The modern day experience of dying has changed in two important respects from that of "the old days". One of these changes is the place where death occurs. Nowadays the majority of deaths take place in hospitals, nursing homes, or other institutions. This used not to happen. An interesting point noted by Freeman, Brim and Williams [1970] is that it used to be the poor who died in institutions while physicians tended to deliver medical care to the homes of richer people. These authors describe "the fashion among American families" (and presumably also all other families in western societies) of delegating the care of dying relatives to

someone else. That someone else is usually an institution, most of which (the hospice movement excepted), are bureaucratically organised for the batch treatment of the large numbers of patients who pass through their doors. Knutson [1970] describes this modern day availability of institutional facilities for dealing with sick people as a defence which is used to protect society at large from death. He compares it with earlier western societies in which "death tended to be a family affair" [p.48]. Calkins suggests that the change in the housekeeping arrangements which comes with the institutionalisation of a patient can be the precipitant of social death. She gives as an example the report of a nurse working on a terminal ward who phoned a female patient's son to ask for permission to cut his mother's hair and received the reply "Goodness, is she still alive?".

The second of these modern-day changes in the experience of dying is the length of time over which death may occur. Thompson [1979] points out that people now find it difficult to accept the inevitability of death because they have such faith in modern day medical science and technology. This belief may be shared by medical staff who have it drummed into them that "death is the enemy". A patient who dies is a "medical failure". Thus, they feel obliged to employ their armoury of life support systems to prop up dying patients. Paton [1969] describes "modern dying" as an "obscenity ... a ritual sacrifice on the altar of technology" [p.591]. As Pattison [1987] observes, dying may now stretch over days, weeks, months or years: "For perhaps the first time in history we have many people who experience a new phase of life - the living-dying interval" [p.49]. He divides this living-dying interval into three clinical phases. First comes the "Acute

Crisis Phase", immediately following the crisis of knowledge of death, and associated with peak anxiety. Second is the "Chronic Living-Dying Phase". Finally comes the "Terminal Phase" which ends at the point of death. Pattison relates the three phases of dying to the concept of "dying trajectories" as first suggested by Glaser and Strauss [1968]. Four dying trajectories have been described: certain death at a known time, chronic death at an unknown time, uncertain death but a known time when the question will be resolved, and uncertain death with an unknown time when the question will be resolved. Most important of these trajectories for a consideration of social death is "certain death at an unknown time" since it is most characteristic of chronic fatal illness. Although death may be certain, the living-dying interval may stretch out over several years. Glaser and Strauss [1968] describe this situation as a "Lingering Trajectory : Institutional Dying". The typical patient has at least one known chronic disease, is "physiologically aged" by their disease and may have only limited mobility or self care abilities. Some may be comatose (Glaser and Strauss [1966] describe the genuinely comatosed patient as a "non-person"), others may be suffering from a degree of dementia.

Calkins [1972] speaks of the importance of recognition as a determinant of whether or not people are treated as socially dead. She discusses the case of a wife who while "extremely brain damaged" was frequently able to recognise her husband. In this case the husband was not able to treat her as socially dead. Calkins suggests that if, however, this woman were to become "permanently comatose, then he could reconcile himself to her death and maintain his self-respect while he attempted to construct another life" [p.35]. Similarly,

Paton [1969] describes some patients as "objects", once loved by their relatives, but now unable to communicate with them because they are existing on the end of a machine. The physical decline of such patients may be very gradual. Glaser and Strauss [1966] refer to many as having been "deposited" and thereafter abandoned in an institution by family members who may regard them as no longer fully alive. Their care is largely custodial. They may need bathing, toileting, feeding or dressing. The belief that such patients have earned the right to die is commonly held - "It's a blessing he died", "He had nothing to live for". When death eventually occurs, it is usually uneventful, often in the absence of family members. "In effect then, these patients drift out of the world, sometimes like almost imperceptibly melting snowflakes" [1968, p.64].

In sum, features which may trigger the social death of people who are known to be dying include: a lingering death (such as might be assumed to allow the relatives to resolve their anticipatory grief and decathect prior to the patient's physical death); the placement of a dying patient into a hospital or other institution, sometimes surrounded by technical equipment; and the inability of the patient to communicate meaningfully or to recognise either their relatives or those involved professionally in their care.

2. Social Death in the Very Old

"It is natural for old people to die". While it may go unsaid, this is the view held by the majority of people - both laymen and health service professionals - nowadays. Kastenbaum [1972] suggests that it is a very reassuring viewpoint: if death is natural for the (very) old then it's unlikely to happen to me for a

long time; death in old people is "appropriate", the world is running the way it's supposed to, old people have lived long enough, at least an old person's death isn't going to take me by surprise. Raphael [1984] also refers to the "natural" death of the elderly - often perceived as a simple and gradual relinquishment of life, maybe peacefully "slipping away" during sleep. All highly acceptable.

The facts bear out this relationship between old age and death. Lowther [1988] quotes figures (Scottish statistics, 1985) which state that only 24% of the population die before the age of 65, 25% between 65-74, 32% between 75-84, and 19% over 85 years old. Doyle [1979] describes dying as increasingly the "prerogative of the older members of society".

While Kastenbaum and Aisenberg [1972] point out that there are many elderly people who do not feel ready for death and who struggle against it with great resilience, this is by no means universal. Lowther [1988] suggests that for the old, death is not necessarily something to be resisted at all costs, but merely the last in a series of losses (of mate, friends, society, etc.): "Death, in a word, is not premature and therefore not necessarily an unwelcome guest" [p.66].

The major reason for this increase in age at death is not in fact modern medical procedures, but the achievements made in public health during the last century. A problem can arise when medicine steps in to prolong the lives of the very old. Isaacs, Livingstone and Neville [1972] describe the more recent advances in medicine and social services as combining to "reverse a biological law". They refer to the "survival of the

unfittest" in today's "developed" societies. Man is the only animal to thus nurture and protect the unfit so that life may close as it began, with a period of prolonged dependency. Isaacs, Gunn and McKechnan et. al. [1971] describe this as the period of "pre-death", characterised by impaired self care resulting from loss of mobility, incontinence or mental abnormality. In their survey of the deaths of elderly people in Glasgow, these authors found that a quarter of all those who died over 65 years old had suffered from prolonged incontinence and mental abnormality over a period of months or years before their death.

A further factor which has been suggested is characteristic of older people is their disengagement from the outside world. As Kastenbaum [1977] reports, this somewhat provocative notion was first referred to by Cumming and Henry [1961]. The idea is that people reach a peak of engagement with the outside world during young-middle adulthood. This is the time when they are raising children, establishing careers and fulfilling responsibilities. With increasing age however, people withdraw from some activities, they interact with a narrower variety of other individuals and they fulfil fewer roles. Wershow [1981] speaks of disengagement theory as important because it actually suggests that frenetic activity may not necessarily be the healthiest way to age. The implication of disengagement theory is that "both society and the aged person prepare for his or her death by this process of mutual withdrawal, of loosening of ties in emotional investment, life space, and time in worldly affairs" [p.60]. The world does not suffer much of a disruption when an aged, disengaged person dies.

Kalish [1969] describes the deaths of elderly people in our society as the least disturbing, because the aged are not especially valued. He cites a study by Kastenbaum which asked nurses what they felt were the appropriate amounts of time and energy to expend in trying to save the lives of a 20 year old, an 80 year old and a pet dog. Results demonstrated the ratio of importance of the 20 year old to the 80 year old to be greater than that of the 80 year old to the dog. This notion of the relative social values of dying patients is also discussed by Glaser and Strauss [1964; Glaser, 1966]. The social value which nurses place on a patient is reflected in the impact of his or her death on the nurse, and frequently also in the care he or she receives. While it is possible to value people on a variety of dimensions (skin colour, ethnicity, education, etc.), Glaser and Strauss describe age as the most important characteristic on which social value/loss is calculated. The reason for this is that age is regarded as the best indication of a person's past, present and future life potentials and fulfilments. Aged patients are thus most likely to be perceived as having had a full past, as contributing little to the present and as having no future worth: "He had nothing more to live for". Although nurses qua professionals might not allow themselves to go along with this belief, western societies may encourage the nurse to discount the aged dying person and their death. It is easier for the nurse to accept the death of an elderly person than that of, say, a teenager. The strain of caring for aged dying people may be less since the nurse is less likely to become socially and psychologically involved with an older person: "they are treated by the nursing staff in the hospital situation as socially dead, while physically alive. Their death itself is often perceived as a social gain

to all involved ..." [Glaser, 1966, p.79]. Similarly, Kastenbaum [1967b] describes dying aged people as having "very low visibility" in the health care world.

Bandman and Bandman [1978] suggest that while society rewards functioning members of the community, non-functioning or mal-functioning members may be treated much less well. Such persons have much less freedom to exercise their rights. The authors' examples of this include the treatment of aged people. They report that in the eskimo culture the practice was (is?) to put an aged, non-functional member of society onto an ice floe or to allow them to wander off to die like Captain Oates. This is paralleled by the placing of elderly people in nursing homes in our society. "Visitors to the western world are appalled by the way we dump our elderly - out of sight and out of mind" [Turner, 1979, p.186].

As Lowther [1988] points out, death in the old is more likely to take place in an institution because they are more likely to be living alone. Markson [1970] suggests that the low relative status of aged dying people may influence not just their care within an institution but also the nature of the institution to which they are admitted. She examined the physical conditions of a group of 174 elderly patients admitted to a New York state (mental) hospital during an 8 month period in 1967. The patients were physically ill with extremely impaired physical functioning (for example, unable to walk, comatose). Markson suggests that the admission of most of these elderly people to a psychiatric hospital was inappropriate and that they should have been receiving treatment or terminal care for their physical disorders in a general hospital ward. She lists three reasons why the older physically ill patient is

selected for transfer to the state hospital. Firstly, their lives have little social worth - they are already dying socially, having given up roles and with little future ahead of them. They are "disposable". Secondly, they are more likely to die than younger people (who as a consequence are more likely to be given the chance to oscillate between home and the general hospital). Thirdly, the elderly have low social status and lack of power. Markson describes the state hospital as functioning as "a geriatric house of death to which the elderly are relegated ..." [p.47].

Old age has also been linked to the process of anticipatory grief. Fulton, Gottesman and Owen [1982] found the death of an elderly parent to be significantly less disruptive, emotionally less upsetting and of less social impact than the death of either a spouse or a child. They suggest that the reason for this is that the death of an elderly parent has low grief potential. Fulton and Fulton [1971] were the first to discuss the notion of "grief potential", the idea that the degree or intensity of grief at the time of a death is a function of the kind of death experienced. A "high grief potential" death will usually precipitate what is generally described as "normal grief". Fulton and Fulton's example of such a death is the sudden accidental death of a person upon whom others depend for their physical and/or psychological well-being. Their example of a "low grief potential" death is that of an elderly relative: for many people today this may go by with only the barest acknowledgement. Fulton [1987] points out that adult sons and daughters may have been anticipating the death of an elderly parent for five, ten, or even more years. (An already elderly person's steadily increasing age may cause relatives to consider their death, despite

the fact that they may not have an obvious serious/terminal illness) Fulton contends that the anticipation of the death has allowed them to work through their feelings prior to the death, thus countering the behaviours and emotional reactions expected of "normal" grief: their stress at this time is "muted".

These elements which may occur in the lives of (very) old people (imminent death, physical separation/institutionalisation, anticipatory grief processes in their relatives) might therefore be regarded as increasing their chances of attaining some degree of social death while their physical life continues.

VI. SUMMARY

This chapter has examined definitions and accounts of "social death" and allied terms such as "dehumanisation" or "non-person treatment". Such a situation might be said to have occurred when the behaviours adopted towards and individual were such as might be adopted if that person had died. However, the range of behaviours subsumed by this definition differs widely among both different authors and among different theoretical or professional disciplines.

It was suggested that to be perceived as socially dead may be to be perceived as not fully a person, or as a being for whom life has ceased to be worthwhile. Examples within this category included the irreversibly comatose, or those very severely impaired by mental handicap or dementia.

Having seen that social death may occur as a result of the characteristics of the individual concerned, the idea that it may also result as the end-point of anticipatory grief processes in those close to the individual was raised. Evidence was presented which suggested that just as would be expected from "normal" post-bereavement grief, the resolution of anticipatory grief may be associated with the decathexis, both psychological and physical, from a dying patient. The impact of this situation on patient, relatives and professional caregivers was discussed. This was coupled with a warning that the notion of decathexis from dying patients is somewhat controversial.

Descriptions of two prime candidate groups for social death highlighted a number of the characteristics which appeared to be related to its onset. These included the following: the opportunity for anticipatory grief to have occurred because of a lengthy terminal illness or the great age of the individual; the fact that the physical death of the individual is regarded as "natural" and thus not worthy of much attention; the disengagement or physical separation of the individual; and the inability of the individual to recognise or communicate meaningfully with those around him or her.

These characteristics come together in a group whose social death has not been discussed in detail. This group is composed of people suffering from dementia and the possibility of their social death is raised in the next chapter.

CHAPTER SIX

JOINING THE THREADS: SOCIAL DEATH OF DEMENTIA SUFFERERS AND ANTICIPATORY GRIEF IN THEIR RELATIVES

"Several years ago, Mrs Morgan fell at a break in the pavement and struck her head on the pavement. She suffered a severe cerebral haemorrhage and has not had the best of mental health since then. Now she commonly recognises me and frequently expresses warm appreciation of my visits. She is blind and largely deaf and often I cannot understand what she tries to say. I take apple juice, melons or baby food which does not need to be chewed. Often there is little evidence of recognition except the process of eating. She seems to suffer no pain, except that sometimes in reply to my enquiry she says that her bones ache. She was 94 on April 4th. I sometimes think that living does not seem an asset to her."

[From a letter by A.E. Morgan, introducing "On Drinking the Hemlock", Hastings Center Report, 3rd December, 1971.]

I. INTRODUCTION

Dementia would seem to fulfil the conditions which have been discussed in previous chapters as leading to both the social death of the sufferer and anticipatory grief in their relatives. With regard to the latter, given the association between dementia and premature death, particularly when its onset is relatively early, dementia can be regarded as a "terminal" illness. It is a very lengthy condition and as such might be expected to allow relatives time in which to grieve. It is also a condition which might be expected to give relatives the opportunity to socialise into the bereaved role, as they gradually take over the responsibilities of the sufferer.

With regard to social death, dementia sufferers might be viewed as prime candidates. Two major pathways which might lead towards social death have been identified. One is the resolution of anticipatory grief in those around the sufferer. The lengthy course of the condition of dementia might be assumed to encourage this. The second pathway is via the characteristics of the patient. Again this is fulfilled - people with severe dementia are usually elderly, perceived as near death (or "as good as dead"), sometimes physically separate (in an institution), and generally psychologically separate (because of their inability to communicate meaningfully with, or recognise, their relatives). This chapter examines these issues in more detail.

II. THE "SOCIAL DEATH" OR "SOCIAL LIFE" OF THE DEMENTIA SUFFERER

It may be recalled that in discussions of "social death", the nature of a "person" and a "worthwhile life" (previous chapter), dementia sufferers were often held up as examples of a group for whom life may not be worthwhile anymore. It appeared that by attaining a certain level of dementia an individual might cease to possess those characteristics which would allow us to regard them as a person. Characteristics of "persons", (while depending on the definitions of individual authors) generally revolve around abilities such as rational thinking, sensible communication, and independent goal-directed activities. It follows from this that should an individual cease to be able to perform these functions then (depending on the cut-off level defining personhood/worthwhile life) they become

likely candidates for social death. The discussion and examples which follow enlarge upon this supposition.

1. Is a Dementia Sufferer a Person with a Worthwhile Life?

The notion of dementia as destroying the person is frequently raised in the literature. Aronson and Lipkowitz [1981] describe those around the dementia sufferer as witnessing the "slow extinction of the personality". Alzheimer's disease and other dementias are described by Kastenbaum [1988] as causing "death-in-life". He refers to the situation of a blank mind behind a well known and loved face (the "empty shell") as painful and unnatural for those relatives who have to cope with it. Chiverton and Caine [1989] present Alzheimer's disease as a disorder which "destroys a person".

Howell [1984] acknowledges but does not agree with the view that elderly people with dementia may be regarded as "absent" or "gone". Howell suggests that for anybody giving direct care each patient is fully a person: "although Mr X is different from the person he once was, and to those who knew him in past years may seem to be "less" of a person, to those who care for him day by day he is a fullsome and substantial person indeed" [p.657]. This view is hotly contested by Hermann [1984] in the same volume. He lists the characteristics of dementia as follows. Firstly, there is incompetence: "by the time these patients reach hospital or nursing home care, the main features of what one ordinarily regards as constituting 'being a person' are gone [p.655]. Patients are characterised as unable to explain what it feels like to have dementia, unable to comprehend what, where or why events are happening,

unable to control basic bodily functions. They ultimately reach a "vegetative state". Such patients cannot enter into any sort of meaningful contact with their caregivers. A second characteristic of dementia is the failure of the traditional medical model. Nothing the carer does can realistically slow the progress of the illness or prepare the patient for death. Thirdly, as a result of the eventual helpless dependence of dementia the caregivers are forced into the role of a critical lifeline to the sufferer who would die without their feeding, moving, or other varied caring activities. Thus, in contrast to Howell's thesis, Hermann emphasises the loss of personhood, identity and self-reflection in severe dementia. He contends that absence of personhood may reduce guilt and frustration in professional and family caregivers, and by doing so may result in the more effective care of the sufferer. He suggests that, in comparison to this, those who emphasise the remaining person in the sufferer will be stressed and hurt by their seemingly chaotic behaviour.

A similar stance is taken by Wershow [1981] who points out that despite the attempt to develop therapies for dementia, nothing as yet has been proved to have a significant effect. It is therefore "time that we accept the reality that brain cells, once destroyed, do not regenerate" [p.181]. Policies of care which ignore this are regarded as just "wishful thinking". It follows, therefore that institutions for those with severe dementia require minimal therapeutic input. Instead, these patients require large amounts of nursing care so they can die in as dignified and comfortable a way as they are able. Wershow suggests that efforts to further decrease their suffering and increase their pleasure are illusory. Families should

not feel guilty for their "failure" to cope with severely demented patients at home. Clearly, for Wershow then, these patients have stopped "counting" as persons. As such, a warehousing approach to their care within an institution is quite legitimate.

It might be said that an individual ceases to be regarded as a full person in the eyes of the law when a legal definition of incompetence is made - the fate of a great many dementia sufferers. "Basically, incompetence is a legal conclusion that a person is not able to care properly for himself, his dependants, or his property. ... Diseases, insanity, mental retardation, and sometimes even old age are given as causes of incompetence" [Gilhooly, 1986b, p.134]. Once an individual is declared incompetent and a guardian is appointed, that individual is deprived of a large number of personal rights and civil liberties. Among a list of the rights which are commonly restricted in the United States, Gilhooly cites the following: selling, purchasing, mortgaging or leasing property; making gifts; voting; making or revoking a will; divorce or marriage; driving a car. She describes the individual as having been reduced to "the status of a child in the eyes of the law" [p.135]. In fact it might appear that their status may be reduced before they are even declared legally incompetent: Gilhooly notes that in American law the hearing can take place without either their own presence or even somebody to represent them.

2. Are People with Dementia Likely Candidates for Social Death?

It is interesting that discussions on this issue are limited to the possibility of social death or non-person treatment of dementia patients within the

institutional setting, and usually by professional staff rather than the patient's relatives. Possibly this is because, as has been noted earlier, the institutional situation increases the likelihood of such treatment. But could it also be that to describe family caregivers as treating a person with dementia as socially dead might be perceived as too risky or uncomfortable a conclusion? To describe relatives in this way may imply criticism of a group of people who are already burdened. In fact, of course, it should not. Social death cannot necessarily be regarded as anybody's "fault", but rather as arising from circumstances such as the characteristics of the patient, their living arrangements, and the anticipation of their death by those around them.

Several researchers have used terms or descriptions akin to social death when referring to people with dementia. For example, patients with severe senile dementia have been described as "socially dead" by Glaser and Strauss [1966]. Their care within the institution is custodial. They may not be visited by their families. They "deserve" to die - but because of their impairments have no awareness of their impending death. As a result they may cause less stress in staff (or relatives) than people in whom awareness of dying is clear or - even worse - suspected.

Baker [1976] describes the "striking" similarity between the care required by a newborn baby and that of a totally dependent elderly person. He questions whether the considerable extension in the lives of "totally demented and dependent" elderly patients which can be achieved by modern nursing and medical care is in any sense beneficial to these patients. "Skilled nursing care can maintain life in a frail, elderly

patient whose general condition is such that a comparable state in an animal might well lead to prosecution of the owner" [p.571]. For Baker, the death of such patients would clearly be "a blessing". It is cruel to maintain their lives. Are these patients, then, socially dead?

Kastenbaum [1967b] introduced the term "social visibility" in his description of the terminal stages of a geriatric patient's life. Patients who were relatively well known to hospital staff were defined as more "socially visible" than those who were relatively unknown. Kastenbaum found that patients who were consistently mentally alert were significantly more socially visible than those with some degree of mental impairment. Once again, then, it appears that mental impairment is associated with the social death of dying geriatric patients.

While working as a volunteer in a 150 bedded "convalescent home" for the elderly, Smithers [1977] was able to act as an observer of the ways in which many institutional practices function to encourage "senile" behaviour. Using Goffmann's [1963] framework of the institution as removing a person's individuality and subjecting the inmates to batch treatment, Smithers describes patients as stripped of their identity, deprived of social resources, and as therefore offering little resistance to the institutionally defined version of dependent patient. She found that patients were geographically distributed in three distinct areas according to the institutionally defined versions of their level of competence. The most able and "sensible" patients were near the front of the building and were therefore visible to visitors. The least able "hard core", "senile" patients were at the back: "Here are to

be found the 'screamers, the nutty characters and the strippers'" [p.255]. In this area patients tended to be lined up in front of the nurses' desk. This arrangement made for easier "baby sitting". Because doors were not locked in this home, mobile patients were restrained in chairs. Staff interactions with patients were such as to emphasise their own status and the dependency of the patients, for example, the use of first (or pet) names, and physical familiarity. Smithers notes that the organisational efficiency of the institution is increased when patients are "managed" in a way which lowers their independence and competence. Patients who were designated by staff as "senile" entered a special status whereby they were exempted from taking responsibility for their actions. They paid for this, however, by their non-person status, their loss of many of the rights and privileges of rational individuals, and their relinquishment of the right to expect staff to respond to their demands or explain their actions. "In this framework senility can be thought of as a living death in which one is no longer accorded the rights and privileges extended to the living" [p.273].

This almost automatic assumption that certain patients not only are, but also should be, socially dead, is highlighted by Kastenbaum [1967a]. He reports on "death valley" - the intensive treatment unit of a geriatric hospital. In this ward there was a very low level of communication between staff and patients, and little expectation by staff that patients should be mentally alert, sociable or active. An experimental programme of reality orientation and social activity was introduced onto the ward. The result is described by Kastenbaum as a marked increase in alertness, spontaneous behaviour and communication by patients. Despite this positive result, it was a "success that failed". The activity

programme did not gain the unanimous approval of staff working either in or outside the ward. Kastenbaum does not discuss this, but could it have been that staff expected the patients in "death valley" to be socially dead, and thus were unable to tolerate the evidence from the activity programme that at least some patients might be socially quite alive?

3 Hints of Social Death in Dementia Patients who Receive Family Care

While the studies which follow do not mention "social death" or non-person treatment by family caregivers, they appear to be discussing these very issues.

Hirschfeld [1978, 1981] describes the results of a study of 30 people with "irreversible senile brain disease" and their primary caregivers. One of the major aims of her study was to explore the factors which influence a family to continue caring for these dementia sufferers versus those which lead a family to consider institutionalisation. She found that none of the social, demographic or impairment characteristics of either the dementia sufferer or their carer had a statistically significant impact on decisions to institutionalise. Caregiver and sufferer morale and tension did impact on decisions to institutionalise, as did caregiver management ability. However, by far the most significant predictor of desire to institutionalise the sufferer (assessed on a 5-point scale ranging from "Unwilling to even consider institutionalisation for the future" to "In the process of institutionalisation") was caregiver "mutuality". (Discussed briefly in the Chapter Two.) Mutuality was related to the caregiver's ability to both find gratification in the relationship with the impaired

person and meaning from the caregiving situation, and also to perceive the impaired person as reciprocating by virtue of their existence. Having operationalised mutuality, Hirschfeld found her study population fell into the following four distinct groups REGARDLESS of the actual severity of the disease or any of the socio-demographic variables. Group 1 - High Mutuality, "Internally Reinforced": despite severe impairment the dementia sufferers all retained an important function in the lives of their caregivers who in turn believed that the loss of the sufferer would be a major loss in their own lives. Group 2 - High mutuality, "Externally Reinforced": the sufferer and the caregiver both propped each other up, each doing what the other, for mental or physical reasons, was unable to do. Thus the presence of the dementia sufferer was essential to the caregiver's style of life. Group 3 - Low Mutuality: whatever the level of cognitive impairment of the sufferer it was perceived by the caregiver as an immense problem in their ability to relate emotionally. These families were overwhelmed by the impact which dementia was having on their lives. Group 4 - No Mutuality, "Survived": the common factor was that none of the sufferers seemed to play any positive role in the lives of the caregivers, all of whom would be relieved to know that the sufferer was being cared for in an institution, and some of whom would be relieved to know that the sufferer had died. Viewed from our own perspective, does it not seem that these definitions of "mutuality", (certainly those of high "externally reinforced" versus the low "survived" groups) bear a large similarity to definitions of the presence or absence of social death of the dementia sufferer? Caregivers in the high "externally reinforced" mutuality group continue to relate to the sufferer as an important person. They must perceive the sufferer to

be socially alive. Caregivers in the low/no mutuality groups are unable to perceive the sufferer as a person with whom they can have a meaningful relationship. Death of the sufferer, or at least their removal to an institution would be a blessing. This interpretation of Hirschfeld's results is reinforced by some further comments which she makes, as follows. Firstly, whenever "loss of self" affected areas which had been central to the former carer-sufferer relationship, the impact of this decline weighed heavily upon the carer. Secondly, most family members exhibited distress and sadness when speaking of the sufferer's lack of interest or "vegetating". Thirdly, the meaning which the carer attached to the sufferer's inability to recognise people seemed to determine the severity of the problem which they experienced. In all three of these cases, what is being discussed are aspects of the loss of the individual "person" of the sufferer.

Johnson and Catalano [1983] describe two major adaptive mechanisms adopted by the family carers of impaired elderly people. These are "distancing" versus "enmeshing" techniques. "Distancing" strategies occur when the sufferer's mental and physical status impair their relationship with the primary caregiver. The carer in turn finds his or her increasing responsibilities (and often also the dyad's social isolation) intolerable. They cope with the situation by increasing the distance between themselves and the sufferer. One option is to increase their physical distance by seeking alternative methods of caring for the sufferer, for example, institutionalisation. A second option is to increase their psychological distance while maintaining physical proximity, for example, involving other family members to share the care, or defending themselves with systems of

rationalisation ("I've done all I can"). According to Johnson and Catalano the other major adaptive mechanism which may be adopted by family carers is "enmeshing". As the dependency of the sufferer increases, the carer-sufferer relationship intensifies. "Social regression" is one example of the enmeshing strategy: the carer-sufferer dyad withdraw from social involvements and become increasingly isolated. The partners have no-one to rely on but themselves and they are therefore forced to become more interdependent. A second example of the enmeshing strategy is "role entrenchment". This occurs when caregiving is accepted as a permanent, full-time role which takes precedence over all other roles. The caregiver re-defines the situation in order that they are able to perceive it as offering some tangible benefits in itself. Caregiving gives new meaning to the carer's life. Again, viewed from our perspective, might we not expect distancing techniques to be more often associated with the socially dead sufferer? On the opposite side of the coin, would it be possible to adopt an enmeshed strategy with a sufferer whom you did not perceive to possess at least some degree of social life?

Motenko [1989] points out that the vast bulk of the literature with regard to the family caregivers of dementia sufferers is concerned with the stresses and burdens which they experience. In contrast, the importance of the rewards derived from caregiving have not received much attention in the literature. In a study which employed face-to-face interviews with 50 women caring at home for a husband with dementia, Motenko found the following. Firstly, perception of change in marital closeness was significantly correlated with gratification from caregiving. Thus, wives who reported either that they had always been

close to their husbands and remained so, or that they had never been close to their husbands and weren't now, were more gratified than wives who were close before but no longer close after the onset of illness. Secondly, wives who gave care out of "reciprocity" or "tender loving care" were highly gratified, whereas those who gave care out of a sense of responsibility had low gratification from caregiving. Thirdly, gratification from the marriage decreased the longer the patients were sick (ie. gratification decreased with increasing impairment): "As the disease progresses, husbands are less able to be partners in a marriage. They can no longer be husbands" [p.170]. Is what we are seeing here a relationship between carer gratification (from either their role or their marriage) and their continued perception of their husband as still their husband, the man he always was, and thus deserving of their care? In other words, might gratification from the caring situation be more likely when the dementia sufferer is socially alive?

Gratification is one thing, caregiver burden may be another. Motenko [1989] also found an inverse relationship between severity of the husband's impairment and frustration in the wife. Similar results were reported by Pruchno and Resch [1989]: caregiver burden had a non-linear relationship with sufferer forgetful behaviours. Burden was lower when forgetfulness was slight (mild dementia) and when forgetfulness was very severe (severe dementia/"vegetative" state). Could it be that, as suggested by Hermann [1984] (see the beginning of this section), caregiving becomes less stressful once dementia sufferers become so severely impaired that they lose their personhood?

In a survey of family involvement in nursing homes, York and Calsyn [1977] report that "somewhat surprisingly", the number of family visits to the 76 patients in their study was not related to the amount of physical or mental deterioration of the older relatives. The mean number of visits per month was 12, countering the myth that families abandon or "dump" impaired elderly relatives in homes. However, the authors found that 42% of the families reported enjoying less than half their visits. Enjoyment was not related to what was done on the visit, nor physical or sensory disabilities of the patient. Enjoyment of visits was, however, related to the amount of mental deterioration of the patient; specifically to patient self-care disability, impaired cognitive functioning and poor personal appearance. These features might be regarded as much more important factors in the "person" of the patient than their physical or sensory disabilities. Maybe what York and Calsyn are describing here is that it is no fun visiting an institutionalised elderly patient who has lost those features which made them an individual "person" in the eyes of their relatives - in other words, it is no fun visiting someone who is socially dead. Visiting the dead is unpleasant.

III. MIGHT THE EMOTIONAL REACTIONS OF THE FAMILY CAREGIVERS OF DEMENTIA SUFFERERS BE ANTICIPATORY GRIEF?

We have seen that dementia gradually erodes the person of the sufferer, often leaving them to linger in a death-like or vegetative state. We have also seen that this process will occur over a span of several years in most cases. Given these facts, might not the caregivers of dementia sufferers be the most obvious "mourners

without a death"? (The condition discussed by Gosling [1980] and noted in Chapter Four.)

A number of authors have suggested - in more or less specific terms - that the family caregivers of dementia sufferers do experience grief. These studies will be reviewed in the first two parts of this section. Emotions associated with the process of institutionalisation are often referred to in terms of a grief reaction - the separation in living arrangements being perceived as a rehearsal for the final separation which will occur when the sufferer dies. The last part of this section will examine this issue in more detail.

1. Studies which Specifically Refer to a Grief Reaction in Family Caregivers

Berezin [1970, 1977] refers to the way in which old age brings with it various changes which can be regarded as loss or threatened loss; for example, failing eyesight or hearing, memory defects, loss of muscle power, thinning hair, retirement, the departure of children from home. He suggests that not only the ageing person him or herself, but also their family and friends will react to these changes as "the beginning of the end". Berezin also refers to "a more extreme example, when an elderly person is afflicted with an organic brain condition, a senile dementia, with the resultant changes in personality, there is obviously a significant loss of previously well-known person" [1970, p.56]. The reaction to this loss will be varying degrees of anxiety, grief or depression. Berezin writes that this grief must be coped with, but cannot be fully resolved or completed until the death of the aged person occurs. Berezin suggests that a suitable term

for this unresolvable grief reaction is "partial grief". Partial grief in family members, according to Berezin, may include anxiety, guilt, helplessness (since they can do nothing to alter the steady downhill course of the elderly person's life), and ambivalence. While family members may actually wish for the death of the elderly person this is something which cannot be openly expressed. As such, it may be handled by denial: "Some of us have had the experience of observing a spouse or a child talk to an aged person with far advanced organic brain deterioration as if they were holding an understandable conversation" [1970, p.60]. He cites as an example a woman who refused all family and professional suggestions that her extremely severely demented husband might be cared for in hospital, misinterpreting certain behaviours as rational and therefore as suggesting that he was going to recover. Berezin indicates that wishes for the death of such an individual can usually not be expressed until after it has actually occurred - when it was a "blessing", a "relief" after such suffering.

Lezak [1978] describes what it is like to live with the "characterologically brain injured patient". Her examples come from her experiences of running a drop-in discussion group for family members of brain injured patients (whose conditions "represented almost the entire spectrum of common adult-onset brain disorders). While her subjects were not limited to dementia sufferers, many of the characteristics she describes are typical of dementia, and her paper has been quoted by authors working with the relatives of dementia sufferers. Lezak cites five characteristics of brain injured patients which are likely to create adjustment problems for their families. These are: firstly, impaired social perceptiveness resulting in self-

centred behaviour; secondly, impaired control and self regulation resulting in impulsivity, restlessness and impatience; thirdly, stimulus bound behaviour resulting in inability to plan and initiate activities; fourthly, specific emotional alterations (commonly apathy, silliness, lability, irritability and excess/lack of sex drive); and finally, inability to learn from experience. The family as a whole may experience a number of problems as a result of this. Examples include frustration, the need to alter roles and responsibilities, feeling trapped, isolated or abandoned with the patient. Lezak regards spouses as having particular problems; they live in a social limbo because their partners cannot participate in social activities, but they are not free to look for a new partner. In addition, "The spouse cannot mourn decently. Although he has lost his mate as surely and permanently as if by death, since the familiar body remains, society neither recognises the spouse's grief nor provides the support and comfort that surrounds those bereaved by death" [p.593].

In her small study of the principal supporters of elderly persons suffering from a dementing illness and living in the same household, Wheatley [1979] cites examples which may be regarded as the expression of a sense of loss. One lady referred to the emotional strain and distress of having to watch her mother trying but unable to do things that she used to be able to do (such as the washing or making the beds). It was also sad to be surrounded by things that reminded her of her mother's former skills. She quotes similar comments from other subjects: "It's very hard, it's very hard when you see her like that", "It's terrible, a wasted life", "It's heartbreaking". Wheatley found that supporters tended to dwell on things which the

dementia sufferer had been able to do prior to the illness but now found difficult or impossible (rather than upon those things which they never had the chance to do). She suggests that this is understandable since it is easier to mourn the loss of something tangible rather than something that might only have been anticipated.

Kapust [1982] describes living with dementia as "the ongoing funeral". The illness challenges the usual notions of sickness since the health care system cannot provide active interventions, treatment or cure. Whatever the quality of care provided by the family and professionals the clinical course of dementia will head downhill. "Gone is the patient's ability to work and to love. Only fragments of familiar behaviour and personality remain as sorrowful reminders to the family of what has been lost. The healthy spouse and family experience life as an ongoing funeral: the person they once knew is dying, a little at a time. The family grieves for the losses yet there are no formalized rituals to help them through this time" [p.80]. However, the continued life of the patient, in whatever form that may be, means that this mourning process cannot reach a stage of "healthy resolution". Kapust presents the family reactions as changing over time as the dementia progresses. (The similarity of this sequence of family reactions to Kubler-Ross's [1970] stages of anticipatory grief is worth noting.) The early responses are denial and anger. In the initial stages of the illness, because of its insidious onset and the usual physical well-being of the patient, families make excuses for odd behaviours or explain them as "just getting old". As the patient's impairments become more noticeable the family may try to isolate them from their friends, either because of

their own embarrassment or their wish to protect the patient. Eventually the family's denial breaks down and they experience anger and frustration, directed either at the patient or at professional caregivers. At this stage, according to Kapust, there is often a disruption of familial roles and responsibilities as healthy members take over the gaps left by the now disabled patient. Often these changes involve undoing patterns which have been established over decades. There is also the "social dilemma": how do you interact with friends when your companion is a dementia sufferer?". Many families solve this problem by avoiding it and isolating themselves socially. Kapust describes the final stages of the family reactions to a dementing relative as depression while they mourn their loss. Kapust and Weinraub [1984] refer to this loss as having two aspects. Firstly, the relatives are aware of the dementia sufferer's loss of competence and skill. Secondly, they themselves have lost the person they once knew - usually spouse or parent. They cite the comments of members of a relatives' support group on this theme of loss, including one woman who described herself as a "walking widow".

Similarly, Sheldon [1982] raises the need to discuss issues of loss with the relatives of patients with dementia in order to help "support the supporters". She also highlights the difficulty which relatives may have in accepting the diagnosis and the need for the message to be followed up and amplified. This difficulty may be related to the anxiety associated with such a diagnosis - Sheldon cites two questions which are frequently asked by adult children: "Why did it happen to my parent?" and "Will this happen to me when I am old?". She suggests past relationships will have a major impact on how the relatives cope once the diagnosis is

recognised. A good previous relationship should provide a better basis for continued loving care. Sheldon presents the unresponsiveness or inappropriate responses of the patient as most difficult for the family to cope with. If they express anger, or even irritation at the patient, then guilt will follow. She describes this guilt as often recurring when the patient eventually dies, and suggests that "some families do their mourning when the patient's personality alters, but most go through the normal process of grieving"[p.187].

The similarity of the emotions which the family members of dementia sufferers experience to a grief reaction is also noted by Rabins, Mace and Lucas [1982]. Eighty-seven percent of the primary caregivers of 55 dementia patients whom they interviewed cited chronic fatigue, anger and depression as a problem in themselves. The authors describe relatives as having difficulty differentiating between feelings of anger, sadness, depression and fatigue, and they suggest that "this is similar to Parkes' findings that these feeling states coexist during grief" [p.335].

While admitting that it has not been documented, Boutselis [1983] refers to clinical observation as suggesting a difference in the type of burden felt by spouses versus children caring for a person with senile dementia. Noting that the slow progressive losses associated with dementia can be difficult and painful for relatives to accept, she suggests that there may be more of an emotional content in the burden expressed by spouses. Boutselis says that the reason for this is that while all relatives face the daily problems of providing care, spouses are often going through a grief process at the same time. This is indicated by the fact

that if a spouse is asked how much their husband or wife's impairments bother them they will often reply that a certain problem is bothersome not because it creates practical difficulties but because it is a painful reminder that the husband or wife is changing. Boutselis seems to suggest that adult children do not go through this process when she writes that their experience of the burden is different from that of spouse caregivers.

Teusink and Mahler [1984] note the similarity of the family responses to Alzheimer's disease to the five stage mourning process described by Kubler-Ross. While recognising that there are differences in the ways in which individual families handle the situation they describe the reactions of families coping with the disease as "similar to the reactions of families coping with death", and as "normal steps in a process of coming to terms with this overwhelming illness" [p.152]. They document these steps as follows: denial, overinvolvement, anger, guilt, and finally resolution or acceptance. Stage one, "denial" occurs when family members notice memory losses but explain them away. While noting that to some extent this may simply represent lack of knowledge about normal aging versus dementia, Teusink and Mahler comment that some families fail to recognise even grossly disturbed behaviour, focussing instead on the patient's well functioning remote memory. The authors suggest that denial can serve a defensive function, allowing the family to postpone dealing with the pain of the loss. Denial is followed by stage two, "overinvolvement". This occurs once the impairments of the dementia sufferer become more obvious to their relatives. While it can amount to a realistic compensation for the losses of the sufferer (for example, taking over financial responsibilities),

it may become exaggerated (for example, the relatives who sacrifice their own social lives, freedom or health to care for the sufferer). Stage three of coming to terms with Alzheimer's disease in a family member is "anger". Anger may be the result of the burden of caring and the behaviour of the sufferer. Teusink and Mahler suggest it may also arise from the feeling of having been abandoned by the still living but non- or mal-functioning spouse or parent. This anger is often projected onto the professionals who are trying to help the family caregivers. As anger lessens it is followed by stage four, "guilt". Once again, while some guilt may be realistic as family members recognise their own anger or wishes that the sufferer could die, the authors suggest that some is unrealistic, for example, relatives may believe that they have somehow contributed to the illness by not maintaining a perfect relationship with the sufferer when they were well, or by not acting on the early signs of the Alzheimer's disease. The final stage is "acceptance". According to Teusink and Mahler, acceptance only comes once the relatives understand the nature of the disease, learn to cope with the problems it presents, work through their own anger and guilt, and recognise that they have lost the person they once knew. The authors point out that acceptance is made more difficult because of the insidious onset of the disease, its long progressive course and the preservation of the patient's usual physical well-being and appearance, particularly early on in the illness.

Death and isolation are two of the "existential" issues relating to the predicament of the relative supporting a demented elderly dependent at home, according to Levine, Gendron and Dastoor et. al. [1984]. With regard to the theme of death, the authors comment that

"clinicians working in the field are familiar with the 'widowhood' of the wife of the severely demented Alzheimer's patient, as she attempts to cope with a death that never ends, and a mourning process that can never properly take place because the dead personality lingers in a surviving body" [p.217]. They suggest that while coming to terms with the death of the sufferer, the carer must also come to terms with their own death - and with the fact that for every day spent being a caregiver, their own life is passing them by. They suggest that attempts to repress this "awful reality" may result in severe anxiety in the caregiver. Isolation and loneliness are frequently complained of by carers - while physically present, a patient with severe dementia may be psychologically unavailable. Because of their physical presence the caregiving relative is constantly reminded of their separation and inability to communicate. Once again, the authors comment on the anxiety-provoking nature of such a situation.

Rabins [1984] describes the variety of emotions which the family of a dementia patient may experience over time as "chronic grief". As with other accounts of this reaction, he mentions the possibility of denial when relatives find it difficult to assimilate information about the condition, followed by specific anxieties either about the possibility of their having caused the dementia or about the patient going "crazy". He reports that feelings similar to those found in acute grief - sadness and depression, anger and frustration, guilt and hopelessness - may be experienced. This grief is for someone who has not died but has become different. Distress in relatives is exacerbated by their uncertainty about the future, associated with the often uneven deterioration of patient functioning.

These emotional reactions are expanded upon by Mace and Rabins [1985] in a book aimed specifically at the family caregivers of confused elderly people. They discuss some of the thoughts which may go through the minds of the relatives while they give care. Examples include the possibility that the impaired person may die at home, the question of whether they are suffering and if so whether it is fair that their life should be prolonged, the fact that someone they have loved will never be the same again, and the changes in relationships, roles and responsibilities within the family. Mace and Rabins aim to reassure their readers that negative feelings are "OK" or normal in the caregivers situation. They list anger, helplessness, embarrassment, guilt, worry, grief, depression and isolation. They explain the notion that grief is associated with loss rather than just restricted to bereavement, thus losses and changes in the person with dementia may result in chronic grief in the family caregivers. Certain losses or changes may be particularly important, for example, loss of the ability to communicate, or changes in the personality. (Both of these could be regarded as symbolising a loss of the essential individuality and personhood of the sufferer.) Mace and Rabins attempt to redress the balance by including some more positive emotions on their list: laughter, love, joy and hope.

Enlow [1986] presents a personal view of "Coping with Anticipatory Grief" when she discusses her own reactions to the severe mental and physical impairments of her elderly institutionalised mother: "This daughter could handle the death of her beloved mother, but this living death, the loss of mother as I once knew her is a loss that leaves grief unresolved" [p.36]. Enlow links her own grief reaction to the stages of death

preparation identified by Kubler-Ross, but suggests that it is dominated by anger, frustration, hopelessness and helplessness because while her mother's life lacks quality, neither is she granted the relief of death. She recalls times when she has thought of her mother in the past tense, as if she were already dead, and notes the guilt which this brings. Presumably Enlow would class herself as among the "Not-Officially-Bereaved" [Gosling, 1980].

2. Studies Which Do Not Explicitly Refer to a Grief Reaction in Family Caregivers

One characteristic which all the works cited in the above sub-section share is that they are not based on studies which specifically set out to examine or assess the emotional reactions experienced by the relatives of dementia sufferers. The majority are anecdotal discussion articles, some based on the authors' experiences while running support groups with relatives, others not clearly based on any specific means of gathering information about the supporters' reactions at all. A few, more recent studies have addressed reactions (usually depression) which might be regarded as part of grief, in a more specific and objective way. However, their remit has not been to investigate grief per se in these relatives. These studies will now be reviewed.

Goldman and Luchins [1984] present 3 cases of major depression requiring hospitalization in spouses of patients with progressive dementia. In each case the awareness of the dementia and the increasing burden of care seemed to be the major precipitants of the depression. The authors discuss these findings in the context of the progressive loss of intellectual

functioning and/or personality in the dementia sufferer as being the cause of a reaction similar to bereavement in their family.

While investigating the relationship between marital intimacy, perceived strain and depression in 20 spouse caregivers of dementia sufferers, Morris, Morris and Britton [1988b] observed a positive association between loss of intimacy and depression. They suggest that it may be not only the behavioural disturbances but also the sense of loss associated with the decrease in intimacy that contributed to depression in these caregivers.

One of the findings of a study by Moritz, Kasl and Berkman [1989] concerning the health impact of living with a cognitively impaired elderly spouse was a significant association between cognitive impairment in wives and depressive symptomatology in husbands. (There was no such relationship between cognitive impairment in husbands and depressive symptomatology in wives.) Moritz et. al tie this result in with those studies which have demonstrated the health impact of bereavement to be greater on widowers than on widows. They suggest that the impact of the "loss" of a spouse through cognitive impairment has a similar impact to loss through death. "The emotional strain of witnessing and adapting to spouses' mental, behavioural and personality changes together with the loss of companionship and intimacy are likely to contribute to increased depressive symptoms" [p.s-25]. They comment that it would have been interesting to compare the magnitude of the impact on the caregivers of individuals with recent onset versus long-term impairment, in order to examine for the possibility of changes over time.

In a study which was designed to examine the relatives' perception of the deterioration in intellectual function, the problems they perceived and their responses to a situation in which the sufferers had only mild dementia (ie. "the beginnings of dementia"), Pollitt, O'Connor and Anderson [1989] obtained results which surprised them. They found that these relatives did not see themselves as carers or the elderly person as demented. The authors interviewed the primary caregivers of 34 elderly people (most over 80 years old) who had been diagnosed via the CAMDEX as suffering from mild dementia. In the early stages of dementia the affected person may still have a good "social facade" and be able to cope with regular daily routines. While the carers could usually judge the extent of the impairment with a fair degree of accuracy, they did not acknowledge its implications or appear concerned about the condition. Instead, they gave explanations which couched the impairments of the sufferer in terms of "normal ageing", some sort of temporary aberration, attention-seeking behaviour, a natural extension of a long-standing characteristic or as a result of physical problems. Pollitt et. al. comment that "it was not always clear in these instances whether the relatives were trying to persuade us or themselves that everything was still alright" [p.12]. Similarly, the relatives did not appear to perceive the difficulties associated with the dementia sufferers' impairments as "problems", nor themselves as "carers". Most received little support from others, either on a formal or an informal basis. Again, the authors suggest that this might have a defensive element in that they were "declining to put their conception of normality to the test by isolating themselves from other people" [p.24]. In their discussion of these results Pollitt et. al. suggest that there are identifiable stages in carers'

perceptions of dementia. To begin with, changes are accommodated and explained away. As the condition gets worse it becomes recognised as an illness which brings problems, until finally with the "loss" of the person they once knew, the relatives experience a bereavement reaction. Again, Teusink and Mahler's [1984] paper is cited.

Might denial of dementia also be demonstrated by professionals? Dubler [1982] suggests that health professionals may assume that the prospect of escalating cognitive decline and other impairments may be so terrifying that patients should not be told. What follows is an "oppressive silence" as professionals withhold information from not only the patients themselves but also their family caregivers. It may be easier for the professionals to deal with dementia sufferers and their families in this way. O'Connor, Pollitt and Hyde et. al. [1988] note this situation but point out that not all patients reach a state of hopeless incompetence and "we found time and again that relatives benefited from talking about their difficulties, and those who felt able to talk to their doctors valued this greatly" [p.1110].

3. Institutionalisation of a Dementia Sufferer - the Emotional Reactions of Their Relatives

It was noted in the Chapter Two that family caregivers are generally loathe to institutionalise dementia sufferers. There are far greater numbers of people with dementia living in the community than in institutional care (hospital, nursing home or homes for the elderly).

Both Cath [1972] and Tobin and Kulys [1981] note the common pattern of care as the elderly person becomes

increasingly impaired to be increasing family input (even if this only comes from one primary caregiver). Often the dementia sufferer is moved into the caregiver's own home in an attempt to stave off institutionalisation. Cath describes none of the family members as wishing to take the responsibility for institutionalisation, which may be regarded as the equivalent of "a death sentence". To lessen their guilt, family members employ defences in order to delay the institutional decision: some may insist that the dementia sufferer does not really have all that many problems, others may isolate themselves in order to put off having to discuss the problems with anyone else. In Cath's view, the decision to institutionalise "amounts in effect to the final annihilation of a parental image" [p.30].

In this context it may be regarded as perfectly appropriate for family members to experience grief at this time. Relatives may therefore feel not only guilt, but also anger (often projected at professionals) and depression at the impending loss of someone they have loved and cared for. As Kapust [1982] points out, institutionalisation may be the first separation which an older married couple have experienced after years of marriage. And it is likely also to be the final separation. Sheldon [1982] describes institutional care as associated with "the power of the death-bed promise" [p.187]. The ability of the institution to dispossess inmates of their roles and destroy their individual identities, as described by Goffman [1963] is not a secret in western societies. As Cath [1972] indicates: "There is no point in shutting one's eyes to the truth that in our culture an elderly person in a caretaking institution has few rights and dignities and in effect has had to renounce his social and citizen roles. No

one in a nursing home or in a hospital remains an influential citizen" [p.33].

While the family caregivers of dementia sufferers may not talk of "social death", "mortification" or "dehumanisation" in so many words, they are only too well aware of its occurrence. We can therefore assume that of course they will attempt to prevent it happening to dementia sufferers whom they regard as still socially alive. If it does have to happen they will experience grief for the sufferer who has thus lost much of his or her individual personhood. But what of the institutionalisation of a dementia sufferer who is already socially dead? Could it be that they have nothing to lose? Hirschfeld's [1978, 1981] discussion of "mutuality" (see previous section in this chapter) might indicate that institutionalisation of an already socially dead dementia sufferer would be welcomed by family caregivers.

IV. SUMMARY

The lives of some dementia sufferers may not fulfil the criteria which have been considered necessary in order to qualify as a "person" with a "worthwhile life". The severity of dementia needed to fail the "personhood"/"worthwhile life" tests will obviously vary depending on the level of attributes chosen to mark the pass line. It tends to be associated with "vegetative" states, inability to recognise or communicate with others, and completely helpless dependence. There is fairly clear evidence of such patients as receiving non-person treatment within institutions. There are also hints of the perception of dementia sufferers as to some degree socially dead (possibly regardless of

their level of impairment) by relatives who are caring for them outside an institution.

Family caregivers are frequently characterised as grieving the loss of the person with a worthwhile future life while the sufferer's body continues to exist, and particularly if institutionalisation is imminent. Despite a number of anecdotal discussion papers on this topic, the author found no studies which set out to make an objective assessment of the presence of grief in the caregivers of the dementing elderly.

We are also left with something of a "chicken and egg" problem. As with the more general literature on social death, some of the papers reviewed in this chapter appear to link the onset of anticipatory grief with the prior presence of social death (For example, the notions that the "loss of the previously well known person" [Berezin 1970, 1977] or institutionalisation with its associated loss of roles etc., will trigger anticipatory grief in relatives.) On the other hand, other papers suggest that social death follows anticipatory grief. Which comes first?

CHAPTER SEVEN

AIMS OF THE PRESENT STUDY

"Just before she died she asked, 'What IS the answer?' No answer came, she laughed and said, 'In that case, what is the question?'"

[The last words of Gertrude Stein. From "Gertrude Stein: A Biography of Her Work", Donald Sutherland, New Haven: Yale University Press, 1951, p.203.]

The aims of the present study were to explore the concepts of the "Social Death" of dementia sufferers and the "Anticipatory Grief" of their caregiving relatives.

It might be possible at this stage to state the aims as a lengthy list of the hypothesised relationships between the various factors to be investigated. However, this is not felt to be appropriate; the study was exploratory, and pages of hypothesised relationships are likely to obscure rather than clarify the more basic aims of the study.

The aims of the present study, then, were to answer the following questions.

1. Does The Nature Of The Reaction Experienced By The Relatives Of Dementia Sufferers Constitute Anticipatory Grief?

Previous studies have demonstrated that these relatives experience a significant "subjective burden". Can this be entirely attributed to the objective burdens of the caregiving task, or might it result at least in part

from their recognition of the various losses associated with dementia? Anecdotal reports suggest that the relatives of dementia sufferers do experience grief in the face of both the sufferer's loss of competence and their own loss of the person they once knew. Do caregiving relatives perceive themselves to be grieving a loss? Do they demonstrate the emotional, behavioural and physical characteristics of grief? Do they experience the social aspects of loss?

2. Does Anticipatory Grief Occur In Stages With The End-Point Being That Of Resolution?

Anticipatory grief is almost invariably characterised, like "normal" grief, as a staged process. The typical lengthy course of dementia might be expected to provide carers with years in which to pass through an anticipatory grief reaction. Do relatives of dementia sufferers pass through stages which, although variously named by different authors might be characterised as shock and denial, followed by anger and protest, then depression and despair, and finally acceptance and resolution? If they do pass through these stages, how long does the process take?

3. Is The Nature Or The Severity Of Caregiver Anticipatory Grief Related To Individual Caregiver Or Sufferer Characteristics, Or To Their Relationship?

These factors have been demonstrated to have an impact on the normal grief process, and also upon the subjective burden of caregivers. Do they also impact upon anticipatory grief?

4. Are Dementia Sufferers Perceived As Socially Dead By Their Caregiving Relatives?

We have seen (chapters five and six) that the characteristics of dementia sufferers may mean they are among the most likely candidates for social death, if not top of the list. Are they perceived in this way by their relatives? Do relatives treat dementia sufferers as a task rather than a person? Do they discount the sufferer socially, ignoring them or speaking about them in their presence? Do they withdraw physically from the sufferer? Do they believe that the sufferer would be robbed of nothing by death and thus describe death as a "blessing"?

5. Is The Staging Of Anticipatory Grief Linked To The Social Death Of The Dementia Sufferer?

It has been noted (chapters four and five) that the onset of an individual's social death has been linked to the resolution of anticipatory grief in their loved ones. It is assumed that decathexis will occur at this stage, resulting in social death for the patient (that is, non-person treatment, physical or psychological separation). At what point do dementia sufferers begin to receive treatment accorded to socially dead people? Is it associated with the final stage of their relatives' anticipatory grief? Alternatively, is the onset of social death associated with certain "not-a-person-anymore" characteristics (for example, apathy, inability to make meaningful contact with those around them, or entry to an institution) in the sufferer? If this is the case, does the social death of the sufferer trigger the onset of anticipatory grief in their relatives?

6. Are Anticipatory Grief And Social Death Linked To The Caregiver's Well-Being or Subjective Burden?

If anticipatory grief occurs, does its presence impact upon the carer's well-being? If anticipatory grief occurs as a staged process, are there certain periods during which the relative experiences greater subjective burden or when they find it more difficult to cope with the task of caring? If social death occurs, does its presence impact upon the carer's well-being or ability to cope? If so, is well-being greater, and is it easier to cope with a socially dead person whom you may be able to treat as a task? Or is there better well-being, and is it easier to cope with a socially alive person whom you regard as worthy of, and able to participate in some sort of human-to-human relationship?

7. Are Anticipatory Grief And Social Death Linked To Institutionalisation?

Are caregivers more willing to institutionalise a dementia sufferer once they have resolved their own grief? Are they more willing to institutionalise a dementia sufferer whom they perceive as already socially dead? Does institutionalisation of a dementia sufferer trigger anticipatory grief in their relatives and/or result in the social death of the sufferer?

The remainder of this thesis describes the methods which were used in an attempt to seek the answers to these questions, and describes and discusses the results which were obtained.

PART TWO

METHOD

CHAPTER EIGHT

METHOD: STUDY SAMPLE, PROCEDURES, MATERIALS AND MEASURES

"The purpose of exploratory investigation is to move toward a clearer understanding of how one's problem is to be posed, to learn what are the appropriate data, to develop ideas of what are significant lines of relation, and to evolve one's conceptual tools in the light of what one is learning about the area of life." (Blumer, 1970, p33.)

I. INTRODUCTION

In view of the lack of research into the actual process of anticipatory grief - other than on a post hoc basis - or into social death, this investigation was of necessity exploratory. In his description of exploratory procedure, Blumer (1970), points out that its flexibility need not mean that there is no direction to the inquiry, but rather that the focus is originally broad but becomes progressively sharper as the inquiry proceeds.

The present study derived its data from semi-structured interviews with the caregiving relatives of dementia sufferers. These interviews were based on a "Carers' Questionnaire", the final version of which evolved over a series of stages. These were as follows: firstly, preliminary discussions with professionals and open-ended interviews with a very small number of carers; secondly, a pilot study employing the initial draft of the Carers' Questionnaire; and finally, a modification of the questionnaire for use in the present study. The remainder of the main body of the thesis describes the

employment of the final version of the Carers' Questionnaire and the results which emerged. The reader who wishes to trace the evolution of the Carers' Questionnaire, together with the results of the earlier studies, can find details in Appendices One, Two, Three and Four. (Appendix One, "Preliminary Investigations"; Appendix Two, "Pilot Study"; Appendix Three, "Formalising the Carers' Questionnaire and Coding Frame"; Appendix Four, "Carers' Questionnaire - Pilot, Final Version, and Coding Frame".)

The remainder of this chapter describes the method of the present study. This involved conducting semi-structured interviews with the caregiving relatives of dementia sufferers, based on the final version of the "Carers Questionnaire". The chapter has three further sections. First is an overview of the sample, together with descriptions of the demographic characteristics of both the carers and their dementing relatives, plus the behavioural characteristics of the dementia sufferers themselves. This is followed by a report of the procedures involved in contacting and interviewing the carers. The third section is a brief description of the materials and measures of the present study, namely the final version of the Carers' Questionnaire and its Coding Frame. (The next chapter presents the variety of techniques used to analyse the data which emerged from the interviews.)

II. SAMPLE

1. Description of Sample .

The sample comprised 100 relatives of patients with a primary diagnosis of senile dementia. At the time of

the interview, the dementia sufferer lived with the carer in 61 cases, in their own home in 16 cases, and in long-term institutional care in 23 cases. The sources of the sample are detailed in Table 8.1 (below).

Table 8.1
Sources of Sample Group of Caregiving Relatives Forming Main Study

<u>Source of Subjects</u>	<u>N</u>
- Dykebar Hospital (Paisley) psychogeriatric day hospital records.....	9
- Dykebar Hospital (Paisley) in-patient ward records.....	5
- Hawkhead Hospital (Paisley) in-patient ward records.....	4
- Stobhill Hospital (Glasgow) psychogeriatric day hospital records.....	14
- Leverndale Hospital (Glasgow) Florence Street psychogeriatric day hospital records.....	2
- Southern General Hospital (Glasgow) relatives' support group.....	9
- Ravenscraig Hospital (Greenock) psychogeriatric day hospital records.....	10
- Re-Education of Dementia Sufferers' (REDS) project (Glasgow) relatives' support group.....	4
- Motherwell Alzheimer's Disease Society project.....	26
- Paisley Alzheimer's Disease Society project.....	13
- Alzheimer's Disease Project (Gartnavel Royal Hospital, Glasgow).....	4
TOTAL N = 100	

The result of drawing the sample from such a variety of sources was that the subjects were spread over a wide area, within a 20-25 mile radius of Glasgow city centre. The vast majority of this geographical area is working class, the economy having been based until recently upon the heavy industries of steel manufacturing, ship building and other large-scale engineering works.

Formal ethical permission to conduct the study was received from the Greater Glasgow Health Board and from the Inverclyde (Greenock area) Ethical Committee. (See Appendix Five) The research (pilot version) had already received the approval of the Dykebar Hospital Ethical Committee (Hawkhead Hospital is part of the Dykebar unit) and therefore a separate ethical submission was not required in order to conduct the main study in these two hospitals. Informal permission to conduct the study was received from the Re-Education of Dementia Sufferers (REDS) project, the Alzheimer's Disease Project, and from the Motherwell and Paisley Alzheimer's Society Projects.

2. Demographic Characteristics of the Sample of Caregivers and Dementia Sufferers

CHARACTERISTICS OF THE TOTAL CAREGIVER SAMPLE

1. CARER GENDER: The sample comprised 26 male and 74 female caregivers.
2. CARER AGE: The average age of the total caregiver sample was 59.8 years (S.D. = 12.7, range = 28-81 years).
3. CARER MARITAL STATUS: Half (N = 51) of the total caregiver sample were married with a retired spouse. The rest were married with a working spouse (N = 21), single (N = 10), divorced (N = 8), married with an unemployed spouse (N = 6), widowed (N = 3), or separated (N = 1).
4. CARER EMPLOYMENT STATUS: The majority of the total caregiver sample were themselves retired (N = 55). The rest were housewives (N = 19), in part-time employment

(N = 13), in full-time employment (N = 8), or unemployed (N = 5). Of the 13 in part-time employment, 2 had changed from full-time work in order to care for the dementia sufferer. Of the 60 not in paid employment (retired, unemployed and housewives) 19 had given up work in order to care for the dementia sufferer.

5. CARER SOCIAL CLASS: The social class of the majority of the caregiver sample as determined by occupation was "skilled manual" (N = 63). The rest were "professional" (N = 4), "other non-manual" (N = 22), and "partly" or "unskilled manual" (N = 11).

6. CARER EDUCATION: Most had left full-time education at an early age: 13 years (N = 5), 14 years (N = 41), 15 years (N = 30), 16-21 years (N = 23). Only one was educated to degree level.

7. CARER HOUSING: Of the 65 subjects who completed information about their housing, 28% described their home as "semi-detached", 22% lived in a tenement, 18% in a terrace, and 18% in a maisonette (4 in a block). Of these 65 subjects, 35 (54%) rented their home, 83% of them from the local authority. The other 30 (46%) owned their home, 57% of them via a mortgage.

8. CARER INCOME: Of the 46 subjects who completed information about their weekly family income, the majority had a below average income: £50-£100 in 14 (30%) and £100-£150 in 14 (30%). 6 subjects (13%) had a family income of over £300 per week.

CHARACTERISTICS OF THE TOTAL SAMPLE OF DEMENTIA SUFFERERS

1. SUFFERER GENDER: The sample comprised 42 males and 58 female sufferers.
2. SUFFERER AGE: The average age of the total sufferer sample was 75.5 years (S.D. = 8.1, range = 54-92 years).
3. SUFFERER MARITAL STATUS: The majority (N = 52) of the total sufferer sample were married with a retired spouse. The rest were widowed (N = 44), single (N = 2), married with a working spouse (N = 1), or married with an unemployed spouse (N = 1).
4. CARER-SUFFERER BLOOD/ROLE RELATIONSHIP: The relationship of the sufferer to the caregiver was as follows: spouse (N = 50), sibling (N = 3), mother (N = 35), father (N = 9), and mother-in-law (N = 3).
5. SUFFERER LIVING ARRANGEMENTS: Most of the sufferers lived within the community; either with the caregiver (N = 61), or in their own home (N = 16). The rest (N = 23) lived in institutional care (hospital or nursing home).
6. SUFFERER SOCIAL CLASS: The social class distribution of the dementia sufferers was very similar to that of their caregiving relatives, the majority being "skilled manual" (N = 73), and the rest "professional" (N = 1), "other non-manual" (N = 16), "partly" or "unskilled manual" (N = 9), and unemployed (N = 1). (Collecting the present sample from an area with an economy traditionally based around heavy industry has resulted in an over-representation of skilled manual workers.)

DIFFERENCES BETWEEN MALE AND FEMALE CAREGIVERS

1. Male carers were significantly older (mean = 65.0 years) than female carers (mean = 57.9 years) ($t = 2.54$, $p = 0.013$).
2. Male carers were related to significantly younger sufferers (mean = 72.6 years) than female carers (mean = 76.5 years) ($t = 2.15$, $p = 0.034$).
3. There was a significant interaction between carer gender and marital status (chi-square = 18.11, $p = 0.006$). Female carers were more likely than male carers to be married with a working spouse, or divorced; male carers were more likely than female carers to have a retired spouse, or to be single.
4. There was a significant interaction between carer gender and employment status (chi-square = 15.02, $p = 0.005$). Female carers were more likely than male carers to be working (either full- or part-time); male carers were more likely than female carers to be unemployed or retired. No male carers classed themselves as "housewife".
5. Although there were differences between male and female carers in terms of their relationship to the sufferer (females more frequently caring for their mothers or mothers-in-law than males, and males more frequently caring for a spouse than females), this interaction was not significant.
6. There was a significant interaction between carer gender and the living arrangements of the sufferer (chi-square = 6.38, $p = 0.041$). Female carers were more likely than male carers to be related to a sufferer who

was still living in their own home, or was in an institution; male carers were more likely than female carers to be looking after a co-resident sufferer.

DIFFERENCES BETWEEN MALE AND FEMALE DEMENTIA SUFFERERS

1. Male sufferers were younger (mean = 73.7 years) than female sufferers (mean = 76.9 years), but this difference did not quite reach a significant level ($t = 1.97$, $p = 0.052$).

2. Male sufferers were related to significantly older carers (mean = 63.0 years) than female sufferers (mean = 57.4 years) ($t = 2.24$, $p = 0.028$).

3. There was a significant interaction between sufferer gender and marital status (chi-square = 16.45, $p = 0.0025$). Male sufferers were more likely than female sufferers to be married. Female sufferers were more likely than male sufferers to be widowed.

4. There was a significant interaction between sufferer gender and their living arrangements (chi-square = 6.94, $p = 0.031$). While male and female sufferers were equally likely to be co-resident with the carer, male sufferers were more likely than female sufferers to be living in an institution, and female sufferers were more likely than male sufferers to be living in their own homes.

INTERACTION BETWEEN CARER-SUFFERER BLOOD/ROLE RELATIONSHIP AND SUFFERER LIVING ARRANGEMENTS

There was a significant interaction between carer-sufferer blood/role relationship and sufferer living arrangements (chi square = 26.20, $p = 0.001$). Spouse

sufferers were most likely to be co-resident with the carer. Mothers were more likely than fathers to be co-resident, while fathers were more likely than mothers to be living in an institution.

INTERACTION BETWEEN CARER AND SUFFERER GENDER

There was a significant interaction between carer and sufferer gender (chi-square = 15.13 after Yates' correction, $p = 0.000$). While female carers were equally likely to be looking after a male or a female sufferer, male carers were far more likely to be looking after a female sufferer than a male. (Of the 26 male carers, only 2 were looking after a male sufferer.)

3. Behavioural Characteristics of the Dementia Sufferers

TIME SINCE ONSET AND DIAGNOSIS OF DEMENTIA

The average time since onset of the dementia as estimated by the carers was 6.1 years (SD = 3.4, range = 0.5-15.0 years). The average time since formal diagnosis of the dementia as recalled by the carers was 3.6 years (SD = 2.1, range = 0.1-9.0 years). These two time periods were significantly correlated (Pearson's $r = 0.565$, $p = <.000$)

BEHAVIOURS OF THE TOTAL SAMPLE OF DEMENTIA SUFFERERS

Gilleard's [1984] 34-item Problem Checklist, used in the Edinburgh research studies, was employed to assess the behavioural disabilities and disturbances of the dementia sufferers. Table 8.2 (overpage) demonstrates that, taken as a whole, the carers were related to

dementia sufferers with a fairly severe degree of impairment. 22 behaviours from the 34-item "Problem Checklist" were reported as occurring (either "occasionally" or "frequently") by half or more of the total sample of caregivers. These behaviours were as follows:

Table 8.2
Sufferer Behaviours Reported as Occurring by Half or More of the Total Sample of Caregivers

Problem Checklist Item	Percentage of carers reporting this item's occurrence
Forgets things that have happened.....	100%
Unable to occupy him/herself doing useful things..	98%
Sits around doing nothing.....	94%
Unable to hold a sensible conversation.....	94%
Unable to take part in family converstions.....	92%
Unable to watch and follow TV / radio.....	88%
Disrupts carer personal and social life.....	88%
Not safe if outside the house alone.....	86%
Unable to read newspapers, magazines, etc.....	85%
Unable to dress without help.....	77%
Unable to wash without help.....	77%
No interest in news of family or friends.....	72%
Shows no concern for personal hygiene.....	70%
Careless about own appearance.....	68%
Cannot be left alone for even one hour.....	62%
Unsteady on feet.....	60%
Creates personality clashes.....	55%
Incontinent - wetting.....	54%
Always asking questions.....	53%
Temper outbursts.....	51%
Demands attention.....	51%
Wanders about the house at night.....	50%

Of all the problems reported (regardless of their frequency of occurrence) those listed in Table 8.3 overpage were rated as "a problem" (either "some" or "great") by half or more of the total sample of caregivers.

Table 8.3
 Sufferer Behaviours Rated as "A Problem" by Half or
 More of the Total Sample of Caregivers

Problem Checklist Item	Percentage of carers reporting this item as "a problem"
Disrupts carer personal and social life.....	90%
Demands attention.....	86%
Cannot be left alone for even one hour.....	83%
Noisy, shouting.....	82%
Falling.....	78%
Creates personality clashes.....	77%
Physically aggressive.....	76%
Temper outbursts.....	74%
Vulgar habits.....	73%
Wanders about the house at night.....	72%
Incontinent - wetting.....	70%
Forgets things that have happenend.....	69%
Incontinent - soiling.....	68%
Unsteady on feet.....	65%
Shows no concern for personal hygiene.....	64%
Unable to hold a sensible conversation.....	57%
Unable to wash without help.....	53%
Unable to get in and out of a bed without help....	53%
Unable to get in and out of a chair without help..	52%
Unsafe if outside the home alone.....	52%

(A couple of examples to clarify the meaning of Tables 8.2 and 8.3: of the 51% of carers who reported the behaviour "Demands attention" as occurring, 86% regarded it as a problem; of the of the 77% of carers who reported the behaviour "Unable to wash without help" as occurring, 53% regarded it as a problem. Thus while "Demands attention" occurred much less frequently than "Unable to wash without help", when it did occur it was more often regarded as a problem behaviour.)

Inspection of Table 8.2 demonstrates that the most frequently reported behaviours of the dementia sufferers were "omissions" - generally apathetic behaviours or the inability to take part in family

interactions. The vast majority of sufferers were unsafe outside alone, and almost two thirds could not be left alone, thus causing considerable disruption to the lives of most of the carers. Three quarters needed help with washing and dressing, and half were incontinent of urine. Problem behaviours of "commission" - creating some sort of disturbance or in other ways requiring carer attention were reported to occur in about half the sample of sufferers. Table 8.3 demonstrates that it was these behaviours of commission along with the need for "surveillance" that were most likely to be reported as causing problems to the carers.

DIFFERENCES IN THE BEHAVIOURAL CHARACTERISTICS OF THE DEMENTIA SUFFERERS BY SUFFERER GENDER

There were very few significant differences in the reported behavioural characteristics of male sufferers when compared with female sufferers. With regard to the frequency with which behaviours were reported to occur, only 2 of the 34 items differed significantly: female sufferers were reported as significantly more frequently "Unable to manage stairs" ($t = 2.29$, $p = 0.024$) and more frequently "Not safe if outside the house alone" ($t = 2.52$, $p = 0.014$). With regard to whether the reported behaviours were regarded as a problem by the carers, only one differed significantly between male and female sufferers: "Forgetting things that have happened was regarded as a greater problem in male sufferers ($t = 2.93$, $p = 0.004$).

There were no significant differences for either the estimated time since onset of the dementia for male versus female sufferers, nor for the time since its formal diagnosis.

III. PROCEDURE

1. Contacting the Sample

The sample was contacted in the following four different ways.

1. For the institutions listed below (Table 8.4), the names and addresses of carers whose relative was either attending the day facility or in long-term care were supplied by staff members. ,

Table 8.4
Institutions Where the Details of Caregiving Relatives
Were Given by Staff to the Investigator

<u>Name of Institution</u>	<u>No. of names supplied</u>	<u>No. of positive replies</u>	<u>Response rate (%)</u>
Dykebar psychogeriatric day hospital.....	13.....	9.....	69%
Stobhill psychogeriatric day hospital.....	27.....	14.....	52%
Florence St. psychogeriatric day hospital.....	10.....	2.....	20%
Ravenscraig psychogeriatric day hospital.....	16.....	10.....	62%
Dykebar (psychogeriatric) ward 17.....	13.....	5.....	38%
Hawkhead (psychogeriatric) ward 2.....	9.....	4.....	44%
Alzheimer's Disease Project (Gartnavel Hospital).....	12.....	4.....	33%

The number of names supplied by the staff at these institutions did not represent all the dementia sufferers with whom they had contact. This was because names were only supplied by the staff if, firstly, they felt from their personal knowledge that a relative may be willing to participate in the study, and secondly,

they actually had an address for the caregiving relative. (If a non-institutionalised dementia sufferer lives alone, a day hospital may just have a contact telephone number for the primary caregiver. It was not felt appropriate to make an initial approach to those caregivers by telephone on the grounds that they might feel either coerced to agree to participate or on the other hand might immediately decline.)

These potential subjects were approached by letter which introduced the interviewer as a clinical psychologist, and continued as follows:

I am conducting a research project with people caring for elderly, confused persons. It is to investigate how they feel about their situation, and how they cope with their problems. I understand that you are one of these carers. I therefore wonder if you might be willing to participate in my research? It would involve a discussion concerning both the problems which crop up, and the ways that you have been feeling as you give care. I should add that the staff at (relevant institution) who work with the elderly patients know about this project, and are happy for it to go ahead.

It was felt that it was unfair to ask potential subjects to decide whether or not they wished to participate in the study without a fairly full explanation of the contents of the interview. A tentative appointment to visit was enclosed with the letter. (For the relatives of non-institutionalised dementia sufferers the appointment was sent for a day on which it was known the sufferer attended a day facility, thus attempting to ensure that they would not be present during the discussions.) The potential subjects were provided with a form to complete and return in a stamped addressed envelope if they did not wish to be involved or if the suggested appointment was unsuitable. (See Appendix Five for sample appointment letter - version A - and reply form.)

2. The Motherwell and Paisley Alzheimer's Projects both send their members a monthly newsletter. A letter explaining the nature of the research plus a SAE were provided for the project staff to enclose in the mailings of any caregiving relatives whom they believed might agree to participate. The letter had a cut-off form for the carer to complete and send in the SAE if they thought they might wish to be involved in the research as described in the letter. Those carers who expressed interest were then contacted by the investigator to discuss the research further, and if they then wished, to arrange a convenient time to visit. (See Appendix Five for sample letter - version B.)

Twenty-six positive replies were received in response to the 70 letters sent by the Motherwell Alzheimer's Project, and 13 in response to the 30 letters sent by the Paisley Alzheimer's Project. (Response rates of 37% for Motherwell and 43% for Paisley.)

3. The Charge nurse who ran the Relatives' Support Group at the Southern General Hospital, Glasgow, did not wish to give their names to the investigator, nor for them to receive unsolicited mail. She therefore contacted the support group members herself by telephone. If they were interested, she then sent them a copy of the letter describing the research (the same format as had been used for the Motherwell and Paisley Alzheimer's Project members). If they wished, the support group members could use the form at the end of the letter plus the SAE which had been provided, to send their names and addresses to the investigator. Those carers who expressed interest were then contacted by the investigator to arrange a convenient time to visit.

The Charge Nurse was provided with 15 letters plus SAEs. Nine positive responses were received. It is not known how many potential subjects she contacted who either gave a negative response on the telephone, or who later decided not to express a positive interest to the investigator.

4. The Re-Education of Dementia Sufferers (REDS) project run a Relatives' Support Group. The REDS staff suggested the investigator attend a support group meeting to explain the nature of the research in person, and to give the letters, reply forms, and SAEs to those who expressed interest at the time.

Four positive replies were received in response to the 6 letters handed out at the meeting - however, 3 relatives did not wish to take a letter from the investigator. (A response rate of 49% of all the relatives at the support group meeting.)

2. Conduct of Interviews

Interviews were conducted between September 1989 and April 1990.

A semi-structured interview format, based on the "Carers' Questionnaire" (modified version) was employed in order to yield both qualitative and quantitative data. This method allowed for the presentation of a fixed number of questions to each subject, but with the opportunity for altering their order depending on the direction which the interview took. It also allowed for the alteration of the wording of certain questions if required or if appropriate (although obviously, without changing their meaning in any way).

The interviews took 1¼-2½ hours to complete. In 11 cases the interview was split into two sections - conducted on different days - for the convenience of the carer.

All interviews except one in the main study were conducted in the carer's own home, without the presence of the dementia sufferer whenever possible. The one exception was a caregiver who requested that the interview be arranged outwith his home because his relative was at that time suffering only a fairly mild degree of dementia and did not attend a day facility. Accordingly, this interview was conducted in the interviewer's university office.

In order to counteract any ulterior motives or lack of spontaneity on the part of the subjects, the investigator commenced each interview by introducing herself as a clinical psychologist with some experience of the behaviour of confused elderly people and the potential difficulties which they could present to their caregivers. However, the carers were told that she had no individual knowledge or experience of their own particular relative, nor any direct input to any of the hospital or other day facilities which their relative might attend. The carers were also assured of the confidentiality of their responses. In order to build up rapport and increase the confidence of the subjects, the format of the Carers' Questionnaire allowed for the interviews to commence with requests for basic demographic details of carer and dementia sufferer. This was followed by asking the carers to describe the practical problems encountered while looking after their relative, and then to describe the onset of the dementia - allowing the subjects to tell the story of what they noticed first of all and how a

diagnosis was eventually obtained. The aim of commencing with such topics was to allow the informants to become familiar with the interview situation and the interviewer without having to discuss emotive issues, unless they raised them spontaneously.

All questions were presented to the subjects verbally and ratings made by the interviewer according to the nature of their replies. Action was taken to clarify or form an agreement with the carer on the rating of any unclear replies. ("So that just happens sometimes?" etc.) An attempt was made to remove any interviewer bias from these ratings by providing carers with a 5-point reply "prompt" card ("all the time" - "often" - "sometimes" - "rarely" - "never") on which to base the majority of their responses. However, this did not prove feasible because the carers tended to become so interested in what they were saying about themselves and their emotional or behavioural reactions that they forgot about using the prompt card, knocked it on the floor or down the side of their cushions, etc. Repeated reminders to use the card disrupted the flow of the interview. The use of the reply prompt card was therefore abandoned.

During the presentation of the 34-item Problem Checklist, subjects were provided with a card-backed sheet with criteria for reporting "frequency" and "problem" in large print, and strung above this 34 small pages each with one of the problems listed on it. Carers could therefore turn over the pages to follow the verbal presentation of the problems by the interviewer, while at the same time referring to the criteria for answering the question.

The main study interviews were recorded with a portable battery cassette recorder. Permission to record was gained before producing the tape recorder. In three cases during the main study the subject did not give permission for the interview to be recorded because - despite reassurances - of initial suspicion about the content of the interview. In one of these cases the caregiver commented at the end that she was surprised that the interview had been "just like a normal conversation" and that in fact she wouldn't have minded if it had been taped. During the preliminary and pilot interviews a small cassette recorder had been used which, although discreet, produced low quality recordings. This had made it difficult to review the interviews. Therefore, for the main study a high quality battery cassette recorder was used, with one external microphone. (Although two microphones could have been attached, it was decided that this would have been more intrusive.) Because of the sensitivity of this machine it was able to clearly pick up an interview conversation even when placed at the interviewer's feet. In this way it could remain discreet, and indeed, many respondents remarked that they had forgotten the interview was being taped, and so were surprised whenever the machine switched itself off automatically at the end of a tape.

Interview notes were confined to brief verbatim notes and the marking of response categories. As the interviewer became increasingly familiar with the Carers' Questionnaire, it was possible to include items from a variety of different sections if they were appropriate at a particular point in the interview - but it was not always possible to find the corresponding place within the pages of the

questionnaire in order to mark responses during the interview.

3. Self-Completion Questionnaires

The subjects were not required to complete any paper-and-pencil ratings during the main study interviews. Four questionnaires - the GHQ-28, "How Have You been Feeling Recently?" (Affect Balance Scale), "Coping With The Effects Of Giving Care", and "Living Arrangements" - were given to those carers, who were willing to fill them in (N=70). They were given out at the end of the interview, together with verbal and written instructions for their completion. (Since no carers in the pilot study had reported difficulties or misunderstandings with regard to filling in the questionnaires, it was decided that it would be unnecessary for the interviewer to return and collect the completed forms in person.) The carers were each provided with an SAE for return of their questionnaires. It was suggested that if the carer found any questionnaire difficult or too time consuming, then it should be abandoned.

4. Post-Interview Ratings and Transcriptions

Following each interview the tape recording was reviewed. Missing ratings and post-interview ratings were made at this stage. In addition, all relevant comments or discussions were transcribed in full opposite the appropriate page of the questionnaire. The advantages of this method were that it yielded much valuable qualitative data, and it allowed the interviewer to accurately recall each individual interview situation while making the post-interview ratings and completing the coding frames. The

disadvantage was that it was extremely time consuming: an interview lasting between 75 and 90 minutes took a minimum of 4 uninterrupted hours to transcribe and rate.

5. Thanking the Sample

Following the interview all subjects were sent a letter to thank them for participating. It acknowledged the fact that some of the topics might have been difficult to talk about, and it invited the carer to contact the interviewer in the future if they wished. (No carer had done so at the time of writing.)

IV. MATERIALS AND MEASURES

The interviews with caregiving relatives were based on a "Carers' Questionnaire". Their verbal responses to the questionnaire items, responses to self-completion questionnaires, and post-interview ratings made by the investigator were coded using a coding frame. The Carers' Questionnaire, self-completion questionnaires, and the accompanying coding frame will be described briefly here. (For a detailed description of the evolution of this questionnaire, including the rationale behind the inclusion of each of the items, the reader should refer to Appendices One, Two and Three. The Carers' Questionnaire itself, and its Coding Frame can be found in Appendix Four.)

1. Carers' Questionnaire

The description which follows is ordered and subdivided in the same way as the questionnaire itself,

however, due to the semi-structured nature of the interviews, the items were not necessarily presented to each carer in this order.

A. BASIC DEMOGRAPHIC CHARACTERISTICS OF CARER

Items comprised carer gender, age, marital status, type of (previous) occupation, change in occupational status since onset of dementia in the sufferer, and carer educational details, including any formal qualifications.

B. BASIC DEMOGRAPHIC CHARACTERISTICS OF DEMENTIA SUFFERER

Sufferer gender, age, marital status, and type of previous occupation.

C. GENERAL CARING SITUATION

Nature of carer-sufferer blood/role relationship, and characteristics of the carer's household.

D. SUFFERER CHARACTERISTICS

Items comprised the 34-item Problem Checklist [Gilleard, 1984] covering the reported frequency and problem status of such behaviour problems as incontinence, mobility, disturbed behaviour, excessive demands, impairments in self-care, and forgetfulness. (Carers of dementia sufferers living in the community were asked to answer on the basis of current behaviour problems. Carers of institutionalised dementia sufferers were asked to answer on the basis of behaviour problems just prior to institutionalisation.)

Perceived physical changes in the sufferer were assessed by asking whether the sufferer looked the same as they had done prior to the onset of dementia, and whether they looked physically well.

Carers were asked how much they considered the sufferer had changed overall in comparison with their premorbid state, and how quickly they thought the changes had occurred.

E. REACTIONS TO THE SUFFERER FROM OTHERS (APART FROM CARER)

Items included the amount of change which others appeared to notice in the dementia sufferer, whether this differed from the amount of change noticed by the carer, the behaviour of others towards the dementia sufferer, and whether the carer discussed the sufferer with other people.

F. CARER AWARENESS - KNOWLEDGE AND PERCEPTIONS OF DEMENTIA

Items comprised the number and type of "professional" with whom the carer had discussed the dementia sufferer, plus the carer's descriptions, diagnostic term(s), and prognosis for the sufferer. In addition, carers were asked whether they had less specific experience of dementia through knowledge of the outcome of the illness in other sufferers.

A post-interview rating of the carer's knowledge and perceptions of dementia was included. This comprised a 4-point scale with explicit criteria for ratings in each category of decreasing knowledge with regard to the causes of the dementia sufferer's impairments and changes.

G. CARER'S RECALL OF ONSET OF DEMENTIA

Items included time since both onset and formal diagnosis of dementia, what the carer had first noticed to be wrong with the sufferer, how they learnt the diagnosis and prognosis, whether they had initially

understood and initially believed the diagnosis, and finally, whether they had discussed it with others at the time.

CARER'S EXPERIENCE OF "ANTICIPATORY GRIEF"

This referred to items tapping the behavioural and emotional reactions of the carer to the sufferer and the dementia. Each item was presented twice; firstly with regard to the caregiver's experience "nowadays", and secondly, with regard to "earlier on - sooner after (the sufferer) became ill". All items were rated for frequency of occurrence using 5-point scales ranging from "All the time" to "Never".

H. SHOCK, DENIAL

Carer's experience of the following five items:

- feeling shocked or dazed;
- thinking, "This can't really be happening";
- minimising the problems to others;
- trying to avoid getting emotional;
- finding it difficult to talk about the sufferer.

I. BARGAINING, HOPE

Carer's experience of the following four items:

- hoping sufferer might get better;
- wondering if the doctors had made a mistake;
- looking to the media for news of dementia cures;
- making bargains about cures or improvements.

J. QUESTIONING, ANGER, GUILT

Carer's experience of the following nine items:

- wondering "Why?";
- thinking maybe something more could be done for sufferer;
- blaming self for onset of dementia;
- guilt at enjoying self;

- anger/irritability with others;
- anger directed towards the dementia;
- anger directed towards the sufferer;
- anger directed towards God;
- anger directed towards professionals or social services.

K. GRIEF: PREOCCUPATION, UNFINISHED BUSINESS, DESPAIR

Carer's experience of the following nine items:

- preoccupation with thoughts about the sufferer;
- thinking about how the sufferer used to be;
- wishing the sufferer could be the way they used to be;
- wishing the sufferer could have done certain (unfinished) things;
- wishing to communicate certain (unfinished) things to the sufferer;
- getting upset;
- crying;
- feeling depressed;
- feeling that life has lost its meaning.

L. ACCEPTANCE

Carer's experience of the following three items:

- thinking calmly about the sufferer and dementia;
- thinking calmly about the future for the sufferer;
- accepting the sufferer's dementia.

Post-interview ratings were included to assess the following. Firstly, the intensities of each of the 5 anticipatory grief areas as apparent during the interview (rated on 4-point scales with explicit criteria for making each rating). Secondly, change in the intensity of experience of each of the 5 anticipatory grief areas over time (rated as

"Increased" - "Present but no change" - "Decreased" - "Never present").

M. SOCIAL DEATH OF DEMENTIA SUFFERER

This referred to the degree to which the carer perceived the dementia sufferer as socially dead. Items were designed to reflect the following four areas: firstly, the amount of awareness that the carer believed the sufferer had of their surroundings; secondly, the carer's belief that the dignity of the sufferer should be maintained; thirdly, the carer's anticipation of the sufferer's death; and finally, the carer's perception of the sufferer's life as having lost any positive value. All items were rated using 5-point scales, for either frequency of occurrence ("All the time" to "Never") or extent of carer belief ("Strongly agree" to "Strongly disagree") as appropriate.

The following nine items comprised the Social Death Scale:

- Does (the sufferer) seem to know and understand everything that's going on?
- Does (the sufferer) ever talk about what's happening?
- Is it important to you that (the sufferer always looks their best?
- Do you ever find yourself thinking ahead to the time when (the sufferer) will die?
- Do you ever find yourself rehearsing or going through what might happen, and what you might do straight after (the sufferer's) death?
- Do you ever find yourself thinking about what the future would be like without (the sufferer)?
- Would you agree that death might come as a blessing to (the sufferer)?

- Would you agree that in some ways it is as if (the sufferer) is already dead?

Post-interview ratings were included to assess both the degree of sufferer social death apparent throughout the interview (rated on a 4-point scale with explicit criteria for making each rating) and in addition, to rate the change in carer perceptions of the sufferer as socially dead over time ("Increased" - "Present but no change" - "Decreased" - "Never present").

N. CURRENT FEELINGS

A single item asking about the carer's current most important feeling towards the dementia sufferer.

O. STAGES

An item asking whether the carer believed they had experienced a staged sequence of reactions to the sufferer and the dementia, and if so, to describe these stages.

P. CARING - CURRENT SITUATION AND ATTITUDES OF CARER

Items comprised the amount of time spent by the carer with the sufferer (appropriate for both community dwelling and institutionalised dementia sufferers), the carer's ability to accept help with the caregiving task, the amount of formal and informal support received, and the carer's satisfaction with help from both relatives and professionals.

In addition, carers were asked whether they believed they had had to make sacrifices in order to care, whether their own or the sufferer's needs were most important, whether they felt obliged to care, had ever discussed the possibility of caring or terminal illness with the sufferer, and what they believed the

sufferer's views of the current caregiving situation would be.

The carers of non-institutionalised dementia sufferers were asked if the sufferer had been away for respite care, and for their estimations of the likelihood that the sufferer would enter institutional care both within the next year and (if a place was offered) tomorrow (rated on 5-point scales; "Extremely likely" to "Extremely unlikely").

A post-interview rating of the carer's attitude to caring was added (rated on a 4-point scale with explicit criteria for making each rating).

Q. QUALITY OF CARER-SUFFERER RELATIONSHIP

This referred to items tapping both positive and negative aspects of carer-sufferer interaction. (Based on Machin [1980] and Gilleard, Belford and Gilleard et. al. [1984].) Each item was presented twice; firstly with regard to the current interaction, and secondly with regard to the premorbid interaction. All items were rated for frequency of occurrence using 5-point scales ranging from "All the time" to "Never".

The Quality of Carer-Sufferer Relationship Scales comprised the following areas:

- laughing and joking together;
- feeling cross and angry;
- feeling the sufferer is possessive;
- feeling the sufferer interferes;
- feeling tension/strain in the relationship;
- having upsetting disagreements/arguments;
- trying to ignore the sufferer;
- feeling there are positive times in relationship;
- wishing to get away from the sufferer.

R. CARER STRAIN

A 4-item scale rating the effect which looking after the sufferer had had on the carer's physical health, mental health, social life, and finances. Each item was rated on a 5-point scale ranging from "Not at all" to "Enormously". (Culled from Grad and Sainsbury [1965] - cited in Gilleard [1984].)

S. CARER RELIGIOUS FAITH OR BELIEF

Whether the carer had a religious faith or other belief which had helped them cope with caring for the dementia sufferer, and if so, what it was and how it helped.

T. CARER COPING

Two items, each rated on a 5-point scale with regard firstly to how well the carer believed they were currently coping ("Very well" to "Very badly"), and secondly, whether this had changed over the time they had been caring ("Coping improved a great deal" to "Got a great deal worse").

U. CARER LIFE SATISFACTION

Two items, the first of which asked how the carer currently felt about their life as a whole (rated on a 7-point scale, "Delighted" to "Terrible" - culled from Andrews and Withey [1976, cited in Ford, 1979]). The second item asked whether this had changed over the time they had been caring (rated on a 5-point scale, "Improved a great deal" to "Got a lot worse").

V. OPINION OF INTERVIEW

Items comprised a rating of how the carer felt about the interview overall (rated on the 7-point "Delighted - Terrible" scale), whether any questions should not have been asked, whether topics had been particularly

hard to talk about and whether any questions had been particularly welcome.

2. Self-Completion Questionnaires

GENERAL HEALTH QUESTIONNAIRE - GHQ-28 [Goldberg and Hillier, 1979].

The GHQ [Goldberg, 1978] is a self-administered screening instrument with the aim of detecting psychiatric disorders among respondents in community settings. It consists of questions about the recent experience of psychological and physical symptoms as well as social activities. Each item is rated on a 4-point scale for frequency of occurrence. The usual GHQ scoring system for responses on each item is 0-0-1-1. A respondent is classified as a GHQ "case" if they score above a pre-determined threshold score. Since the intention of the present study was to examine the variables associated with different levels of distress in caregiving relatives, the total GHQ score rather than whether or not subjects could be classified as "cases" was employed.

Numerous studies have examined the validity of the GHQ as a measure of non-psychotic psychiatric distress in a variety of different populations, including community samples (for example, Tarnopolsky, Hand and McLean et. al. [1979], Finlay-Jones and Murphy [1979]).

Several versions of the GHQ are available, involving 12, 20, 28, 30 and 60 items. The 28-item version was employed in the present study. This version has been employed in previous studies of the subjective burden of the informal carers of dementia sufferers (for example, Toner [1987], O'Connor, Pollitt and Roth et. al. [1989]).

"HOW HAVE YOU BEEN FEELING RECENTLY?" : THE AFFECT BALANCE SCALE - ABS [Bradburn and Caplowitz, 1965; Bradburn, 1969].

The ABS was designed as a measure of well-being and has been validated on elderly samples [Moriwaki, 1974]. It consists of 5 positively worded items (for example, feeling "Particularly excited or interested in something"), and 5-negatively worded items (for example, feeling "Very lonely or remote from other people"). The responses to each set of items are summed to produce the "Positive Affect Scale" (PAS) and the "Negative Affect Scale" (NAS). Global affect balance is the result of the PAS score minus the NAS score. In the present study each item was scored on a 3-point scale for frequency of occurrence ("Never" - "Sometimes" - "Often").

"COPING WITH THE EFFECTS OF GIVING CARE"

This questionnaire comprised an assessment of carer coping strategies based on the "Coping Checklist" used by McCarthy and Brown [1986, 1989] to examine the coping strategies of people with Parkinson's disease.

"Coping with the Effects of Giving Care" consists of 15 brief descriptions of cognitive and behavioural strategies for coping with the consequences of major stress. Nine of these are "positive" coping strategies (for example, "Asking others for practical advice and information") and six are "negative" coping strategies (for example, "Criticising or blaming self"). In the present study each item was scored on a 5-point scale for frequency of use in recent months ("Never" to "All the time"). The resulting scales of "positive" and "negative" coping strategies can be summed to produce a third variable, total number of coping strategies employed by the carer.

"LIVING ARRANGEMENTS QUESTIONNAIRE"

This is a 4-item questionnaire which requires the respondent to mark the nearest description to their own home (from 8 categories, for example "Detached", "Maisonnette", etc.); to code details of the rental of their home or whether they are owner-occupiers; and finally, to code their weekly family income (in £50 categories).

3. Coding Frame

The ratings of the majority of items on the Coding Frame to the Carers' Questionnaire obviously correspond to those within the questionnaire itself. However, some additional ratings were added to the coding frame. Some of these (for example, "Carer's Perception of Dementia") were added as a result of hypotheses formed by the investigator after a number of interviews had been conducted. Thus, to some extent, the coding frame represents yet another evolutionary stage of the Carers' Questionnaire. It was possible to complete these additional ratings accurately because of the availability of each carer's comments and opinions which had been transcribed onto the questionnaire (see previous sub-section of this chapter). In addition, since the same investigator conducted the interviews and completed the coding frames, impressions formed while talking to the carer could generally be recalled during the coding. The coding frame also contained some categorical ratings of qualitative data gathered during the interview.

Additions to the following sections of the Carers' Questionnaire were made in the coding frame.

SUFFERER CHARACTERISTICS

Most important change in the dementia sufferer as perceived by the carer was coded into one of ten possible categories ("Appearance"; "Cognitive"; "Personal hygiene"; "Disruptive"; "Apathetic"; "No communication"; "No recognition"; "Emotional"; "Other"; "No single change"). A rating of the sufferer's ability to recognise the carer was added.

CARER'S RECALL OF ONSET OF DEMENTIA

The carer's overall perception of dementia ("Old age"; "An illness, just like any other illness"; "Very horrible/worst possible illness"; "Other") was added.

ANTICIPATORY GRIEF: ACCEPTANCE

Post-interview ratings of degree of acceptance were sub-divided into both intellectual and emotional acceptance.

SOCIAL DEATH OF SUFFERER

A rating of whether or not the carer believed the feelings which they had experienced had been like grief were added. Post-interview ratings of social death were sub-divided into both social death beliefs and social death behaviours.

CURRENT FEELINGS

The carer's current feelings towards the dementia sufferer were coded into one of seven possible categories ("As always"; "Protective"; "Pity"; "Annoyed/Angry"; "Reduced feelings"; "Other"; "Carer unsure").

STAGES

Ratings of both the similarity of the carer's reactions over time to the "classic" anticipatory grief pattern

(shock-hope-distress-grief-acceptance), and of their current grief stage ("Grief not begun"; "Earlier"; "Later"; "Almost over") were added.

CARING - CURRENT SITUATION AND ATTITUDES OF CARER

The carer's principal sacrifice was coded into one of five possible categories ("Social"; "Job"; "Financial"; "Health"; "Other"), as was their reason for caring ("Love"; "Repayment"; "Duty"; "No choice"; "Can't care any longer" - culled from Hirschfeld [1978]).

QUALITY OF CARER-SUFFERER RELATIONSHIP

Ratings of the overall quality of both current and premorbid relationship were added (using 5-point scales; "Excellent" to "Extremely poor").

CARER RELIGIOUS FAITH OR BELIEF

Any help gained by the carer's faith/belief was coded into one of three possible categories ("Spiritual"; "Practical"; "Both").

OPINION OF INTERVIEW

The ratings of the carer's opinion were re-coded from seven to three categories ("Positive - Neutral - Negative").

V. SUMMARY

This chapter has described the method of the present study. This involved conducting semi-structured interviews with 100 caregiving relatives of patients with a primary diagnosis of senile dementia. The demographic characteristics of the sample of carers and their dementing relatives, plus the behavioural characteristics of the dementia sufferers were

presented. The procedures of contacting the sample, conducting the interviews and recording the data were outlined. The final section of the chapter described the materials and measures employed in the study. These comprised the "Carers' Questionnaire" upon which the semi-structured interviews were based, self-completion questionnaires filled in by the caregiving relatives, and the accompanying coding frame. It was noted that the version of the Carers' Questionnaire employed in the present study had evolved via a series of stages; namely preliminary interviews, followed by a pilot study which had employed an earlier draft of the Carers' Questionnaire.

CHAPTER NINE

DATA ANALYSIS

"analyse - (vb) to examine in detail in order to discover meaning, essential features, etc. (C16: from New Latin, from Greek analisis, literally: a dissolving, from analuein, from ANA- + luein - to loosen)"

[Collins English Dictionary, Hanks, Long and Urdang (eds.), 1979]

I. INTRODUCTION

The data which was derived from the Carers' Questionnaire and the self-complete questionnaires (described in the previous chapter) was analysed in a variety of ways. The present chapter describes this data analysis. The chapter is in three main sections, as follows: firstly, the analysis and means of presentation of the qualitative data; secondly, the statistical analyses of the quantitative data; and thirdly, the methods of analysis for evidence of stages in the emotional and behavioural reactions of caregiving relatives. A wide range of statistical techniques was employed, representing both bivariate and multivariate analysis. Each of these techniques is described, together with the rationale behind the choice.

II. QUALITATIVE DATA

1. Content Analysis

As noted in the description of additional codings introduced into the coding frame which were not present in the Carers' Questionnaire (see previous chapter), some very basic content analyses were conducted on the qualitative data obtained from the main study interviews.

The basic idea of content analysis is to classify the words of a piece of text into content categories.

"A central idea in content analysis is that the many words of the text are classified into much fewer content categories. Each category may consist of one, several, or many words. Words, phrases, or other units of text classified in the same category are presumed to have similar meanings." [Weber, 1985, p.12]

The units of text which are coded can vary between one word (ie. coding each word) through sentences, themes or paragraphs, up to coding the meaning of the whole text. The aim is to produce generalizations about the data which are both interesting and useful - the most important use being to relate content to non-content variables [Weber, 1985].

Categorical codings were therefore devised for variables such as "Why is the carer caring", or "Principal sacrifice made by carer". Some of these variables related to the responses made to a particular questionnaire item (for example, "How does your religious faith/belief help you cope?"), while other variables related to a theme running through a group of responses (for example, "Carer's perception of dementia"). The resulting codings could then be used to

relate these variables to quantitative variables such as time since diagnosis of dementia, or current "Shock /Denial" scale score.

2. Illustrative Examples

Much of the qualitative data is presented in the results in the form of illustrative examples. Some illustrate the codings made during the content analysis. However, the majority were used to illustrate the range of responses given by caregiving relatives to the "anticipatory grief" and "social death" items of the Carers' Questionnaire. This use of illustrative material throughout the results section of the main study was not simply to add interest for the reader. Often a carer's comment explained or illustrated a point simply and clearly, making additional interpretations or comments redundant.

III. QUANTITATIVE DATA

A wide variety of statistical analyses were employed. These ranged from descriptive statistics such as frequency distributions; non-parametric tests such as chi square; parametric tests such as Pearson's correlation; and multivariate tests such as factor analysis. Brief descriptions of the statistical methods which were used, together with the rationale behind the choice are contained in this sub-section.

1. Descriptive Statistics

Descriptive statistical analysis means displaying the important features of the data. Firstly, this involves organising the data into some sort of easily

understandable form (for example, displaying the raw data in the form of a frequency distribution, or graphing it as a histogram). Secondly, descriptive statistics involve summarising the data using numerical indices; in particular those of central tendency (usually mean, mode and median) and of spread (usually range or standard deviation). [Miller, 1975].

In the presentation of data from the main study, frequency distributions were used to show the range of responses made to particular items on the Carers' Questionnaire. Summaries of some of the demographic data (for example, carer age) were presented in the form of means, ranges and standard deviations (S.D.).

2. Chi-Square

Chi-square is a "goodness of fit" test. It is a non-parametric test; that is, it makes no assumptions about the shape or variability of the population distributions. It can be used with nominal data (that is measurement at its weakest level: categories of response that are not ordered, scaled or scored, such as political party membership). Chi-square tests the relationship between two variables by assessing the discrepancy between a theoretically expected and the obtained frequency [Rosenthal and Rosnow, 1975]. One of the only restrictions on the use of chi-square is on the size of the sample: if any of the expected cell frequencies is less than 5 then a correction known as Yates' Correction for Continuity should be applied [Ferguson, 1976].

Chi-square was used to analyse data from the main study such as the relationship between a dementia sufferer's sex and marital status, or the relationship between

carer-sufferer blood/role relationship and a carer's perception of whether or not they had experienced grief. Where necessary, Yates' correction was applied.

3. T-Tests

The t-test assesses whether the difference between two group means is significant. It takes into account the individual variability of the scores around the mean in each of the groups. It is a parametric test, thus it should only be used when there is reason to believe that the population distributions do not depart grossly from normal and the population variances are roughly equal [Ferguson, 1976]. (Although, in fact, Iversen and Norpoth [1976] point out that the t-test, like the F-test is a "robust" test and thus is not affected by moderate departures from normality.)

T-tests were used to analyse data from the main study such as whether or not the age difference between male and female carers was significant. The SPSS-^x programme T-TEST GROUPS was employed to specify independent samples. Probabilities of the obtained t-values were based on a two-tailed test of significance. (That is a non-directional hypothesis - that the means are different, but without asserting the direction of the difference.)

4. One-Way Analysis of Variance

In its simplest form, analysis of variance allows us to test the hypothesis that there are significant differences among the means of various groups. (It can be used in the case of just two groups in which case it yields the same probability values as a t-test.) It is a parametric test. The null hypothesis is that the

samples are drawn from populations having the same mean. If the variation between the means cannot be attributed to random sampling error then the null hypothesis is rejected. [Ferguson, 1976]. If the F-ratio which emerges from the analysis of variance test is significant it is then possible to investigate specific hypotheses. One of these "a posteriori" tests (ie. done when the comparisons are not planned in advance) for making pairwise comparisons among means is the Tukey Honestly Significant Difference test [Runyon and Haber, 1976]. The Tukey test is favoured where group sizes and variances are both unequal [Youngman, 1979].

The SPSS-^x programme ONEWAY was used to analyse data from the main study such as the differing scores obtained on the grief scales (for example "Hope/Bargaining" scale, "Acceptance" scale, etc.) by those carers who believed they had definitely grieved, those who were unsure, and those who believed they had definitely not grieved. ONEWAY can analyse several dependent variables by one independent variable. The TUKEY ranges sub-command was chosen because of the unequal group sizes. The 0.05 level of significance is the only one available for this test [SPSS-^x User's Guide, 1983].

5. Pearson's Correlation (r)

Correlation is a measure of association between two variables. There are many types of correlation coefficient. The decision as to which to use depends on (1) the type of scale of measurement in which each variable is expressed; (2) whether the distribution is continuous or discrete; and (3) whether the scores are linear or non-linear [Runyon and Haber, 1976]. The

Pearson Product-Moment Correlation Coefficient (r) can be used for most continuous measures.

The SPSS-^x programme PEARSON CORR was used to analyse data from the main study such as the relationship between time since diagnosis of dementia and scores obtained on the grief scales. The significance levels were based on a one-tailed test (appropriate when the direction of the relationship can be specified in advance of the analysis).

It should be recognised that low correlations may reflect not that the variables are unrelated, but that they are related in a non-linear fashion. This possibility was tested by plotting the relationships graphically.

6. Spearman's Rank Order Correlation Coefficient (ρ)

Spearman's ρ is a non-parametric method of correlation and it can therefore be used for ordered data. Ordered (or "ordinal") data differs from continuous data in that although the data can be ranked (for example, "occurs more often than", "is more difficult than", etc.) the intervals between each rank are not necessarily comparable. (For example, the interval between "never" and "sometimes" may not be the same as that between "sometimes" and "often", but "often" is greater than "sometimes" and "sometimes" is greater than "never".)

Spearman's ρ was used to analyse data from the main study such as the association between time since diagnosis of dementia and scores obtained on the individual grief items. (Pearson's r was not used

because the grief item scores were ordered data.) The significance levels were based on a one-tailed test.

7. Wilcoxon's Matched Pairs Signed Ranks Test

Wilcoxon's test is a non-parametric statistic. It analyses whether the differences between paired observations are significant. It takes into account not only the direction of the differences between pairs but also the relative magnitude of the differences: it gives more weight to a pair which shows a large difference between the two conditions than to a pair which shows a small difference [Siegel, 1956].

Wilcoxon's test was used to analyse whether the differences between the "nowadays" and the "earlier on" scores obtained on the individual grief items were significant. (t-tests were not used because the individual grief item scores were ordered data.)

8. Factor Analysis

The statistics described above represent bivariate analysis; that is, they examine the relationships between pairs of variables. The two statistics which will now be described (factor analysis and multiple regression) represent multivariate analysis. Multivariate analysis is concerned with the joint effects of relatively large numbers of variables. As such it could be regarded as much more representative of "the real world", where variables are far more likely to act in unison than separately. Certainly multivariate analysis could be regarded as much more appropriate to the data which is gathered during the process of research with the caregivers of dementia sufferers. Here, for example, the effects of carer age

may be confounded by the effects of carer-sufferer blood/role relationship, or the effects of length of time over which caring has occurred may be confounded by the effects of degree of sufferer impairment. The main reason why these techniques have not been used more frequently in the caregiving literature is presumably because relatively large samples are required. In addition, the mathematical techniques are more complex than those required for bivariate statistical techniques - however, the use of computer statistical analysis packages means that this potential difficulty is eliminated.

Factor analysis is a way of measuring a general variable (a factor) underlying a large set of variables. It is useful because working with a large number of variables can be difficult and it can also be somewhat redundant if they are really just different measures of another more general variable. Exploratory factor analysis is used when a researcher has a large set of variables and suspects that they could be summarised by a few underlying factors, but is not certain what those factors would be [Hedderon, 1987]. The correlation matrix between all pairs of variables serves as the starting point for factor analysis. The correlations between variables arise from the "sharing" of common factors [Norusis, 1985]. Since factor analysis is based on correlation coefficients, similar conditions for the suitability of variables apply. For example, nominal measures cannot be used as they stand. Youngman [1979] suggests that most higher level data - ordinal, interval or ratio, is suitable so long as it is linear. Gilleard, Boyd and Watt [1982] for example, performed factor analysis with problem checklist items. Each of these is scored on 3-point scales for frequency ("never" - "occasionally" - "frequently/continually").

The SPSS-^x programme FACTOR was used to explore the underlying structure of the relationship between three different sets of items. These were the 34 problem checklist items (frequency of occurrence scores); the individual "anticipatory grief" items; and the "social death" items. The default options of a varimax orthogonal rotation were chosen. The rotation of the factors means simplifying them so that each variable tends to load highly on one factor. Orthogonal rotation results in factors that are uncorrelated. Varimax is the most commonly used rotation method. It attempts to minimise the number of variables that have high loadings on a factor with the aim of increasing the interpretability of factors. For ease of interpretation the SORT format was chosen. This simply sorts the factor pattern matrix so that variables with high loadings on the same factor appear together. Following repeated exploratory factor analyses on the problem checklist items (frequency scores) and the individual "anticipatory grief" items, the number of factors to be extracted was set at 6 and 5 respectively. This was because to use the default option of extracting factors with an eigenvalue greater than 1.0 would have produced 10 problem checklist factors and 9 "anticipatory grief" item factors. The increase in the total variance explained by the additional factors would have been 13.8% in the case of the problem checklist items and 16.3% in the case of the grief items. It was decided that this advantage would be offset by the relatively large number of factors which would then have to be included in further analyses - quite a disadvantage when one of the aims of the factor analysis was to simplify the data.

The outcomes of the three factor analyses will be presented here. It might be argued that in one sense

they form "results" and thus should appear in the section of the thesis devoted to results. However, the factors extracted were themselves used in further analyses. In addition, the presentation of the factor analyses here allows the results section to concentrate more clearly on exploring the concepts of the social death of dementia sufferers and the anticipatory grief of their caregiving relatives by focussing on the answers to the questions specified as the aims of the present study.

FACTOR ANALYSIS OF THE PROBLEM CHECKLIST

The six behavioural domains which had been obtained via factor analysis of the 34-item Problem Checklist (frequency of problems) are shown in Table 9.1 (over page).

The factors which emerged were labelled as follows: "Depend", "Can't do", "Incontinence/Hygiene", "Apathy", "Disturb", and "Demand". This solution accounts for 55.4% of the total percentage of variance. Including only those items which had loadings of 0.5 or greater on each behavioural domain incorporates 24 of the original 34 problem checklist items.

The "Depend" factor, which accounted for the highest proportion of the total variance comprised largely physical dependency problems. However, they are also problems which occur in severe dementia - for example, carers described sufferers who could not manage stairs because they had "forgotten how" rather than because they were physically disabled: the carer would therefore have to accompany the sufferer, sometimes coaxing them foot by foot from one stair to the next. The second factor, "Can't do" represented the dementia

Table 9.1
Principal Components Analysis of the 34-item Problem
Behaviour Checklist.

<u>Factor name</u>	<u>Factor loading</u>
I : "DEPEND" (Percent of variance = 24.5)	
Unable to manage stairs.....	0.823
Unsteady on feet.....	0.805
Unable to get in and out of chair unaided...0.	0.753
Unable to walk outside house.....	0.750
Unable to get in and out of bed unaided.....	0.682
Falling.....	0.624
Needs help at mealtimes.....	0.510
II : "CAN'T DO" (Percent of variance = 9.5)	
Unable to read papers, magazines, etc.....	0.739
Unable to follow T.V. / radio.....	0.611
Unable to dress without help.....	0.588
Unable to wash without help.....	0.554
III : "INCONTINENCE/HYGIENE" (Percent of var. = 6.6)	
Incontinent - wetting.....	0.729
Incontinent - soiling.....	0.714
Shows no concern for personal hygiene.....	0.596
Vulgar habits.....	0.525
IV : "APATHY" (Percent of variance = 5.9)	
Sits around doing nothing.....	0.681
Unable to occupy self doing useful things...0.	0.634
Unable to hold a sensible conversation.....	0.554
V : "DISTURB" (Percent of variance = 4.7)	
Temper outbursts.....	0.782
Noisy, shouting.....	0.748
Uses bad language.....	0.687
Physically aggressive.....	0.545
VI : "DEMAND" (Percent of variance = 4.3)	
Wanders about the house at night.....	0.775
Demands attention.....	0.581

sufferer's inability to do things which required less physical intervention from the carer. "Incontinence/Hygiene" is fairly self explanatory, comprising the sufferer's inability to toilet him or herself or to show concern for cleanliness. "Apathy" represents

losses of purposeful behaviours or the ability to communicate verbally; as such it might be regarded as the behavioural factor which came the nearest to representing "loss of the person". The fifth factor, "Disturb" refers to noisy, aggressive, or bad tempered behaviours. The final factor, "Demand" represents behaviours which demanded the carer's attention, either intentionally, or simply out of their concern for the sufferer's safety.

This analysis demonstrates that the problems reported by the carers did not represent a simple description of degree of dementia, but rather that they were multi-dimensional.

FACTOR ANALYSIS OF CURRENT GRIEF ITEMS

The five components which had been obtained by factor analysis of the intensities of the individual grief items ("nowadays") are shown in Table 9.2 (over page). The five factors which emerged were labelled as follows: "Disbelief/Hope"; "Mourn"; "Protest"; "Yearn"; and "Deny".

This solution accounts for 54.1% of the total percentage of variance. Including only those items which had loadings of 0.5 or greater on each component incorporates 22 of the original 30 individual grief items.

The format of the Carer's Questionnaire was based around the notion of five components of grief, culled from the "staging" of grief literature. These "initially-specified" components, it will be recalled, were labelled as follows (over page, final paragraph):

Table 9.2
Principal Components Analysis of the Individual Grief Items.

<u>Factor name</u>	<u>Factor loading</u>
I : "DISBELIEF/HOPE" (Percent of variance = 25.2)	
- Think doctors maybe mistaken.....	0.76
- Consult media for cures.....	0.69
- Make bargains.....	0.66
- Hope sufferer might get better.....	0.65
- Accept what has happened.....	-0.57
- Think maybe something more could be done..	0.53
- Think "It can't be ..."	0.52
II : "MOURN" (Percent of variance = 9.3)	
- Get depressed.....	0.86
- Feel own life has lost it's meaning.....	0.82
- Cry when think of sufferer.....	0.76
- Get upset when think of sufferer.....	0.65
III : "PROTEST" (Percent of variance = 8.0)	
- Angry with God.....	0.66
- Irritable with others.....	0.63
- Angry it happened.....	0.63
- Think maybe contributed.....	0.62
- Angry with formal help.....	0.60
IV : "YEARN" (Percent of variance = 6.1)	
- Guilty if enjoy self.....	0.78
- Wish sufferer could be the way they used..	0.72
- Look back to past.....	0.65
- Preoccupied with sufferer.....	0.53
V : "DENY" (Percent of variance = 5.5)	
- Pretend problems less to others.....	0.91
- Difficult to talk to others.....	0.88
- Try to avoid emotion.....	0.60

Labelling of "initially-specified" components of grief:

- "Shock/Denial"
- "Hope/Bargaining"
- "Questioning/Anger/Guilt"
- "Preoccupation/Unfinished Business/Despair"
- "Acceptance"

The result of the factor analysis of the individual grief items would seem to vindicate the initial hypothesis in that the structure obtained by factor analysis is not a gross distortion of the initially-specified components of grief. There are some obvious differences, however. Whereas the initially-specified components grouped shock, disbelief and denial together, and separate from hope and bargaining, the components obtained via factor analysis group disbelief and hope together, clearly separate from denial. In addition, while the initially-specified components grouped preoccupation with the sufferer and the past together with sadness and despair, the components obtained via factor analysis separate these items (into "Yearn" and "Mourn"). Finally, while the initially-specified components included one of "Acceptance", those obtained via factor analysis do not, instead grouping lack of acceptance into the "Disbelief/Hope" component.

Because there was not a complete parallel between the five initially specified components of grief and those obtained via factor analysis, analyses were be carried out for both the initially-specified components (I.S. components) of grief, and for those components which had been obtained via factor analysis (F.A. components).

FACTOR ANALYSIS OF THE SOCIAL DEATH SCALE

The three factors which had been obtained by factor analysis of responses to all nine items on the Social Death Scale are shown in table 9.3 (over page). The factors were labelled: "Anticipate Death", "Life Pointless", and "Unaware".

Table 9.3
Principal Components Analysis of the Social Death Scale
Items.

<u>Factor name</u>	<u>Factor loading</u>
I : "ANTICIPATE DEATH" (Percent of variance = 29.3)	
Think ahead to time sufferer will die.....	0.885
Rehearse what might do after the death.....	0.880
Think of future without sufferer.....	0.837
II : "LIFE POINTLESS" (Percent of variance = 20.8)	
Appearance of sufferer unimportant.....	0.806
As if sufferer already dead in some ways....	0.662
Death might come as a blessing to sufferer..	0.569
III : "SUFFERER UNAWARE" (Percent of variance = 13.3)	
Sufferer doesn't know what's going on.....	0.761
Sufferer doesn't talk about what's happening.	0.758
Independence of sufferer unimportant.....	0.562

This solution accounts for 63.4% of the total percentage of variance, and includes all of the social death scale items at a factor loading of over 0.5.

The three factors which emerged were very clear. The first two related to carer beliefs concerning, or behaviours towards, the sufferer. The "Anticipate Death" factor comprised thinking ahead to the sufferer's death, imaginal rehearsal of the time shortly after the death, and thinking of life without the sufferer. The "Life Pointless" factor comprised believing that the dementia sufferer's death might come as a blessing, that in some ways they were already dead, and that their personal appearance had ceased to be particularly important to the carer. Finally, the "Sufferer Unaware" factor tapped not only carer behaviours or beliefs but possibly also sufferer impairments. These items were that the sufferer had apparently lost contact with his or her environment,

did not talk about what was happening, and that their continued independence - at whatever level - had ceased to be important to the carer.

9. Multiple Regression

"The advantage of multiple regression is that it shows both the combined effects of a set of independent variables and the separate effects of each independent variable controlling for the others." [Hedderon, 1987, pp.103-104.]

Basically, what multiple regression does is to take a dependent variable and to investigate its relationships with two or more independent variables. This allows a fuller explanation of the dependent variable since few phenomena are caused by just one thing. It also removes the possibility of distorting influences from the other independent variables. Youngman [1979] diagrams this notion, as shown in Figure 9.1 (over page).

Hedderon [1987] points out the drawbacks of multiple regression. One of these is that it applies best to an analysis in which both the dependent variables and the independent variables are normally distributed interval variables. However, "ordinal variables are commonly used as well, and moderate deviations from normality do not bias the results greatly" [Hedderon, 1987, p.104]. In fact, regression analysis can also handle dichotomous variables, which gives it the advantage of being applicable to categoric data. Categoric data can be made dichotomous by "dummy variable coding". (For example, coding Conservative, Liberal, Labour and SNP as $SNP = 1$, $Conservative = Liberal = Labour = 0$. ie. coding "SNP" or "not SNP".) Lewis-Beck points out that there is some disagreement over how serious the

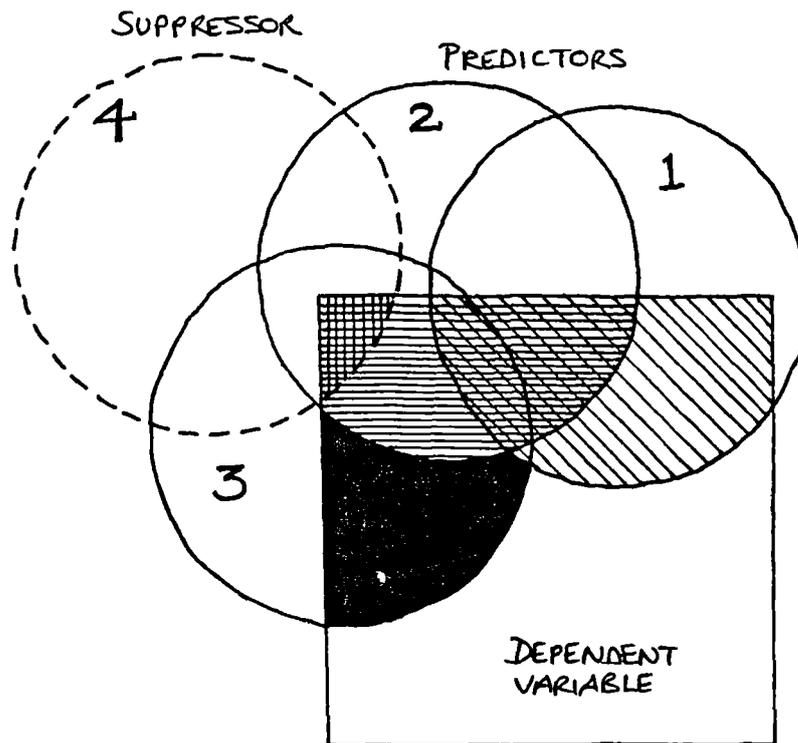


Figure 9.1 Representation of relative values of predictors.

Variables 1 and 2 are substantial predictors, also covering most of the contribution of variable 3. Variable 4 is a suppressor, increasing the overall prediction by suppressing the unwanted effects of variables 2 and 3 rather than through a correlation with the dependent variable.
 [From Youngman, 1979, p.115]

violations of the regression assumptions are. (At one extreme, some researchers argue that regression analysis is "robust" and so not meaningfully influenced by violations of assumptions, while others argue that it is "fragile".) He believes that "clearly, some of the assumptions are more robust than others. The normality assumption, for instance, can be ignored when the sample is large enough ..." [p.30]. Cohen [1968] also attests to the robustness of multiple regression in the face of violations of normality assumptions in

the data, particularly when reasonably large samples are used.

What is harder to establish is what is a "reasonably large sample". Lewis-Beck [1980] cites examples where $N=32$ and $N=44$. He points out that as sample size increases, a given coefficient is more likely to be found significant with the result that for "very large samples such as election surveys of 1000 or more" it may become too easy to find significant coefficients. Youngman [1979], in discussing stepwise multiple regression suggests that the minimum sample size should be $N=100$.

In addition to deciding what sample size (N) is adequate, a decision also needs to be made concerning the number of variables to be entered into the equation. One of the outputs from a multiple regression equation is the "Multiple R". The Multiple R indicates the relationship between the independent variables and the dependent variable. The R^2 for a multiple regression equation indicates the proportion of variance in the dependent variable "explained" by all the independent variables. Since the aim is to have a more complete explanation of the dependent variable, it is obviously desirable to have a high R^2 . It is theoretically possible to increase R^2 by adding more and more independent variables to the equation. (Indeed, a "perfect" $R^2 = 1.00$ could be achieved by entering $N-1$ variables [Lewis-Beck, 1980].) An additional problem caused by entering a large number of variables into the multiple regression equation is highlighted by Cohen [1968] as follows. If your sample size is $N=100$ and you enter 40 variables into the equation, then at a .05 significance level you would expect 2 variables to emerge as significant by chance.

So what have you proved if 4 or 5 emerge as significant at the .05 level? They cannot all be real effects - but which have emerged by chance? Youngman [1979] also points out that the number of variables should be kept low - but then goes on to cite an author [Darlington, 1968] who apparently suggests a maximum of between 50 and 100 predictors (independent variables)! Hedderson [1987] briefly discusses the effects of number of cases relative to variables, noting that a small number of cases relative to the number of variables can bias upwards the estimated R^2 . The adjusted R^2 is corrected for the number of cases. When the sample size is less than 10 cases per variable the adjusted R^2 will considerably decrease relative to the unadjusted R^2 if the sample size is reduced. The implication therefore seems to be that 10 or more cases per variable is advised.

In view of the above information, plus the fact that the sample size in the present study was $N=100$, the conclusion reached was that the maximum number of variables per multiple regression analysis should be limited to 10. This raised the following problem. In the exploratory analyses which aimed to uncover those variables which were related to the various "stages" (or scales) of caregiver "anticipatory grief", to dementia sufferer "social death", to caregiver subjective burden/wellbeing, and to caregiver willingness to institutionalise, more than 10 variables raised themselves as possible candidates. (From the reading of previous studies - cited in the introduction to this thesis, and from exploratory correlation matrices.) It was therefore decided to conduct each of these analyses in two "rounds" - rather like a knock-out sports competition. In the "first round" a number of multiple regression analyses would be conducted, and

those variables which emerged as significant would then be entered into a single "second (final) round" analysis. While there are no references to this procedure in the literature, in informal discussions other researchers could see no theoretical reasons why it should not be used. Obviously one disadvantage is that those variables which emerged as significant from the first round of analyses did so only when controlling for interaction effects with the other variables in their section of the first round, and not with every single variable, entered into the first round. The results of each of the "first round" analyses are presented in the Appendix Nine. The results section of the thesis presents the results of each of the "final round" analyses.

Youngman [1979] highlights an additional consideration in the choice of variables to be included in multivariate analyses. This is tautology. This can occur when a number of seemingly different measures are constructed from the same basic data. "Certainly it is hardly ever legitimate to include both subtest and total scores in a multivariate analysis unless the objective is specifically to examine the relationship between them" [Youngman, 1979, p.96]. This consideration was borne in mind, particularly when variables were chosen for inclusion in the sufferer impairment equations for each of the analyses. It was decided to include the scores on each of the factors which had emerged from the factor analysis of the 34-item problem checklist (frequency scores). This meant that although it might have been "nice" to include the total problem checklist frequency score (as an index of overall impairment) or the total severity of problems score (which was related to the frequency scores, since unless a problem occurs it obviously cannot be rated

for severity) the inclusion of these two scores was not possible.

The SPSS-^x programme REGRESSION was therefore used to uncover those variables which were related to the various "anticipatory grief" scales, to the dementia sufferer's "social death", to caregiver wellbeing, and to caregiver willingness to institutionalise. The STEPWISE method of selection of independent variables was chosen. In it, more independent variables than are considered relevant are included so that the method itself can identify the significant predictors, entering decreasingly important factors into the equation. It is "probably the most commonly used method" [Norusis, 1985, p.48]. MEANSUBSTITUTION was chosen, so replacing missing values with the variable mean. Cohen [1968] argues that this method of "plugging empty spaces" in the data sheet is legitimate. This is because "... the method proposed can be thought of as reflecting the fact that the population studied contains missing data, and fully incorporates the fact as positive information" [Cohen, 1968, p.438]. The sample size in the majority of the multiple regression analyses was that of the carer sample (ie. N=100). The exceptions to this were the analyses of the dependent variables GHQ-28 score and ABS score, and of the dependent variable "Willingness to Institutionalise". For the two questionnaire scores, the sample size was limited to those carers who had completed the questionnaires (N=70). For the "Willingness to Institutionalise" variable, the sample clearly had to be limited to those carers who were not related to a dementia sufferer already living in long-term institutional care (N=77). (While it is recognised that some readers may regard conducting multiple regression analyses on samples of this size as "risky", the

results which emerged did not appear to be unreasonable.)

The presentation of the results of the analyses include the following three pieces of information. (1) The adjusted R^2 . (As previously noted, this represents the proportion of variance in the dependent variable associated with variance in the independent variables and corrected for the number of carers.) (2) The BETA WEIGHTS of each variable entered into the final equation. (Final beta - this represents the average standard deviation in the dependent variable associated with a standard deviation change in the independent variable when the other independent variables are held constant. For example, if the beta for X is 0.2, this means that an increase of 1 S.D. in X will cause an increase of 0.2 S.D. in Y, and a decrease of 1 S.D. in X will cause a decrease of 0.2 S.D. in Y.) (3) The F-ratio from the analysis of variance table for entry of each significant variable into the equation. (The total observed variability in the dependent variable is divided into two; that which is attributed to the regression, and that which is not - labelled "the residual". $F = \frac{\text{Mean Square Regression}}{\text{Mean Square Residual}}$)

Large F-ratios therefore represent larger amounts of variance attributable to the regression.)

10. Guttman Scales

Guttman scales have the property that it is possible to construct an individual's score from his or her total score alone [Youngman, 1979]. This is because they are cumulative.

In two areas within the data analysis (social death beliefs and behaviours, and willingness to institutionalise tomorrow or next year) very simple Guttman scales could be constructed. These made "intuitive" sense as well as fitting the data which emerged from the Carers' Questionnaire in the main study.

IV. EVIDENCE FOR STAGES IN ANTICIPATORY GRIEF - ANALYSIS PROCEDURES

One of the aims of the present study was to examine the data for suggestions of "staging" over time in the emotional and behavioural reactions of caregiving relatives. Analysis for evidence of stages was conducted in two ways.

One approach was to examine the relationship between the intensities of different carer reactions and the time since either onset or diagnosis of dementia in the sufferer. In the present study this analysis was undertaken both by correlating the intensities of different carer emotional reactions with time, and also (to test for non-linear relationships) by graphing the intensities of carer reactions against time.

The second approach was to compare the intensities of different carer reactions "nowadays" with "earlier on". This was done both on a whole sample basis (using Wilcoxon's Matched Pairs Signed Ranks test to compare scores on individual grief items over time) and also on an individual-by-individual basis (by displaying the pattern of "nowadays" and "earlier on" grief scale scores graphically). If the reactions of the carers had changed over time this would be evidence of some sort

of alteration in emotions or behaviours over time. If those reactions which are generally regarded as occurring early on in the "anticipatory grief" process (such as shock or denial) had tended to decrease, while those reactions which are generally regarded as occurring towards the end of the process (such a depression) had tended to increase, then this would be stronger evidence in favour of a "classic" stage theory of anticipatory grief (for example, Kubler-Ross [1970]).

These approaches are explained in greater detail in Chapter Twelve - the section of the results which presents the evidence for stages in caregiver anticipatory grief. The decision to place what would appear to be a part of the "method" within the "results" of the thesis was made in order to aid the reader's understanding of the somewhat complex rationale behind the analyses which had produced the results which are presented.

V. SUMMARY

This chapter has presented details of the analysis of the data obtained from the Carers' Questionnaire and the self-complete questionnaires which were filled in by the caregiving relatives who comprised the subjects of the present study.

The qualitative data was subject to simple content analysis in order to classify certain sections into content categories. It was also used in order to illustrate examples or points within the text.

The quantitative data was subject to a variety of statistical analyses. These ranged from descriptive statistics such as frequency distributions; non-parametric tests (chi-square, Spearman's rank order correlation, and Wilcoxon's matched pairs signed ranks test); parametric tests (t-tests, one-way analysis of variance, and Pearson's correlation); multivariate analysis (factor analysis and multiple regression analysis); and Guttman scales.

The final section of the chapter detailed the two approaches which were employed in the search for evidence of stages in the emotional and behavioural reactions of caregiving relatives. The first of these was to examine the relationship between different carer reactions and time since onset or diagnosis of dementia in the sufferer, the second approach was to compare current with previous carer reactions.

The chapters which follow present the results which emerged from the analyses of the data gathered from interviews with caregiving relatives and analysed as detailed above.

PART THREE

PRESENTATION AND DISCUSSION OF RESULTS

CHAPTER TEN

RESULTS - AN INTRODUCTION AND A DESCRIPTION OF THE KNOWLEDGE AND PERCEPTIONS OF DEMENTIA HELD BY CAREGIVING RELATIVES

I. INTRODUCTION

This is the first of eight chapters which present and discuss the results of the Carers' Questionnaire.

This chapter presents the knowledge and perceptions of dementia held by caregiving relatives. This is important, because unless dementia is perceived as a fatal illness and/or as an illness which leads to continued losses in the sufferer, it cannot possibly lead to a reaction in the relatives which could be termed "grief". In addition, unless the dementia sufferer is perceived as having changed (such as having lost their "personhood" or having lost whatever it was that made their life worthwhile), it is unlikely that he or she will be perceived as socially dead.

The following seven chapters set out to answer the questions set as the aims of the present study (see Chapter Seven). As a reminder to the reader, these questions were:

1. Does the nature of the reaction experienced by the relatives of dementia sufferers constitute anticipatory grief?
2. Does the anticipatory grief occur in stages, with the end-point being that of resolution?
3. Is the nature or the severity of caregiver anticipatory grief related to individual caregiver or sufferer characteristics, or to their

relationship?

4. Are dementia sufferers perceived as socially dead by their caregiving relatives?
5. Is the staging of anticipatory grief linked to the social death of the dementia sufferer?
6. Are anticipatory grief and social death linked to the caregiver's well-being or subjective burden?
7. Are anticipatory grief and social death linked to institutionalisation?

Throughout this section of the thesis, data of both a qualitative and a quantitative nature is presented. "Raw" data is generally shown in the form of the relevant questionnaire item together with the distribution of responses given by the sample of carers. The majority of the qualitative data is in the form of quotes from the carers themselves.

To return to the focus of the present chapter; did the caregiving relatives of dementia sufferers perceive themselves to be experiencing a loss? Did they perceive their dementing relatives to have changed? This chapter attempts to answer these questions by examining the knowledge and perceptions of the sufferer and the illness which were held by their carers. In particular it seeks to determine whether carers perceive dementia as a terminal illness which brings with it continually greater losses of function.

The chapter asks first how the sample of carers picked up their information and perceptions of dementia. This is followed by a survey of the range of knowledge and the perceptions of the illness which were held by this group of carers. The final section of results reports on the ways in which the carers perceived the sufferers to have changed as a result of the dementia.

II. HOW DID CARERS PICK UP INFORMATION ABOUT DEMENTIA?

1. Discussion with Professionals

Table 10.1 shows, in descending order, professional groups with whom the carers had spoken.

Table 10.1
Profesionals With Whom Caregiving Relatives Had Had Contact

<u>Professional group</u>	<u>Spoken to by % carers</u>
	(N = 100)
General Practitioner.....	90
Psychiatrist.....	68
Other *	66
Day Hospital Nurse.....	31
Pyysician/Geriatrician.....	16
In-patient Ward Nurse.....	16
Community Psychiatric Nurse.....	6
Health Visitor.....	3

* Other = usually a representative from the "Alzheimer's Society".

All 100 carers reported having discussed the sufferer's illness or behaviour with one or more professional people. The average number of different professional groups they had spoken to was 3.1 (S.D. = 1.0, range = 1-7).

 * ***** *
 * * * * * * *
 * * NOTE: The names of all subjects, any * *
 * * professional staff, and all local * *
 * * places have been changed from the * *
 * * original in the results presented * *
 * * throughout this thesis. * *
 * * * * * * *
 * ***** *

Mrs. McAdam, for example, had discussed her husband's dementia with their G.P. (whom she recalled gave her the diagnosis of "pre-senile dementia or Alzheimer's disease"), a psychiatrist, a health visitor (who suggested she apply for "Attendance Allowance") and the psychogeriatric day hospital relatives' support group. She described her G.P.s as particularly helpful insofar as the provision of factual information was concerned:

... and now we have a new doctor and recently when I went about what I thought was circulation trouble he said "No - it's part and parcel, this follows the pattern". So I said, "Well, what else can I expect?", because I'd rather know the score. "Well" he said, "a person loses the ability to do everything and loses all knowledge; the last thing to go is their own name". ... Oh, I'd rather know what you're up against, because you don't get so many frights.

Mrs. Nash reported that she had discussed her mother-in-law's illness with the G.P., psychiatrist, and day hospital nursing sister during relatives' support group meetings. She appeared to have found this useful both in terms of increasing her knowledge of dementia and also because of the support which had been given to her. Another carer, Mrs. Calder also referred to the information providing function of the support group:

They had different people giving us talks, and I sent away for the (Alzheimer's Society) newsletter thing - you get all the gen - so it was all more or less what they say, that's what I was experiencing.

Not all carers were entirely satisfied with the information which they had received, however. Mrs. Nathan, for example, reported that the G.P. had given her no information, and she had only talked about her mother-in-law with members of the Alzheimer's Society, which she did not seem to have found particularly helpful: (over page)

The doctor, she just comes in now and again, very seldom to tell you the truth. Nobody's ever gone into it in depth - even the club folk don't tell me much ... occasionally I go to the meetings.

2. How Carers Learned the Diagnosis of Dementia

Table 10.2 describes the way in which the carers reported they had learned the diagnosis of dementia. By far the majority of caregiving relatives were told the diagnosis of dementia by a professional, most usually a doctor.

Table 10.2
How Caregiving Relatives Learned the Diagnosis of Dementia

	<u>% of carers (N = 98)</u>
Told by another.....	88%
Gathered from media/reading.....	5%
Already knew about dementia.....	5%
Learnt diagnosis in another way.....	2

Mrs. Edwards, was one of the majority of carers who learnt the diagnosis from a doctor, in her case, by discussing her husband's illness with their G.P.:

He told me he was suffering from Alzheimer's disease and he said it wasn't a thing he was going to get better of, it was going to be progressive.

Another carer, Mrs. Deans recalled that although she had not given her a specific diagnosis, the psychiatrist had discussed her husband's illness in the following terms:

"There's no betterness" ... there was nothing specific from the scan - it was like wee mini strokes he was having, but she said "there's nothing that's curable".

Although almost all carers had been told the diagnosis of dementia by a professional, several reported having correctly guessed it some time prior to the "official" pronouncement of the diagnosis. Mr. Denny, for example, had been told by a psychiatrist a year prior to the interview that his wife had senile dementia, however this had not been news to him:

I've accepted for a long while she's got senile dementia, because T.V. programmes show you how they act, and I would say that's what's wrong with her.

Not every carer, however, had learnt the diagnosis via either "official" sources, or by having gradually realised what must have been wrong with the sufferer. For example, one carer, Mr. Nichol appeared to have diagnosed his wife's Alzheimer's disease solely via what might be assumed to be the somewhat traumatic route of a radio programme which he heard one day while he was at work:

I was listening to a radio programme at work and I said "Gosh, that's Barbara, that's Barbara, that's Barbara" ... pre-senile dementia, Alzheimer's disease they were talking about - I perhaps had seen it before that but hadn't paid a lot of attention to it, but by this time it had just twigged.

One of the carers who had some previous knowledge of dementia (other than via the media) was Mrs. Tait. She reported having guessed that her husband had Alzheimer's disease and she just asked the doctor for the diagnosis in order to confirm her suspicions:

My mother had Parkinson's disease and Alzheimer's and he was putting me in mind of my mum, some of the things that he was doing.

A very small number of carers reported that they had never been given an "official" diagnosis, but had

assumed it from the care which the sufferer was receiving. Mrs. Niven, for example, said that she had never been given her mother's diagnosis, but guessed because she attended the psychogeriatric day hospital:

I just know she goes to R. Hospital, that's the - it tells you on it "Senile Dimension" - I mean ... nobody's ever told you but you'll find that with everybody else - there's a lot of folk have got it and they've never been told official they've got it.

3. Discussion with Lay People

Carers also discussed the sufferer with non-professional people: only 4 out of 99 who were asked had not discussed the sufferer's illness or behaviour with others.

QUESTION : Who do you discuss ... with?

% of carers (N = 88)

Family only.....54%

Friends only.....7%

Both.....39%

It is perhaps not surprising that the most popular confidants were other family members. Not only were they likely to be close to the carer, but they were also likely to have some knowledge of the sufferer, both before and since the onset of dementia.

Mrs. Tait, for example, was in close contact with her family with regard to her husband's dementia:

Anything that goes wrong at all, I tell the family - yes, my sister's always there, I see my sister every day.

Mrs. Tapp felt that her mother's dementia had actually brought her closer to the rest of her family:

This has been something recent that my son and daughter-in-law has appreciated what you're

going through. I don't think they realised what it was like until recently.

Not all family members were supportive, however. Miss Maguire, for example, believed that the rest of her family did not wish to become involved in caring for her father, so she didn't discuss his condition with them:

My sisters aren't interested. Because of that it puts me off speaking to them - I think they figure that it's my job.

The majority of carers commented that they would only discuss the sufferer with people who knew them well and were obviously concerned. Mrs. McAllister, for instance, talked about her husband with friends and relatives as follows:

When they ask for him ... they say they know it's difficult to cope ... I wouldn't tell strangers, it's only to people that have known him

Four percent of carers stated that they did not discuss their relative's dementia with other lay people. Mr. Napier was one of these:

Well, I've just sort of carried on myself - I'm a bit of a loner that way.

4. Knowledge of the Fate of Another Dementia Sufferer

QUESTION : Do you, or did you, know anyone else who has, or had, the same thing wrong with them as ...?
% of carers (N = 99)

Yes.....	54%
Carer unsure.....	2%
No.....	44%

The 54% of the sample who knew another dementia sufferer either at the time of the interview or

previously did so via living with other elderly relatives, or via a support group, or else via their experience with elderly neighbours or friends.

One of those who had had previous family experience of dementia was Mrs. Marsh. She had understood her husband's diagnosis and prognosis because some of his relatives had also suffered dementia:

His mother went like that, and his sister - she was placed different because she lived herself - she went to hospital ... the two of them are dead.

Attendance at a relatives' support group allowed carers to share their experiences of living with dementia, and in some cases to meet other sufferers (brought by relatives who were unable to arrange anyone to sit with their sufferer). Mrs. Abbott, for example, had not come across another dementia sufferer,

Not in my daily dealings, but since I've went to the dementia club I've had contact there.

Other carers had come across dementia sufferers one way or another in their "daily dealings". For example, Mrs. Mann reported that her neighbour had suffered Alzheimer's disease and was eventually admitted to hospital where he had died 5 years previously. Mrs. Newark had also come across dementia before her mother developed the illness:

When I worked in the shop there was a customer that came in and she had her mum, she was a frail wee thing, just used to stand at the window and wave like a child, and I got talking to her - and then another old gentleman came into the shop and his wife had taken it and he gave me a booklet and I read it, and that's really how ... and seeing mum doing different wee things I thought, "This is probably what's wrong with her".

III. EXTENT OF CARER KNOWLEDGE ABOUT DEMENTIA

1. The Diagnosis

Of the 96 subjects asked, 96% were able to repeat a diagnosis for the sufferer's illness as given to them by a professional (either "dementia", "Alzheimer's disease", "(pre) senile dementia", or "multi infarct dementia"). Four percent said they had never received an official diagnosis from a professional, but of these only one was unable to give an appropriate description, if not official diagnosis of the sufferer's illness.

Sample answers to the "What is wrong with ...?" set of questions follow. They are all "correct", and listed in order of roughly decreasing technicality.

- Pre-senile dementia - Alzheimer's disease.
- Dementia - Alzheimer's disease, in fact, the first time I heard the word 'Alzheimer's' I couldn't even pronounce it!
- My G.P. told me from the beginning it was senile dementia.
- She's got hardening of the arteries I was told, of the brain, and Dr. T. told us she'd got Alzheimer's.
- Dementia due to age.

Not all carers were able to give an "official" diagnostic term to the sufferer's illness, however, this did not necessarily mean that they did not understand what was happening. For instance, Mrs. Cameron's husband suffered from multi-infarct dementia. Although she understood the implications of this, and that it meant he had suffered "little shocks", she was unable to give an official diagnosis. She described her anxiety when she spoke to the psychiatrist, and her recall of the interview when he gave her the diagnosis:

... he (the psychiatrist) gave me 3 initials - I can't remember what they were, and he said he could take small ones like that and get better

from them or some day he could just take a fatal one.

Another carer, Mrs. Calkins was unable to give a diagnosis, but once again demonstrated knowledge of the illness and it's implications for the future. She was presumably mistaken when she recalled her G.P. as having told her that her husband had "arthritis in the head" (possibly "atherosclerosis"?). She described what was wrong with her husband as "age in general". However, she did know that his prognosis was "downhill" and that his memory was impaired.

2. The Prognosis

QUESTION : Do you think that ... will get better?
% of carers (N = 100)

Yes, definitely..0%
Carer unsure.....2%
No, definitely..98%

Almost every carer acknowledged that the sufferer would not get better. Their comments tended to go further than this, associating dementia with progressive deterioration and death. Thus, for this group of caregivers, dementia in their relative was a terminal illness. Mrs. Bailey, for instance, described her mother as suffering from "a deterioration in the faculties". Mrs. Cooper said of her mother's future:

There's only one thing can happen to her,
that's when her life ends isn't it?

Mrs. Law referred to her mother's dementia as follows:

There's no cure for it - they tell you it's
part of the brain dying off. I know in young
people the brain cells can come back, but in a
case like my that, you know that they don't get
better.

One of the two carers who was reported themselves unsure of whether or not the sufferer might improve was

Mr. Campbell, whose father was hospitalised with dementia. He stated that his father's condition might improve "if they could find something to stimulate his mind".

3. General Knowledge About Dementia

Following the interview, each of the 100 subjects was rated according to their general knowledge about dementia. Table 10.3 shows the results of this rating.

Table 10.3
Rating of Carers' General Knowledge About Dementia
(N = 100)

<u>% of carers</u>	<u>Knowledge rating (Highest - Lowest)</u>
54%.....	Acknowledges illness, names dementia, aware brain changes -> behavioural change, progressive, rough time scale.
41%.....	Correct name, some awareness affects brain, prognosis downhill.
4%.....	May name, little knowledge of illness or prognosis.
1%.....	Can't name, no obvious knowledge of reasons for condition or prognosis.

There was a significant relationship between higher carer knowledge about dementia and the number of different professionals with whom they had talked concerning the sufferer and the illness ($r = .321$, $P = .001$).

Examples of the range of caregiver knowledge about dementia follow. Mrs. Abrahams, whose knowledge was rated in the highest bracket, explained her understanding of the mechanism of her mother's dementia as follows:

It's like parts of the brain dying - the part maybe that told you how to tie your shoelaces, if that part died, you wouldn't know how to do

that again ... so that was it, you'd forgotten how to do that for ever, so I had actually accepted that and I had sort of been watching these various things going on, that she would forget how to do these various things.

Mr. Yates also exhibited this high level of understanding:

It's the brain cells dying and sooner or later the brain cells that control the bodily functions will die as well and that will be it.

Mr. Inglis' description of his wife's dementia was rated within the second highest knowledge bracket:

It's something to do with the brain - something affects the brain and it doesn't - say, whatever chemicals are going to the brain, they're not getting supplied to the brain.

Mrs. Neary's description received the same rating:

It's the cells in the brain are done - they're kind of worn out.

One of the carers whose knowledge was rated in the third (next-to-lowest) bracket was Miss Bain, who said of her mother's fairly mild illness

Well, I've just accepted it, just thought 'that's it, she's forgetful and that's all I can do about it' - and the doctor told me 'hardening of the arteries' and I just felt she could have been a lot worse, could have been in bed with me having to attend to her.

The only carer to receive the lowest knowledge rating was Mrs. Taylor. She described her husband's dementia as follows:

He's wandered - I've never given a name to it. She did not appear to either understand nor wish to understand his illness:

I'm afraid I've just sort of slid through life if you know what I mean - we had a daughter and she died and when she died I said 'well, it must have been our turn for something', so when

this happened I thought, 'well, it must be our turn for this.

IV. CARER PERCEPTIONS OF DEMENTIA

Following the interview, subjects' perceptions of the illness were rated either via direct or indirect comments. Table 10.4 shows the results of this rating.

Table 10.4
Ratings of Carer Perceptions of Dementia (N=94)

<u>% of carers</u>	<u>Carer perceptions of dementia</u>
12%.....	Dementia = Just what happens when you get old.
66%.....	Dementia = an illness, just like any other illness.
21%.....	Dementia = a very horrible/worst possible illness.
1%.....	Dementia = other perception.

Among those carers who regarded dementia as just what happens when you get old was Mrs. Davis, who said of her mother's illness:

Well, the way I just feel is it's my mum getting old and the brain cells are not working - I don't really feel it's an illness, I just feel it's part and parcel of old age ... the way my mum is at the moment I just feel it's part and parcel of old age.

Mr. Hall also perceived his mother's dementia as a natural and normal consequence of ageing:

... I just took it it was just wear and tear and old age, quite truthfully speaking.

The majority of carers appeared to regard dementia as an illness, just like any other illness. Mrs. Newton, for instance referred to the way in which she thought about her mother's illness as follows: (over page)

Oh, it's an illness, I think it's an illness, I suppose I look on it - just a malfunction of the brain I think I look on it.

Another of the carers who clearly regarded dementia as just an illness was Mr. Clark, who described his perception of his wife's dementia as follows:

I feel it's just an illness, it's like a cancer, a heart attack, it's just a part of the body that's dying - it'll affect all parts of the body 'cos it's brain cells.

The perceptions of dementia held by about one fifth of the carers were much more negative. This group was rated as regarding it as a very horrible/worst possible illness. Mrs. Thom, for example, said of her mother's dementia:

The whole thing is just overwhelming, the awfulness of it, the knowing that whatever you do the end will be the same.

Mrs. Edgar was another of the carers whose perceptions of dementia were extremely negative. Speaking of her mother, she stated:

It's a horrible illness, it's devastating, it's the worst thing.

In an attempt to elucidate what distinguished those carers who perceived dementia in such different ways, a comparison of the three groups of carers divided by their perception of dementia ("old age", "just an illness", and "horrible / worst illness") was made in terms of the following variables:

- carer age.....		Via one-way analysis of variance
- sufferer age.....		
- total frequency of problem behaviours.....		
- overall sufferer change estimated by carer.....		
- time since onset of dementia.....		
- time since diagnosis of dementia.....		

- carer sex.....
 - sufferer sex.....
 - carer-sufferer blood/role relationship.....
 - sufferer living arrangements...
- Via chi-squared analysis.

The results of these analyses are presented in Tables 10.5 (below) and 10.6 (over page).

Table 10.5

One-way analysis of variance comparing subjects whose perception of dementia was old age (Group 1), just an illness (Group 2), horrible/worst illness (Group 3), on carer and sufferer age, total problem behaviour frequency, estimated overall sufferer change, time since onset and since diagnosis of dementia.

	Group 1	Group 2	Group 3	Sign. group diff.#	d.f.	F
Carer age (yrs)	.64.7...	59.7...	58.4.....	2,90...		0.92
Sufferer age (yrs)	..83.1...	74.6...	74.2..1>2,3...	2,92...		5.92
Total problem behav. freq.	..30.8...	35.9...	34.8.....	2,88...		1.02
Overall estim. suff. change	...3.9....	4.2....	4.2.....	2,90...		0.62
Time since onset (yrs)6.0....	6.0....	6.5.....	2,92...		0.16
Time since diagnosis (yrs)	.2.8....	3.5....	3.6.....	2,87...		0.52

** = $p < .01$

= Tukey honestly-significant-difference method, significance level set at .05

The only one of the above variables which did differ significantly across the three groups was sufferer age: those carers who regarded dementia as "old age" were looking after significantly older sufferers (on average ten years older) than those who perceived it as "just an illness", or as "a horrible/worst illness". They did not differ in terms of carer age, sufferer impairments, or time since onset/diagnosis. Nor did they differ in

Table 10.6

Proportion (%) of subjects whose perceptions of dementia was old age (Group 1), just an illness (Group 2), horrible/worst illness (Group 3), in terms of carer and sufferer sex, blood/role relationship, and sufferer living arrangements.

	Group 1	Group 2	Group 3	χ^2	2
<u>CARER SEX</u>					
Male (N=25).....	16.....	72.....	12.....	0.67	#
Female (N=69).....	10.....	64.....	26.....		
<u>SUFFERER SEX</u>					
Male (N=40).....	10.....	65.....	25.....	1.27	
Female (N=53).....	13.....	68.....	19.....		
<u>SUFFERER RELATIONSHIP TO CARER</u>					
Spouse / sibling (N=50)....	10.....	68.....	22.....	0.43	
Parent / in-law (N=43)....	14.....	65.....	21.....		
<u>SUFFERER LIVING ARRANGEMENTS</u>					
Own / carer's home (N=71)..	10.....	66.....	24.....	0.18	#
Institution (N=22).....	18.....	68.....	14.....		

= after Yates' correction.

terms of carer or sufferer sex, sufferer relationship to carer, nor on whether or not the sufferer was institutionalised.

V. CARER PERCEPTIONS OF CHANGES IN THE SUFFERER

1. Overall Change Ratings

QUESTION : Overall, and taking everything into account, how much is ... changed compared with how they used to be?

	<u>% of carers (N = 100)</u>
No change - exactly as they always used to be.....	0%
Slight change, but almost the same as they always were.....	4%
Moderate change, somewhat the same as they always were.....	18%
Great change, only slightly like they always used to be.....	35%
Complete change, nothing like they used to be.....	43%

Clearly, by far the majority of these relatives perceived a massive overall change in the sufferer compared with the way they remembered them.

While carers were given no guidance as to which aspects of "change" to focus on while making this assessment, their answers and comments on this topic demonstrated the importance of the sufferer's personality rather than their cognitive ability as it related to the amount of change which the carers perceived.

Mrs. Elliott and Mrs. Niven were among those who rated the sufferer as only slightly changed. Their comments emphasised the preservation of the sufferer's (in both cases the carer's mother) premorbid personality characteristics rather than their cognitive ability. Mrs. Elliott said:

My mum was always a kind of bossy woman, that I wouldna' say she's changed all that much - only for the mind no' functioning - I mean if her mind was working I'd have no problem with my mother ... I wouldna' say she's changed that much.

Similarly, Mrs. Niven commented,

Well, she's still my mother - the personality's a bit dimmed, certainly, but it's still there - I wouldn't say it's a different person I'm looking at ... they're not dramatic changes ... I mean if her total personality had changed and she was cursing and swearing like some of them do, yes, that wouldn't be her.

One of the carers who perceived moderate amounts of "overall" change was Mrs. Tear - once again referring in her comments to the personality rather than the cognitive capacity of the sufferer. She pointed out that while she was still able to see some of the familiar characteristics of her mother, others who knew her less well may not do so: (over page)

Because she obviously worries about me ... so I know that my mum is still there underneath. But other relatives who perhaps - they haven't got this - they must wonder who this person is, sitting there, because she won't bear any resemblance to Nancy.

Over 40% of the sample regarded the sufferer as greatly changed. Mrs. McAdam, for example, said of her husband:

Now and again there's a flash of himself, but it's only now and again.

Mr. Napier tearfully described how his wife has become increasingly changed, until there was nothing of herself left at all:

She's got worse and worse since she's in the hospital - when she was in the hospital at first, she was walking about and then gradually she didn't know me but she looked forward to me, she used to like to see me, she knew the face, but all that's gone too now ... well, there's nothing there at all, just - nothing.

In order to investigate whether the carers' estimates of overall change in the sufferer were accurate, the overall change estimates were correlated with the somewhat more objective measure of scores on the 34-item Behaviour Problem Checklist. Table 10.7 (over page) presents the results of correlations (Pearson's r) between overall change estimates with the total overall problem frequency scores and with the frequency scores from the individual problem domains which had been obtained via factor analysis.

There is a significant positive relationship between the carers' estimates of overall sufferer change and overall sufferer impairment as estimated by total problem frequency score. However, this result can be seen to arise from only half of the six problem behaviour domains. These are the domains which might be

Table 10.7
Correlation Coefficients (Pearson's r): Estimates of Overall Sufferer Change with Problem Checklist Frequency Scores

<u>Problem behaviour domain</u>	<u>Pearson's r</u>
"Depend".....	0.097
"Can't do".....	0.297 ***
"Incontinence/Hygiene".....	0.169 *
"Apathy".....	0.423 ****
"Disturb".....	0.059
"Demand".....	-0.060
TOTAL PROBLEM FREQUENCY SCORE.....	0.258 **

* = p<.05 ** = p<.005 *** = p<.001 **** = p<.000

regarded as most representative of sufferer "loss of person": "Apathy" relates to the loss of purposeful behaviours or the ability to communicate verbally; "Can't do" relates to behaviours of omission; "Incontinence/Hygiene" relates to loss of ability or concern with regard to personal hygiene. The other three behavioural domains were completely unrelated to carer estimates of overall sufferer change. This result is consistent with comments which the carers made about the changes in the sufferer.

2. Most Important Change in Sufferers

QUESTION : What would you say is the most important change in ...?

The responses of the 96 carers who answered this question were categorised following the interview as shown in Table 10.8 (over page).

The emphasis on the importance of the personality and interactive behaviours was again highlighted when carers described the most important change in their relative.

Table 10.8
Most Important Change in Dementia Sufferers as
Perceived by their Caregiving Relatives (N = 96)

<u>Nature of Change</u>	<u>% of carers</u>
No communication/No recognition.....	27%
Apathetic behaviour.....	19%
No single change.....	19%
Cognitive changes.....	14%
Other changes.....	7%
Personal hygiene.....	6%
Disruptive behaviour.....	4%
Emotional changes.....	4%
Appearance.....	1%

No communication/No recognition was at the top of the list. In this sample about a quarter of the carers reported that the sufferer did not recognise them. (Out of 93 carers who were asked, 55% reported the sufferer definitely recognised them, 22% reported that the sufferer sometimes recognised them, and 23% that the sufferer definitely did not recognise them.)

One of the carers who described the sufferer's inability to recognise familiar people as the most important change was Mrs. Abrahams, who described her mother as follows:

She doesn't recognise her family at all ... she can't even remember the children now, whereas before she was totally involved with them ... and that, I think, upsets me more than anything.

Similarly, for Mr. Denny the most important change in his wife was

She's just fading away, she's going away all the time ... a gradual going away from me, she doesn't know who I am.

Inability to communicate sensibly was the other "personality" characteristic which carers frequently

mentioned as the most important change in the sufferer. Mr. Sadler, for example, said of his mother:

You can't converse with her about anything, you can't tell her if somebody had got married or somebody had died, she wouldna' know what you were talking about.

The following comments highlight other areas of "most important" overall change in the dementia sufferer as perceived by their caregiving relatives. Apathetic behaviour was chosen by Mrs. McBride as the most important change in her father: "He was always that active and now you just see him sitting". Mr. Gill suffered from only a mild degree of dementia and did not exhibit significant behavioural changes. For Mrs. Gill, her husband's cognitive changes were the most important of the changes which she perceived: "This lack of memory and questions I think". Disruptive behaviour was selected by Mrs. Tapp, who found her mother's "black moods - and she orders you out of the house" the most important changes, because she would never have behaved like that previously. In her choice of personal hygiene as the most important change, Mrs. Timms also compared her mother's premorbid behaviour with her current behaviour: "Compared the way my mammy used to be, when she does these things I'll say 'Och, Mammy, that's terrible - you were never like that' ... I mean, she was never like that". The emotional changes (or losses) in his wife were the most important for Mr. Neil: "I would say the worst I find is that she doesn't seem to have any emotions or feelings". Mrs. Abbott chose her husband's personal appearance as the most important change; the reason for this choice being that it had obviously altered significantly: "Unfortunately he had Bell's palsy about 4 months ago and I'm afraid it twisted his face". The most important change chosen by Mr. Yardley with regard to his father had to be

classified as "other": "It's this cleanliness thing - going over and over the house cleaning". Finally, Mrs. Tait was unable to pick a single most important change in her husband, "it's just the whole situation".

3. Physical Changes in the Dementia Sufferers

QUESTION : Does ... look the same as he/she used to?
% of carers (N = 100)

Exactly the same.....	31%
Almost the same.....	24%
Somewhat the same.....	22%
Hardly the same.....	14%
Not at all the same.....	9%

QUESTION : Does ... look physically well?
% of carers (N = 100)

Looks very well.....	44%
Looks fairly well.....	16%
Looks alright.....	13%
Looks rather unwell.....	20%
Looks extremely unwell.....	7%

Clearly, despite the cognitive, emotional and behavioural changes, the majority of carers reported that the physical condition of the dementia sufferers was generally fairly good.

Mrs Nisbett had been surprised that her mother still looked exactly the same as she always did, since she had previously assumed that dementia was obvious to observers:

It doesn't change her looks ... there's no difference in her eyes, which - you know, I used to think you could tell somebody with dementia, you know, you would see it in their eyes, or - of course, you don't.

One of the carers who regarded the sufferer as looking somewhat the same was Mrs. Mann. She regarded her husband's physique rather than his face to have

changed:

He's lost his physique - he was very erect and he's gone kind of stooped, and he's lost a bit of weight.

Fewer than 10% of the carers perceived the sufferer's looks to have completely changed. Two of those who did were Mr. Tassie and Mr. Fergus. Mr. Tassie's wife did not look at all the same as he remembered her, however the changes appeared to be general rather than specific:

Oh, she's changed a lot - see the last 4 years, she's aged 20 years. Oh she was smart as a bee.

Mr. Fergus also thought his wife's looks had completely changed:

Lucy's looks have changed drastically over the years she has had it - she's thinner now, she's smaller, she's lost a lot of weight".

4. Speed of Changes in the Dementia Sufferers

QUESTION : How quickly have these changes occurred?

	<u>% of carers (N = 90)</u>
Extremely fast/sudden.....	14%
Fairly fast.....	12%
Moderately fast.....	12%
Fairly gradual.....	12%
Extremely gradual.....	49%

Half of the 90 carers questioned described the changes which had occurred in the sufferer as having been very slow. This perception was not entirely subjective: carer assessment of speed of change was significantly associated with the length of time since the onset of the dementia ($r = 0.505$, $P = .000$). The greater the time since the carer recalled they first noticed "something" wrong with the sufferer, the more gradual they perceived the changes to have been.

Only 5 of the total sample of carers had first noticed something wrong with the sufferer within a year or less prior to the interview. One of these was Mrs. Earl, who had first noticed something wrong with her mother about a year before the interview - she described the changes which had occurred as "very quick". In comparison, Mrs. Nathan's mother-in-law had been ill for the past 8 years. Mrs. Nathan described the changes which she perceived in her as follows:

She's deteriorating slowly ... there's nothing dramatic.

VI. DISCUSSION

The information, understanding and "open-ness" about the dementia sufferer and their illness among the present sample of caregivers was generally high. They were clearly aware of the implications of continued deterioration in function and eventual death which a diagnosis of dementia implies. The average number of different "professional" groups with whom the carers had spoken was three - and the maximum number was as high as seven. Almost all could give the name "dementia" to the illness, and many could be more specific about the diagnosis. General knowledge about the course of dementia was also good.

This result contrasts with earlier studies which found considerable vagueness about the diagnosis and prognosis of dementia sufferers among their caregiving relatives [Gilhooly, 1980; Gilleard and Watt, 1982 - cited in Gilleard, 1984]. This probably arises as a result of the following factors. Firstly, over the past 10 years the subject of dementia has come out of the media closet. There have been TV documentaries, radio

programmes, newspaper and magazine articles about dementia, often highlighting the plight of the community carers. Public knowledge and acceptance of dementia is therefore likely to have increased over this time. (This is also suggested by the finding that some carers had learned - or at least suspected - the dementia diagnosis long before hearing it from a professional, because of information picked up from the media.) Secondly, and possibly arising from the findings of the earlier studies, greater efforts may be being made to explain dementia to caregiving relatives in 1990 than were made in 1980. In particular, a written "Carers' Booklet" (based on Toner [1987]) is now made available via some psychogeriatric day hospitals and community psychiatric nurses. This is printed in colour, has a fairly simple reading ease score, and provides information on dementia, coping techniques and available support services. The Alzheimer's Society provides written information to members, and the local projects (Motherwell and Paisley) send out monthly newsletters. The few carers who were related to dementia sufferer involved in the Gartnavel Hospital Alzheimer's Project would of necessity have received information about the illness, since as part of the project they would have been interviewed themselves (indeed some were acting as cognitively intact controls and so received regular psychometric testing), and they would have given autopsy permission for their relative. In addition to these sources of information, relatives may have increased their knowledge of the nature of dementia via discussions. Monthly relatives' support groups were available through all the psychogeriatric day hospitals involved in the main study, as well as through the REDS project and through the Alzheimer's Society. Relatives of institutionalised dementia sufferers were generally

welcome, and were often able to impart information as one who had "been through it". Some relatives in the sample were in contact with two support groups simultaneously! Finally, information on an individual basis might have been available through the GP or psychiatrist caring for the dementia sufferer. This represents what is probably the most idiosyncratic source of information, depending on the interest, knowledge, time, and disclosure policies of the doctor in question.

The finding that the level of caregiver knowledge about dementia was significantly and positively related to the number of professionals with whom they had talked about the illness makes both intuitive sense and - assuming that high carer knowledge is something to be aimed at - suggests that the general policy should continue to be to provide a variety of different professional inputs to the caregivers of dementia sufferers. Of course, there is also the possibility that the direction of the relationship here is not the one that immediately springs to mind: could it be that those carers with greater general knowledge about dementia are able to seek out a greater number of different professional groups from whom to ask for support?

The perceptions held by the carers of the changes which had occurred in the dementia sufferers did not appear to be entirely subjective. The single "overall change" rating was significantly related to the overall amount of impairment as assessed by the Problem Checklist frequency scores. It was interesting that in particular it was related to the amount of change in what we might regard as the attributes of a "person" - apathy, incontinence/personal hygiene, and inability to perform

activities such as washing or dressing. It was not related to the amount of physical dependency, disturbing, or demanding behaviour. In addition, the "speed of change" rating was significantly related to the length of time since onset of the dementia - a longer time being associated with a slower estimated speed of change. This result may have occurred not because the speed of change actually was faster for those seen closer to the onset, but rather because it was easier for them to recall how the sufferer had been prior to the onset of the illness, so even fairly mild impairments would be estimated as having occurred more quickly. In comparison, those caring for a sufferer who had become steadily more impaired over a period of several years would be more likely to perceive this as a gradual deterioration because it had taken place over such a long period.

But what of the carers' overall evaluative perceptions of dementia? What objective factors were they basing their perceptions of dementia as either "just old age", "just an illness", or "a very horrible/worst possible illness" on? Even here, the perceptions had some basis in fact: those who appeared to perceive dementia as "just old age" really were caring for very elderly sufferers - 10 years older on average than those related to carers who perceived the dementia as an illness (whether a very horrible one, or not). However, further differences between the groups with regard to basic carer or sufferer demographic or relationship characteristics were not apparent. (For example, one group of sufferers was not found to be "very horrible" in terms of presenting a greater total number of problem behaviours, nor to have changed to a greater overall extent as estimated by the caregiver.)

What, then, might have caused some carers to perceive dementia in such negative terms while the majority perceived it as "just an illness"? For a somewhat analogous situation, we could turn to Beck's cognitive theory of emotional disorders. Williams [1984] summarises the three main components of this theory as being the following. (1) The presence of "negative automatic thoughts": the "negative cognitive triad" - a negative view of the self, the world, and the future. (2) The presence of "systematic logical thinking errors", such as overgeneralisation or selective abstraction with a negative bias. (3) The presence of "depressogenic schemata": that is, general long-lasting attitudes or assumptions about the world by which the individual both organises his or her past experience and classifies incoming information about the world. Beck [1985] likens an individual's construction of a particular situation to taking a photograph. In the same way as a camera's settings may alter the picture it takes, so might an individual's "cognitive setting" alter "whether the mental image or conception is broad, skewed, or narrow, clear or blurred, accurate or distorted" [1985, p.38]. Beck [1967] believes that certain "depression prone" individuals are vulnerable because they have developed a constellation of "enduring negative attitudes". These attitudes may not always be discernible, but may be activated by an appropriate set of conditions. (This is described by Haas and Fitzgibbon [1989] as a "Stress-Diathesis Model of Cognition in Depression".) Where do such concepts or attitudes about oneself and one's world come from? Beck [1967] suggests that they develop early in life, and result from experiences and from attitudes and opinions communicated by others. To return to those carers who perceive dementia to be "a very horrible/worst possible illness": if this perception is not anchored in the

in the degree of impairment of the sufferer, might it then be an enduring negative attitude towards dementia? Could it have arisen from early experiences or from opinions communicated not only by those around the carer but (perhaps more importantly nowadays) by the power of the media?

VII. SUMMARY

This chapter serves as an introduction to seven further chapters, each of which will address one of the aims of the study by presenting and discussing the results obtained from interviews with caregiving relatives.

The main aim of the chapter was to investigate whether the caregiving relatives of dementia sufferers perceived themselves to be experiencing a loss. The chapter opened with a survey of the ways in which carers pick up information about dementia. While all had spoken to at least one "professional", information was also widely available via the less formal routes of the media, knowledge of the fate of another dementia sufferer, or discussions with family and friends. General knowledge concerning the diagnosis and its implications tended to be good among the carers in the present study, and it was significantly associated with the number of different professional groups with whom the carer had been in contact. Evidence for the perception of dementia as a terminal illness was available from their comments concerning the inevitability of the sufferer's deterioration and death. No carer thought the dementia sufferer would definitely get better. The carers' evaluative perceptions of dementia could be categorised as "old age", "just an illness", and "a very horrible/worst

illness". While carers who categorised dementia as "old age" were related to older sufferers, there were no other significant differences to distinguish the groups. The majority of carers perceived a massive overall change in the dementia sufferer in comparison with their premorbid state, with the emphasis being placed on personality and "personhood" (recognition and communication) rather than cognitive or appearance changes.

These results confirm that dementia was generally perceived by the present sample of carers as an illness bringing with it continued losses and eventual death in the sufferer. As such it might be expected to result in "anticipatory grief" reactions in caregiving relatives. Whether or not this was the case will be examined in the chapter which follows.

CHAPTER ELEVEN

EVIDENCE OF ANTICIPATORY GRIEF IN THE CAREGIVING RELATIVES OF DEMENTIA SUFFERERS

I. INTRODUCTION

The aim of this chapter is to present the experiences of caregiving relatives within the context of anticipatory grief. It is largely descriptive, relying on the comments of the subjects themselves. Much of the chapter is constructed by presenting one or more of the anticipatory grief questionnaire items followed by the numerical pattern of responses made by the subjects to that particular item, together with illustrative examples of the various responses.

The six sections which follow this introduction focus on various aspects of the emotional reactions of the relatives over the period of the dementia. The first of these, which is concerned with initial reactions highlights firstly the almost universal tendency to deny the first signs of dementia as nothing to worry about, and secondly the way in which the nature of the initial reaction to the diagnosis depends on the previous experiences and beliefs of the relative in question. Subsequent sections focus on the five components of anticipatory grief as initially specified in the carers' questionnaire, namely: "Shock/Denial"; "Hope/Bargaining"; "Questioning/Anger/Guilt"; "Preoccupation/Unfinished Business/Despair"; and "Acceptance".

Section VIII highlights some of the social aspects of the situations in which caregiving relatives find

themselves, again from the perspective of whether they may constitute preparation for bereavement.

The final section of results in the chapter reports on whether or not caregiving relatives actually perceived themselves to be grieving. This appears at the end of the chapter because unless a carer brought the topic up spontaneously, it was not discussed until after all the other components of grief items, thus ensuring that the notion that they might be grieving did not bias the carer's previous statements and descriptions of their experiences.

This lengthy chapter closes with a discussion which examines the results as presented in order to answer the question of whether or not the nature of the reaction experienced by the relatives of dementia sufferers constitutes anticipatory grief.

II. CAREGIVERS' FIRST REACTIONS TO THE DIAGNOSIS

As has been noted earlier, almost all the sample of carers (86 out of 98 asked) learnt the diagnosis because they were told by somebody else. Out of these 98 carers, 70 (71%) described themselves as learning the diagnosis suddenly, while 28 (29%) learnt it gradually. The reason for what might appear to be a discrepancy between these two results is that some carers gradually suspected that the sufferer may have had dementia, so that although they were "officially" told the diagnosis, it was really only a formality. On the other hand, some carers described themselves as only gradually having taken in the diagnosis and implications after having been officially told.

The following analysis demonstrates that although the majority of carers believed the diagnosis was true, they recalled that when first told what was actually wrong, their knowledge of dementia and its implications was fairly hazy.

QUESTION : When you first heard what was actually wrong with ... did you understand immediately what that meant?

% of carers (N = 94)

Yes, completely.36%
Was unsure.....33%
No, not at all..31% ,

QUESTION : When you first heard what was actually wrong with ... did you believe it?

% of carers (N = 92)

Yes, definitely.73%
Was unsure.....13%
No, not at all..14%

While carers cited a variety of immediate reactions to the diagnosis, by far the most common were variations of "shock". The reaction of the carer was clearly related to their understanding of, and beliefs about the concept of dementia at the time of the diagnosis. The following brief case studies demonstrate the variety of initial reactions to the diagnosis, together with the reasons for their occurrence. They also demonstrate an almost universal delay between the carer noticing something wrong in the sufferer and their actually being informed of the diagnosis. (As has been noted earlier, the average time since onset of the dementia as estimated by this sample of carers was 6.1 years, whereas the average time since formal diagnosis was estimated to be 3.6 years.) Several of the carers in the examples which follow mention putting off seeking professional help or diagnoses for the sufferer during this period. Apparently they were attempting to

deny the evidence of the sufferer's unusual behaviour, attributing it to "old age" or hoping it would just go away.

Mr. Oliver: Shocked at his wife's diagnosis

Mr. Oliver had first noticed something wrong with his wife about 7 years prior to the interview. She became forgetful and started to argue with him. 3 years later he took her to their G.P., and she was referred to a psychogeriatrician who diagnosed Alzheimer's disease. The news was "difficult" to believe. Mr. Oliver understood what it meant because:

I'm a reader - I knew what Alzheimer's was, but I never - I said "Christ, it canna' be for wee Naomi" - but it was.

His perception of Alzheimer's was entirely negative:

When they said that, I said, "that's that, she's doomed", it's a death sentence, it's like AIDS, see when they say you've got Alzheimer's - they tell me it's progressive, degenerative, there's nae cure and it'll get worse - well, she's dead, same as AIDS.

Mr. Yates: Disbelief at his mother's diagnosis

Mr. Yates was not aware of the onset of his mother's dementia (about 7 years prior to the interview), because he was living in the south of England at the time:

I didn't notice anything, but she had been noticing it, she was forgetting, she wouldn't phone me and I would be saying "I'm doing all the phoning here, it's costing me a fortune!" She couldn't remember the number, that's the point, and she wouldn't tell me that ...

One day Mr. Yates phoned his mother and got no reply, so he called the neighbour who discovered that she had had a stroke. Mr. Yates discussed his mother's case with the doctor in the hospital following the stroke:

He wanted me to let him take her in permanently and I said "No, I don't want that, I'm not sticking her away in a home and forgetting her, I don't want that" ... they told me she was gone and she wouldn't remember me and she wouldn't remember anything anymore and she should be put away.

Despite what the doctors had said, Mr. Yates did not really understand what they were telling him, nor did he believe it:

I kept thinking to myself, "Well, I'll get through to her somehow or other, I'll bring her back" - but it never happened, nothing happened, and I kept trying - I would take her to places which used to be - I even walked her around Govanhill one day, and walked her along the Clyde and tried to bring things back to her, but it didn't work.

Mrs. Young: "Devastated" at her husband's diagnosis

Mrs. Young had first noticed something wrong with her husband about 9 years prior to the interview:

At the beginning it was just so gradual, it was just small incidents, forgetfulness and all that, and sense of direction and things ... I let it go for a while saying "I don't think it's serious, it may be alright". However, I took him to the doctor and the doctor sort of - it was just the way the doctor looked at me and said "It's just old age, we're all getting on", but from that I deduced there was just something that he couldn't do anything about, a natural process kind of thing ...

It wasn't until about 7 years later that:

They started saying "dementia" ... he was in S. Hospital for 8 weeks, a geriatric ward ... if he'd passed away then you felt that he'd have passed away without having this carry-on, poor soul.

When "dementia" was first mentioned:

I didn't know very much about it, I just knew there wasn't any betterness for it, I knew that much about it ...

Mrs. Young believed the diagnosis:

I knew what it was alright, because they gave

me a book about it and everything fitted in the way the book stated it would fit in.

At the time she felt:

... devastated, I just went cold, I had just staved off suspicion, and like everyone else, I just staved it off because I felt I couldn't face up to it.

Mrs. Tait: Would rather her husband had died

Mrs. Tait's husband had started behaving oddly about 4 years prior to the interview. She was working full-time then and he started to argue with the neighbours while she was away during the day. About 6 months later he was in hospital with regard to a physical disorder and "the head doctor" told Mrs. Tait that her husband had Alzheimer's disease. She understood what this meant because her mother had also suffered from Alzheimer's. Mrs. Tait had felt then:

... and I still feel now that I would rather he would die before he gets very bad, I would rather - God forgive me - I would rather he would die than have to end up in hospital and getting to the state that my mother got to, I wouldn't like to see that at all.

Mrs. Park: Did not understand her mother's diagnosis

Mrs. Park had first noticed her mother's forgetful behaviour about 10 years prior to the interview:

She was buying a lot of tins, groceries, and putting them in the room - she didn't need them, she'd too many.

To begin with, Mrs. Park dismissed this behaviour:

... my mother's house was - there always was plenty of groceries in it and that, and I just thought "Well, she's just buying extra" - but there was a bit too much extra.

3 years later, Mrs. Park discussed her mother's behaviour with the G.P., who referred her to a psychiatrist: (over page)

... and she told me that my mother had senile dementia and could she put her name down for a bed up in H. Hospital, but at that time my mother wasn't nearly as bad as she is now.

Mrs. Park believed the psychiatrist, but she didn't understand the implications of the diagnosis. Because of this, she was not really too bothered by what the psychiatrist had told her:

Mrs. P: Well, I never thought, you know, at the time I thought my mother would stay at what she was at, but never in my wildest dreams - I mean, she wasn't incontinent or anything like that, and I never in my wildest dreams thought it would go into what it is now.

H.S: So you didn't feel too bad?

Mrs. P: No, no.

Mrs. Innes: Relief at her mother's diagnosis

Mrs. Innes had first noticed something wrong with her mother about 4 years prior to the interview. She was in hospital herself and:

... she used to come and visit me when there was no visiting, everyday, and everyday I used to say to her, "There's no visiting", but everyday she came.

At the time Mrs. Innes dismissed this behaviour because, "I thought it was just old age". Two years later, Mrs. Innes' mother was referred to a psychiatrist who told Mrs. Innes the diagnosis and gave her the phone number of the Alzheimer's Society in order that she could arrange to be mailed with further information, etc. Mrs. Innes reported that the psychiatrist told her that her mother "would deteriorate over the years, starting with her memory, and then her eating habits or her washing habits", but at that stage "I didn't know anything ... I hadn't a clue what Alzheimer's disease was at all". Her reaction was that:

I was relieved to know what was wrong, because before that her doctor wasn't very good with

it, she just kind of put it down it was my problem and I would have to get on with it.

III. EVIDENCE OF A COMPONENT OF "SHOCK/DENIAL" IN THE REACTIONS OF CAREGIVING RELATIVES

1. Were Caregiving Relatives Shocked or Dazed about the Dementia?

QUESTION : Nowadays, do you ever feel shocked or dazed about what's happening to ...?

% of carers (N=100)

Never.....	76%
Rarely.....	7%
Sometimes.....	7%
Often.....	4%
All the time.....	6%

QUESTION : Earlier on, sooner after they became ill, did you ever feel shocked or dazed about what was happening to ...?

% of carers (N=100)

Never.....	44%
Rarely.....	1%
Sometimes.....	8%
Often.....	16%
All the time.....	31%

Over half the sample of carers described themselves as having felt shocked or dazed by the sufferer's dementia at one time or another.

Those carers who had not guessed for themselves what was wrong with the sufferer were, not surprisingly, most shocked by the diagnosis. Mrs. Abraham, for example, was shocked by an almost throw-away remark from the doctor which made her suddenly realise what was wrong with her mother:

I felt total shock to be perfectly honest, he said "and of course, her deafness is a problem, but that coupled with her brain

failure ...", and that was when it sort of drew me up short that that was - because I had put it down to her age before - I had to sort of re-think the whole thing.

The shock for Mrs. Thom was because not only was she told her mother's diagnosis, but at the same time it was suggested that her mother be institutionalised. She also described her shock in physical terms:

Doctor T. in B. Hospital said to me - I think it was 4 or 5 weeks that mammy had been in there - she said to me that it was premature senile dementia and there was nothing to be done about it, and indeed their advice was that she should be permanently hospitalised, she should go into long term care - now, that was like, you can imagine, being hit in the face with a brick - I remember I just said "What?".

On the other hand, carers who had already guessed what was wrong with the sufferer were less likely to feel shocked or dazed. As Mrs. Tear put it, "it wasn't a sudden shock, we had noticed everything ourselves - it was a case of we wished the medical profession would get a move on".

2. Did Caregiving Relatives Experience Disbelief with Regard to the Dementia?

QUESTION : Nowadays do you ever find yourself thinking "this can't really be happening to ..."?

% of carers (N = 99)

Never.....	78%
Rarely.....	5%
Sometimes.....	10%
Often.....	3%
All the time.....	4%

QUESTION : Earlier on, sooner after they became ill, did you ever find yourself thinking "this can't really be happening to ..."?

% of carers (N = 99)

Never.....	58%
Rarely.....	0%
Sometimes.....	9%
Often.....	12%
All the time....	21%

More than half the carers reported that they had never experienced disbelief at the illness or the sufferer's behaviour. Some linked this to their trust in a professional diagnosis made after medical tests.

Mrs. Edgar, for example, did not experience disbelief at her mother's illness, partly because it was obvious to her that something was wrong, but also because she had been able to gradually understand and assimilate the extent to which her mother would become impaired:

No, I didn't find it difficult to believe, I think because I had known for such a long time that there was something wrong, I think it came as a relief, and at that time I didn't know as much about this, which I'm glad, I'm glad I didn't know as much about the incontinence for a couple of years.

Several carers described knowing that in the face of the facts they had to believe what was wrong, but at the same time not wishing to do so. Mrs. Earl, for example, experienced this with regard to her mother's diagnosis:

Not when the doctor told me, no, I couldn't believe it - my young sister did - I just know now that I've got to accept it.

It could be difficult to believe the diagnosis and prognosis when the sufferer still appeared physically well. Mr. Clark, for example, found this with regard to his wife: (over page)

You can't believe that it's happening to her, a person that's been so healthy all her life, oh, it's a hard thing to accept.

One carer, Mrs. McCann, described how her emotional disbelief (despite intellectual acceptance of the implications of her husband's growing impairments) was suddenly brought to a halt during a discussion with "the specialist":

Mrs.McC: I think it's so gradual, the beginning, that you're getting to accept it before you realise it's happened.

H.S: So were you relieved to get a diagnosis?

Mrs.McC: I was the opposite, my reaction to that was the opposite - that doctor just spelt out to me exactly that the brain was damaged and that was it. I was very very upset then - I mean, I had known this for years, I didn't need him to tell me that and I remember thinking then, "My goodness, I've watched films and I've seen people come through that where they where they've known a thing then been told it and I've said 'But they know that - what they getting upset for?'" - but it really upset me I found, when the doctor actually - I mean, he was telling me things and, "That's it, there's no hope, things can only get worse".

H.S: He was making you face it?

Mrs.McC: Uh huh, for all I had faced it myself, and faced it for a good few years, I'm talking about the specialist, not our own doctor, somehow that was just very final, you know.

3. Did Caregiving Relatives Consciously Avoid Painful Emotions with regard to the Dementia Sufferer?

QUESTION : Nowadays do you ever try to avoid getting emotional when you think about what's happened to ...?

% of carers (N = 97)

Never.....	22%
Rarely.....	15%
Sometimes.....	26%
Often.....	15%
All the time....	22%

QUESTION : Earlier on, sooner after they became ill, did you ever try to avoid getting emotional when you thought about what was happening to ...?

% of carers (N = 96)

Never.....	22%
Rarely.....	11%
Sometimes.....	18%
Often.....	17%
All the time....	32%

By far the majority of carers had consciously suppressed painful emotions (described by most as "bottling them up") in the face of the sufferer's illness.

"Bottling up" emotions was generally regarded as a "bad" thing by carers, and as making them feel worse in the long run. For example, Mrs. Edgar, who cared for her severely demented mother and her elderly but mentally unimpaired father gave the impression that bottling up emotions was a bad thing when she described her way of "loosening up":

Sometimes you keep it in ... sometimes I find it's really good if I'm on my own and I have some wine and something'll trigger it off, either a phone call or some music, and I'll start crying and I'll cry for about an hour, and my heart's breaking just from the pain of having mum suffer all these degradations and embarrassments and dad trying to struggle around ... it seems when I've talked to doctors about it that it's there but I don't let it out because I'm such a controlled person, but when I have a couple of glasses of wine it loosens me up and it's a good thing to do ... the next day I feel so much better.

There were various reasons for avoiding painful emotions. Some carers believed that if they were to become too emotional about the situation, they would cease to be able to care for the sufferer. Mrs. Kelly, for example, believed that she had to remain in control

emotionally in order to cope practically with her mother:

You canna' get upset, because the way I look at it is, "I get upset, what happens to her?"

Mr. Yardley, whose father suffered mild dementia was another example of a carer who controlled his emotions. He did this by consciously suppressing any of the thoughts about his father which he knew might be upsetting:

Mr. Y: If I had dwelt on it I'd have maybe got worse, so I just put it from my mind.

H.S: If you thought about it -

Mr. Y: Yeah, I would get a bit peeved about it, yeah.

H.S: Has it been like that all along?

Mr. Y: If I looked at him long enough - you see, I don't, I don't want to do that, I can turn myself off that way, but, prior to him going into hospital (a recent brief admission for a physical complaint) and even yesterday, I felt a pang and I turned myself off, you know.

H.S: You feel you've got to control your emotions - like saying "I've got to bottle it up"?

Mr. Y: Well, that's what I've done, I mean I've got to do that ... I could get very vexed very easily thinking about my father, and that's how I don't, you know, I just turn myself off and just think of something else and just get on with it.

Other carers attempted to avoid outbursts of emotion in front of others because it would be embarrassing, for example, Mrs. Abrahams stated:

I don't like people to see me losing the place ... I used to go along sometimes and maybe my mother would say something and I'd come back here after I'd seen her onto her bus to the day centre and I'd be standing in there maybe preparing a meal or washing the dishes or something with tears blinding me, just thinking about what she said, you know, it used to get to me then.

Some carers bottled up their emotions because they had no-one to share them with, for example, Mrs. McAdam referred to the fact that her only confidant, her sister, had died the previous year, when she said:

This is it, you bottle it all up, it's quite

true - which doesn't do you any good - I only bottle my emotions up now because I've no-one to unload them on.

Carers were not usually able to avoid all thoughts and emotional reactions with regard to the sufferer and the caregiving situation indefinitely. Several described how they handled outbursts of emotion on their own. For example, Mrs. Neary stated:

You know, sometimes I feel like bursting into tears - you know, really screaming - and I've seen me go to that door and stand there for about five minutes just to calm myself.

Mr. Yates also left the sufferer (his mother), and went off on his own when he felt emotional:

That's why I go away on my own, that's why I go and walk along the canal bank, or go and scream somewhere.

About one fifth of the carers stated that they had not tried to avoid getting emotional. These carers tended to be the ones who received emotional support from frequently visiting local relatives. Mr. Dunn, for example, received daily visits from both his daughters who helped him care for his severely demented wife and also did the housework and shopping. His children also took him and his wife over to their own homes at the weekend. Mr. Dunn stated that this family support and sharing of the tasks of caring was the reason for him not bottling up his emotions.

4. Did Caregiving Relatives Minimise the Problems to Other People?

QUESTION : Nowadays do you ever try to pretend to other people that the problems which ... has are less than they really are?

	<u>% of carers (N = 100)</u>
Never.....	75%
Rarely.....	8%
Sometimes.....	8%
Often.....	5%
All the time.....	5%

QUESTION : Earlier on, did you ever try to pretend to other people that the problems which ... had were less than they really were?

	<u>% of carers (N = 99)</u>
Never.....	58%
Rarely.....	6%
Sometimes.....	10%
Often.....	10%
All the time.....	16%

The major reason which carers gave for "playing down" the dementia sufferer's problems was protection from embarrassment; either that of the sufferer, themselves, or the people with whom they and the sufferer had contact. Obviously a carer is really only able to successfully play down the extent of the sufferer's impairments when they are not completely obvious to others; that is, early on in the process of the dementia. Most carers found playing down the problems quite a strain, and commented on how much easier they found being in company with the sufferer once they had disclosed the nature of the illness and the real extent of the problems.

Mrs. Toner tried to cover up for her husband's impairments until she herself became clinically depressed:

For the first two years it was just "bad memory", or he'd start a sentence and didn't

finish it, so you finished it for him ... I thought "There's no point in telling anyone else meantime" - my sons knew, I told them, but I think - you can hide it so long. It wasn't until I was ill that I thought "I've got to admit this now" - it got much easier then.

Mr. Tassie commented that although he continued to try to "cover up" his wife's severe dementia from his friends, her impairments must have been quite obvious:

Mr. T: In fact you try to hide it, hide it from other people.

H.S: Have you always?

Mr. T: I've always done that - people ask me "How's your wife?", "Oh, she's getting on", I'll say, "She's getting on alright" - you try and cover up she's not, 'cos they know her as she was ...

Several relatives mentioned playing down the extent of the problems as a result of their own embarrassment at the sufferer's behaviour, for example, Mrs. McCann discussed her husband's failed attempts at social interaction:

At the beginning I think it can be a wee bit embarrassing at times - if you were out in company and maybe talking about something, then when Ken would join in a bit we were onto something else ...

One carer, Mrs. Thom, pointed out that sometimes it was necessary to avoid allowing the sufferer to embarrass other people by their behaviour:

I tried to avoid having conversations with people - if I was out in the street with my mum I would cross the road because I found it very difficult to deal with the other person's discomfiture - they would come over and say "Hello, Nora, how you getting on?", and if this load of rubbish came out, they were absolutely - you know - and that bothered me, I never felt embarrassed for me, but I did feel awfully sorry for the people ... I can laugh now, but it sure as hell wasn't funny then.

Mr. Lees, caring for his wife, noted that because of the sufferer's lack of insight, embarrassment stemmed from the attitudes and expectations of those around them, rather than from the sufferer him or herself:

In the early stages it was embarrassing, but the embarrassment stemmed from us rather than from my wife. I think that you resent that there's something wrong with them and you're embarrassed for them ... but the fact that neighbours and people know now and you know yourself what's wrong, it doesn't make any difference now, you're not the least bit interested in what people think now, that part's disappeared entirely.

A second, though far less common reason which carers gave for pretending to other people that the sufferer's problems are less than they really are, is that they believed that if others knew the extent of the sufferer's impairments, the sufferer may be removed from the carer to an institution. Mr. Yates was a case in point. He sacrificed financial support for his mother because of the extent to which he minimised her impairments in front of a professional:

When the social worker at R. Hospital asked me to put in for Attendance Allowance, I didn't get it, mainly because I didn't admit to the doctor that she was as bad as she was - you know, I kept saying "Oh, she can do that" - I was so frightened that they were going to say "She's got to go in permanently" that I talked her out of it - we didn't get the Attendance Allowance, and the social worker wouldn't have it, she said "It's absolutely ridiculous", because she'd seen her, she'd been down to the ward and seen her - but it was my fault because everything he said "Can she do ...?", "Can she put on her shoes?", "Can she dress herself?", "Oh, yes, yes" - I didn't tell her she put them on the wrong feet.

While the majority of carers had played down the extent of the sufferer's problems to other people at one time or another, there was a group who reported that they

never had. The impression given by their comments was that they had been determined to demonstrate to others that they were facing up to the nature of the diagnosis and it's implications, and possibly also to demonstrate that they had mastered the situation which they found themselves in. Mr. Gibson, whose mother suffered severe dementia was one such carer. He demonstrated some anger at the attitudes of other people to the illness, as shown in this example: (over page)

We don't hide it, we didn't hide it, we'd take her along to the church on Sunday - chapel and that - people knew she wasn't well, it's Alzheimer's disease she has, and I think people - you know, there's been a lot of publicity about Alzheimer's in the last year especially, you know, Jonathan Miller and things like that, and Alzheimer's week - people are beginning to realise what it is. But I think, you know, any form of mental illness, people are scared of it - I've actually said it to - it was a very close friend of my mother's, "It's not contagious, you can actually come in", because I was very upset, she's never come near my mother.

5. Did Caregiving Relatives find it Difficult to Talk About the Sufferer?

QUESTION : Nowadays do you ever find it's difficult to bring yourself to talk about what's wrong with ... with other people?

% of carers (N = 100)

Never.....	66%
Rarely.....	9%
Sometimes.....	15%
Often.....	5%
All the time.....	5%

QUESTION : Earlier on, did you ever find it was difficult to bring yourself to talk about what was wrong with ... with other people?

% of carers (N = 99)

Never.....	55%
Rarely.....	6%
Sometimes.....	11%
Often.....	14%
All the time....	14%

It was usually difficult for carers to talk to other people about the effects of the dementia unless they were close family or friends who had known the sufferer for a long time, or else they were members of a relatives' support group with personal experience of caring for another sufferer. Discussion with acquaintances was usually limited to rather general, vague statements about the condition of the sufferer, for example, Mrs. Newark reported that if people asked how her mother was, "I'll just say 'Much the same', or 'She doesn't get out much', things like that".

Reasons which were given for not discussing the sufferer with others included the carer's own difficulties in dealing with the topic, and the stigma attached to mental illnesses. Mr. Oliver, for example, did not like to talk about his wife's illness for the following reason:

... the majority of people don't know what Alzheimer's disease is, you're committing yourself and you're telling them in Scottish language that she's with the birds, and you don't like to do that.

Mrs. Timms described how, early on in her mother's illness she was too easily upset to risk talking to others, whereas once she began to accept the illness she also became able to talk - at least in general terms - about her mother with friends:

I couldna' meet anybody in the street ... you know how folks say "How's your mammy?", but I

got I couldna' talk to anybody 'cos I felt that stupid I was starting to cry, you know, when folk mentioned "How's your mammy?" and all that, but now, as I say, up at the shops, "How's your mammy?", "Oh, she has her good and bad days."

Mrs. Church resented people who enquired after her husband because she believed that they were not really interested in what she had to tell them:

Most people outside will say "How's Eddie?" - they're not really interested in Eddie, they just want a fresh bit ... only nosey folk that want to poke in, or just a matter of form.

One carer, Mrs. McCabe, described the way in which she told her friends about her difficulties with her mother, but at the same time she made light of the problems: apparently telling, while not really telling:

Mrs.McC: Friends in work always ask "How's your mum doing?", and I can talk to close friends about it, because they know mum.

H.S: Have you been able to do that all along?

Mrs.McC: Aye, I've told them ... and 'I'll tell them things and have them all laughing and I'll say "It's alright laughing, but we've got to face it".

Carers who were able to talk about the sufferer's behaviour with others generally found this helpful themselves, for example, Mrs. Nisbett commented:

Mrs. N: I find I like talking about the problems because I think it helps.

H.S: Have you felt like that all along?

Mrs. N: Uh huh, you know, when I was at my work everybody would ask me "How's your mother?" ... that, you know, it was bearable when you were talking about it.

Several carers remarked how attending support groups had helped them begin to talk openly about the difficulties they faced, having first heard others who were experiencing similar problems. For example, Mrs. Timms described how talking about her mother became easier once she had attended a relatives' support

group:

I go to the meetings and that, and there's a lot of carers there that, well, when I first started going I never spoke because - well, I wasna' pulled up for it, just somebody said, "We don't hear you", I said "No, because I canna'", I just, but, everybody that spoke was my mammy, was the things that my mammy was doing to the extent that you got that it didn't hurt so much ...

IV. EVIDENCE OF A COMPONENT OF "HOPE/BARGAINING" IN THE REACTIONS OF CAREGIVING RELATIVES

1. Did Caregiving Relatives Hope that the Dementia Sufferer Might Get Better?

QUESTION : Nowadays do you ever find yourself hoping that ... might get better?

% of carers (N = 100)

Never.....	69%
Rarely.....	2%
Sometimes.....	12%
Often.....	2%
All the time....	15%

QUESTION : Earlier on did you ever find yourself hoping that ... might get better?

% of carers (N = 99)

Never.....	55%
Rarely.....	3%
Sometimes.....	12%
Often.....	7%
All the time....	23%

Approximately half the sample of carers had at some stage hoped that the sufferer might get better.

Carers who stated that they were "always" hopeful tended to describe this as at the back of their minds, and as something which allowed them to carry on with the tasks of caring. Mr. Neil, for example, stated with regard to his severely impaired wife: (over page)

As I say, you always say to yoursel' like that she'll maybe get better, you know, I suppose that's what keeps you going all the time - plus your affection for her ... I think that's what keeps you going.

Carers who stated that they were hopeful had usually at the same time accepted the diagnosis and prognosis on an intellectual level. For example, Mrs. Saville described a hopeful episode with regard to her mother's dementia in the following terms:

Mrs. S: It's so ridiculous - when I was in one day in the shop, this woman was in one day talking about her sister and, you know, she was beginning to get forgetful and everything, but the doctor had given her pills that were marvellous and they were sending Oxygen to the brain or something, and I was saying "Can you get me the name of them?", but I never got the name of them yet, but I don't think - you know, I've said to the doctor, "Is there anything?", and she said "No, there's nothing", so that's it. So whether the doctor had given this woman just sweetie pills or aspirins or something, maybe just psychologically she would be thinking -

H.S: Or she'd got the wrong end of the stick?

Mrs. S: Uh huh, that's right, but you feel, right away you feel "Oh, I wonder", you know, "I wonder if this will?"

One factor which could make carers sometimes hopeful that the sufferer might get better was if the downhill progress of the dementia appeared to them to have halted, for example, Mrs. Edwards stated:

There's days when he's fine, and then you'll say, "Oh my, this is ... there's a change alright, he's great!", then other times, ... back to square one again. You think you have him and all of a sudden that's it - it all depends on how he feels.

Some carers reported that in the very early stages they were hopeful that they could intervene in order to get the sufferer better. For example, Mrs Cooper described

how she had tried to reverse the deterioration in her mother:

At the beginning I used to shout at her to try and bring her round ... it doesna' make any difference ... I mean, this was away at the beginning when it was going, you know, and you try to kind of bring her back - but not now, there's no bringing her back, I've tried and I've done my best and you've just got to wait and see what happens ... I mean, when I brought her here I actually thought I could bring her round to what she was, but - when she came here at the beginning I had her in at the baking and everything, but she couldna' even remember what she'd put in it and that was it - I mean, you used to do things thinking "I'll get her to do this" and "I'll get her to do that", but it didn't make any difference ... she's got no interest in nothing.

The (approximately half of the total) carers who stated that they had never felt hopeful that the sufferer might get better couched this in terms of being "realistic" in the face of the obvious and continuous deterioration in their condition. One carer, Mrs. Edgar, contrasted her own realistic approach to her mother's dementia with that of her elderly but mentally unimpaired father. When asked if she had ever felt hopeful that her mother might get better, she replied:

I think I'm too realistic for that thought ... my father thinks that way, he thinks - because I've given my father all the literature I could find to read, I don't know whether he's read it or not, he doesn't like to discuss it ... but my father constantly corrects my mother, and I say "Why are you doing that, dad, because it doesn't really matter", and, "Oh well, I know that it's important to try and keep her in our world", but sometimes it takes so much out of him trying to keep her in our world that for his sake he'd be better to humour her and let her ramble on ...

2. Did Caregiving Relatives Wonder if the Dementia had been Mis-diagnosed?

QUESTION : Nowadays do you ever wonder whether the doctors have made a mistake about what's wrong with ...?

% of carers (N = 98)

Never.....	98%
Rarely.....	0%
Sometimes.....	0%
Often.....	1%
All the time.....	1%

QUESTION : Earlier on did you ever wonder whether the doctors had made a mistake about what was wrong with ...?

% of carers (N = 97)

Never.....	88%
Rarely.....	0%
Sometimes.....	6%
Often.....	2%
All the time.....	4%

Clearly, few carers had ever thought that the doctors might have mis-diagnosed the dementia.

The two carers who described themselves as often/ constantly thinking that the doctors had made a mistake at the time of the interview had only recently received the diagnosis of dementia. One of these carers, Mrs. Ure, continued to be hopeful about her father's condition, because although she had been told by the doctor that "we think it's Alzheimer's", and all tests for other disorders had so far proved negative, she had yet to receive the result of the final test, a brain scan, upon which she was pinning all her hopes:

I mean, I still even say to people, "But if it isn't that - if it's something they can help him with", you know, cure him - you've still got that wee type of thing, you think, "Och, it might not be that - it could be other things", you know, you still feel that.

A few carers stated that although they accepted the diagnosis, they had thought at first that the negative prognosis might have been a mistake, and had therefore attempted to intervene in a variety of ways to halt the downhill course of the dementia. Mrs. Thom, for example, believed that she would be able to prevent further deterioration in her mother's condition:

I felt that given all the right circumstances, and all the right food, and the right care, I felt that we could soon get things back on an even keel ... it was as if they (the doctors) were speaking of the future in terms of their limited resources, and that I could do - from a time viewpoint I felt that, well obviously, nurses and doctors haven't got time to sit and - whereas I have, and we can get through this.

Other carers, for example, Mr. Gibson, and Mr. Inglis, attempted more dramatic methods of halting or reversing the predicted course of the dementia. Mr. Gibson and his family, thought with regard to their mother:

To start with ... you know, the doctor was wrong - we went to Lourdes, you know, to get a cure there - maybe they'll find something some day to reverse the process - deep down, you admit it that there was nothing - you come to accept that.

Mr. Inglis tried taking his wife for homoeopathic treatment for her dementia:

As a matter of fact I took her to the homoeopathic about two and a half years ago ... I just fell away from it ...

By far the majority of carers reported that they had never thought the diagnosis might be a mistake, basing this belief on their faith in the doctors and on any medical tests which had been conducted. For example, Mrs. Carr stated the doctors could not have been mistaken because "they're trained, and it was quite a while before they told me". Mrs. Edwards also trusted the medical profession: "I would never doubt the

doctors, because they explained it to me". It was the results of the medical tests which convinced Mr. Keddie: "they've made the brain scan and I won't question it, I won't question it - I know that it's a fact and I'm just living from day to day".

3. Did Caregiving Relatives Look Out for News of Cures in the Media?

QUESTION : Nowadays do you ever find yourself looking out for news articles or T.V. or radio programmes which might give hope of a cure for ...?

% of carers (N = 99)

Never.....81%
Rarely.....1%
Sometimes.....9%
Often.....7%
All the time.....2%

QUESTION : Earlier on did you ever find yourself looking out for news articles or T.V. or radio programmes which might give hope of a cure for ...?

% of carers (N = 98)

Never.....77%
Rarely.....1%
Sometimes.....10%
Often.....10%
All the time.....2%

While almost all carers stated informally that they looked out for information about dementia in the media, particularly on television, by far the majority said this was just a matter of general interest, or to see that they were not alone, or to pick up tips which might help them cope better with the sufferer. Very few said that they were actually looking for information about cures.

Mrs. Ure reported that she watched T.V. programmes for general information, but with hope at the back of her mind: (over page)

It's a bit of both - I'm quite interested in things like that anyway, but it is a bit of "Maybe there is something", and "Is there anything new coming up?".

A few carers mentioned - in somewhat vague terms - having heard signs of a breakthrough in dementia treatment via the media. Mr. Neil, for example, stated, with obvious hope:

There was another programme on the tele - I just didn't catch it ... they were showing you a woman, I think she was about 50 and this - I don't know whether he's a doctor or a professor - he's got a cure for it, well, he thinks he has a cure, maybe in about 2 years time like - they're testing it for side effects or something just now, but he reckons maybe in about 2 years time like, it might be available you know.

The majority of carers, however, picked up information from the media purely for interest, or to help them cope with the sufferer. As Mrs. McAleer stated, "I know fine my father will never be cured now, he'll just deteriorate". Mrs. Thom described herself as having been "hungry for information" earlier on in her mother's illness. Mrs. Edgar also described herself as seeking out information about dementia, even though she might find it distressing:

I grab everything - and I watch everything on television - I'll maybe video it and if I'm not emotionally ready to watch it, I'll wait ... yes, I would pick up anything on it, I know as much as possible that a lay person could know about it, I think.

Information about future T.V. programmes was passed on in relatives' support groups, where carers also sometimes swapped or watched video tapes of programmes they had missed. Within families, information about media presentations of dementia might also be passed on between members, for example, Mrs. Tapp (who regarded

the notion of a cure for her mother as "pie in the sky") said:

My daughter-in-law has teletext - she'll phone me and say "There's a programme on Alzheimer's on the tele tonight", and we'll watch it.

4. Did Caregiving Relatives Make Bargains about the Progress of the Dementia?

QUESTION : Some people in your situation find themselves making bargains - for example, "If only ... would get better then I would never get angry with anyone again", or "If only someone would find a cure for ... then I would really believe there was a God", etc.

Nowadays, do you ever find yourself making bargains like that?

% of carers (N = 98)

Never.....	69%
Rarely.....	1%
Sometimes.....	14%
Often.....	10%
All the time.....	5%

QUESTION : Earlier on did you ever find yourself making bargains like that?

% of carers (N = 97)

Never.....	68%
Rarely.....	0%
Sometimes.....	14%
Often.....	11%
All the time.....	6%

The majority of the sample of carers had not bargained about cures or improvements for the sufferer's condition, again relating this to acceptance of the diagnosis and prognosis.

A few carers were able to give specific examples of the ways in which they bargained about the illness. Mrs. Edwards, for example, stated that she bargained constantly:

You keep saying that in your own mind all the time, you'll say "Oh my, if he'll be a bit

better, I'll try and be a wee bit more patient now, a wee bit more understanding, I'll try and not lose my temper.

Mrs. Neary bargained for another good day:

Well, I'm not a religious person ... but, yeah, I feel that this is one good day, maybe tomorrow will be better and I can deal with things better and I feel "I shouldn't have said that to him".

Several carers described not bargaining for a cure or even an improvement, but instead, on a somewhat lower level, asking for the dementia to just stay as it was, or for the sufferer to appear contented. Mrs. McAdam, for example, described herself as follows:

I just say "If it would just stop at this, not getting any worse" - I'm hanging on, by my fingertips, but I'm hanging on, "If it just didn't get any worse", "If I could get my sleep at night", and things like that, I'd settle for that, you know.

Mrs. Saville prayed for her mother's comfort:

I mean, you go to bed at night - my mother's the first person I pray for, and I hope she's happy and comfortable ...

However, most carers would have agreed with Mr. Turner's statements that hope for a cure for his mother was "an impossibility", and as for making bargains, "no, I've never felt like that".

V. EVIDENCE OF A COMPONENT OF "QUESTIONING/ANGER/GUILT"
IN THE REACTIONS OF CAREGIVING RELATIVES

1. Did Caregiving Relatives Question the Reason for the Dementia?

QUESTION : Nowadays do you ever ask yourself, "Why did this have to happen to ...?"

% of carers (N = 100)

Never.....33%
Rarerly.....15%
Sometimes.....24%
Often.....25%
All the time.....3%

QUESTION : Earlier on did you ever ask yourself, "Why did this happen to ...?"

% of carers (N = 99)

Never.....28%
Rarely.....12%
Sometimes.....24%
Often.....28%
All the time.....7%

Two thirds of this sample of carers were asking themselves why the sufferer had developed dementia, while a slightly greater number had asked themselves this question at some time in the past. Although the majority were questioning why it had happened to the sufferer, some carers also included themselves in the question, ie. "And why did it have to happen to me?". Some carers did have their own theory as to the cause of the dementia, but most stated that they simply did not know the answer to the question which they were asking themselves.

A variety of reasons were cited by carers as causing them to wonder why the sufferer had become ill. Some suggested that they asked themselves this question because the premorbid health of the sufferer had been

good and thus they had not been the "type" of person whom the carer would have expected to develop dementia. For example, Mrs. Park contrasted her mother's premorbid and current states:

Sometimes I've said that, "Why my mum?", because she was that outgoing and anyone you speak to - "Oh May, she was always well dressed and organising the house" - she always had the house spotless, and just things like that.

Others contrasted the sufferer not with their own premorbid state, but with other, mentally unimpaired people of similar ages when they wondered why the dementia had developed. For example, Mr. Yates referred to a very famous, unimpaired, elderly lady and compared her with his own, very severely demented mother:

Oh, I sometimes - I look at the Queen Mother, and I think "She's 90, and she's still wandering around".

Often, carers commented simply on the unfairness of the fact that the sufferer had developed dementia as they asked the question "Why?". Mrs. Baird, for instance, commented to the effect that her husband had been a good man and thus hadn't deserved dementia:

Why? Because he's worked all his days and he's a good husband, a good father to his children - I just didn't see how that should happen to him.

Mrs. Ure believed that the reason for questioning her father's dementia was also one of its apparent unfairness, in this case because of his relatively young age (54 years):

... and I think I say "Why?" because he's so young - I think if he was an older person you could accept it more, you know, you could say, "Well, he's had a life", but I think it's because he's so young that you think, "Why? Why at this age?".

Carers occasionally also related the "Why?" question to themselves, for instance, Mr. Gibson's grandmother had

developed dementia and been cared for by his mother who now had Alzheimer's disease herself and was being cared for by Mr. Gibson:

Saturday mornings I'll wake up at 6 O'clock - "Why her?" ... I think with this before - we stayed with my grandmother ... sometimes I say "Why the hell me again? Why the hell have I got it?" ... and you get people saying "That's what you're here for" - bullshit! I shouldn't have to look after my mother, you know, take her to the toilet and things like that.

While the majority of carers stated that they had no idea why the dementia had occurred, those theories which were advanced generally fell into one of four categories. These will now be presented (the order of presentation is not significant).

The first category of causal theories consisted of those carers who attributed the onset of the dementia to a previous injury in the sufferer, for example, Mrs. Irvine's husband had been wounded out of the army:

When Harry was in the army he was discharged, and on his discharge paper it said "Unfit for military service", and as I used to say to him ... I said, "It covers a multitude of sins" - ... and I still feel - I may be wrong - that head injury had something to do with it, and the doctor said, "Well, it could have, but", he said, "at the end of the day it comes to one thing", but I feel "Does it come to the one thing?"

The second category of causal theories belonged to those carers who suggested that contaminants, in particular, aluminium may have caused the dementia. This information had come to them via the media. Mrs. Deans, for example, had not been convinced by reassurances that her husband's long-term use of antacid medication had nothing to do with the onset of his Alzheimer's disease:

I feel that about all this Gaviscon that he takes - I mean, I've listened to those

programmes about all this aluminium - of course they say that this can happen to anyone whether they've taken those tablets or not.

A third category of causal theories which some carers mentioned was that dementia might be inherited. Obviously this notion caused them anxiety about the possibility that other family members might develop the illness at some time in the future. This was demonstrated by Mrs. Scott's comments about the reasons for her husband's illness:

Bob can tell me that when he came back from the navy his father didn't know him, that his father obviously had this dementia problem - he was in his 70s, you know - he says, "I always remember coming in and my father saying 'Who are you?', ... and then his sister developed this, and I sometimes say to myself, "Is this hereditary? Could it be hereditary?", ... and yet I don't know if they've proved it or anything, they tell you that it's not hereditary, I don't know ... sometimes I think "My gosh, what's going to happen to my own family now?".

The final major category of causal theories referred to as a possible cause of dementia was that the sufferer had somehow brought it on themselves. Mr. Yates, for example, believed that his mother had not looked after herself properly:

Sometimes I look at her and I am angry, and I think, "You should have looked after yourself better", she didn't eat, trying to get food down her was impossible, I mean, a spider used to eat more than her, and sometimes I think that had a lot to do with it - that a lot of it was physically brought on herself, but you can't live for other people, I suppose.

Similarly, Mrs. Earl suggested that her mother had developed dementia because of loneliness, since she was living on her own in a large building.

While the above four categories form the most commonly suggested reasons for the onset of dementia in the sufferer, there were some more idiosyncratic

suggestions. Mr. Tassie, for example, was quite definite in attributing his wife's dementia to the fact that she had suffered "two shocks in one week"; the birth of a grandchild with spina bifida, and the death of a brother in a road accident. Mr. Nye, a lay preacher, suggested that "being a religious person" he often wondered if his wife's dementia was "a really true test of one's faith".

Those carers who stated that they had never questioned why the sufferer had developed dementia presented an air of philosophical resignation to the illness. Their comments demonstrate this, for example:

- No way, it just happened to hit her, fair enough, it could have happened to someone else.
- No, I've never really - I mean, why do some people get knocked down? ... it's an inevitable part of life, it's the way the cookie crumbles.
- I think it's just your lot - I'm not a person that - I don't feel sorry for myself very much.

2. Did Caregiving Relatives Question Whether they were to Blame for the Onset of the Dementia?

QUESTION : Nowadays do you ever wonder whether you may have somehow contributed to ... getting ill?

% of carers (N = 100)

Never.....93%
 Rarely.....0%
 Sometimes.....7%
 Often.....0%
 All the time.....0%

QUESTION : Earlier on did you ever wonder whether you may have somehow contributed to ... getting ill?

% of carers (N = 99)

Never.....91%
 Rarely.....1%
 Sometimes.....8%
 Often.....0%
 All the time.....0%

Clearly, it was unusual for carers to consider blaming themselves for the onset of the dementia. The reasons cited by those carers who had done so could be categorised under two headings.

One category of self-blame consisted of things which the carer had previously said or not said, done or not done. For example, Mrs. Saville wondered whether she might have contributed to her mother's dementia, as follows:

... when I get into bed at night - I start thinking about all the things, you know, that happened, and things like that - maybe I should have done something differently, or maybe I shouldn't have done that ...

The second category of self-blame mentioned by a few carers was the notion that the dementia was a punishment for something which they themselves had done. For example, Mr. Napier tearfully suggested that he may have contributed to his wife's dementia:

You wonder if - is it a punishment for something you've done, you know, for she never ever did anything ... so you then come to the one thing, "Is it something I've done?".

The majority of carers, however, had never blamed themselves for the onset of the dementia. Mrs. McCaw, for example, responded to the question with "Oh no - that's no' - I feel it just happened, and this is it". Indeed, the question of possible self-blame seemed so odd to one carer, Miss Maguire, that she commented at the end of the interview that she could not understand why it had been asked.

3. Did Caregiving Relatives Question Whether Something More Could be Done for the Dementia Sufferer?

QUESTION : Nowadays do you ever think that maybe something more could be done to help ...?
% of carers (N = 100)

Never.....68%
Rarely.....6%
Sometimes.....11%
Often.....12%
All the time.....3%

QUESTION : Earlier on did you ever think that maybe something more could be done to help ...?
% of carers (N = 99)

Never.....61%
Rarely.....5%
Sometimes.....17%
Often.....11%
All the time.....6%

Those carers - approximately one third of the sample - who did think that something more could be done to help the sufferer generally did so within the constraints set by the dementia. In other words, while they were not expecting anyone to effect a miracle cure, they believed that more help could have been given to improve the sufferer's quality of life, or simply that more interest might have been shown in the sufferer.

Mrs. Deans, for example, suggested that perhaps something more could be done to help her husband's physical disorders. (He suffered from a hiatus hernia and what she described as "a hot throat", and she was considering sending him for a private medical consultation.)

I feel I want to try and help him as much as we can. I know we can do nothing about the dementia, we're told there's nothing we can do, but I feel that for the discomfort that he has ...

Help to increase the sufferer's enjoyment of life was mentioned by some carers, for example, Mrs. Dewar suggested that someone should take her mother on outings:

I don't know why there isn't even outings at times, to take her away for a day or whatever - I mean, I don't know the system, maybe they don't have the people to do these things - that there's not enough social workers or whatever to do these things.

Other carers felt that increased help of a more general kind should be offered to the sufferer. Mr. Tassie, for example, suggested that he and his wife should receive increased financial help.

Several carers expressed the belief that something more could be done to help the sufferer in terms of their receiving more interest and attention from others. The majority of these carers discussed their answers in terms of formal professional help rather than informal family help. Mrs. Lennox, caring for her husband, for example, said:

Well, I sometimes think I should have more help with him - or somebody to come in and suggest something ... sometimes I feel my doctor doesn't bother about him much.

Approximately two thirds of the carers were of the opinion that nothing more could be done to help the sufferer. This was based on the fact that they knew the dementia would lead to a deterioration in the sufferer's condition whatever therapeutic input was received. Mr. Inglis, for example, stated:

We tried different things, but there's no' much really - with the type of condition and the little bit I know about it, I don't see how they can cure the brain in her condition - I think it'll just deteriorate.

The impotence of others to help his wife's condition was also expressed by Mr. Nye: (over page)

I think they're limited really, they're victims of circumstance, perhaps the N.H.S. or research people are needing to do their homework a bit better, I don't know ...

4. Were Caregiving Relatives Angry About the Dementia?

QUESTION : Nowadays do you ever feel angry about what's happened to ...?

	<u>% of carers (N = 100)</u>
Never.....	59%
Rarely.....	6%
Sometimes.....	21%
Often.....	12%
All the time.....	2%

QUESTION : Earlier on did you ever feel angry about what had happened to ...?

	<u>% of carers (N = 99)</u>
Never.....	57%
Rarely.....	9%
Sometimes.....	18%
Often.....	13%
All the time.....	3%

Fewer than half the sample of carers reported that they were angry at the dementia. Among those who were angry, their reasons for this could be divided into one of three categories. First was the fact that it was their relative and not someone else they knew who had developed dementia. (It may be recalled that this was also one reason why carers might question why their relative had become ill.) The second category of reasons for anger at the dementia was that it had robbed the sufferer, or the couple, of what was regarded as a rightful part of their life. The third category of reasons for anger at the dementia was simply the effects which the dementia had had on the sufferer.

Examples of carers who had experienced anger at the unfairness of the illness included Mrs. Baird, who felt angry about the fact that her husband had not deserved to become ill:

I'm just angry at different people you see and you say, "Well I don't know why it doesn't happen to them, and it happens to somebody that it really shouldn't have happened to", sort of style.

The second category of anger at the illness was expressed by those carers who believed that dementia had robbed the sufferer of a part of their life. Mr. Napier, for example, whose wife (aged 68 years) was in long-term hospital care with severe dementia, stated:

See, what annoys me is the way it happened to us, being so young - I think if she'd have been in her 70s or that, you could have accepted it better - I feel we were robbed of part of our life, you know.

The third category of anger at the dementia was directed towards the effects of the illness on the sufferer. This, however, was less common than the above two categories. One carer, Mrs. Thom, described anger at the effects of the illness on her mother. Thus, whenever her mother's behaviour became difficult to cope with she attempted in her mind to separate her mother herself from the dementia:

I'm able to see my mum as almost two dimensional - there is my mum and there is the illness and I love the one and hate the other, and I often have to say to myself, "That wasn't my mum, that was this dreaded -" ... I get angry, and sometimes - incredulous would be a better word - because some things happen or don't happen, for instance, this morning I took mum to the toilet, and she was in her wheelchair and she had her hands clasped, and she couldn't unclasp her hands, and I got her up and she was at the grab rail, and she couldn't get her hands - I had to take them apart and strength was phenomenal ... and I'll say to her sometimes, "I can hardly believe that you can't do that", and that is the truth, I can hardly believe that she cannot do it, that her brain

cannot tell her hands to separate and yet she is provided from somewhere with this colossal strength to keep them together - I find that odd, I can't sort that out in my head ... so it would be fair to say that that would be me angry with the illness because, yes, that frustrates me to hell.

Those carers who reported that they were not angry at what had happened to the sufferer tended to report a belief that "something had to happen", or that they were not the only ones to suffer in this way and therefore simply had to accept it. For example, Mr. Oliver suggested that his wife's dementia had to be accepted, because:

Why should it not be you? The opposite question's there ... I don't entertain any of that (anger at the illness) - that's rubbish.

Mr. Tassie referred to the fact that he had not been angry about his wife's severe and disruptive dementia because:

Something would have happened - it's God's way of working ...

5. Were Caregiving Relatives Angry with God about the Dementia?

QUESTION : Nowadays do you ever get angry at God for what happened to ...?

	<u>% of carers (N = 99)</u>
Never.....	87%
Rarely.....	4%
Sometimes.....	6%
Often.....	2%
All the time.....	1%

QUESTION : Earlier on did you ever get angry at God for what had happened to ...?

% of carers (N = 98)

Never.....	86%
Rarely.....	3%
Sometimes.....	7%
Often.....	3%
All the time.....	1%

The small proportion of the sample of carers who reported that they had felt angry at God with regard to the dementia had found themselves questioning either their religion or else how God could have allowed the dementia to have occurred. One carer, Mrs Ure, had briefly stopped attending chapel. Although she felt that this was partly due to the time which caring for her non-resident mildly demented father took up, that was not the only reason:

... I said to the priest I felt as if I was just - really tired and I thought "Oh, I'm no' going", and as I say, I think I felt a wee bit kind of angry, but I'm back now, I'm back again and I feel better about being back.

Carers who felt it was unfair that God had allowed the dementia to occur included Mr. Gibson, whose grandmother had suffered from dementia before his mother:

I mean, I think I'm quite a religious person, and you do question, "Why us again?", I mean, what's he trying to prove - he did it once, does he need to do it again?

Clearly, the majority of carers had not experienced anger directed towards God. For some of these the reason was that they did not believe in God anyway. Those who did believe in God expressed a philosophical approach: all sorts of bad things happen in the world besides dementia, and God must have had a reason for allowing them to happen. For example, Mr. Sadler

stated:

In the world a lot of things happen and we can't explain how God allows it - a lot of things happens, not only older people, young children, and wars and deaths and things, you know, so we really don't know how these things happen.

6. Were Caregiving Relatives Angry with Those Offering Formal Support Services to the Dementia Sufferer?

QUESTION : Nowadays do you ever get angry with any of the professionals or social services who are involved with ...?

	<u>% of carers (N = 99)</u>
Never.....	71%
Rarely.....	8%
Sometimes.....	12%
Often.....	8%
All the time.....	1%

QUESTION : Earlier on did you ever get angry with any of the professionals or social services who were involved with ...?

	<u>% of carers (N = 99)</u>
Never.....	60%
Rarely.....	10%
Sometimes.....	19%
Often.....	10%
All the time.....	1%

Three major factors were cited by those (approximately one third of the sample) carers who reported that the professionals involved in the dementia sufferer's care had made them angry. These were: firstly, initial difficulties over the diagnosis, or the carer perceiving that they could have been told what was wrong earlier on; secondly, professionals either saying there was nothing they could do, or doing nothing to help; and thirdly, professionals who made what were perceived by the carers as somewhat fatuous suggestions.

With regard to the handling of the initial diagnostic period, Mrs. Tear stated that:

I have a little bit of "Why couldn't you have seen something? Or put a little more effort into finding out?".

Mrs. Baird believed that her doctor should have given her more information about the implications of her husband's diagnosis. She said:

The only thing I was really mad at was that nobody really made it easier and made me understand, as time went on, what it would be ... they wouldna' tell me anything - I think the likes of these things, that the doctors, if they think that you're able to take it, they should be able to tell you, and that's it, and accept the inevitable - but I've never had any talks to the doctor or anything, it's just "It's Alzheimer's", and that's it, that's the way you were told, and that's it as well.

The majority of carers' anger directed towards the professionals was because of what was perceived as a lack of interest in the dementia sufferer. Mr. Gibson, for example, referred to his mother's doctor as follows:

I feel with him that that's what she's got; accept it, there's nothing else I can do - we've got to chase him up for anything.

Mrs. Gillies described herself as increasingly angry with the doctor because "the spell between the visits is getting greater". Mrs. Thom spoke of professional care in the following terms:

... absolute rubbish ... we're nobody's child ... the boundaries changed and B. Hospital didn't want to know people outside their catchment area, and we were then the responsibility of H. Hospital who do not want to be responsible for anybody.

A few carers cited what they regarded as rather silly or ill-informed suggestions from professionals, which had made them angry. Mrs. Irvine's husband, for example, refused to attend the day centre. She reported

her conversation with the G.P. about this as follows:

... he said, "Does he go?", and I said, "Well, he won't go", and he said, "Well, just keep plugging, just keep pushing" - and that's it as far as he's concerned, and I thought, "How on earth do I keep plugging or keep pushing?".

Those carers who reported that they had not been angry with the professional carers referred to the fact that the professionals had done all they could, or done their best, and in some cases they were very full of praise for the professional care which had been available to the sufferer. Mr. Tassie, for example, described his wife's doctor in the following terms:

The doctor's always up, "You get this", and "You get that" - I've a good doctor, don't get me wrong, the doctor's told me if I want anything it's there for me.

Mr. Oliver referred to the consultant psychiatrist's request that his wife attend the day hospital as follows:

... so he invited her, she's there at that centre at Elsie Street, see, I didn't ask them to see her, what I've always got is she's there by invitation. I didna' say "Oh, gonna take her in?", no way, the big man sent me a written invitation to bring her along.

A large number of the carers who were interviewed had contact with the Alzheimer's Society, or the sufferer attended an Alzheimer's Society day care unit. Praise for "the Alzheimer's" was almost universal, for example:

- We've had lots of help, the Alzheimer's were very good, they just sort of took over.
- ... as far as the Alzheimer's is concerned, I think they're marvellous, really good.

7. Were Caregiving Relatives Generally Angry or Irritable with Those Around Them?

QUESTION : Nowadays do you ever get feelings of anger or irritability with other people?

% of carers (N = 100)

Never.....47%
Rarely.....17%
Sometimes.....24%
Often.....12%
All the time.....0%

QUESTION : Earlier on did you ever get feelings of anger or irritability with other people?

% of carers (N = 99)

Never.....40%
Rarely.....18%
Sometimes.....30%
Often.....11%
All the time.....0%

Over half the sample of carers described having been angry with other people at some time since the sufferer had developed dementia. For some carers this consisted of those around them having to bear the brunt of a general irritability which resulted from the task of caring for the sufferer. For others it was anger specifically directed at others (besides professionals and the sufferer him or herself) whom the carer perceived to have been insensitive to the situation in some way.

Mrs. Timms was one of those who described general irritability with others since she had been caring for her mother:

I'm jumping at everybody for nae reason at all ... I'm really turning against everybody, I'm just jumping and I feel as if I'm aye moaning and I feel as if they're all fed up with me and they say, "Och, there she goes again", but they don't understand what's involved with my mammy.

Miss Maguire described quite violent outbursts of anger

which she attributed to having to care for her demented father. She was in a particularly stressful situation: aged 28, she lived alone with her father in an isolated cottage following the death of her mother the previous year:

Well, I do have outbursts of anger - my sister's been the brunt of a few, and I did it to my friend, smashed a bottle against his wall - that was only a fortnight ago. ... Possibly it got rid of some aggression, but all that would do would be for me to lose friends - I mean, even my neighbours have fallen out with me because I had a tantrum when I was round visiting them, and they haven't forgiven me, because I just came out with a lot of words that I shouldn't have used.

Carers who believed they had good reason for becoming angry with others included Mrs. Bailey, who said of her family:

Sometimes I resent the fact that they don't seem to think that I could be doing with a wee break - it would be nice if they said, "I'll come over and help you out" - they don't see, sometimes, what's in front of their nose ...

Another carer, Mrs. Tear, felt angry with her brother who despite taking no part in their mother's care stated that he did not wish her to receive respite care.

Those carers who managed not to become angry or irritable with others generally attributed this either to long-standing personality characteristics, or else to the fact that there was no-one else to become angry with. Mr. Inglis, for example, described himself as "a man with two faces - I'd rather agree with people than disagree with them". Mrs. McAdam, on the other hand, had no-one to bear the brunt of any anger which she might have: "There's no-one to be angry with - not even a cat to kick!"

8. Were Caregiving Relatives Angry with the Dementia Sufferers Themselves?

QUESTION : Nowadays do you ever get angry with ...?
% of carers (N = 100)

Never.....27%
Rarely.....20%
Sometimes.....31%
Often.....22%
All the time.....0%

QUESTION : Earlier on did you ever get angry with ...?
% of carers (N = 99)

Never.....8%
Rarely.....20%
Sometimes.....43%
Often.....24%
All the time.....4%

By far the majority of carers had at one time or another been angry with the sufferer. This is not surprising in view of the often disruptive, waring, or unpredictable behaviour caused by dementia - behaviour described by one carer, Mrs. Christie, as "silly things that you could accept from a child". Almost all carers who displayed their anger to the sufferer subsequently felt guilt as they recalled the situation and thought to themselves, "but they couldn't help it". Mr. Gibson gave a most vivid description of the ways in which he had been provoked to anger by his mother's behaviour:

There is a book they give you - how to deal with a lot of things - "Go to another room if you feel angry". I'm running out of rooms to go to. As I say, my mum, she is aggressive, singleminded - trying to take her clothes off at night, "Don't do that!", and all the rest of it - "Shut up!". You do get angry, and then you think, "Wait a minute, it's not her fault", but it's not my fault either ... there are actually some times that you feel that you're going to snap, you could hit her ...

Behaviours which were cited as particularly anger-provoking included "about twelve hours" of "talking, talking, talking demented", the sufferer doing things which the carer had (repeatedly) requested them not to do, the sufferer engaging in dangerous behaviours such as leaving the gas on but unlit, and trivial things such as the sufferer being unable to put the car seat belt on.

Those carers who reported not getting angry with the sufferer could be divided into two groups. One group simply did not get angry because they loved the sufferer and accepted that the dementia was causing their behaviour. The other group made a conscious effort not to get angry because they said doing so only made things worse, increasing the dementia sufferer's agitation and/or their own stress.

In the first group, those carers who did not get angry with the sufferer because they loved them, came Mr. Dunn, caring for his wife. He stated:

Mr. D: I canna get, I couldna' get, well, that's what I'm saying, after so many years, you couldna' just all of a sudden change.

H.S: So even when she's awkward, you stay calm?

Mr. D: Aye, that's right, you might feel for a second, you know, if she gets a wee bit stubborn - when you're trying to take off her stockings and she's pushing, I mean, she doesna' really understand who I am, you see - it's things like that.

H.S: But you calm straight down again?

Mr. D: Aye, and I just kind of pet her, you know, and say, "We're going to bed, dear", and she just calms down.

Mr. Nye fell into the second group of "never angry" carers, having learnt over the time during which he had cared for his wife that there was no point being angry with her because the only result had been to increase his own guilt: (over page)

There's no point in it, because as I say, the guilt complex - you would probably, you wouldna' be human if you didna' get frustrated, and frustration of course inevitably leads to anger. You wouldna' be human if you didna' get angry at times, but you've just got to put a break on it right away, because you know fine, if you did get angry, again you would be - the guilt complex would surface ... but as time goes on you learn to accept it and you realise - you sit down and think about it and you realise it's a pointless exercise getting either frustrated or angry.

The reason why Mrs. Park controlled her anger was so that her mother in turn did not become even more upset or agitated:

I think - like, people with Alzheimer's, you make them irritable, but if you're sort of calm, they'll be calm.

9. Were Caregiving Relatives Guilty about Resuming or Enjoying Life Without the Dementia Sufferer?

QUESTION : Nowadays do you ever get guilty feelings at being able to enjoy yourself?

% of carers (N = 98)

Never.....	49%
Rarely.....	8%
Sometimes.....	10%
Often.....	14%
All the time....	18%

QUESTION : Earlier on did you ever get guilty feelings at being able to enjoy yourself?

% of carers (N = 97)

Never.....	43%
Rarely.....	4%
Sometimes.....	12%
Often.....	23%
All the time....	18%

The majority of carers interviewed commented that it was extremely difficult for them to get out and enjoy themselves without the sufferer. Unless the sufferer had very mild dementia and could be left safely alone,

or else was institutionalised, the only "free" time available for most carers was the few hours during which the sufferer was receiving some sort of formal day care. Other carers did not even have this. This situation therefore dominated the comments of the 50% of carers who described feeling guilty if they enjoyed themselves.

Some carers did describe guilt simply at the fact that they might have been doing something enjoyable without the sufferer. Mr. Nye described guilt with regard to his wife as his "constant companion":

That is the predominant factor in your life - it becomes a part of your life really, you find that, even going away for a short time and she's not with you - she doesn't want to go, and there's somebody with her, of course - it's always at the back of your mind, it never leaves you, it's your constant companion, I suppose it's something you've become indoctrinated with, down the years.

Carers frequently referred to guilt at leaving the sufferer, in case they had some sort of accident. For example, Mrs. Quail described herself as "more of a prisoner" than her husband, who in fact had only fairly mild, recently diagnosed dementia, and was still able to find his way round their local area:

If I'm out - I go to my pal's, well, I used to, every Thursday, just for a couple of hours, but it all depends on how he is, but if he's no' I don't go ... but I'm no sooner out and I'm desperate to get back, you know, just to see if everything's O.K., that he hasn't went out again, and things like that.

For some carers, this guilt about the sufferer's safety continued even while they were receiving day care. For example, Mrs. McEwan stated:

Mrs. McE: Well, I feel - even when he's at the day care centre ... all the time I'm out I'm saying, "Oh I'll need to hurry back here incase he's home and I'm no' - they've brought him back and I'm no' there" - I worry that way.

H.S: It spoils going out?

Mrs.McE: It spoils, it just - it takes the good of it away, the pleasure.

Relatives of institutionalised dementia sufferers also described feeling guilty at being able to continue their lives. A particular source of difficulty was leaving the sufferer to go away on holiday on their own. Mrs. Lennox, for example, described how she had thought about her husband while she was away on holiday. Even though she had been determined to enjoy herself, she had felt "a wee bit guilty":

Well, I did take a holiday ... anyway, when I took that holiday I felt I missed him. Why? Why should I? I was away on my own, you know, it was a bus run and I was away for a week ... and I just said, "Why was he no' with me?"

Mrs. Deans' daughter had suggested to her that she take a holiday without her husband, but she stated that "I wouldn't do that ... I would feel guilty".

Approximately half the sample of carers stated that they did not feel guilty if they did manage to enjoy themselves without the sufferer, although for some, this had not always been the case. For example, Mrs. Ure described having to balance up the guilt at leaving her (mildly demented) father against the needs of the rest of her family:

I think at first when it happened, you know, when we were told, I did feel like that, I was going out - I'm not saying I've got a great social life - but when I was going out I'd think, "I shouldn't be out, my dad's sitting in the house", you know, but I wouldna' say now if someone invites us out I'd say "I can't because I have to make sure my dad's alright", because we've got other family, you know, it's no' just down to me because we've got other family.

Some carers reported never having experienced guilt with regard to their own enjoyment. Mr. Turner, for

example, stated that he could relax when he went out and left his mother:

I go to the club and I have a few pints and I forget all my worries ... when I'm out I've no worry.

One carer, Mrs. Scott, made an interesting statement. Referring to the fact that since her husband was still able to be safely left on his own, she was determined to enjoy herself without guilt, mindful of the days to come when this would not be so easy:

Well, I go out on a Wednesday on my own ... and it's all ladies ... and I look forward to that and I can leave him himself ... but I keep looking, you know, I feel the day's going to come when he won't be able to be left himself, so that's why I'm trying to make the most of it and get out on my own as long as I can.

VI. EVIDENCE OF A COMPONENT OF "PREOCCUPATION/
UNFINISHED BUSINESS/DESPAIR" IN THE REACTIONS OF
CAREGIVING RELATIVES

1. Were Caregiving Relatives Preoccupied with Thoughts
about the Dementia Sufferer?

QUESTION : Nowadays do you ever find yourself preoccupied with thoughts about ...? (So that it's difficult to think about anything apart from him/her.)
% of carers (N = 99)

Never.....	26%
Rarely.....	12%
Sometimes.....	14%
Often.....	13%
All the time....	34%

QUESTION : Earlier on did you ever find yourself preoccupied with thoughts about ...?

% of carers (N = 98)

Never.....	24%
Rarely.....	15%
Sometimes.....	12%
Often.....	12%
All the time....	36%

Approximately three quarters of the total sample found themselves preoccupied with thoughts of the sufferer, although to varying degrees. The majority of them commented that their preoccupation was related to the need for constant vigilance when caring for a dementia sufferer; they had to keep the sufferer in their mind to ensure their safety. However, this was not true for all carers - some found that the dementia sufferer remained in their minds even when they had relinquished responsibility for their care.

Among those whose preoccupation with the sufferer might be classed as worrying about their safety was Mrs. Dewar, who remarked that she worried whenever she left her mother alone in the house: "If I'm out she's at the back of my mind". A non-resident carer, Mrs. Norden, described worrying about how her mother had managed over-night:

H.S: Can you ever forget about her?

Mrs. N: No I can't - and when I waken in the morning I think, "I wonder if she's O.K?", no, I can honestly say that she's always near the front of my mind.

It was by no means only the non-resident carers who found themselves constantly worrying about what the dementia sufferer was up to. Mrs. Newark, who lived with her husband and her moderately demented mother commented:

I'm maybe sitting watching the T.V. here and one ear's listening for mum, and I'll get up,

and Bill will say, "Where you going?" - "Just to see mum's alright", and I go through ... I'm not at peace, you know, you're up and down and up and down.

Others commented that even when they knew the dementia sufferer was perfectly safe, their thoughts remained upon them. Mr. Tower, for example, concluded that he thought about his wife even when she was attending the day care centre:

Well, if I'm occupied with my mate I do forget her for that time - but at the same time I'm watching the clock for to go back and pick her up, so, am I forgetting her or am I no forgetting her? No, you're not really forgetting her, she's in your mind - no, I wouldn't say I was forgetting her. You're getting relief from watching her and you appreciate that, but you're still thinking about her, how she is going to be herself.

Institutionalisation of the dementia sufferer did not necessarily mean that the carer stopped thinking about them either. For instance, Miss Bain described how she continued to think of her mother who was living in a nursing home at the time of the interview and whom she travelled by bus to visit daily:

Ms. B: Well, I do still tend to think about her, naturally, because you miss her when she's not here of course, it's only natural that you miss her.

H.S: Are you thinking of her more or less since she went in?

Ms. B: More in my mind, yes I would say so.

Those carers who did not find themselves preoccupied with the dementia sufferer attributed this either to the fact that they had no need to worry because they knew the sufferer was safe, or else to the fact that they were good at occupying their minds with other things.

One carer who had ceased to worry was Mrs. Abraham, whose mother had been placed in a nursing home. She compared the worry and preoccupation which she had experienced pre- and post-institutionalisation:

You worried about her all the time ... not so much now, you still have the wee thought at the back of your mind, "How is she?", but not so much now because you know she's being looked after now, and she's safe - I think really the fact that she's safe means more to me than anything else.

Some carers described managing to occupy themselves with thoughts and activities apart from the dementia sufferer. Mr. Inglis, for example, stated that he was "not really" preoccupied with his wife

I'm a kind of person that messes about doing things ... I keep myself occupied ... I can't sit still, I've got to keep - I'm always thinking of something, or fixing something, or doing something, you know ... I don't sit and get morbid.

2. Did Caregiving Relatives Think about the Sufferer's Life Prior to the Onset of Dementia?

QUESTION : Nowadays do you spend time looking back and thinking how ... used to be?

% of carers (N = 98)

Never.....	20%
Rarely.....	27%
Sometimes.....	30%
Often.....	20%
All the time.....	3%

QUESTION : Earlier on did you spend time looking back and thinking how ... used to be?

% of carers (N = 96)

Never.....	22%
Rarely.....	34%
Sometimes.....	25%
Often.....	17%
All the time.....	2%

The majority of carers reported that they had spent time remembering the sufferer prior to the onset of the dementia. This tended to occur in two ways. Firstly, some carers described simply reminiscing about the past, sometimes with photograph albums or other reminders. The second, apparently more painful, way of thinking about the sufferer was to actively compare how they had been prior to the onset of the dementia with their current state. ,

Reminiscing with others about her mother and "clinging onto the past" was described by Mrs. Newark:

... we talk sort of in the past, it's silly, I mean the past's forgotten now, she'll never come back the way she was, but you always cling onto that - I don't know why.

Several carers described being prompted into reminiscing by photos or other reminders of the way the sufferer had been prior to developing dementia. Mrs. Carr, for instance tried not to dwell on the past, but even so, she found herself taking out photograph albums and remembering. Mr. Yates also described trying not to think about how his mother had been prior to the dementia, but even so, being subject to sudden, unexpected reminders:

It makes you depressed if you think about it, so I just don't think about it - I mean, sometimes I'll go out and I'll go to an area of Glasgow that I haven't been in for a long time and that'll bring back memories ... but I don't consciously keep thinking about them, I try not to, I try to put them back.

Reminiscing was not necessarily always sad. Mrs. McCaw stated, "You've happy memories, you know". Because of this, some carers made a conscious effort to try to remember the sufferer the way they had been prior to the onset of dementia. For example, Mrs. Nisbett

preferred to remember her mother as she had been rather than to think of her current condition:

It's hard to remember them the way they were, although I try to remember her the way she was.

The other way of remembering the sufferer before the onset of dementia involved comparing their premorbid with their current state, which invariably saddened those carers who did so. Mr. Keddie, for example, described being upset when he compared his recently diagnosed sister with "how able she was" - she had been a psychiatric nurse, and he therefore regarded her development of dementia as somewhat ironic.

Several carers recalled the things which the sufferer used to be able to do, for example, Mrs. Norden said of her mother:

Sometimes I feel like that, yes - because my mother was a great listener and she could listen to your problems, but of course she's a problem - she is the problem now.

Within the one fifth of the sample of carers who reported that they did not reminisce about the sufferer, some appeared to be actively stopping themselves from doing so, while others simply did not appear to think much about the past, unless prompted by others. Mr. Dunn, for example, believed that thinking about the way his wife used to be would not be a good thing to do:

Certainly, if I was sitting looking back the way it wouldn't help me very much - it's just - each day'll take care of itself, you know.

Several carers reported, as did Miss Bain, referring to her own thoughts about her mother: "I just think of how she is now". Mr. Nugent said with regard to reminiscing that "I havna' come to that yet", while Mrs. Glen described herself as "more worrying about what's going

to happen" to her mother rather than thinking about how she had been prior to the onset of the dementia.

3. Did Caregiving Relatives Wish the Dementia Sufferer Could Return to their Premorbid State?

QUESTION : Nowadays do you ever wish or yearn for ... to be the way he/she used to be?

% of carers (N = 98)

Never.....	36%
Rarely.....	13%
Sometimes.....	14%
Often.....	29%
All the time.....	8%

QUESTION : Earlier on did you ever wish or yearn for ... to be the way he/she used to be?

% of carers (N = 96)

Never.....	35%
Rarely.....	17%
Sometimes.....	16%
Often.....	24%
All the time.....	8%

Wishing or yearning for the sufferer to be the way they used to be was frequently reported, generally as a desire for the whole situation to get back to normal, the way it always was, but sometimes as simply for the sufferer to become miraculously unimpaired. Carers who engaged in such thoughts usually described them as producing sadness.

Mr. Neil wished everything could get back to normal, which would have meant he could stop caring for his severely impaired wife and return to his trade as a plasterer:

Well, this is what you wish, like, that it was back to normal sort of thing, because you know, you've got a good idea, that that will never be, like.

Similarly, Mrs. Saville said that throughout her

mother's illness she had been "just wishing everything could be alright".

For other carers the wish was simply that the sufferer could be restored to their premorbid condition. Mrs. Cooper, for instance, wished her mother could be "alright", but suggested that this wish had become less intense as she had come to accept the reality of her mother's current state:

I wish she was the way she was, but it'll never come, will it ... I think at the beginning it was harder than it is now because you know that it's not going to get any better.

The impression given by the one third of the sample of carers who reported they did not spend time wishing for the dementia sufferer to be the way they used to be was one of acceptance of the situation as it was now: the sufferer had had their life and their condition would never improve. Mrs. Davis, for example, summed up why she did not spend time wishing her mother could be "back to normal" as follows:

I don't think in those terms because I know she'll never be back to normal, she can only get worse, I know that within myself - there's no betterness for it.

Mr. Dunn also expressed the belief that his wife had had a good life, but that there was no going back:

Oh no (he didn't wish for the past), we've had a good fair innings - I've no regrets at all.

4. Did Caregiving Relatives Wish the Dementia Sufferer
Could Complete any Unfinished Business?

QUESTION : Nowadays do you ever wish that ... could have done certain things that he/she hasn't been able to?

% of carers (N = 96)

Never.....73%
Rarely.....2%
Sometimes.....13%
Often.....10%
All the time.....2%

QUESTION : Earlier on 'did you ever wish that ... could have done certain things that he/she hadn't been able to?

% of carers (N = 94)

Never.....73%
Rarely.....5%
Sometimes.....13%
Often.....7%
All the time.....1%

The regrets which were expressed by the one quarter of the sample of carers who did so were frequently not about specific things which they wished the sufferer could have done before developing dementia. Instead they tended to be much more general: that the sufferer could have had a "better" life overall. These beliefs were almost invariably expressed by child rather than spouse caregivers.

Those carers who expressed this belief, that the sufferer had had a "hard" life in general included Mrs. Kelly, who discussed her wishes for her mother in the following terms:

She never had a good life ... (I wish) that she could have done something else better, oh aye, that's what I feel an' all, I feel if she could have enjoyed a wee bit of life before - I say it's a pity it happened when my dad died, no' a couple of years after it, 'cos she could have

enjoyed that wee bit, because she never enjoyed hersel' that much when my dad was alive.

Those carers who were a little more specific in the things which they wished the sufferer could have done generally emphasised the belief that the sufferer, although still alive, was currently missing out on any enjoyment from their life. This group included both child and spouse caregivers. For example, Mrs. McCabe, whose mother had dementia expressed her regrets as follows:

I just know she'll never get any better and I feel sad when people that were at school with her and that, they come up and talk to her and they're still living a healthy, active life, going out and enjoying - and this is the time my mum and dad could be enjoying each other's company ... I mean, 'my dad's a pensioner and so is she - I mean, this is the time they could be enjoying life together, getting here, there and everywhere, visiting the family - and the car, they've got the car, they could be in the car down at Ayr, having their flask.

Mr. Nolan referred to the way in which he and his wife were now unable to do all the things which they had been planning and looking forward to:

We were looking forward to - after we had the children after they went their own way we went to a different place every year - just in Britain, you know ... I always think, "I wish we could have done a lot more", you know, because the two of us were free then.

Three quarters of the carers stated that they did not ever wish the sufferer could have done certain things before developing dementia. It was not surprising that these carers expressed the belief that before the onset of dementia the sufferer had fulfilled their criteria of whatever constituted a complete life. These criteria differed, sometimes it was having had a "good" life, sometimes it was having had friends, and sometimes it

was having been away on a variety of holidays. Mrs. McEwan, for example, described her previous life with her husband, currently suffering from dementia, as follows:

I mean, we enjoyed our life - we went holidays here, there and everywhere, we flew out to Jersey every turn around, we went to America, we went here, there and everywhere, we made the best of it.

Similarly, Mrs. Glen referred to her mother's life in the following terms:

Mrs. G: She's had a hard life, hen, but - no, she'd ay plenty of friends and she got about plenty.

H.S: So there's no regrets?

Mrs. G: No, no, for all she had a hard life, hen, she'd quite a good life, hen, you know.

5. Did Caregiving Relatives have Things they Wish to Say to the Dementia Sufferer?

QUESTION : Nowadays do you ever find yourself wishing that you could say things to ... that you haven't been able to?

% of carers (N = 93)

Never.....	70%
Rarely.....	2%
Sometimes.....	13%
Often.....	13%
All the time.....	2%

QUESTION : Earlier on did you ever find yourself wishing that you could say things to ... that you hadn't been able to?

% of carers (N = 91)

Never.....	70%
Rarely.....	13%
Sometimes.....	11%
Often.....	3%
All the time.....	2%

Almost one third of the carers stated that they sometimes found themselves wishing they could say certain things to the dementia sufferer, however none of them mentioned anything specific which they felt had

been left unsaid. Instead, carers either expressed a general wish to be able to talk to the sufferer as they used to prior to the onset of the dementia, or else to be able to reassure severely demented sufferers that they would continue to love and care for them.

Among those carers who wished that they could converse with the sufferer as they used to was Mr. Gibson. He described talking to his severely impaired mother as follows:

I'll say stupid things to her to try and communicate with her - you wish at times something would happen to you and you could just sit down and talk to my mammy for a wee while - you want to talk to her but you can't, so you just say stupid things.

Mrs. Nisbett wished that she could confide in her mother the way she used to:

... to have a good talk - uh huh, and that's the way, you know, we used to have good conversations and I do miss that.

The other group of carers who wished they could say things to the dementia sufferer referred to a desire to reassure them. For example, Mrs. Gemmel wished she could communicate with her mother:

Yes, you know, say things like, "We're here to look after you and we're not here to leave you", sort of thing ... because she's obviously frightened and she's not understanding what's happening to her own body, her own mind, and I keep wishing that I could get into her own mind to know how she's feeling.

The majority - approximately two thirds - of the sample of carers reported that they did not find themselves wishing they could say certain things to the sufferer. This group obviously included those whose sufferer was not so impaired as to be unable to communicate with a degree of sense: they referred to the fact that they

could still talk to the sufferer. Others in this group, however, were not able to communicate sensibly with the sufferer. They expressed the belief either that they felt satisfied that there was nothing left unsaid between themselves and the sufferer, or else that they did not speak to communicate with the sufferer but could demonstrate their continued love through non-verbal methods.

Mrs. Elliott, for example, was still able to talk with her mother:

She can still say things ... and you give her wee cuddles and things like that which are always returned - I don't think she's unhappy.

Mrs. Baird believed that she had no "unfinished business" in terms of things which needed saying to her demented husband:

No, no, we've had a great life - even now it's still good, although he doesn't remember a lot of things, but it still doesn't make much difference that way, definitely not.

Those carers who referred to the fact that there was no need to try to communicate their love or reassurances to the sufferer verbally included Mrs. McAdam. She believed that words were not necessary in order to communicate her continued love for her husband:

... it's a funny thing, words don't always penetrate, but a touch - we cuddle ... it gets through when words don't always get through.

6. Were Caregiving Relatives Upset by the Dementia in the Sufferer?

QUESTION : Nowadays do you get upset when you think about ...?

% of carers (N = 100)

Never.....	4%
Rarely.....	10%
Sometimes.....	39%
Often.....	36%
All the time.....	11%

QUESTION : Earlier on did you get upset when you thought about ...?

% of carers (N = 98)

Never.....	4%
Rarely.....	27%
Sometimes.....	38%
Often.....	19%
All the time.....	12%

Expressions of sadness with regard to the condition of the dementia sufferer were almost universal among the sample of carers. Sadness was associated with the losses of the sufferer: current losses and degradations in comparison with their premorbid state, and anticipated losses which the carer could do nothing to prevent.

Mrs. Kelly described the thing which had upset her most was her mother's confusion and inability to recognise her:

She keeps calling me her mammy and things like that and that's when I feel it for her, I really do.

Mrs. McCabe described her own feelings with regard to her non-resident mother's various losses as:

I think it's constantly sad, because every time you see her - I mean, every week there's something else that - I mean, she's just going down and down.

The impotence of the carer to reverse the situation and their anticipation of future losses in the sufferer was another potent cause of sadness. For example, Mr. Nugent said of his wife:

Sometimes when you see her and you can't do nothing about it - that's what gets you, you know, there's nobody you can turn to, there's nobody can help you.

Mrs. McEwan described herself as follows:

More sadder and sadder all the time - we know ourself he'll definitely get worse, it's a thing you know, there's no cure for.

A variety of somewhat idiosyncratic reasons were cited by carers who reported never or only rarely becoming upset (sad) when they thought about the dementia sufferer.

One carer, Mrs. McBride, consciously tried to stop herself becoming upset by her mother-in-law's dementia, on what she regarded as doctor's orders:

I try not to think about it, because that was one of the things the doctor said to me. He says, "Don't let it prey on your mind, she's had her life, you're just in the middle of yours so don't let her dominate you".

Mrs. Elliott described herself as much less upset by her mother's dementia than she would have been had she suffered from a physical illness:

... it's just an inevitable fact of old age that it hits some people and it doesn't hit others - I'd rather she was the way she is than perhaps totally paralysed but still mentally alert and knowing that she cannot move a muscle.

Mrs. Baird, one of the carers who stated that they had never been upset by the dementia appeared never to have considered the illness in terms of loss. Despite her husband's dementia, she said:

I've always been cheerful, all my days I've

always looked on the brighter side of everything - I've never let anything get me down to that extent.

7. Did Caregiving Relatives Cry about the Dementia in the Sufferer?

QUESTION : Nowadays do you ever cry about what has happened to ...?

% of carers (N = 100)

Never.....	24%
Rarely.....	20%
Sometimes.....	42%
Often.....	14%
All the time.....	0%

QUESTION : Earlier on did you ever cry about what had happened to ...?

% of carers (N = 98)

Never.....	28%
Rarely.....	30%
Sometimes.....	33%
Often.....	9%
All the time.....	1%

The three quarters of the sample of carers who described having cried about the sufferer related this - not surprisingly - to those factors which had made them sad and upset; that is, to the current and anticipated losses of the dementia sufferer. Mrs. Norden for example, cried because she perceived her mother to have lost those things which had previously made her life worthwhile:

Sometimes I've seen me, maybe some nights as I come up the road, maybe crying, because I think "Oh, mother, God help you" - she doesna' really know what's going on sometimes and she's only really existing, you know, she's not living now - that's the way I feel about it now, anyway.

Mr. Yates cried when he came across sentimental reminders of his mother as she was:

... sometimes I'll go in there and put on a tape, and that's me away ... I'll think, "Oh God, what's the matter with me - switch it off

quick!".

One carer, Mrs. Saville, described having become more tearful since she had placed her mother into a nursing home. She related this to her anxiety and regrets about the decision to institutionalise:

... actually, sometimes I'm worse since she's been in the home. I'm more weepy because I think maybe I didn't do enough, or maybe I should have tried harder to keep her at home, you know, things like that.

Several carers described consciously "bottling up" their tears and as a result experiencing sudden outbursts of emotion. For example, Mrs. McCaw described episodes of crying and sadness with regard to her husband's dementia:

Mrs.McC: I get very emotionally upset, I really do, and when I'm alright I can cope, I'm fine, and other days I just can't take it.

Several carers also described not consciously crying about the sufferer, but instead finding themselves more emotionally labile than they had been prior to the onset of the dementia. This was most clearly referred to by Mrs. McAdam:

H.S: Do you ever cry about what has happened to Ted?

Mrs.McA: Not very often - not but what I do cry sometimes, but for other things, so maybe there's an underlying feeling - maybe, I mean, I cry at television, I cry at reading a book, things like that which - maybe I'm in a more emotional state ... I'm maybe crying for something that isn't all that important.

Some of those carers who reported that they did not cry about what had happened to the sufferer had done so at an earlier stage in the illness. They said that they did not cry any more because they had accepted what was wrong, or because there was no point in doing so. For example, Miss Bain said with regard to her mother:

I felt to myself, "It's no good you going on crying because it's no use, no point.

Yet other carers said they had never cried about the sufferer simply because they were not that type of person. Mrs. Davis, for example, described believing it was unfair that her mother had developed dementia and herself as "upset to see the way she's carrying on", but she did not cry because "I'm not the weepy type of person".

8. Did Caregiving Relatives feel Depressed?

QUESTION : Nowadays do you ever feel depressed?
% of carers (N = 100)

Never.....	28%
Rarely.....	18%
Sometimes.....	36%
Often.....	18%
All the time.....	0%

QUESTION : Earlier on did you ever feel depressed?
% of carers (N = 98)

Never.....	31%
Rarely.....	29%
Sometimes.....	31%
Often.....	8%
All the time.....	2%

The majority of carers reported that they had felt depressed at times during the sufferer's illness. Most related this to the combination of the dementia plus the caregiving situation itself.

Mrs. Dewar, for example, described feeling depressed and worried in her situation as co-resident carer to her mother:

You just feel at times everything's - between problems with my mum, the worry of how you're going to cope if anything happens ... that's one of the things you find, wondering how you're going to cope, that's constantly on my

mind I think - and then other personal things that upset you in the house - I think you feel at times that, just, well, everything's on top of you and you canna see a way out, you feel trapped.

This feeling of being trapped in the situation with her increasingly impaired husband was also (tearfully) expressed by Mrs. McEwan:

To me, what it's like as far as I'm concerned is as if at times you're in a big dark tunnel, you've no light at the end of it.

Mrs. Bailey described the "isolation" of her situation as the sole resident carer to her demented mother as the most depressing factor:

The isolation can get to you at times, you're not able to keep up with your other friends or visit to the same extent.

Other carers described spells of depression about the situation triggered by factors such as a series of nights when sleep was prevented because the sufferer was wandering around the house.

While not asked directly, several carers spontaneously reported that they had received antidepressant medication from their own G.P.s at some stage during the sufferer's illness, and one had received E.C.T. on an outpatient basis, for clinical depression which she believed could be directly attributed to her husband's dementia.

Yet others had not received a formal diagnosis of depression, but their descriptions indicated that they might well be so. For example, Mrs. Timms, non-resident carer to her mother, had stopped bothering with her own appearance, while Mrs. Kelly, resident carer to her mother was spending lengthy periods of the day in bed.

Those carers who said that they did not feel depressed tended to focus on the need to accept the sufferer's illness and to concentrate on giving them as good a life as possible. Mr. Dunn, for example, appeared to have accepted the situation and was determined to make the best of the rest of his severely demented wife's life:

Mr. D: I just like to think that I'm making her happy - everything I do in here, it's all for her good.

H.S: To make the best of everything?

Mr. D: To make the best of everything - I'm second in here.

A few carers stated that it was not in their nature to become depressed, for example, Mrs. Abercrombie stated that "I've never been a person that really went depressed".

9. Did Caregiving Relatives Feel that their own Life has Lost its Meaning?

QUESTION : Nowadays do you ever feel that life has lost its meaning for you?

% of carers (N = 98)

Never.....	50%
Rarely.....	18%
Sometimes.....	28%
Often.....	4%
All the time.....	0%

QUESTION : Earlier on did you ever feel that life had lost its meaning for you?

% of carers (N = 97)

Never.....	55%
Rarely.....	27%
Sometimes.....	15%
Often.....	2%
All the time.....	1%

Half the carers reported that they had at times felt that their life had lost it's meaning. It should be

stressed that this did not mean that they were actively suicidal - indeed, none appeared to fulfil such criteria. Instead by this they tended to mean that their own role as caregiver, or the impairments of the dementia sufferer had taken any enjoyment or purpose out of their lives. Mrs. Lennox, for example, living in a tower block with her demented husband who was on the waiting list for long-term hospital care stated, "I feel I'm not living, know what I mean?".

Several carers remarked that the sufferer's dementia had blotted out any thoughts of the future. Mr. Tassie, caring for his wife, for instance, said:

There's actually no future to me, you're only waiting on time, you're only waiting on when you're going and that - there's no future - no future for her and none for me ... that's all it is, you're just waiting on God taking you now, that's the way I look at it.

The same beliefs were expressed by Mrs. McAdam, caring for her husband,

I get the feeling that time is running out for both of us ... there is none (future) and as I say, we've lost two or three good friends - within the last two years about four or five people - and I think that makes you feel a little bit loathe to start new friendships ... like even being on holiday you meet new people, but I wasn't in any mood to start new friendships.

By far the majority of carers who did sometimes feel that their own life was meaningless also mentioned that they could lift themselves out of this mood if something pleasant happened. For example, Mrs. Earl, who described herself as frequently feeling as if life was meaningless since her mother had developed dementia, and who cried on and off throughout the interview, described days out to visit a friend in another town and commented, "Oh yes, when I go there I

really enjoy it". Similarly, Mr. Clark, whose wife was in long-term hospital care described how he forced himself out of depressive ruminations:

Mr.C: Well, you can sit, hand in pockets and just sit back here and say nothing to nobody, but that would last now and again -
H.S: You have to try and pull yourself together?
Mr. C: You've got to get up and go, haven't you.

VII. EVIDENCE OF A COMPONENT OF "ACCEPTANCE" IN THE REACTIONS OF CAREGIVING RELATIVES

1. Did Caregiving Relatives Accept the Sufferer's Dementia on an Intellectual Level?

QUESTION : Nowadays do you feel as though you have accepted what has happened to ...?

% of carers (N = 94)

Never.....1%
Rarely.....2%
Sometimes.....2%
Often.....19%
All the time....76%

QUESTION : Earlier on did you feel as though you had accepted what had happened to ...?

% of carers (N = 92)

Never.....8%
Rarely.....30%
Sometimes.....10%
Often.....9%
All the time....43%

Clearly, the vast majority of the sample reported that they felt as though they had accepted the sufferer's dementia most of the time. Their answers to this question focussed on intellectual acceptance of the dementia. This high level of acceptance is not really surprising given that the sample of carers had contact with Health Service and sometimes also Alzheimer's

Society staff with regard to the impairments which they had recognised in the sufferer.

Comments made by many of the carers emphasised that in the face of the facts they had had to accept the dementia on an intellectual level, whether or not they really wanted to do so. This was clearly demonstrated by Mr. Tassie's remark about his wife's illness:

It was difficult to accept, but I've got to accept it, I've got to, it's not that I want to accept it, I've got to accept it.

Carers also pointed out that the slow course of dementia meant that their acceptance had gradually - and in some cases perhaps almost unknowingly - increased. As Mrs. Arnold said about her mother's illness, "I think it came on so gradually that you just sort of accept it". Similarly, Mrs. McCabe presented the way in which she and other members of her family had gradually got used to her mother's dementia:

I think we've more or less resigned ourselves to it ... at first we thought it couldna' be that, but we had to face up to it. Facing up to it's the main thing ... I think it's easier for me now because I'm getting used to it, I don't think it's easier from the fact that she's no' doing so many things, she's still doing them, I just find it easier to cope with, I'm more used with it now.

Another carer, Mrs. Scott also described how she had been gradually able to face and accept the facts about her husband's dementia:

At first when I went (to an Alzheimer's Society relatives' support group meeting) they said, "Are you wanting to know how this can advance?" and I said, "No" - I didn't want it, because I wasna' willing to accept that this was what it was, I said, "No, I don't want to know", but then when you're reading and that I said, "Well I do want to know", you know, you sort of come round to it ... you can accept it.

With time, living with dementia can become just a normal part of the carer's life. It was described by Mrs. McBride as "just routine now, it's just routine".

2. Did Caregiving Relatives Accept the Sufferer's Dementia on an Emotional Level?

QUESTION : Nowadays can you think calmly about what's wrong with ...?

% of carers (N = 94)

Never.....	5%
Rarely.....	16%
Sometimes.....	19%
Often.....	32%
All the time....	28%

QUESTION : Earlier on could you think calmly about what was wrong with ...?

% of carers (N = 92)

Never.....	11%
Rarely.....	40%
Sometimes.....	18%
Often.....	18%
All the time....	12%

Thinking calmly about the dementia was taken by the carers to mean a different thing from accepting it. It was the difference between emotional and intellectual acceptance of the illness - and clearly it was more difficult to achieve than simply accepting the truth of the diagnosis and prognosis: only about a quarter of the carer sample reported that they were able to think calmly about what was wrong with the sufferer all of the time.

The difference between intellectual and emotional acceptance was described by Mrs. McEwan:

H.S: Can you think calmly about what's wrong with Davy?

Mrs.McE: No - I've accepted it, but I worry about it.

H.S: Have you ever felt calm about it?

Mrs.McE: I've never felt calm, that's how I think I

took the nervous breakdown and all that ... I mean, I've accepted the fact that my husband had that and it was my responsibility to look after him, but I just feel -

H.S: You accept it in your head, but not in your heart?

Mrs.McE: That's the very thing.

Several carers described attempting to appear calm to others in the face of the illness, usually by trying to put the sufferer out of their minds. In other words, they only felt calm when denying the dementia. Mrs. Carr, for example, said:

I can take it calmly pretty well most of the time, but I don't try to think too deeply.

What happened when such carers stopped the denial for a period was described by Mrs. Irvine, whose husband suffered a moderate degree of dementia:

If I think about it too much I can end up in tears - on my own - I mean, I can be walking along the street and it comes into my head and I can just be blinded with tears.

The other method of appearing calm in front of others was simply to put a brave face on, despite feeling emotional inside. This was described by Mrs. Saville:

It's been difficult all along, it's been very difficult all along - I've tried to put a brave face on it, you know - but really inwardly it's like a turmoil, and as I say it has been really a very, very terrible time.

Among those carers who described themselves as able to think calmly about the sufferer's dementia all or most of the time the emphasis was again on the need to completely accept the illness and get on with the task of coping with it, because the situation could not be altered. Several carers described reaching this stage of emotional acceptance only gradually. Mrs Nash, for example, referred to her emotional preparations for the death of her severely impaired mother-in-law in the

following terms:

I've come through the barrier - I can cope now with her.

3. Did Caregiving Relatives Accept the Dementia Sufferer's Future on an Emotional Level?

QUESTION : Nowadays can you think calmly about the future for ..?

% of carers (N = 94)

Never.....	12%
Rarely.....	37%
Sometimes.....	18%
Often.....	18%
All the time....	15%

QUESTION : Earlier on could you think calmly about the future for ...?

% of carers (N = 91)

Never.....	11%
Rarely.....	43%
Sometimes.....	21%
Often.....	14%
All the time....	11%

Thinking calmly about the sufferer's future was even harder than simply thinking calmly about their having dementia. The future for the dementia sufferer meant increasing impairment and death. Half the sample of carers reported that they could never, or only rarely feel calm when faced with such prospects for the sufferer.

A major problem about considering the future which several carers mentioned was that although they knew the sufferer's general prognosis, they could not make any specific plans because they did not know exactly if or when certain impairments or behaviours would occur, nor when the sufferer might die. This was clearly anxiety provoking. Mr. Napier, for example, referred to himself as unable to think calmly about his wife's

severe dementia because, "see, I don't know how long this will go on - it could go on for years". Mrs. Newark said, "I panic - worry - what's ahead? I don't know".

Anxieties about the future death of the sufferer were common. While carers may have accepted the illness, this obviously did not always include accepting the death and all it implied. Several carers described having thought the sufferer had actually died. For example, Mrs. McEwan and her husband:

H.S: Can you think calmly about the future for Davy?
Mrs.McE: You can't, when you think on the future - never knowing what's coming next - you just canna', you canna', you just canna', you worry - you're lying in bed and his feet - oh my God, they're like - I often wonder sometimes if I'm not lying beside a corpse - I waken up and get up many a night to see if he's alright ... and if I don't get an answer I'll get up and look and I'll say, "Oh aye, he's breathing".

Mrs. Dewar referred to her anxiety about discovering her mother had died in the night:

There's mornings I've been frightened to go into the room, not knowing what way I might find her, in case maybe something has occurred - you know.

One carer, Mrs. Saville, whose mother was in a nursing home was anxiously anticipating how she would cope when she received the news of her mother's death:

I think - this may sound terrible - but I think if I ever get a phone call to say that my mother has passed away or is very ill, I don't know what I'll do - I'll feel so terrible that I don't even know if I'll be able to cope with that.

Mrs. Nisbett reported that she worried even further into the future, and wondered how she would cope in the period following her mother's death:

I think - I know what's going to happen eventually - and I say to myself, "What's going to happen to me then? Am I going to be able to pick up my life? How long is it going

to take me to get over grieving?" - you know, you worry about all they things.

The strategy which a large number of carers used in order to cope with their anxieties about the sufferer's future was to dismiss it from their minds, and a great many mentioned taking "one day at a time". Mr. Oliver, for example, said:

Of course I think about the future - but I try not to - I try to take a day at a time, you know.

Mrs. Park said she hadn't consciously thought about her mother's future:

Mrs. P: I haven't thought about the future - no, I really haven't thought about it.

H.S: Because you don't like to?

Mrs. P: I think maybe in the back of my mind I do think about it, but then I'll say, "No, don't bother about it" - but in the back of my mind -

H.S: Because it's not nice to think of the future?

Mrs. P: That's right.

Some carers, however, were able to think calmly about the sufferer's future life and death. For various reasons they referred to themselves as having accepted what was going to happen.

Mrs. Elliott, who described caring for her moderately demented mother as "to me it's just a normal course of events" said that she could think and plan calmly for the future. Mrs. Niven clearly felt there was no alternative but to accept her mother's future, and was able to speak of it quite calmly:

H.S: Can you think calmly about the future for your mum?

Mrs. N: Aye, there's nothing you can do about it, you canna change anything.

One carer, Mrs. Abraham, whose mother was in long-term institutional care described the way in which she felt

she had already accepted the loss of her mother, leading her to anticipate that she would be able to cope calmly with the death:

When she's in there I feel - I've already lost my mother, really, that's the way I feel about it, I've already lost her - and over and above that I've given up her house along there and I've done all that side of things, that it really - when anything happens to her, well, I won't have the same trauma, because I think part of the trauma of someone going like that is breaking up their house, you know, going through all their things, whereas - well, I won't have that any more.

VIII. EVIDENCE OF SOCIAL PREPARATION FOR BEREAVEMENT IN THE CAREGIVING RELATIVES OF DEMENTIA SUFFERERS

The results of the 34-item Problem Checklist demonstrated that 88% of the carers regarded the dementia sufferer as having somehow disrupted their personal and social life (12% "sometimes" and 76% "often"). Of these carers, 21% regarded this disruption as "some" problem and 69% as a "great" problem. But did the disruptions which they experience constitute social preparation for bereavement?

To the extent that many carers described taking over the roles which were previously held by the sufferer, the answer to the question of whether caregivers experienced social preparation for bereavement must be "yes". This applied mostly to spouse caregivers, rather than those caring for parents. One example of this was Mrs. Neary, who described, with obvious pride, how she had had to take over some of the practical tasks previously performed by her husband:

... we've had a windbreaker that Keith put up, well, the wind blew 2 big panels out of that, but I fixed them myself - I struggled, but I

done it, just by watching Keith when I was younger, screwdrivers and things like that, and then I painted it.

Male carers must gradually take over the housekeeping tasks of their wives, and this was not infrequently perceived by them in terms of a job, to replace their previous paid employment. Mr. Salter (aged 80 years) described this with regard to caring for his wife:

... the way she went, I said "I've got a job now, just like being at work", so when I get up in the morning I make her breakfast and that, and I clean the house, make her dinner, peel the tatties, do everything like that, and I try to make that a day's work, looking after her, so that my mind's occupied.

With regard to going out to attend social occasions, some carers seemed determined, while the dementia sufferer was still able, to continue to take them out and allow them to join in as they would have done prior to the onset of the illness. The "risk" for carers who did this was that they might have to disclose the fact of the dementia to a greater number of people. Mrs. McCann described this happening when she went out with her husband:

We still go out, and I'll go out as long as we possibly can - we've always gone dancing a lot, and we still go dancing, but if we go to where there's a bar and that, I have to go up and get the drink and first it's embarrassing to walk up to a bar and there's men and sometimes there's man you know and they'll give you a crack, "What you doing this for?", but I find if I tell them straight why I'm doing it, they're very helpful.

The social life of the relatives of non-institutionalised severely impaired dementia sufferers was usually non-existent. While the genuinely bereaved also tend to have severely curtailed social lives, the difference is that if they are invited out and do wish

to go, then at least they are free to do so. Carers, on the other hand, were restricted by the need to stay at home and oversee the sufferer.

One effect of remaining indoors with the sufferer almost all the time was that carers might become socially isolated and withdrawn - they had nothing to talk about apart from life with the sufferer. Mrs. Lennox described this in herself:

I'm never out at all ... my social life's taboo - has been for 'two years, in fact I get to a stage if I do get a break and go out - I like indoor bowls and bowling, but I havna' been out an awful lot - when I do go out I've no talk for anybody ... it's changed me because I feel withdrawn a bit when I'm with people and I listen to all their chattering and I'll say "My goodness - did I ever chat like that?", and I'm not interested.

Carers often described finding that despite the fact that they were unable to get out and visit friends, their friends did not compensate by instead coming over to visit them. Social isolation was described by Mrs. Tait:

There isn't many people now comes around the house at all, as far as visitors, it's only family really, because it's got to the stage now that people have stopped asking me out, because I can't get ... and they've just gone their own merry way.

Previous acquaintances were described as gradually reducing their contact with the sufferer (and thus also with the carer) because the sufferer was unable to interact in the way that they had done previously. Mr. Salter, who looked after his wife, described the situation in this way:

You get to know your friends - I can go to houses and where before we were very welcome, now they're - you go there and you come away and you say "Well, I don't think we'll be back again for a long while"

The reactions of the carers to this situation where they were unable to go out and make social contacts, and in addition had ceased to receive social visits from old friends varied. It could be very difficult to bear if a large part of the carer's life had been previously spent involved with, and enjoying, social occasions. Mrs. McEwan was in tears when she described the social results of caring for her husband:

It's disrupted my whole life terrible ... I was never in, I was always out, I mean from I retired to - I went to all the clubs, I went to every club and I used to take him.

(Her husband was by then too impaired to accompany her to the clubs, and as a consequence she was unable to go either.)

On the other hand, some carers accepted this situation as their lot in life. One example of this attitude was Mrs. Mccaw:

You just accept it now, this is the thing. I don't get out as often as I did ... I just go if I can, and if I can't, I just phone my friend and say I can't make it ... I don't take part now in anything. I used to be on a lot of committees and things, but I just have to forego all that.

Another reason which some carers gave for accepting the situation was their own age. It appeared that some carers regarded disengagement as natural and inevitable with age, believing that whether or not their spouse had developed dementia, they would have dropped a large part of their own social life. Mr. Lees, caring for his wife, described this:

I could well imagine if I was much younger then it'd be a problem, but obviously at my age and at her age the problem has eliminated itself in that you wouldn't be running about in any case, you'd be more settled and set in your ways.

Another factor which could make the situation of social isolation easier to bear was if the carer-sufferer dyad had always tended to spend their free time together or at home. An example of this situation was that of Mr.

Dunn, who cared for his very impaired wife, May. Although they had no social life apart from family visits, he did not really regard this as a problem:

We were always together, May was never some place that I wasn't and I was never anywhere than our family, we were always at our family at the weekend, the two of us, we were always together".

There were a few carers who were fortunate enough to receive a great deal of support from their family which allowed them to compensate for the negative social effects of caring for a dementia sufferer. Mr. Fergus, who cared for his wife, was relieved by relatives four evenings a week. He used this time to go out socially and also to attend music lessons, commenting "I've a better social life than lots of people".

Disruptions in the carers' social or personal lives could be more extensive than simply a restriction on participating in social occasions. Mrs. Baird described having to give up her job in order to care for husband in the following terms:

It's the thing I miss most - I really do miss it - it was only part time right enough, but I thoroughly enjoyed it and I looked forward to it and I felt - well, it kept me going ...

This aspect of the change in a carer's personal and social life is plainly not a preparation for bereavement, nor is it behaviour expected of bereaved persons.

While the carers of dementia sufferers may experience anticipatory preparation for bereavement in terms of learning new skills or living socially isolated lives, one aspect of bereavement which they obviously cannot experience is actually living without the body of the person. The importance of the presence of the body of the dementia sufferer - representing the fact that in

some ways, and despite all their impairments, the sufferer was still there, was referred to by several carers. For example, Mr. Tassie cared for his wife, who was extremely impaired and exhibited a great deal of disruptive behaviour. Despite this, he said:

I say to myself "If God takes me afore her, what's going to happen to her, and if she goes afore me, what am I going to do?". ... Don't get me wrong, you've got to bear it, but I don't think I'd last long because I'd feel lonely and everything. ... She's here, she's always here ... I'll say to myself "She's sitting there and that's - having her sat there, that's all I want".

It might be argued that the best preparation for bereavement is the institutionalisation of the dementia sufferer. From some perspectives this must be true, since it removes the constant physical presence of the sufferer from the carer's life. Mr. Nolan, for example, found that following the institutionalisation of his wife he was actually able to forget her - in the knowledge that she was being cared for - while he went away on holiday. A further similarity to the bereavement situation, for non-resident carers, following the institutionalisation of a dementia sufferer, is the need to "break up" the sufferer's house and dispose of their possessions. Mrs. Innes' mother had been admitted to long-term hospital care a few months prior to the interview, and she had put off doing this, because it symbolised to her the loss of her mother:

Mrs. I: I get the feeling that giving up the house is going to be a bad time for me because everybody says that.

H.S: It's sort of symbolic?

Mrs. I: Uh huh, giving up the house is an end of that, and they say that'll be a bad time for me ...

However, the evidence from the 23 carers of institutionalised sufferers who were interviewed was that in no cases were their lives going on as if the sufferer had completely ceased to exist. The frequency of carer visits to the sufferer ranged from once a day to once every 2 weeks, with the majority visiting at least once a week. In some cases, the carer's life still appeared to revolve almost entirely round the needs of the sufferer, as though they had been unable to accept the fact that the sufferer had been physically removed from their own lives. Clearly these carers would not be prepared for the death of the sufferer, which, when it occurred, would be likely to create an enormous void in their lives. Mr. Napier was an example of one such carer. His wife was in long term hospital care, suffering from a very severe degree of Alzheimer's disease. He spent every afternoon feeding her:

I go up every day to see her and the reason is I really don't see how they can cope, I mean, taking about three-quarters of an hour to give her a yoghurt followed by a wee tub of rice and some fruit mixed together and then I give her a wee tub of ice cream and a bottle of that Lucozade, and it's all got to be done with a teaspoon, the Lucozade's got to be sucked with a straw - sometimes even that's difficult, you've got to coax her and coax her ..."

Mrs. Carr had visited her husband in hospital every day for over a year, until she was advised by her own doctor to cut down on her visits. Now "I go Tuesdays, Thursdays, Saturdays and Sundays, and if John's not well I go in extra and I phone". These examples are both of spouse caregivers. While children might visit their institutionalised parents less frequently than if the sufferer was a spouse, there was no evidence among this sample of them having abandoned their parent and continued their own lives as though the dementia sufferer had died. For example, Mrs. Park's mother had

been living in a nursing home for 4 months at the time of the interview. Mrs Park's routine was to take her mother out on Wednesday afternoons, to the shops or for a coffee, and to bring her home for the whole of every Sunday, not taking her back until almost 10.00pm.

IX. DID THE CARERS PERCEIVE THEMSELVES AS HAVING EXPERIENCED GRIEF?

1. Evidence for the Perception of their Emotional Reactions as "Grief" among Caregiving Relatives

Seventy-five of the carers were asked whether they felt the feelings which they had experienced had been like grief. The answers to this question appear below.

QUESTION: Have your feelings been like grief?
% of carers (N = 75)

Yes.....	72%
Unsure.....	9%
No.....	19%

Clearly, the majority of carers did agree that the feelings which they had experienced since they became aware that their relative had dementia had been like grief. Most of carers who felt like this related their feelings to the loss of the "person" of the sufferer. For example, Mr. Nolan, whose wife was a long term hospital patient with severe dementia believed he had experienced grief for her, the reason being:

That person has gone, that person has gone,
it's no longer the same person at all.

Mr. Black, whose wife also suffered from severe dementia expressed similar feelings:

It's as if somebody had died, a part of the
person has died, that's what it is, isn't it?
I can't share it with anyone.

The examples above concerned the relatives of severe dementia sufferers. Did relatives of less severe dementia sufferers, whom we might expect to have experienced fewer losses also experience grief? It seems that they did. The same beliefs were tearfully expressed by Mrs. Scott with regard to her husband whose dementia was fairly mild (for example he was still able to find his way independently around their neighbourhood). Even so, Mrs. Scott expressed feelings of loss:

It is like grief - he has died actually - I mean it's just not the person that you've lived with all these years - he's just like a stranger sometimes you know - often I think that it's like living with a stranger, and yet it's not a stranger, you know it's your husband, but just so different.

Another carer, Mrs. Lennox described the experience of suddenly realising that she had "lost" her husband - again, at a time when his dementia was not so severe that he was unable to interact with and recognise her. When asked whether she felt as if she had been experiencing grief as a result of her husband's dementia, Mrs. Lennox replied as follows:

Yes, ... there's no doubt about that ... I remember going into the doctor's and letting a flood of tears roll one day and I couldn't speak to him, and I said to him, "I've just come back to tell you that I realise my husband's away ... he'll never be the husband I knew". And that's three years ago I felt like that ... that's what I told the doctor that day.

The grief of the carers was often described as an all-pervasive sadness. Mrs. McAdam, for example, said with regard to her husband's dementia:

... the grief is there, it's always there, I don't know when I could say I was last happy, when I could, you know, laugh spontaneously ...

Similar comments were made by Mr. Nye, with reference

to having to learn to live with his grief in the face of his wife's dementia:

It's a permanent grief really, it's a permanent thing - it's no' something that just comes and goes, it's with you, it's with you, in fact you just learn to accept that it's just something you've got to learn to live with ...

Several carers expressed the belief that they had experienced grief with each successive change in the dementia sufferer's condition, which might also be regarded as successive losses of the previous person. For example, Mrs. McCabe stated that her feelings since her mother developed dementia have been like "constant" grief as she noticed current losses and anticipated future ones:

It's like a constant grief I think - that you're never ever going to get over it, it's like never ending - I mean every time she's doing something else, and with the books you're reading you know it's another step down, it's another stage she's hitting, that she's going to go through this now - that - I mean, it's never ending, I mean, you're just beginning to cope with this stage she's hit, and then another one, you know, it's like a slippery slope. Sometimes she does things and I think, "I don't believe that", it's crazy ... it's like a map, it's like looking at a map and you know exactly what she's going to do next.

The comparison between grief before and after a death was made by one carer, Mrs. Dodd, who felt that she had a certain amount of grief to expend, and it was possible to do this before a person actually died (the classic "hydraulic model" of the effects of anticipatory grief on post-bereavement grief). With regard to her father, Mrs. Dodd stated:

Mrs. D: I have felt a lot recently that if anything happened to my father I wouldn't cry because most of it's been done.

H.S: Do you think your feelings have been like grief?

Mrs. D: Yes, that's right - and the same thing happened with my husband (who died of cancer) - I didn't shed a tear at his funeral, because it had all been done over the 2 years beforehand, and the same thing's happening with my father, just the same, I mean I would cry more if my cats died".

This notion was also expressed by Mrs. Irvine, with regard to her anticipated reaction to the her husband's death:

I have said to my son that if and when anything happens to his dad, I just couldn't grieve - I feel that I've done all my grieving, I feel that I've done all my grieving - because the person I'm with is a stranger.

However, another carer, Mrs. McEwan, believed exactly the opposite; that she was grieving but would be unable to resolve this grief until her husband did actually die. The longer he lived, the worse she felt:

H.S: Do you think your feelings have been like grief?

Mrs.McE: A grief, and the grief's no' going to ease up - if - they often say to you, "A living grief's worse than a dead grief", which I thoroughly believe. Since I've experienced this with my husband I think - well, he's out o' this world, he's here but he's no' here because his mind's no' there - he's there in body.

H.S: But if he'd died you'd have got over it?

Mrs.McE: I'd have - you'd get over the grief quicker than what you do with this going on and on and on and on and on - going on and on.

Not all carers were so certain that their emotional reactions could be regarded as "grief". For example, although Mrs. McBride also perceived the loss of her mother-in-law, she was unsure whether she had experienced grief:

Mrs.McB: The person's not there anymore, it's just somebody you can't communicate with, they look the same, but they're no' the same.

H.S: Do you think your feelings have been like grief?

Mrs. McB: Sometimes, sometimes she's just Daisy, and

then other times she's just not the same person.

About one fifth of the sample of carers were quite clear in reporting that the feelings which they had experienced should not be classified as "grief". These carers emphasised the presence of the person of the dementia sufferer. For example, Mrs. Quinn regarded her mother's dementia as not yet serious enough to have taken away her person:

H.S: Do you think your feelings have been like grief?

Mrs. Q: Not really ... although my mum is so confused and all the rest of it, she's not ... having seen a few cases on the television I've seen the bad cases where people, they're not like human beings, well, my mum's not like that, although she's, her mind's pretty bad gone, she's still reasonably sensible and you can sit and have a bit of a conversation with her that she's still a person in herself and she's not bad enough in life to have they kind of thoughts.

It was noted above that the belief that they were experiencing grief was not exclusive to the carers of very severely demented sufferers. Is the opposite true? In other words, might some of the carers of more seriously impaired dementia sufferers believe that they have not actually experienced grief? Again, the evidence suggests that this would seem to be the case. For example, despite her mother's severe dementia, did Mrs. Davis feel as though she had been grieving?

No, I still feel I've got my mum and I feel I'm lucky - even though my mum's got the dementia, I count my blessings and I say I'm very lucky to still have my mum, and even though she can't remember anything, you can sit and talk to her, you know, you can talk and she doesn't even know what you're talking about, but she's still there and I count myself very lucky I've still got her.

Another carer of a severely impaired dementia sufferer,

Mrs. Baird, emphasised the positive aspects of her husband's condition over recent years when she denied that her feelings had been like grief:

No, no - and he's come through such a lot, I mean, he come through the big operation on his back and the oncology department at the W. Hospital - he's really done marvellous and I don't think of it in that way at all, no I really don't.

2. What Distinguished the Emotional Reactions of Those Carers who Believed They Had Experienced Grief From Those Who Have Not?

In order to answer the above question, the scores for each of the initially-specified (I.S.) components of grief were compared across three groups of carers by means of a one-way analysis of variance. The three groups of carers comprised those who reported that they had definitely experienced grief since the onset of dementia in the sufferer; those who were not sure; and those who reported that they had definitely not experienced grief. The results of this analysis appear in Table 11.1 (over page).

ANOVAs comparing group differences on the I.S. components of grief scales revealed the following results. Those carers who perceived themselves to have definitely grieved had, earlier on in the period of the illness, experienced significantly greater "Shock/Denial", "Hope/Bargaining", "Questioning/Anger/Guilt", and "Preoccupation/Unfinished Business/Despair" than those carers who perceived themselves as definitely not having grieved. In other words, earlier on in the period of the sufferer's dementia, the "definite grievers" had exceeded the "definite non-grievers" on all four of the I.S. components of grief which might be

of "Questioning/Anger/Guilt", "Preoccupation/Unfinished Business/Despair", and "Acceptance".

As might be predicted, the scores of the group of carers who were unsure as to whether or not they had experienced grief tended to fall mid-way between the other two groups. They more often approximated those of the "definite non-grievers" than those of the "definite grievors".

It thus appears that those carers who reported that they had experienced grief were correct in asserting that they had experienced more distress than those who reported that they had not experienced grief.

3. What Distinguished Those Carers Who Believed They Had Experienced Grief From Those Who Had Not?

In order to answer the above question, a comparison of the three groups of carers ("definite grievors", "unsure" and "definite non-grievors") was made in terms of five basic demographic and relationship variables. These were:

- | | |
|--|--|
| - Carer age..... | Via one-way
analysis of
variance |
| - Sufferer age..... | |
| - Total frequency of
problem behaviours..... | |
| - Overall sufferer change
estimated by carer..... | |
| - Time since onset..... | |
| - Time since diagnosis..... | Via chi-
squared
analysis |
| - Carer sex..... | |
| - Sufferer sex..... | |
| - Carer-sufferer blood/role
relationship..... | |
| - Sufferer living arrangements... | |
| - Carer perception of dementia... | |

The results of these analyses are presented in Tables 11.2 and 11.3 (over page).

Table 11.2

One-way analysis of variance comparing subjects who reported they had definitely grieved (Group 1), were unsure (Group 2), and had definitely not grieved (Group 3), on carer and subject age, total problem behaviour frequency, estimated overall sufferer change, and times since onset and since diagnosis of dementia.

	Group 1	Group 2	Group 3	Sign. group diff.#	d.f.	F
Carer age.....	59.4	58.3	59.6		2,72	0.02
Sufferer age....	74.3	76.3	78.4		2,72	1.55
Total problem behav. freq. ..	35.1	34.3	31.6		2,70	0.56
Estim. overall suff. change....	4.1	3.4	4.0		2,72	2.23
Time since onset.....	6.2	5.2	6.1		2,72	0.24
Time since diagnosis.....	3.8	3.5	2.8		2,68	0.97

= Tukey honestly-significant-difference method, significance level set at .05

Table 11.3

Proportion (%) of subjects who reported they had definitely grieved (Group 1), were unsure (Group 2), and had definitely not grieved (Group 3), in terms of carer and sufferer sex, blood/role relationship, sufferer living arrangements, and carer perception of dementia.

	Group 1	Group 2	Group 3	χ^2
CARER SEX				
Male (N=19).....	68	11	21	0.12#
Female (N=56).....	73	9	18	
SUFFERER SEX				
Male (N=31).....	81	3	16	1.85#
Female (N=44).....	66	14	20	
SUFFERER RELATIONSHIP TO CARER				
Spouse / sibling (N=38).....	77	8	15	0.93#
Parent / in-law (N=37).....	65	11	24	
SUFFERER LIVING ARRANGEMENTS				
Own / carers home (N=59).....	68	10	22	0.64#
Institution (N=16).....	88	6	6	
CARER PERCEPTION OF DEMENTIA				
Old age/Just ill (N=51).....	67	10	23	3.64#
Horrid/worst (N=19).....	95	0	5	

= After Yates' correction.

The results presented in Tables 11.2 and 11.3 demonstrate that while "definite griever" did differ significantly from "definite non-griever" in terms of their emotional experiences, they did not differ in terms of carer age or sex, sufferer age or sex, carer-sufferer blood/role relationship, nor on whether the sufferer was living in an institution or not. Neither did the "definite griever" differ with regard to the degree of sufferer impairment (as assessed by total problem checklist frequency and carers' estimates of overall change), nor with regard to the length of time since either onset or diagnosis of dementia in the sufferer. Although there was a tendency for those carers who perceived dementia to be a very horrible/worst possible illness to believe that they had also experienced grief more often than those who did not hold such a negative evaluative perception of the illness, this difference did not reach statistical significance.

X. DISCUSSION

The nature of the emotional reactions and behaviours which the carers described in the present study did seem to correspond to those which have been noted in previous observational studies of what has been termed "anticipatory grief" in the relatives of dying patients. (Unfortunately, since these studies do not present any quantitative results, neither the proportions of the samples who experienced each reaction, nor the frequency with which each reaction occurred can be compared with the results of the present study.)

1. Caregivers' First Reactions to the Diagnosis

The most common reactions to the diagnosis were recalled as shock and disbelief. There were descriptions of sensations akin to a physical blow upon receipt of the diagnosis. The shock was - not surprisingly - greater for those who had not suspected what was wrong prior to the official diagnosis. There was evidence of initial denial of the early signs of dementia: an average of 2½ years between the carer first noticing something wrong and actually receiving a diagnosis. These reactions are very similar to the early descriptions of the ways in which parents react to the news of a fatal illness in their child. For example, Bozeman, Orbach and Sutherland [1955] describe initial disbelief, sensations of physical injury, and demands for further opinions in an attempt to prove the diagnosis incorrect. Similarly, Chodoff, Stanford and Friedman et. al. [1964] note the vague uneasiness of parents prior to the diagnosis of cancer in their child, and the reception of the diagnosis as a physical blow with an insulating feeling of unreality.

2. Emotional and Behavioural Reactions of Caregiving Relatives

SHOCK AND DENIAL

There was evidence of continued occasional disbelief, of the conscious denial of emotions and of the playing down of problems. These were also seen by Chodoff, Stanford and Friedman et. al. [1964] in the parents of children suffering from neoplastic diseases. They described this isolation of affect and denial as internal "defensive" behaviours. In the present study they were by no means ubiquitous: although two thirds

had bottled up their emotions, only about one third had experienced disbelief, had ever tried to play down the problems, or found it difficult to talk about the sufferer. It could be hypothesised that disbelief or denial is somewhat more difficult to maintain in the face of dementia than in the face of an illness such as childhood leukaemia. The behaviours of a person with a moderate degree of dementia, such as wandering, losing things, emotional lability, inability to manage zips or buttons, refusing to get washed, etc. are difficult to normalise - particularly if you have known that person for a great many years. Not only that, but the relatives of dementia sufferers often have the brain scan results as further objective proof of the validity of the diagnosis. In addition, children with leukaemia can often appear to be fairly well - often it is the side effects of the treatment which seem to make them ill. They may also experience periods of remission when again they become apparently well. How much more comfortable in such circumstances to believe that their illness was never really leukaemia and has now gone away. While dementia may not progress at a constant rate, there are no periods of remission. The other reason why disbelief may be less usual in the face of dementia than was reported in the face of childhood leukaemia is that dementia is usually associated with old age, a time when some sort of illness is often seen as "natural". (And indeed, as has been shown, a time when even dementia may be seen as "natural".) In contrast, in the second half of the twentieth century, severe childhood illness or death is not natural.

HOPE AND BARGAINING

Activities such as following the media or bargaining for cures were unusual in the present sample, although

about half had hoped the sufferer might get better at some time or another. Previous studies of anticipatory grief have described "hope" in varying degrees. Kubler Ross [1970] describes some families as arranging expensive trips for the patient to famous clinics as part of "shopping for cures". In the present study this was uncommon (the opportunity to do so is less within the Scottish NHS than within the American system of private clinics) - but the equivalent had occurred, with dementia sufferers having been sent for homoeopathic treatment and to Lourdes. Bozeman, Orbach and Sutherland [1955] describe the continued hope of mothers whose children's leukaemia reached a remission. Natterson and Knudson [1960] note the expressions of hope for new treatments by the parents of children with leukaemia. Again, there is a major difference between dementia and childhood leukaemia. Even during the 1950s and 1960s when the prognosis for leukaemia was inevitably grim, there were some treatments on offer: even if they did not work, they might provide hope of remission. The fact that there was any treatment at all might offer some hope of a "break-through" sometime - maybe very soon - to the parents who formed the focus of the early anticipatory grief studies. Dementia is different. While there may be vague talk of breakthroughs in the media, no treatment is on offer at present. The vast majority of community carers regard day hospital placement as offering respite care, not hope of a cure. Hospitalisation means death, not rehabilitation. Carers know this. Any hope, therefore, has no real basis in fact.

QUESTIONING, ANGRY PROTEST AND GUILT

The "search for the meaning" of why their relative had dementia was common in the present sample. Several of

the early descriptive studies of anticipatory grief note this example of a "mastery operation" [Futterman, Hoffman and Shabsin, 1972; Futterman and Hoffman, 1973]. However, guilt and self blame which are almost always described in the observational studies of anticipatory grief in parents were unusual among the present sample of carers. This could be attributed to the fact that parents play the role of protector to their children. If a child burns its hand a parent will blame him or herself. If a child contracts leukaemia a parent may also blame him or herself. People with dementia have been responsible adults prior to the onset of the illness. Blame for dementia may therefore be placed on environmental, genetic, or behavioural factors - but seldom on the actions of others.

While they might not have blamed themselves for the onset of the dementia, this does not mean that guilt was not prominent among the present sample of carers. It was almost ubiquitous following episodes of anger with the dementia sufferer: after the heat of the moment has passed the thought, "but they couldn't help it - it was because they have dementia" meant that carers tended to place the responsibility for upsets onto themselves. Guilt could also occur if a carer went out or enjoyed him or herself without the dementia sufferer. Grief theorists would attribute this to guilt regarding the enjoyment and resumption of one's life without the sufferer. For some carers this did seem to be the case. This was particularly if they were related to a dementia sufferer in long-term care. In such cases a carer would often perceive him or herself as abandoning the sufferer to go away on holidays or trips.

Episodes of anger were common in the present sample. However, the most frequent sources of the anger were the dementia sufferers themselves, because of their unpredictable or tiresome behaviours. While anger is almost always described as a component of anticipatory grief, it rarely results directly from the behaviour of the fatally ill person. People who are dying from a physical illness do not generally behave in ways which are so trying to deal with. (Although their own frustrations or grief may result in behaviours which are difficult for others to understand, they are likely to be rather different from, and also less permanent than the changes which result from dementia.) Studies of anger and hostility in anticipatory grief describe it as most commonly directed towards medical staff who are perceived as not only the harbingers of bad news, but as somehow also the cause of that bad news, and in addition as having failed in their own roles of preventing or curing the illness. Anger has also been described as directed towards God for allowing the illness to happen, or displayed as a general irritability towards others. Among the present sample of carers, fewer than half reported experiencing anger at the fact that the dementia had happened, and anger directed towards God was very unusual, although it had occurred. Anger directed towards the formal or professional services which had been offered was reported by about one third of the sample. Sometimes this did not seem entirely without justification. Services and information to support the caregiving relatives of dementia sufferers do vary, and if an individual general practitioner is not particularly interested in the situation, or perceives him or herself as powerless to help, then visits may be few and far between. Where services were good (for example, certain day hospitals, or the Alzheimer's Society

projects) the carers in the present sample generally recognised this. Finally, general irritability had been experienced by at least half the sample. But again, this could often be related to the stress of caring for the dementia sufferer.

PREOCCUPATION, UNFINISHED BUSINESS AND DESPAIR

Early observational studies of the reactions of the parents of children with fatal illnesses noted the need to spend as much time as possible with the child [Richmond and Waisman, 1955], physical clinging [Bozeman, Orbach and Sutherland, 1955], preoccupation with thoughts of the child [Chodoff, Stanford and Friedman et. al., 1964], and overprotection [Tropauer, Franz and Dilgard, 1977]. While three quarters of the present sample of carers found themselves preoccupied to varying degrees with the dementia sufferer, for the majority this was a legitimate worrying about their safety. However, some did describe preoccupation with the sufferer when the need for vigilance had been removed - for example while the sufferer was in day or long-term care. In addition, for some relatives of institutionalised dementia sufferers, daily visiting was the rule. Was this "clinging"?

Preoccupation with earlier times is generally regarded as a part of grief and anticipatory grief. [Lindemann, 1944; Parkes, 1970; Richmond and Waisman, 1955]. Thinking back to how the sufferer had been prior to the onset of dementia was frequently reported by the present sample of carers, as well as wishing everything could be the way it used to be. It is possible that such thoughts would be more easily triggered by the presence of a dementia sufferer (representing not only a constant reminder of the fact that the person is

definitely not the way they used to be, but also a constant disruption to the household routine) than by the absence of a person who had actually died. "Unfinished business" - wishing the dementia sufferer could have done certain things which they had been unable to do, or wishing to say certain things to the sufferer - was reported by some carers among the present sample, but was not very common. The completion of any unfinished business is regarded by many writers as an important part of the anticipatory grief process, in order to reach the stage of mutual acceptance and what might be regarded as a "good death". "If they are able to share their common concerns they can take care of important matters early and under less pressure of time and emotions" [Kubler Ross, 1970, p.149]. It is difficult to share common concerns with a person whose communication skills are impaired. Even so, the majority of carers believed that they could still communicate their love and concern to the dementia sufferer using non-verbal means (or even simply by the fact that they were continuing to care for them), and in this way they seemed to be attempting to resolve any unfinished business. It is interesting that it was the child rather than the spouse caregivers who tended to wish the sufferer could have had a "better life" in general. Children were in a position to blame the sufferer's spouse for giving them a "hard life". Spouses on the other hand, had shared and invested in the sufferer's life and this was presumably the reason why they tended not to perceive it in negative terms.

Despair is the emotional reaction most commonly associated with normal grief, and it also features in all the descriptions of anticipatory grief. For many lay people "grief" is synonymous with sadness, depression and crying. Sadness about what had happened

to the dementia sufferer was reported by almost every carer. Their comments linked their sadness to the current and anticipated losses associated with dementia. Again, it might be suggested that in comparison with the physical illness (usually malignancy) which formed the focus of the early observational studies of anticipatory grief, the losses associated with moderate-severe dementia are far more obvious. Someone with a physical illness may be weak, or they may have lost the physical ability to engage in certain activities, but they are usually able to communicate, to share and to remain essentially themselves. This is not the case in dementia. The tiny number of carers who did not report sadness did not appear to associate dementia with losses in the sufferer. The majority of the carers had cried at some time or another. The majority had also felt depressed at times during the sufferer's illness, although this tended to result not solely from the fact of the dementia, but also from the exhausting "no-way-out" situation which the majority of carers found themselves in. These were also the reasons which were given by that half of the sample of the carers who had felt at times that their own life had lost its meaning.

ACCEPTANCE

Finally, what of acceptance? This end-point of the grief (or anticipatory grief) reaction is often portrayed as some sort of blessed state, achieved only by those who have passed through the valley of truly experiencing and sharing the painful emotions of grief. The carers in the present study clearly distinguished between intellectual and emotional acceptance. It would be hard not to experience intellectual acceptance in the face of the obvious deficits of a moderately-

severely impaired dementia sufferer. Emotional acceptance was apparently not so easy - only about a quarter reported thinking calmly about the dementia all the time, and thinking about the future was even more difficult. Given the uncertainty over the length of life which the sufferer might have left, the uncertainty over the progression and pattern of impairments which might occur, and the uncertainty over the carer's own future health and ability to cope, it is not surprising that anxiety was common. The ongoing changes in the situation which occur when caring for a dementia sufferer mean that calm acceptance is probably an impossible goal for which to strive.

3. Arguments For and Against Labelling the Reactions of Caregiving Relatives "Anticipatory Grief"

Does establishing that at least some of the caregiving relatives of dementia sufferers report having experienced at least some of the emotions which other studies have labelled "anticipatory grief" allow us to conclude that what these carers experience can also be labelled "anticipatory grief"? Not necessarily. The arguments for and against the labelling of the emotional reactions of caregiving relatives as "anticipatory grief" will be considered in turn.

ARGUMENT AGAINST LABELLING THE REACTIONS OF CAREGIVING RELATIVES "ANTICIPATORY GRIEF"

The argument against labelling the reactions of caregiving relatives "anticipatory grief" is simple: that all the emotions or behaviours described above represent reactions or coping techniques in the face of a difficult situation, but do not represent grief or anticipatory grief.

Coping is defined by Weisman as "... what one does about a problem in order to bring about relief, reward, quiescence, and equilibrium" [1979, p.27]. The results of principal components analysis on the Ways of Coping Checklist - WCCL - [Aldwin et. al., 1980, cited in Vitaliano, Maiuro and Russo et. al., 1987] elucidated seven coping strategies. These were as follows:

- Problem focused (making a plan of action and following it);
- Wishful thinking (wishing you could change the situation);
- Growth (changing or growing as a person in a good way);
- Minimising threat (making light of the situation);
- Seeking social support (talking to others and accepting sympathy);
- Blaming self (feeling responsible about the problem);
- A mixed scale (containing both avoidant and help-seeking strategies).

(The WCCL asks respondents to focus on a current serious stressor - it is by no means limited to coping with loss.)

These definitions of coping can be related to the reactions reported by the caregiving relatives in the sample.

The caregivers showed evidence of denial. Denial is an avoidant coping strategy. If my car starts to make a funny noise I may attempt to deny the possibility of imminent breakdown by turning up the radio. If I return from holiday and my kitchen smells damp I may attempt to deny the possibility of a leaking pipe by opening the window. I hope the problems will go away. I am clearly exhibiting denial, but I am not grieving - I am experiencing a problem, but it is not loss.

Many of the caregivers in the sample reported experiencing shock when given the diagnosis of dementia

in the sufferer. But shock may occur after any piece of surprise news, either good or bad. If the plumber's bill for fixing the leaking kitchen pipe is higher than I expected, I may be shocked. If I do particularly well in a test when I didn't expect to, I may be surprised.

The coping strategy of "wishful thinking" would cover both the carers' reports of hope or bargaining (what might be termed "future-directed" wishful thinking) and wishing the dementia sufferer could be the way they had been ("past-directed" wishful thinking). Again, wishful thinking need not be limited to coping with grief.

The same goes for the coping strategy of directing blame onto someone or something, or onto oneself (described by Weisman [1979] as the coping strategies of "externalise/project" and "moral masochism" respectively). Certainly anger and frustration could not be regarded as unexpected in those caring for dementia sufferers: the ability to remain entirely unruffled in such circumstances is perhaps more surprising.

The question "Why?" may be posed in response to a variety of situations - but again, not limited to the aftermath or anticipation of loss. "Why did the gale blow down my fence?" "Why did I win the competition?"

Even sadness and depression might be explained away as reactions to the restrictions placed upon the carers' own lives, the objective burdens which they must cope with, and the uncertainty and helplessness which are a part of their lives as a result of being the primary caregiver to a dementia sufferer. The argument would presumably run: but who wouldn't be depressed by such a situation?

ARGUMENTS FOR LABELLING THE REACTIONS OF CAREGIVING RELATIVES "ANTICIPATORY GRIEF"

There are two reasons for suggesting that the caregiving relatives of dementia sufferers experience anticipatory grief.

The first - and perhaps most convincing - reason is that the majority (almost three quarters) of those who were asked believed that their experiences had been like grief. The comments which these carers made associated their own reactions with the fact that the dementia sufferer "has changed", "has gone", "is not the person he/she was", "has died". These carers were aware of reacting to the loss of the dementia sufferer. When they were posed the "Have your feelings been like grief?" item they were not surprised. They knew what the interviewer was asking. One carer even spontaneously raised the "hydraulic" notion of a fixed amount of grief to be experienced either before and/or after a death, a part of which she believed she had already worked her way through. In contrast, the comments of the 20% of carers who were sure that they had not experienced grief demonstrated that they did not appear to regard themselves as having experienced a loss.

Of interest is the fact that those carers who believed that they had experienced grief were experiencing "anticipatory grief" (as measured by the Carers' Questionnaire) to a significantly greater degree than those carers who believed they had not experienced grief. At the time of the interview, as well as earlier on in the illness, the "definite grievers" were experiencing significantly more distress than both the definite non-grievers and those carers who were unsure

whether or not they had grieved. Despite the clear differences in the extent of "anticipatory grief" experienced by those who believed that they had experienced grief in comparison with those who did not, the two groups did not differ in terms of basic demographic characteristics, nor in terms of the extent of impairment in the demented relatives.

The second reason for suggesting that the caregiving relatives of dementia sufferers experience anticipatory grief comes from the result of the factor analysis of the "nowadays" grief items (see Chapter Nine, "Data Analysis"). The factors which emerged from principal components analysis of the items (F.A. components of grief) did not correspond exactly to the components - or "stages" - of grief as initially specified in the Carers' Questionnaire (I.S. components). The two F.A. components of "Yearn" (comprised guilt, looking back to past, wishing sufferer could be the way they used, and preoccupied with sufferer) and "Protest" (comprised items anger at God, at dementia, at formal help, irritable, and self-blame) are similar in item content to the main clusters of variables found by Parkes [1986]. He produced a correlation matrix of "psychological measures" made among 22 London widows in the year following bereavement. Parkes described, "two main types of variable that go together and create two general trends of reaction to bereavement ... (although) it should be remembered that components of both these modes of reaction are found in most bereaved people" [1986, p.225]. The first of these two modes of response is the passive mode, oriented towards the dead husband, and similar to the F.A. component "Yearn" in the present study. (It comprised Parkes' items "preoccupation with thoughts of the deceased", "clear visual memory of him", "sense of his continued

presence", "tearfulness", and "illusions of the deceased".) The second was the active mode where the survivor, instead of calling to the lost person to return, angrily turns to face a potentially hostile world - similar to the F.A. component "Protest" in the present study. (It comprised Parkes' items "irritability and anger", "restlessness", "tension", and "social withdrawal".) Parkes goes on to state there was no support from his study for the notion of a general factor of "defensiveness" because reactions such as "numbness", "difficulty in accepting the fact of the loss" and "avoidance of reminders" were not significantly intercorrelated. Although this is true, the correlation between "difficulty in accepting the fact of loss" and "avoidance of reminders" approached significance in his study (for $df=20$, $p<.10$ for the r . cited), but the relations between "numbness" and either "difficulty in accepting the fact of loss" or "avoidance of reminders" do not approach significance [Tables of significance, Ferguson, 1976]. Given this, Parkes is perhaps rather too dismissive in rejecting the notion of a general factor of "defensiveness". In the present study the F.A. component "Deny" would represent such a general factor, while the component "Disbelief/Hope" would include Parkes' notion of numbness.

In another study Jacobs, Kosten and Kasl et. al. [1987] used factor analysis to identify dimensions of psychological distress associated with bereavement. They administered their 38 Bereavement Items scale (BI - for details of the construction of this scale, see Appendix Three, "Formalising the Carers' Questionnaire and Coding Frame") to "acutely bereaved widows and widowers". Four factors emerged that could be understood within the framework of attachment theory.

(It should be noted that these factors accounted for very small amounts of the total variance. Together they only explained 12.5% of the total variance.) The authors labelled these factors as follows. "Sadness, loneliness and crying" (comprising feeling blue, feeling depressed, feeling sad, loneliness, feeling about to cry, crying, feeling happy [recoded], enjoying life [recoded], and tension). "Numbness and disbelief" (comprising feeling stunned, feeling numb, disbelief, loss of control, feeling about to burst, and dread of impending trouble). "Perceptual set and searching" (comprising calling the spouse's name, feeling drawn to places and things of the spouse, vivid mental images, auditory illusions, and feeling the presence of the spouse). "Distressful yearning" (comprising feeling upset, yearning, preoccupations with the deceased, and feeling about to cry). There is a fairly striking similarity in the content of the two factors "sadness, loneliness and crying" and "distressful yearning" which had been obtained from people who were experiencing conventional grief and the F.A. components "Mourn" (comprised items depressed, own life lost meaning, cry, and upset) and "Yearn" respectively. There is also some resemblance between Jacobs et. al.'s factor "numbness and disbelief" and the F.A. component "Disbelief/Hope". Jacobs et. al. did not include items tapping denial or angry protest, while the present study did not include items tapping perceptual set and searching.

The factor analysis of the individual grief items in the present study therefore resulted not only in a set of factors which make intuitive "sense" but also that correspond somewhat to clusters of reactions experienced in "conventional" grief.

RESOLUTION OF ARGUMENTS FOR AND AGAINST LABELLING THE REACTIONS OF CAREGIVING RELATIVES "ANTICIPATORY GRIEF"

What can be concluded from the above arguments? The most reasonable conclusion - as with so much within social science - is probably that there is some truth in both arguments.

Berry and Zimmerman [1983] discuss the reactions of parents of mentally or physically handicapped children in the following terms: "... two separate processes are occurring at the same time. Parents are mourning the loss of the normal, healthy child they expected to rear, while simultaneously assuming care responsibilities for the disabled child who is now part of their family" [p.275]. It would appear that exactly the same processes are occurring for the caregiving relatives of dementia sufferers. Those who perceive the dementia as a horrible illness, or to have resulted in losses of the person of the dementia sufferer experience "anticipatory grief". At the same time they are coping with the everyday tasks that result from being the primary informal caregiver to a dementia sufferer. A carer may be questioning why dementia struck their relative, but at the same time they are washing last night's soiled sheets. They may be wishing the sufferer could be the way they used to be, but at the same time they are wondering how to get out tonight because the sitter has let them down, and they are acting like a broken gramophone record, answering the same question that the sufferer asked just two minutes before, and again two minutes before that. They may be feeling sad at the way their relative is nowadays, but at the same time they are running for the bus to visit that relative in the somewhat depressing, locked, long-stay psychogeriatric ward of the local psychiatric

hospital. This scenario is far more likely to fit the facts of the emotional and behavioural experiences which make up most caregivers' daily lives than the attempt to explain their reactions entirely as either "coping techniques" or "anticipatory grief".

The clear variations in the intensities of the reactions between carers, and the association between more intense reactions and a carer's perception of having grieved the losses of the dementia sufferer, suggest that caregiving relatives experience anticipatory grief to varying degrees. However, these results indicate that the reactions of up to three-quarters of the caregiving relatives sampled may be conceptualised as - at least partly - "anticipatory grief".

XI. SUMMARY

This chapter has presented results concerning the emotional and behavioural reactions of carers with regard to their dementing relatives.

Delay between first noticing something wrong with the dementia sufferer and becoming aware of the diagnosis was almost universal. There was evidence of denial by caregiving relatives during this early pre-diagnostic stage, however, the diagnosis was believed once it had been given formally. Initial reactions to the diagnosis depended on the knowledge and beliefs concerning dementia which were held by the carer at that time. The most common reaction was a degree of shock.

Evidence of each of the five components of grief as initially stated (see Chapter Eight) was presented

within this chapter, as follows. "Shock/Denial" was demonstrated by the large number of carers who had consciously avoided or "bottled up" painful emotions, played down the extent of the problems, or found it difficult to discuss the dementia sufferer with others. Expressions of disbelief were uncommon. "Hope/Bargaining" tended to be unusual, and where present, to focus vaguely on the situation not getting any worse. This was related to clear acceptance of the prognosis associated with a diagnosis of dementia. "Questioning/Anger/Guilt" was demonstrated firstly by the majority of carers who had asked themselves why dementia had occurred in their relative. Self-blame or anger directed towards God were rare, however, general irritability was more common, and anger resulting from the behaviour of the dementia sufferer had been experienced by almost every carer. Some guilt was expressed at the resumption or enjoyment of life without the dementia sufferer, although for many community carers the obligations of care meant there was little or no opportunity to engage in pleasurable activities outside the home. "Preoccupation/Unfinished Business/Despair" was evident in the vast majority of carers who expressed sadness at the losses resulting from dementia in their relative. Crying was not uncommon, nor was feeling that their own lives had become somewhat meaningless. Preoccupation with the sufferer tended to revolve around their well-being and safety, and was frequently justified by the unpredictable behaviour of people with dementia. The perception that certain things had been left "unfinished" between carer and sufferer was unusual. "Acceptance" by carers on an intellectual level was the norm, however, complete emotional acceptance of the current and future effects of dementia on the sufferer were somewhat less usual.

There was evidence that being related to a dementia sufferer could constitute social preparation for bereavement, since it necessitated learning new roles, and also activities such as the disposal of the belongings of institutionalised sufferers. Like the bereaved, the caregiving relatives frequently suffered social isolation. However because of the obligations of care they often had even fewer opportunities for social engagement than the truly bereaved.

Three-quarters of those caregiving relatives who were asked perceived themselves as having experienced grief. This perception was associated with the reporting of more intense emotional and behavioural reactions.

Comparisons were made between these results and previous descriptions of anticipatory grief. Arguments were presented both for and against labelling the reactions of the caregiving relatives of dementia sufferers "anticipatory grief". The argument against such a label suggested that the emotional and behavioural reactions of carers could be regarded as coping strategies which need not necessarily be related to loss. The arguments for the label "anticipatory grief" pointed out the following. Firstly, the high proportion of carers who related their reactions to the "loss" of the dementia sufferer. Secondly, the similarity of the structure of the reactions of the caregiving relatives to that of "conventional" grief. It was concluded that describing the reactions of the caregiving relatives as "anticipatory grief" is justified. However, the intensity of this anticipatory grief varies between carers, and may be occurring in parallel with efforts to cope with the more practical burdens of caring.

CHAPTER TWELVE

EVIDENCE FOR AND AGAINST THE STAGED EMERGENCE OF COMPONENTS OF ANTICIPATORY GRIEF IN CAREGIVING RELATIVES

I. INTRODUCTION

The previous chapter presented results, largely of a qualitative nature, which demonstrated that many of the caregiving relatives of dementia sufferers appeared to experience emotional reactions similar to those described in the anticipatory grief literature.

The current chapter seeks to answer whether, as predicted by the "stage" view of anticipatory grief, these emotional reactions emerge in a phasic or staged fashion. The quantitative analyses are presented largely in the order in which they were conducted, with the aim of giving the reader an indication of the exploratory nature of the questions and hypotheses which arose.

Analyses of the relationship between the intensities of each component and the length of time over which grief had occurred were conducted, as well as of the interrelationships between the various components of grief. Since, it is argued, the analysis of data on a whole-sample basis may cancel out individual phased patterns of anticipatory grief, both group and individual analyses are presented in two separate sections.

The fourth, descriptive, section presents the beliefs of the carers themselves with regard to whether or not

they had experienced stages in their reactions since the onset of dementia in the sufferer.

The final section of the chapter discusses the results obtained with reference to the previous literature concerning the "staging" of grief and anticipatory grief.

II. SEARCH FOR THE RELATIONSHIP BETWEEN "COMPONENTS" OF ANTICIPATORY GRIEF AND TIME - WHOLE SAMPLE ANALYSIS

Is there any relationship between the various "components" of grief and the time over which grieving might be assumed to have occurred?

In an attempt to answer this question, analyses were conducted for both the five initially specified (I.S.) components of grief ("Shock/Denial"; "Hope/Bargaining"; "Questioning/Anger/Guilt"; "Preoccupation/Unfinished Business/Despair"; and "Acceptance") and also for the five components which had emerged through the factor analysis of the individual grief items (F.A. components - "Disbelief/Hope"; "Deny"; "Protest"; "Yearn"; and "Mourn").

1. Correlations Between Components of Grief and Time

The relationships of the intensities of the various components of grief with both time since the diagnosis of the dementia and also the carers' estimated time since onset of dementia were examined. This was because a number of carers had been aware of the probable diagnosis before its official pronouncement.

Tables 12.1 and 12.2 present the correlation coefficients (Pearson's r) between the current ("nowadays") intensities of each component of grief (ie. the total score obtained by a carer on that component scale) and the lengths of time both since the carer first noticed something wrong with the sufferer and also since the carer received the diagnosis of dementia.

Table 12.1

Correlation coefficients (Pearson's r) between current scores on the five I.S. components-of-grief scales and carers estimations of times since onset and diagnosis of dementia.

I.S. components of grief "Nowadays"	Time: Onset	Time: Diagnosis
Shock/Denial.....	-0.072.....	-0.041
Hope/Bargaining.....	-0.156.....	-0.088
Questioning/Anger/Guilt.....	-0.037.....	0.022
Preoccupation/Unfinished- Business/Despair.....	-0.153.....	0.056
Acceptance.....	0.173*.....	-0.078

* = $p < .05$

Table 12.2

Correlation coefficients (Pearson's r) between current scores on the five F.A. components-of-grief scales and carers estimations of times since onset and diagnosis of dementia.

F.A. components of grief "Nowadays"	Time: Onset	Time: Diagnosis
Disbelief/Hope.....	-0.228*.....	-0.148
Deny.....	-0.003.....	-0.000
Yearn.....	-0.013.....	0.099
Protest.....	0.062.....	0.089
Mourn.....	-0.130.....	0.029

* = $p < .05$

The only significant association between scores on the I.S. components-of-grief scales and time was a positive relationship between "Acceptance" and time since onset of the dementia as estimated by the carers.

The only significant association between scores on the components-of-grief scales obtained via factor analysis of the individual grief items and time was a negative relationship between "Disbelief/Hope" and time since onset of the dementia as estimated by the carers. (It should be noted that one of the individual items comprising the initially specified "Acceptance" component of grief is also one of the 7 items which make up the "Disbelief/Hope" scale. This common item - "Accept what has happened" may account for the fact that the intensity of both these components was found to be significantly related to time since onset.)

2. Graphical Presentations of the Intensities of the Components of Grief with the Passage of Time

It might be argued that a significant positive or negative correlation with time could be expected for those components of grief which it has been suggested in the literature occur towards the beginning or towards the end-point of grief. However, the argument might continue to suggest that it could not be expected for those components which it has been suggested occur in the middle of grief, since their relationship with time would not be predicted to be linear. This argument is more easily expressed by referring to an idealistic diagram of the progression of grief stages with time, as suggested by the "stages of grief" literature. (Figure 12.1, over page.)

In the ideal world predicted by this diagram the component "Shock/Denial" would have a significant inverse relationship with time since grieving had begun, while the component "Acceptance" would have a

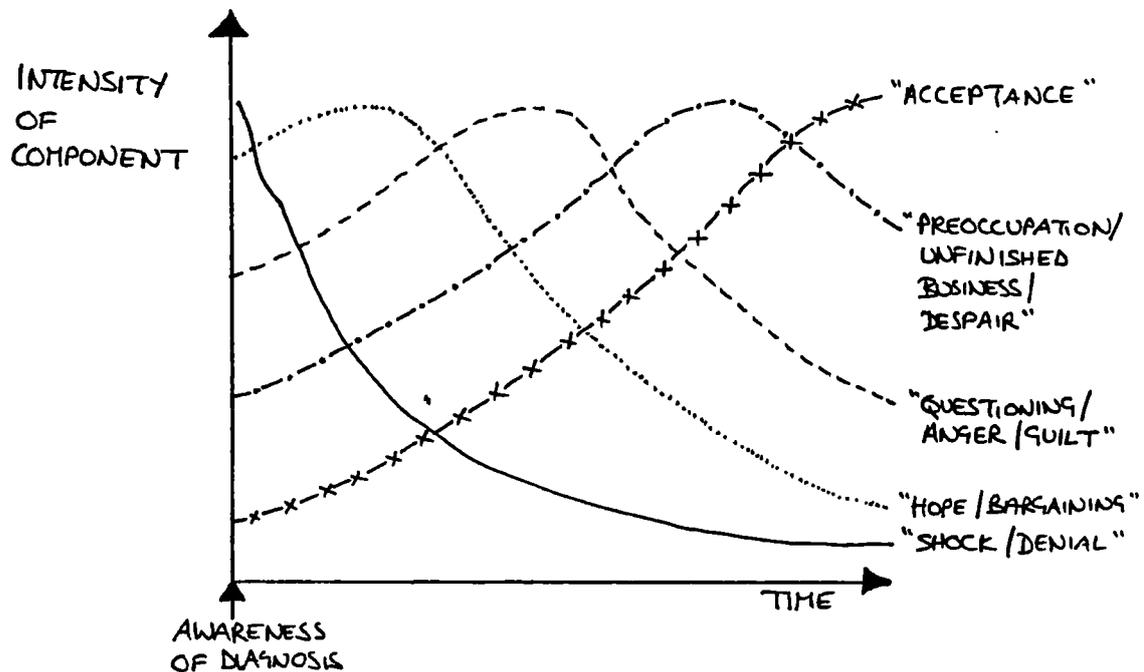


Figure 12.1 Idealistic diagram of changes in the intensity of the components of grief with time. [Based on Jacobs, Kosten and Kasl et. al., 1987, p43]

significant positive relationship. However, the components "Hope/Bargaining", "Questioning/Anger/Guilt" and "Preoccupation/Unfinished Business/Despair" would have a non-linear relationship with time since grieving had begun and thus a non-significant Pearson's correlation coefficient.

The possibility of a gradual emergence of one component of grief after another with the passage of time since grieving might have been assumed to have begun was examined graphically. The mean scores for each "nowadays" component were plotted against time on a year-by-year basis. Component of grief scores were represented as a percentage of the maximum possible score on that scale so all components could be represented on the same graph. (Figures 12.2 - 12.5)

-
- = I.S. component "Shock/Denial"
 - = I.S. component "Hope/Bargaining"
 - = I.S. component "Questioning/Anger/
Guilt"
 - .-.-.-.- = I.S. component "Preoccupation/Unfini-
ished Business/Despair"
 - x-x-x-x- = I.S. component "Acceptance"

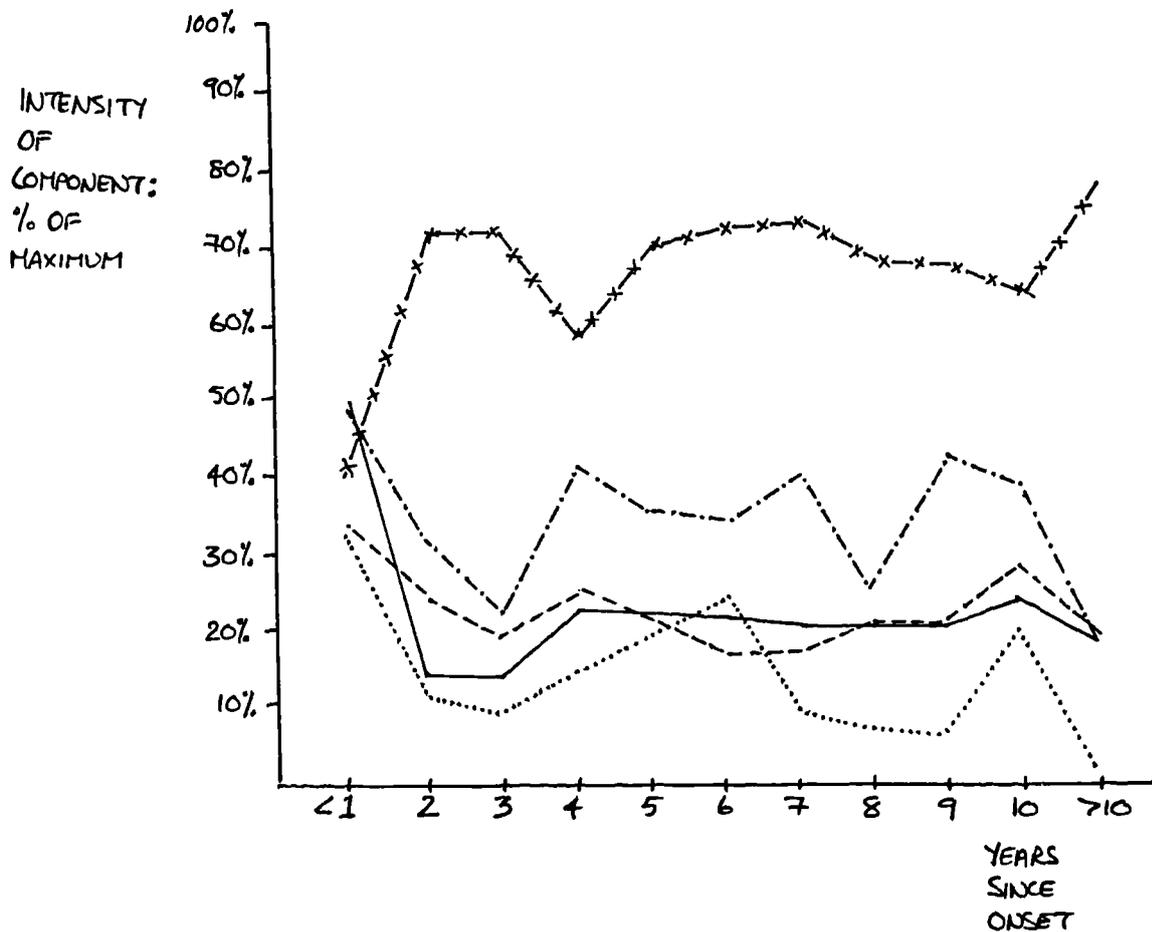


Figure 12.2 : Graph of current mean scores (across whole sample of carers) on each of the five initially-specified (I.S.) components of grief scales, plotted against time since ONSET of the dementia.

-
- = I.S. component "Shock/Denial"
 - = I.S. component "Hope/Bargaining"
 - = I.S. component "Questioning/Anger/Guilt"
 - .-.-.- = I.S. component "Preoccupation/Unfinished Business/Despair"
 - x-x-x-x- = I.S. component "Acceptance"

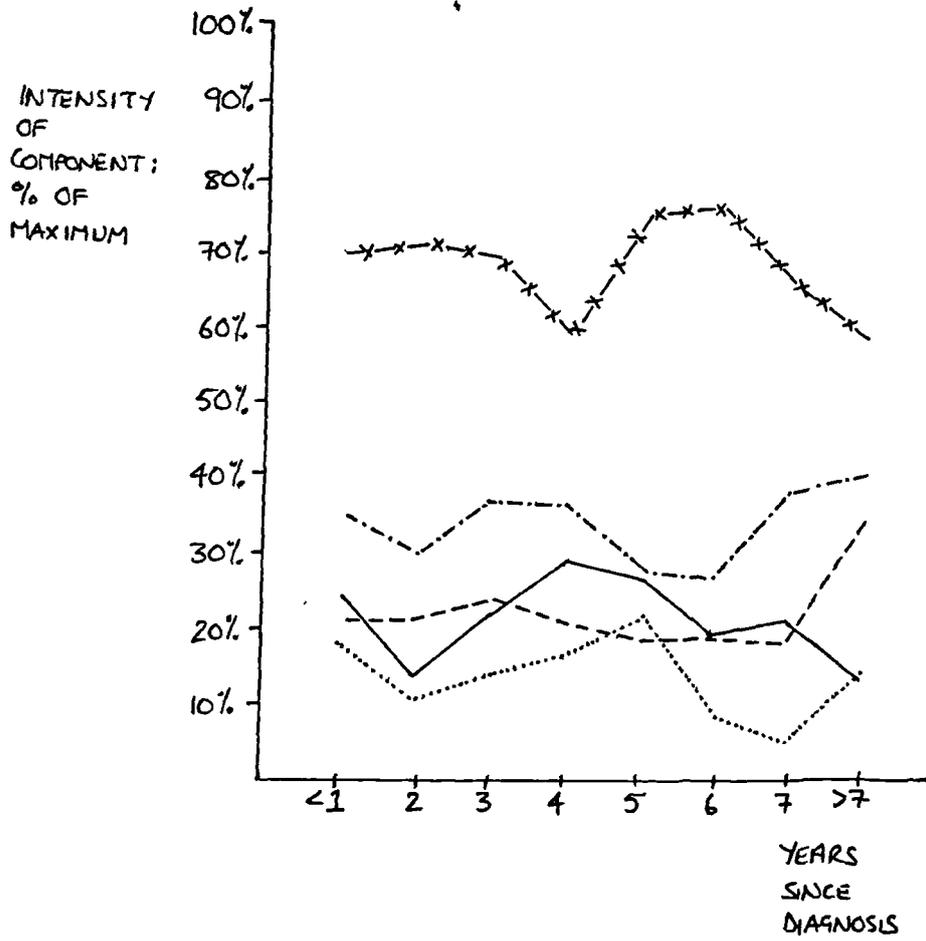


Figure 12.3 : Graph of mean current scores (across whole sample of carers) on each of the five initially-specified (I.S.) components of grief scales, plotted against time since DIAGNOSIS of the dementia.

-
- = F.A. component "Disbelief/Hope"
 - = F.A. component "Deny"
 - = F.A. component "Protest"
 - .-.-.-.- = F.A. component "Yearn"
 - x-x-x-x- = F.A. component "Mourn"

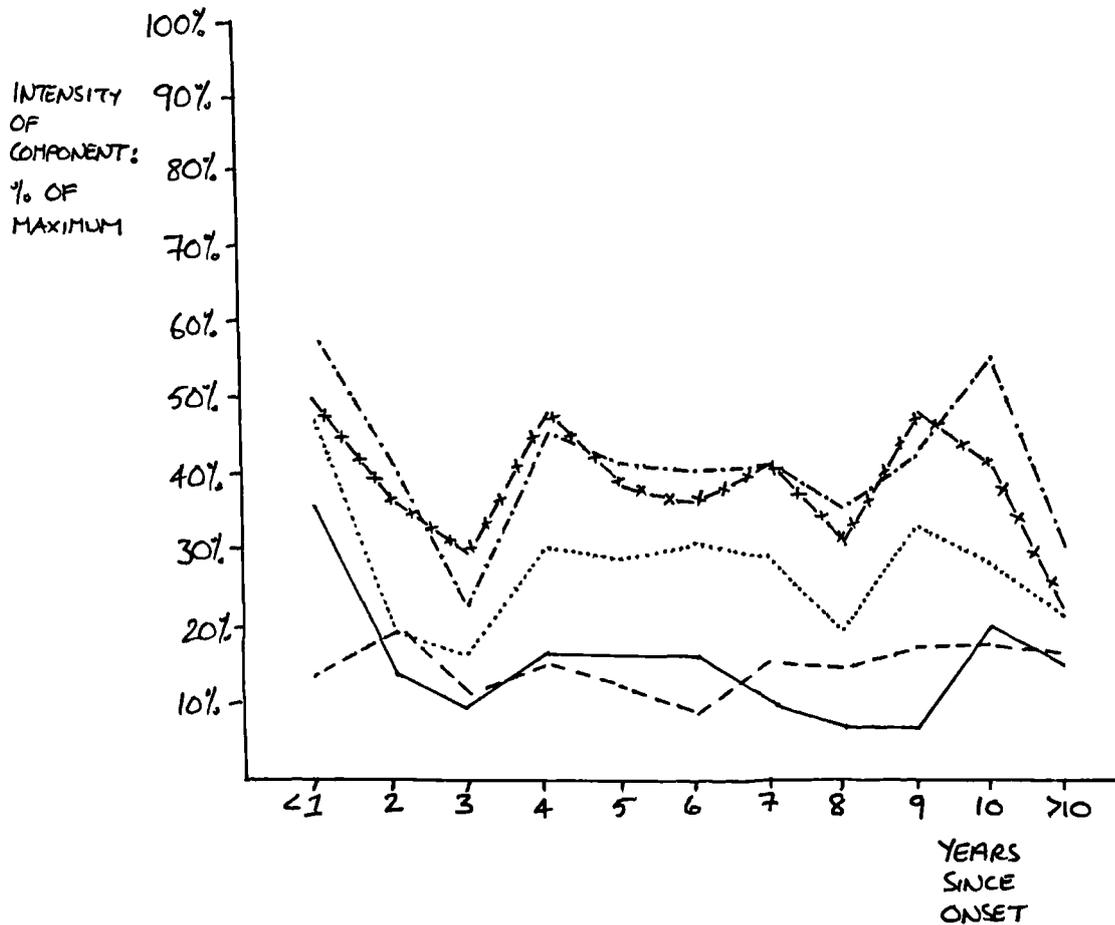


Figure 12.4 : Graph of mean current scores (across whole sample of carers) on each of the five F.A. components of grief scales (obtained via factor analysis), plotted against time since ONSET of the dementia.

-
- = F.A. component "Disbelief/Hope"
 - = F.A. component "Deny"
 - = F.A. component "Protest"
 - .-.-.-.- = F.A. component "Yearn"
 - x-x-x-x- = F.A. component "Mourn"

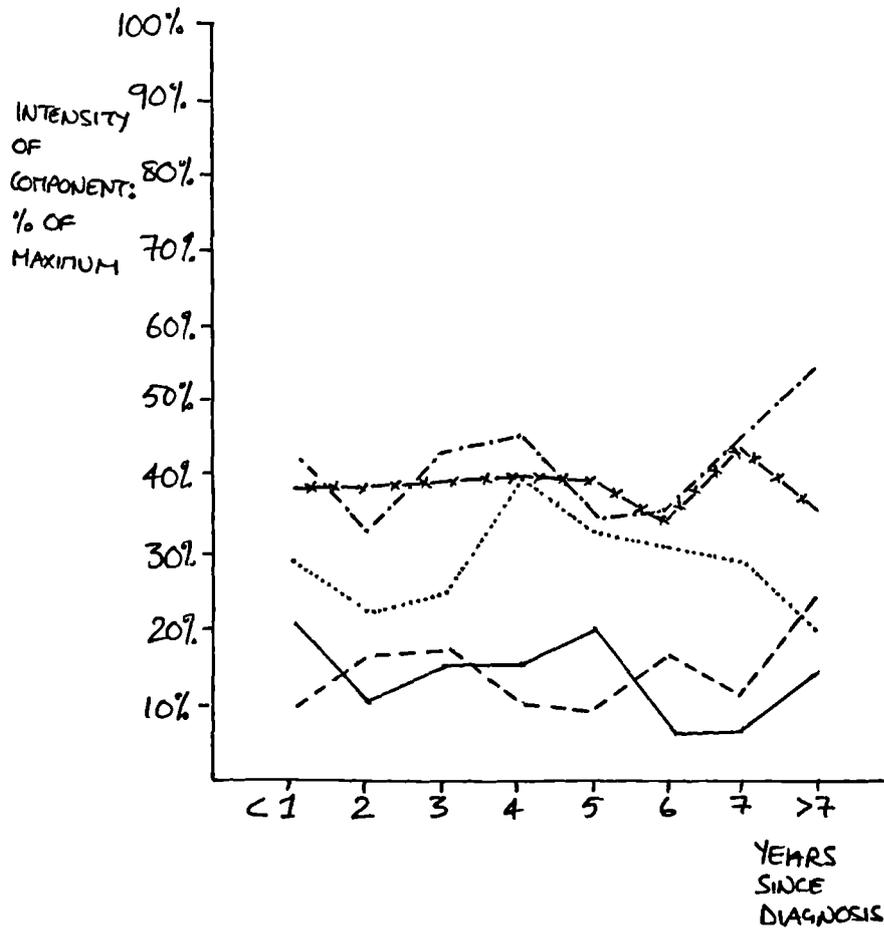


Figure 12.5 : Graph of mean current scores (across whole sample of carers) on each of the 5 F.A. components of grief scales (obtained via factor analysis), plotted against time since DIAGNOSIS of the dementia.

None of these four graphs could be said to demonstrate - even if only to a very slight extent - the pattern of changes in the intensity of the components of grief over time which might be found in the ideal world as predicted by the traditional "stage" theory of anticipatory grief. The overall impression given is one of stability in the intensities of each component over time rather than the gradual emergence and disappearance of one component after another.

In addition, the graphs demonstrate that - taking the sample as a whole - some of the components (particularly I.S. component "Hope/Bargaining") were on average experienced only very little or not at all.

3. Correlations between Individual Grief Items with Time

It would appear from the analyses conducted so far that the only evidence of a clear staging of the components of anticipatory grief in this sample of caregiving relatives, was a significant decrease in F.A. component "Disbelief/Hope" with greater time since the carer first noticed something wrong with the sufferer. This was paralleled by a significant increase in the I.S. component "Acceptance".

Was there, then, any relationship between the individual grief items (rather than the components of grief) and the time over which grieving might be assumed to have occurred? Table 12.3 presents the correlation coefficients (Spearman's rho) between current scores on each individual grief item and time both since the carers first noticed something wrong and since the diagnosis of dementia in the sufferer.

Table 12.3

Correlation coefficients (Spearman's rho) between scores on each individual "nowadays" grief item and carers estimations of times since onset and diagnosis of dementia.

Grief scale item ("Nowadays")	Time: Onset	Time: Diagnosis
Feel shocked/dazed.....	-0.111....	-0.119
Think "It can't be ..."	-0.221**..	-0.180*
Pretend problems less to others.....	-0.015....	-0.013
Try to avoid emotion.....	0.003....	-0.011
Difficult talking to others.....	0.026....	0.058
Hope might get better.....	-0.218**..	-0.089
Think maybe doctors mistaken.....	-0.134....	-0.129
Consult media for cure.....	-0.017....	0.076
Make bargains.....	-0.048....	-0.023
Ask "Why?".....	-0.098....	-0.058
Think maybe something more to help..	-0.135....	-0.061
Think maybe contributed.....	0.095....	0.046
Guilty if enjoy self.....	0.108....	0.034
Irritable with others.....	-0.004....	0.046
Angry dementia happened.....	0.068....	-0.023
Angry with sufferer.....	-0.124....	-0.046
Angry with God.....	0.181*....	0.198*
Angry with formal help.....	0.022....	0.034
Preoccupied.....	0.023....	0.057
Look back.....	-0.037....	0.073
Wish for past.....	0.049....	0.184*
Wish sufferer could have done.....	0.019....	0.011
Wish could say.....	0.061....	-0.045
Upset when think of sufferer.....	-0.054....	0.010
Cry when think of sufferer.....	-0.036....	-0.010
Dpressed.....	-0.029....	0.054
Own life meaningless.....	-0.118....	0.022
Think calmly about what's wrong.....	0.006....	-0.159
Think calmly about future.....	0.132....	-0.085
Accept what's happened.....	0.230**..	0.109

* = p<.05 ** = p<.02

The intensities of few of the individual grief items were significantly related to the length of time over which grieving might have been expected to have occurred. A greater time since estimated onset of the dementia was associated with significantly less thinking "this can't be happening to the sufferer", less hope that the sufferer might get better, more

anger with God and more (intellectual) acceptance of the dementia. A greater time since diagnosis was significantly associated with only three individual grief items: thinking "this can't be happening to the sufferer"; anger with God; and wishing or yearning the sufferer could be the way they used to be.

4. How Separate Were the Components of Grief, One From Another?

If each component of grief emerges separately over time then one might expect the relationship between the intensities of the components at any one time (for example, "nowadays"), to be fairly small. In addition, one might perhaps also expect the defense of shock/denial/disbelief to be negatively related to expressions of emotion. The degree of the relationship between each of the current components of grief was therefore examined. The correlation matrix for the I.S. components of grief is detailed in Table 12.4, and that for the F.A. components in Table 12.5

Table 12.4
Correlation matrix: I.S. components of grief

	Shock/ Denial	Hope/ Barg.	Quest/ Anger/ Guilt	Preoc/ Un.Bus/ Despair	Accept
Shock/ Denial.....	1.000	0.329	0.212	0.423	-0.536
Hope/ Bargaining.....		1.000	0.273	0.409	-0.378
Questioning/ Anger/Guilt.....			1.000	0.638	-0.518
Preocc./Unfin Bus./Despair.....				1.000	-0.595
Acceptance.....					1.000

* = p<.05 ** = p<.01 *** = p<.001

Table 12.4 demonstrates that - while they can be separated via factor analysis - each of the components of grief, apart from "Acceptance" are positively related, and they are all negatively related to "Acceptance". Thus, rather than being shocked OR hopeful OR angry OR sad, if a caregiving relative is experiencing one of these emotions, it is likely that they will also be experiencing the other at the same time. The only either/or would appear to be between the variety of generally distressing emotional aspects of grief (represented by the first four I.S. components) in comparison with the final component of "Acceptance".

Table 12.5
Correlation matrix: F.A. components of grief

	Disbelief/ Hope	Deny	Protest	Yearn	Mourn
Disbelief/ Hope.....	1.000	0.173	0.172	0.318	0.347
				**	***
Deny.....		1.000	0.107	0.256	0.336
				**	***
Protest.....			1.000	0.272	0.420

Yearn				1.000	0.445
Mourn.....					1.000

** = p<.01 *** = p<.001

Table 12.5 demonstrates a positive relationship between the current intensities of most of the F.A. components of grief. "Disbelief/Hope", "Deny" and "Protest" were not significantly inter-related, although all three of these components were related to "Yearn" and "Mourn". There are no negative correlations on this table and thus no support for the hypothesis that "Disbelief/Hope" or "Deny" are incompatible with expressions of emotion (such as "Yearn" and "Mourn").

5. Comparison of Experiences "Nowadays" versus "Earlier on"

Each carer had been asked to state not only how they felt "nowadays", but also how they had felt "earlier on" during the period of the dementia. While "earlier on" did not signify any particular time, it allowed carers to report whether their experience of each individual grief item had increased, decreased, or remained about the same over time. Carer reports of the changes of individual grief items were analysed using Wilcoxon's Matched Pairs Test. The results of this analysis appear in Table 12.6.

Table 12.6

Significant differences (Wilcoxon's matched-pairs signed-ranks test: z) between scores on each "nowadays" individual grief item when compared with "earlier on".

Grief scale item	Number of carers who reported that over time item was:			z
	INCREASED	DECREASED	UNCHANGED	
Feel shocked/dazed.....	4.....	48.....	48.....	-5.57***
Think "It can't be ..."	5.....	34.....	60.....	-4.65***
Pretend problems less to others.....	2.....	25.....	72.....	-4.00***
Try to avoid emotion.....	14.....	24.....	58.....	-1.97*
Difficult to talk to others.....	3.....	23.....	73.....	-3.74***
Hope might get better.....	2.....	21.....	76.....	-3.51***
Think doctors maybe mistaken.....	0.....	10.....	87.....	-2.80**
Consult media for cure.....	0.....	5.....	93.....	-2.02*
Make bargains.....	2.....	4.....	91.....	-1.36
Ask "Why?".....	5.....	15.....	79.....	-2.07*
Think maybe more to help.....	7.....	17.....	75.....	-1.93
Think maybe contributed.....	1.....	2.....	96.....	-1.07

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Table 12.6 continued ...

Grief scale item	Number of carers who reported that over time item was:			z
	INCREASED	DECREASED	UNCHANGED	
Guilty if enjoy self.....	10.....	18.....	69.....	-1.87
Irritable with others.....	15.....	18.....	66.....	-1.15
Angry dementia happened.....	13.....	11.....	75.....	-0.34
Angry with sufferer.....	22.....	40.....	37.....	-3.22**
Angry with God.....	2.....	3.....	93.....	-1.21
Angry with formal help.....	8.....	19.....	72.....	-2.33*
Preoccupied.....	15.....	14.....	69.....	-0.24
Look back.....	17.....	9.....	70.....	-1.59
Wish for past.....	15.....	11.....	70.....	-0.89
Wish sufferer could have done.....	6.....	2.....	86.....	-0.63
Wish could say.....	15.....	1.....	75.....	-2.69**
Upset when think of sufferer.....	47.....	20.....	31.....	-2.28*
Cry when think of sufferer.....	37.....	19.....	42.....	-1.46
Depressed.....	39.....	17.....	42.....	-1.87
Own life meaningless.....	24.....	8.....	65.....	-2.03*
Think calmly about what's wrong.....	42.....	13.....	37.....	-4.44***
Think calmly about future.....	20.....	16.....	55.....	-1.37
Accept what's happened.....	45.....	3.....	44.....	-5.68***

* = p<.05 ** = p<.01 *** = p<.001

Approximately half the individual grief items were perceived by carers to have changed significantly over time, and closer examination shows them to occur within particular sections of the I.S. components of grief scales rather than randomly across all scales.

Carers were significantly more likely to report a decrease over time on all five of the "Shock/Denial" scale items ("Feel shocked/dazed", "Think 'It can't be

happening'", "Pretend to others that the problems are less than they really are", "Try to avoid emotion", and "Difficult talking to others"). They were significantly more likely to report a decrease over time on three of the four "Hope/Bargaining" scale items ("Hope might get better", "Think maybe doctors mistaken", and "Consult media for cure"). Carers were significantly more likely to report a decrease over time for one-third of the nine "Questioning/Anger/Guilt" items ("Ask 'Why?'", "Angry with sufferer", and "Angry with formal help"). A significant increase over time in one third of the nine "Preoccupation/Unfinished Business/Despair" items was reported ("Wish could say", "Upset when think of sufferer", and "Own life meaningless"). Finally, carers were significantly more likely to report an increase over time for two-thirds of the three "Acceptance" scale items ("Think calmly about what's happened", and "Accept what's happened")

(Within the F.A. components of grief scales, the pattern is a significant decrease over time in five of the seven "Disbelief/Hope" scale items; a significant decrease over time in all three of the "Deny" scale items; a significant decrease over time in only one of the five "Protest" scale items; no significant changes over time on any of the "Yearn" scale items; and finally, a significant increase over time in two of the four "Mourn" scale items.)

Perhaps of greater note is the high proportion of carers - across almost all the individual grief items - who reported that the intensity of their experience of that particular item had not changed over the time of the dementia. This is also demonstrated in the analysis which follows.

6. Correlations between Individual Grief Scale Items
"Nowadays" and "Earlier on"

The results from the comparison of intensities of the "nowadays" versus the "earlier on" individual grief items (above) indicated that rather than changing dramatically over time, the tendency was for the pattern of a carer's anticipatory grief to remain relatively stable. This was examined further by correlating the "nowadays" and "earlier on" scores for each individual grief item. The results of this analysis are detailed in Table 12.7.

Table 12.7
 Correlation coefficients (Spearman's rho) between scores on each individual grief item for "nowadays" and "earlier on".

Grief scale item	Spearman's rho ("nowadays" X "earlier on")
Feel shocked/dazed.....	0.377***
Think "It can't be ...".	0.440***
Pretend problems less to others.....	0.515***
Try to avoid emotion.....	0.564***
Difficult talking to others.....	0.665***
Hope might get better.....	0.715***
Think maybe doctors mistaken.....	0.408***
Consult media for cure.....	0.841***
Make bargains.....	0.939***
Ask "Why?".....	0.699***
Think maybe something more to help.....	0.652***
Think maybe contributed.....	0.869***
Guilty if enjoy self.....	0.693***
Irritable with others.....	0.682***
Angry dementia happened.....	0.749***
Angry with sufferer.....	-0.006
Angry with God.....	0.880***
Angry with formal help.....	0.686***
Preoccupied.....	0.753***
Look back.....	0.688***
Wish for past.....	0.804***
Wish sufferer could have done.....	0.907***
Wish could say.....	0.924***
Upset when think of sufferer.....	0.244**

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Table 12.7 continued ...

Grief scale item	Spearman's rho ("nowadays" X "earlier on")
Cry when think of sufferer.....	0.379***
Depressed.....	0.541***
Own life meaningless.....	0.702***
Think calmly about what's wrong.....	0.192*
Think calmly about future.....	0.469***
Accept what's happened.....	0.459***

* = $p < .05$ ** = $p < .01$ *** = $p < .001$

The scores for "nowadays" and "earlier on" are significantly related for every one of the grief scale items apart from "Angry with sufferer". This item might be regarded as the one over which caregiving relatives have least control - for example, however calm you are, it is difficult (although not impossible) to maintain that control in the face of extreme or disruptive sufferer behaviour.

III. SEARCH FOR THE RELATIONSHIP BETWEEN "COMPONENTS" OF ANTICIPATORY GRIEF AND TIME - ANALYSIS ON AN INDIVIDUAL BASIS

The problem with taking the entire sample as a whole when analysing the variation of the grief scales over time is that it may obscure individual differences. The possibility still remains that for those components of grief which it has been suggested in the "staging" literature have their peaks in the temporal middle of grief rather than at the outset or at the end-point, if different individuals experience the peaks of these components at slightly different times, the result of looking at the sample as a whole would be a considerable flattening of the peaks over time. It should be said that examination of the graphs of the

mean scores for each component of grief plotted against time (Figures 12.2 - 12.5 in this chapter, Section II) mitigates against the validity of this notion: the overall shapes of the plots do not tend to be curvilinear - neither like upturned cups nor even soup bowls. Instead, if smoothed out they would approximate horizontal lines.

1. Individual Graphical Representations of the
"Pattern" of Anticipatory Grief "Nowadays" versus
"Earlier On"

The only approach which really gets round the above problem is to analyse the carers on an individual-by-individual basis. An attempt was therefore made to represent the "picture" of each individual's changes in the intensities of the components of grief scales graphically.

It might be suggested that the ideal world scenario of the gradual emergence of one grief stage (or component) after another could be represented as a gradual movement of the peak (most intense) grief component over time. That is, initially it might be assumed that "Shock/Denial" would be the most intense component of grief, whereas later that component might have subsided and "Questioning/Anger/Guilt" would be the most intense component, and later still that might have subsided also and "Acceptance" would be the most intense component. This could be represented pictorially as diagrammed in Figure 12.6 (over page).

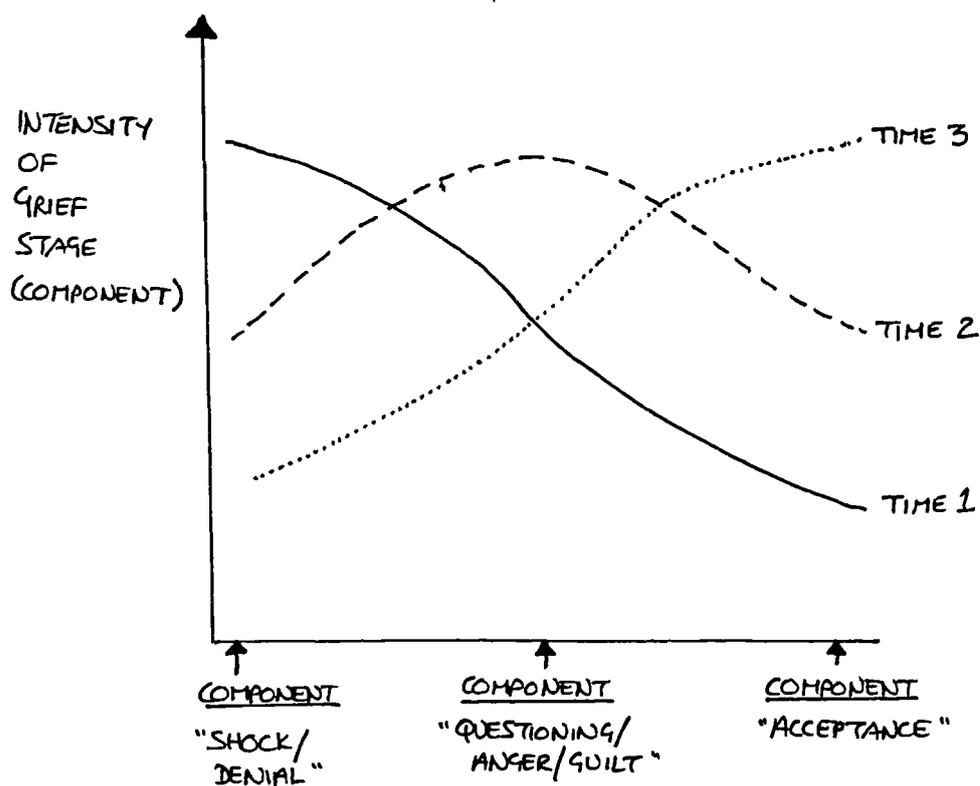


Figure 12.6 Idealistic representation of the gradual emergence of one grief stage (or component) after another, in a single individual.

This approach was taken on a subject-by-subject basis. Graphs were drawn representing the reported intensity of each of the I.S. components of grief for "nowadays" and "earlier on".

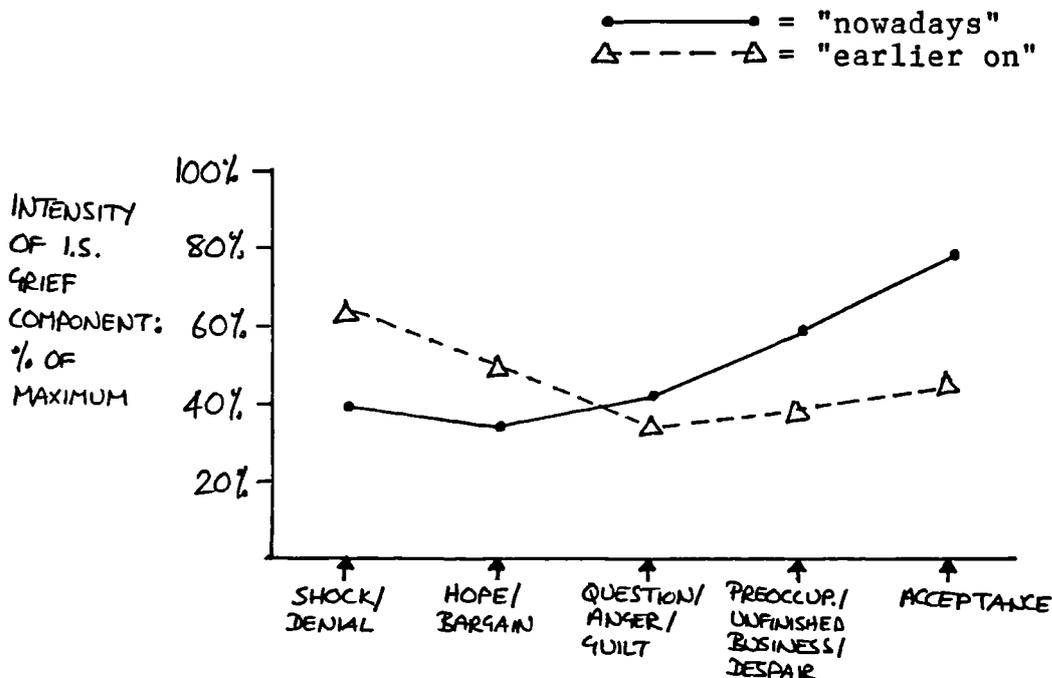
The vertical axis of the graphs represented the intensities of each I.S. grief component. In order to represent each component on the same axis (despite their different maximum total scores), intensity was presented as a percentage of the maximum possible total score. (While it might be argued that representing the scores as standard [z] scores rather than as percentages could have been used, this would have again meant merging an individual's score with that of the total sample. For example, a carer may score moderately highly on the "Shock/Denial" component for "nowadays" and very highly on the same component for "earlier on". Their overall "Shock/Denial" would have therefore decreased over time. However, if all carers' "Shock/Denial" component scores had decreased equivalently, then presentation via standard scores would give the impression that no change had occurred in the intensity of this particular component for this particular individual.)

The horizontal axis of the graphs represented each I.S. grief component, ordered as the literature on the temporal staging of grief might suggest (and as suggested by the evidence already presented with regard to those aspects of grief which had been reported to decrease or increase over time in the carer sample as a whole). This order was: firstly, "Shock/Denial"; secondly, "Hope/Bargaining"; thirdly, "Questioning/Anger/Guilt"; fourthly, "Preoccupation/Unfinished business/Despair"; and finally, "Acceptance".

Sample graphs are presented for three subjects.

Subject 87 : Mrs. Norden, caregiver to her moderately impaired, non-resident, 85 year old mother.

Intensities of initially-specified components of grief - "nowadays" and "earlier on"



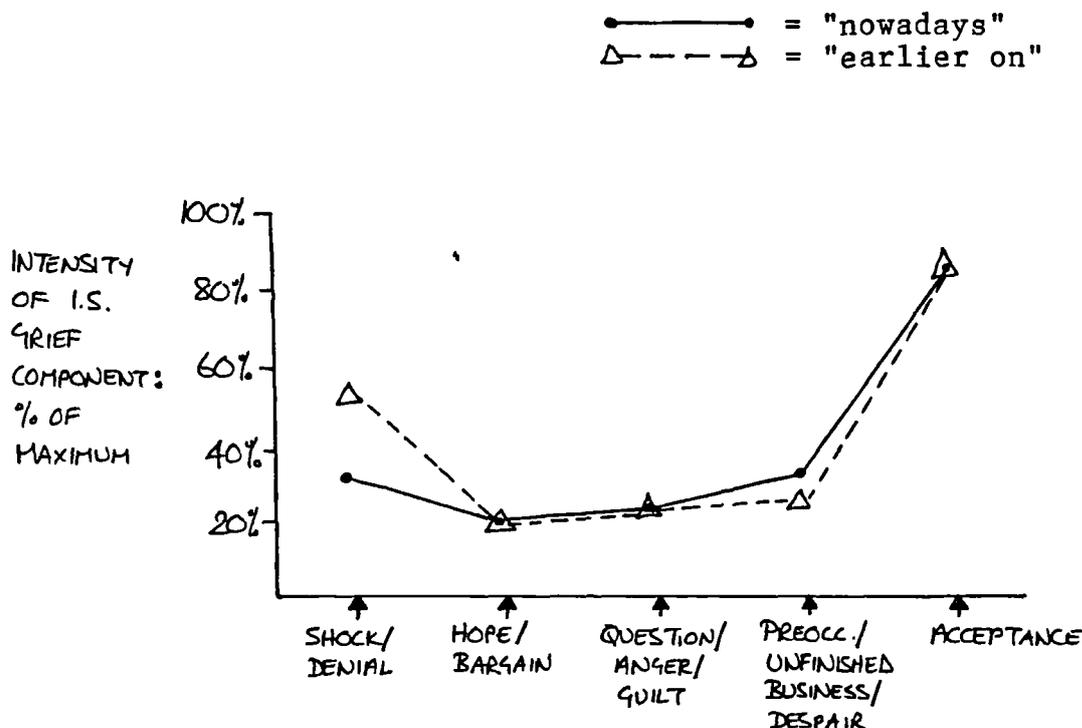
VERDICT = "STAGES"

Mrs. Norden described a pattern of emotions which might be predicted by the "staging" theory of anticipatory grief.

Her mother's senile dementia had been diagnosed by the G.P. 5 years previously, and this was a shock to Mrs. Norden because she didn't know of anyone else in the family who had suffered dementia. The sense of shock had disappeared with time; however, she continued to "bottle up" her feelings. Mrs. Norden's initial hopes that "everything would get better" had also disappeared - her acceptance of the dementia had therefore increased. She had never felt angry at the fact of the dementia, but throughout the illness had felt angry with her mother, and irritable with others whom she perceived as not understanding her problems as a carer. With time she was becoming increasingly preoccupied with her mother, wishing she could confide in her as she had done previously, and tearfully depressed, believing it would be preferable for her mother to die rather than to continue to exist as she was doing.

Subject 65 : Mr. Nichol, caregiver to his very severely impaired, co-resident, 62 year old wife.

Intensities of initially-specified components of grief
- "nowadays" and "earlier on"



VERDICT = "NO STAGES"

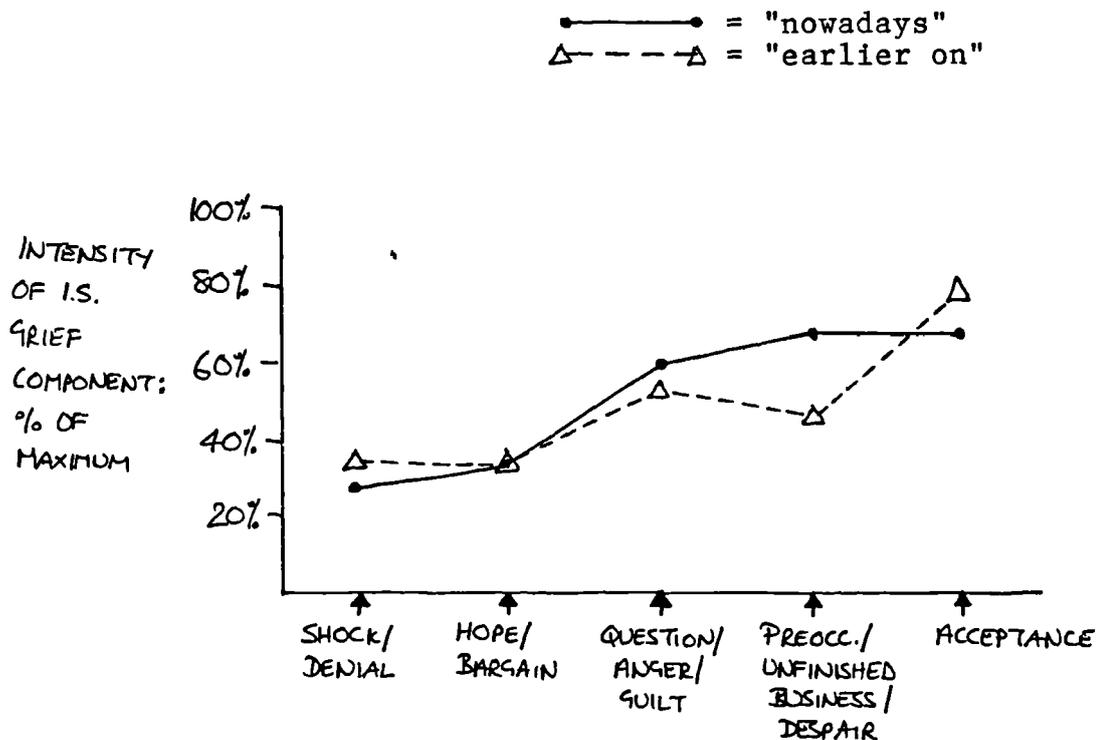
There was no evidence of progression through a number of emotional stages in this case.

Mr. Nichol had given up his work as an engineer to care for his wife, whose Alzheimer's disease had been diagnosed 5 years previously.

He described always having approached the situation as he had approached his daily work; as a problem to be accepted and solved without emotion. He described Alzheimer's as "just fate - if it happens to you, that's it". Although he said he had not been shocked by the diagnosis, until he had started to attend a relatives' support group he had tended to try to hide the fact of his wife's illness from others, and his coping technique had been to suppress emotion. This certainly seemed to be the case during the interview.

Subject 56 : Mrs. Lennox, caregiver to her severely impaired, resident, 79 year old husband.

Intensities of initially-specified components of grief - "nowadays" and "earlier on"



VERDICT = "UNSURE - STAGES"

Mrs Lennox and her daughter had diagnosed her husband's illness 3 years previously: "It was myself that found out he was forgetting things, and I started reading up about it". Her daughter, a health visitor, also sent her literature on Alzheimer's. Mrs. Lennox described herself as having been "hurt" rather than shocked by the illness. She became depressed, thinking back to their earlier married life, and for the first year "I cried and I cried and I cried", until she made a conscious effort to "pull myself together". However, she later became depressed again, this time because of her anxieties about her husband's future, and the daily grind of caring for him. Some anger, at the fact of the illness and at her own situation of being a carer had been present throughout.

Graphs for every subject can be found in Appendix Six.

Each of these graphs was inspected visually (but blind to carer details, since the identification was made via a code number) for "staging". If it appeared that over time there had been a definite decrease in grief components represented at the left-hand end of the horizontal axis plus a corresponding increase in the intensity of those represented at the right hand end (ie. a right-wards movement of the peak identifying the most intense grief component) the subject was classified as "stages". (For example, Subject No. 87 - Mrs. Norden, above.) If this pattern was clearly not present (for example, virtually no changes in emotional reactions over time, or increased shock/hope associated with decreased preoccupation/sadness/acceptance) the subject was classified as "no stages". (For example, Subject No. 65 - Mr. Nichol, above.) If the pattern fell between the two extremes, the subject was classified as "unsure - stages". (For example, Subject No. 56 - Mrs. Lennox, above.)

The result of this classification was as follows:

- 30 carers classified as "stages"
- 28 carers classified as "unsure - stages"
- 41 carers classified as "no stages".

(One carer - Subject No. 3 - could not be classified because she had only been given her husband's diagnosis the previous month and stated that her emotions had not changed over that time period.)

2. What Distinguished the Emotional and Behavioural Reactions of Those Carers Whose Reactions had Been Classified as "Staged" from Those Whose had Not?

In order to answer the above question, the scores for each of the I.S. components of grief were compared across the three groups of carers by means of a one-way analysis of variance. The three groups of carers comprised those whose reactions had been classified as "stages"; those whose reaction had been classified as "unsure stages"; and those whose reaction had been classified as "no stages". The results of this analysis appear in Table 12.8.

Table 12.8

One-way analysis of variance comparing subjects whose emotional reactions were categorised as "stages" (Group 1), "unsure - stages" (Group 2), and "no stages" (Group 3), on the five I.S. components of grief for both "earlier on" and "nowadays".

	Group 1	Group 2	Group 3	Sign. group diff.#	d.f.	F
<u>"EARLIER ON"</u>						
Shock/						***
Denial.....	15.97	15.08	9.64	1,2>3..	2,92	16.25
Hope/						*
Bargaining.....	8.48	7.42	5.78	1>2,3..	2,92	4.60
Questioning/						***
Anger/Guilt....	21.10	18.88	16.63	1>2,3..	2,92	8.70
Preocc/Unfin.						***
Bus./Despair...	23.38	22.12	16.06	1,2>3..	2,85	17.26

Acceptance.....	6.93	7.68	11.36	3>1,2..	2,88	29.39

* = p <.05 *** = p <.001

= Tukey honestly-significant difference method,
significance level set at .05

(continued over page ...)

Table 12.8 continued ...

	Group 1	Group 2	Group 3	Sign. group diff.#	d.f.	F
<u>"NOWADAYS"</u>						
Shock/ Denial.....	8.37	10.35	9.20		2,92	1.57
Hope/ Bargaining.....	5.66	7.39	5.58		2,92	2.97
Questioning/ Anger/Guilt....	17.40	17.85	16.00		2,92	1.09
Preocc/Unfin.						***
Bus./Despair...	22.86	24.92	18.06	1,2>3	2,85	9.55
Acceptance.....	11.61	10.74	11.03		2,90	0.84

* = p < .05 *** = p < .001

= Tukey honestly-significant difference method,
significance level set at .05

Results of the ANOVAS comparing group differences on the I.S. components of grief scales revealed that both the "stages" group and the "unsure - stages" group were currently experiencing greater "Preoccupation/Unfinished Business/Despair" than those whose reaction had been categorised as not staged. Earlier on in the illness the "stages" and "unsure - stages" groups had experienced significantly greater "Shock/Denial" and "Preoccupation/Unfinished Business/Despair" and less "Acceptance" than those whose reaction had been categorised as "no stages". In addition, the "stages" group had experienced significantly greater "Hope/Bargaining" and "Questioning/Anger/Guilt" earlier on than those whose reaction had been categorised as "no stages". This result validates the categorisation of the carers' reactions into the three groups of "stages", "unsure - stages" and "no stages" since the "stages" group were most likely to have experienced distress and least likely to have experienced acceptance earlier on.

3. "Stages", "Unsure Stages", and "No Stages" Classification: A Comparison of the Changes and Inter- Relationships Among the Grief Components Across the Three Groups

A number of the analyses which had been conducted on the whole sample of carers (see this chapter, Section II) were repeated on each of the three groups of carers ("stages", "unsure stages", "no stages") separately. The reason for this was to examine whether or not the changes over time and inter-relationships among the grief components differed across the three groups. Tables presenting the results of these analyses can be found in Appendix Seven. Because of the length of these tables, only brief summaries of the results are documented in this chapter.

INTER-RELATIONSHIPS BETWEEN THE COMPONENTS OF GRIEF

For each of the three groups of carers, correlation matrices showing the inter-relationships among the I.S. components and the F.A. components demonstrate a similar pattern to that of the sample as a whole. As with the whole sample, there were no significant negative correlations (apart from those between I.S. component "Acceptance" and the other I.S. components representing distress) for any of the three groups ("stages", "unsure stages", and "no stages").

COMPARISON OF EXPERIENCES "NOWADAYS" VERSUS "EARLIER ON"

Wilcoxon's matched-pairs signed-ranks test demonstrated the following: out of the total of 30 individual grief items, the "stages" group of carers reported significant ($p < .05$) changes on 13 items; the "unsure

stages" group reported significant changes on 11 items; the "no stages" group reported significant changes on 6 items.

CORRELATIONS BETWEEN INDIVIDUAL GRIEF SCALE ITEMS "NOWADAYS" AND "EARLIER ON"

Spearman's rho correlations demonstrated the following: out of the total of 30 individual grief items the scores for "nowadays" and "earlier on" were significantly ($p < .05$) related for 19 items among the "stages" group; and for 28 items among both the "unsure stages" and "no stages" groups of carers.

These results demonstrate that the group of carers whose reactions were classified as "stages" were most likely to report significant changes in the intensities of the grief items over time. In parallel with this, the intensities of the grief items for "nowadays" and "earlier on" were least likely to be significantly related for this group of carers.

4. What Distinguished Those Carers Whose Emotional Reactions had been Classified as "Staged" from Those Whose had Not?

In order to answer this, a comparison of the three groups of carers ("stages", "unsure - stages", and "no stages") was made in terms of the following variables:

- carer age.....	Via one-way analysis of variance
- sufferer age.....	
- total frequency of problem behaviours.....	
- overall sufferer change estimated by carer.....	
- time since onset.....	
- time since diagnosis.....	

(continued over page ...)

- carer sex.....
 - sufferer sex.....
 - carer-sufferer blood / role relationship.....
 - sufferer living arrangements...
 - carer perception of dementia...
 - carer perception of whether or not they had grieved.....
- Via chi-squared analysis.

The results of these analyses are presented in Tables 12.9 (below) and 12.10 (over page).

Table 12.9

One-way analysis of variance comparing subjects whose emotional reactions were categorised as "stages" (Group 1), "unsure - stages" (Group 2), and "no stages" (Group 3), on carer and sufferer age, total problem behaviour frequency, estimated overall sufferer change, and time since onset and diagnosis of dementia.

	Group 1	Group 2	Group 3	Sign. group diff.#	d.f.	F
Carer age (yrs).....	56.0	61.3	61.3	2,96	1	1.86
Sufferer age (yrs).....	75.0	78.1	74.3	2,96	1	1.89
Total freq. prob. behav.	37.8	36.2	32.6	2,94	2	2.05
Overall estim. sufferer change..	4.3	4.2	4.0	2,96	1	1.25
Time since onset (yrs).....	6.4	6.8	5.6	2,96	1	1.11
Time since diagnosis (yrs).....	4.5	3.4	3.2	1 > 3	2,92	3.77*

* = p < .05

= Tukey honestly-significant-difference method, significance level set at .05.

Table 12.10

Proportion (%) of subjects whose emotional reactions were categorised as "stages" (Group 1), "unsure - stages" (Group 2), "and no stages" (Group 3), in terms of carer and sufferer sex, carer-sufferer relationship, sufferer living arrangements, and carer perceptions of dementia and whether or not they had experienced grief.

	Group 1	Group 2	Group 3	χ^2
CARER SEX				
Male (N=26).....	27	31	42	0.34
Female (N=73).....	32	27	41	
SUFFERER SEX				
Male (N=41).....	24	30	46	0.80
Female (N=58).....	34	28	38	
SUFFERER RELATIONSHIP TO CARER				
Spouse / sibling (N=52).....	25	29	46	2.08
Parent / in-law (N=47).....	36	28	36	
SUFFERER LIVING ARRANGEMENTS				
Own / carers home (N=76).....	23	29	48	5.01*
Institution (N=23).....	43	26	31	
CARER PERCEPTIONS OF DEMENTIA				
Old age (N=11).....	0	73	27	9.2*#
Just an illness (N=62).....	4	67	29	
Horrible/worst illness (N=20).....	26	61	13	
CARER PERCEPTIONS OF HAVING GRIEVED				
Definitely grieved (N=54).....	36	33	31	6.9**
Unsure/definitely not (N=21).....	14	19	67	

* = $p < .10$ ** = $p < .05$
= after Yates' correction.

These results demonstrate that those carers whose emotions were categorised as falling into the staged pattern which might be predicted by "traditional" theories of grief differed from those who were not thus categorised as follows: a significantly longer time had passed since the diagnosis of dementia had been made, and they were significantly more likely to perceive themselves as having grieved. Differences which approached significance were that the "stages" group of carers tended to perceive dementia as a horrible or the worst illness rather than just an illness or a natural consequence of old age. They also tended to be related

to institutionalised sufferers. There was no difference between the three groups ("stages", "unsure-stages", and "no stages") in terms of the basic demographic variables of carer or sufferer age and sex, nor the blood/role relationship between carer and sufferer, nor the impairment or perceived overall changes which had occurred in the dementia sufferer.

5. What About Carers Who Had Only Become Aware of the Dementia Relatively Recently?

The possibility that significant changes in emotional reactions would be most likely within the first year or two following carer knowledge of dementia was investigated. The reason for this was that it might be argued that this period would be the time during which a carer should pass through a series of emotional reactions, and that following this, their "anticipatory grief" should be resolved. (Since "conventional" grief reactions have been demonstrated to occur in phases within the first year or so following a loss.) Table 12.11 (over page) presents the categorisation ("stages", "unsure-stages" and "no stages") of the emotional reactions of those carers who were interviewed two years or less since they had first noticed something wrong with the sufferer. (The majority of carers were interviewed a greater time than two years following the onset, so the numbers in the present analysis were very small.)

Table 12.11
 Categorisation of emotional reactions of carers interviewed less than two years since onset of dementia in the sufferer.

Categorisation: "Traditional" stages of grief	Number of carers
"Stages".....	2
"Unsure - stages".....	4
"No stages".....	5
(Not classifiable.....)	1)*

* = Subject 003, reported emotional reactions unchanged in one month since diagnosis of husband's dementia

The number of cases is too small for a chi-squared test of significant differences from random distribution to be conducted. However, it is clear that there is certainly no bias towards a "stages" classification for the emotional reactions of large proportions of those carers who had only become aware of the dementia relatively recently.

IV. STAGING - THE CARERS SPEAK FOR THEMSELVES

Did the carers perceive themselves to have passed through a number of emotional stages?

QUESTION : Some people would see the way that a person in your situation feels as changing over time - like passing through a series of stages, starting with the time when they first realise that ... has a problem. Are you able to describe stages in your reactions as a caregiver?

	<u>% of carers (N = 90)</u>
Yes.....	70%
Unsure.....	17%
No.....	13%

Although on the face of it these percentages may seem an impressive argument in favour of the staging theory of anticipatory grief, when carers commented on the "stages" which they perceived themselves to have passed through, it became obvious that they were not necessarily always limiting their answers to changes in their emotions, and several found the question very difficult to understand, even when it was rephrased. Of the 70 "Yes" answers, 65 in which the carers had commented more fully were later rated as to whether or not their description appeared to be that of the "traditional" stages of (anticipatory) grief. The results of this rating are shown in Table 12.12.

Table 12.12

Post-interview Ratings of Carer's Description of Emotional Reactions According to Whether or not they Accorded with the "Traditional" Stage Model of (Anticipatory) Grief (N = 65)

- 14%.... "definitely" fitted a traditional stage model (criterion = spontaneously describing "expected" increases or decreases in two or more components of grief).
- 46%.... "somewhat" fitted a traditional stage model (criterion = spontaneously describing "expected" increases or decreases in one component of grief).
- 40%.... did not appear to be describing anything approaching a stage model of grief.
-

One carer who described herself as experiencing changes in her emotional reactions during the time over which her husband had been ill was Mrs. Scott. Her descriptions of decreasing hope, increasing acceptance of the illness accompanied by sadness for past and anticipated losses would "definitely" fulfil the criterion for the traditional stage model of anticipatory grief: (over page)

I think it gets worse as time gets on - sadness you know, because at the start you're always thinking "Oh, he'll get better", or "They'll give him some treatment", or "They'll come up with something", you know. But you realise then that it's just an illness they can't do anything for, and I think it's then that you get really depressed about it ... and you know how he is just now, but you know that things are definitely not going to get better, they're going to get worse - I think this is what makes it worse, you know.

Another carer, Mrs. McAllister, also described a number of "traditional" grief stages in herself - initial denial followed by sadness and increasing reconciliation to the situation of her husband's dementia:

H.S: Are you able to describe stages in your reactions as a caregiver?

Mrs.McA: Yes, oh yes - to begin with, you sort of laugh at it, and then you get irritated when you can't get through to them, and latterly - well, just now, you just feel life to him is certainly not worth living - it's sorrowful to see anyone like that, but there's nothing we can do about it, you've just got to make things as easy as you can.

A few carers described their early reactions following the diagnosis to have been like an overwhelming rush of grief as they anticipated in imagination the almost immediate deterioration of the sufferer into a vegetative state. This was later followed by an acceptance and realisation that in fact the deterioration was going to be much more gradual. Mrs. McBride, for instance, spontaneously described how she had felt when she heard that her father had dementia:

H.S: Are you able to describe stages in your reactions as a caregiver?

Mrs.McB: That's right - I've accepted it now, but then (after diagnosis) it was really sad, just sad, not that I didn't accept it then, but even then it was even as though he had died then at the start - I knew he was never coming back ... but I have accepted it now - you would think he'd died at the start.

Similarly, Mrs. Nisbett referred to her immediate reaction to the diagnosis as being that her mother was going to die, which left her "washed out" of feelings for the future:

H.S: Are you able to describe stages in your reactions as a caregiver?

Mrs. N: Oh aye, I think I've changed, aye.

H.S: How?

Mrs. N: Well, before she came (to live with Mrs. N) I felt - I used to say to my husband I felt I didn't want to go down and see her, and since she's come up - oh, I just feel - it can just wash you out altogether of feelings - I mean, I still think - I still love her, but at the same time, as I say, you're wrestling with yourself, "Is it love or is it pity?" - I just don't know.

H.S: It was like a death sentence earlier, and then the emotional side went away?

Mrs. N: That's exactly what did happen, because I never thought she would live - I mean, even on her 72nd birthday we had this big party organised because I'm saying, "Oh, this'll be her last one, this is definitely it", and here, she's still with us. (Over two years later.)

The descriptions of 40% of those carers who did refer to themselves as having experienced stages in their reactions as a caregiver were rated as "somewhat" like the traditional staged anticipatory grief model. These carers spontaneously mentioned a clear increase or decrease in only one component, most usually that of acceptance or reconciliation. Mrs. Dodd, for example, said with regard to her father:

You sort of reconcile I think - you have to reconcile and come to the stage where you're saying, "I'm not worried anymore".

Similarly, Mrs. Gemmell described herself as having reached a stage of consciously distancing herself emotionally from her mother in order to cope with the situation:

I think I've had to switch off to a certain extent - I feel as if I couldn't get through the day of looking after her, the house,

shopping, etc, if I thought too deeply about my mother and the situation, because I think I would get emotionally upset and I couldn't cope then - I wouldn't like to feel that I would become too clinical about the thing, you know, I feel I've got to draw that line or I'm not helping anybody.

Mr. Yates described himself as changing to reach a stage where all hope for his mother's recovery had gone:

At the beginning I was full of hope that I was going to get her back, and gradually it came through to me, that I'm not going to get her back - I mean, she's not going to mentally come back now.

A small number of carers described their emotional reactions as having been staged, but cyclically rather than linearly. Mrs. Edgar, for example, said:

I go through different stages - right now I'm at a sort of hostile, angry stage, and then it'll pass off and I'll feel sorry ... Constantly at night trying to think of solutions keeps me awake, because you see, I'm the only family member ... your emotions run in a cycle.

Mrs. Saville also described a cycle of emotions (although not necessarily those of "traditional" anticipatory grief) with regard to her mother's dementia:

Mrs. S: It gets more and more trying - at the beginning - you go from being irritable to being sorry, guilty, and forgiving. You know what I mean, and you forgive them for making you feel like this and you want to be very loving towards them, then you go back to being irritable.

H.S: So it goes in a circle?

Mrs. S: That's right.

The descriptions of almost half the carers who had referred to themselves as having passed through stages in their reactions as a caregiver received a rating of not conforming to the traditional staged model of

anticipatory grief. Mr. Tower, for example, said:

Mr. T: Oh, you have to change, you have to change, because your way of living's changed entirely, I mean, I used to go out and come in just as I liked and just tell Brenda, "Oh, are you staying in tonight", or, "Are you going to such and such a place, well, I'm going out with Frank tonight".

H.S: But have your feelings changed?

Mr. T: Oh yes, yes, yes, definitely.

H.S: How?

Mr. T Well, I canna' say any more than I said just now - you miss your freedom ...

Similarly, Mrs. Kelly's descriptions of increased anxiety and introspection would not fulfil the criteria of a staged anticipatory grief reaction in response to her mother's dementia:

H.S: Are you able to describe stages in your reactions as a caregiver?

Mrs. K: Oh aye, right enough, I feel different myself, aye, oh I've changed an awful lot - I feel just now I'm always nervous with the kids, going out crossing roads and everything like that now - I'm uneasy now, I don't know what it is, aye, you just change, I think you more or less grow up I think, and you really think, "What's it all about?" when you look at it and that.

Thirteen percent of the total sample of carers described themselves as not having passed through a series of emotional stages in their reactions as a caregiver. Mrs. Carr, for example, stated:

I think I've just been concerned all the time - I don't see how you could change.

Similarly, Mrs. Abbott said, in answer to the "stages" question:

No, I've just felt the same about it all, you know, I've just tried to accept it and make the most of what we've got.

While Mrs. Cameron could describe stages in her husband's dementia, she could not describe stages in her own reactions:

Mrs. C: The only difference I know is the deterioration from when it started.

H.S: Have you noticed different stages in you?
Mrs. C: No - I don't know, you try to be practical,
because you come to the conclusion that it's
inevitable, you've got to accept it, because if
you wouldna' you'd be round the bend.

The above comments and examples demonstrate that the perceptions of the carers themselves with regard to the possibility that they had experienced stages in their emotional reactions were very varied. Some could distinguish stages, others could not, and yet others found the question difficult to understand and answer. Since the contents of the carers' own comments were used as the criterion as to whether or not they had experienced stages, it may be that a greater number had actually done so (but without adequately describing them) than would appear from the above analysis.

V. DISCUSSION

1. "Staging" - A Discussion of Results From the Present Study Within the Background of Previous Reports

The data from the present study was scoured for evidence of the phasic emergence of distinct emotional "stages". The results which emerged from this exercise suggest that taken as whole, there was considerable stability of the emotional and behavioural reactions over time. In addition, rather than experiencing just one distinct reaction at a time, carers tended to experience either all the generally distressing aspects of grief or else acceptance. Finally, there was evidence that a sub-group of approximately one-third of the sample of carers had experienced a pattern of reactions which corresponded to some extent with the "traditional" stage model of grief or anticipatory

grief [for example, Parkes, 1970; 1986; Kubler Ross, 1970].

The evidence of the present study therefore suggested that while a proportion of caregiving relatives do experience some sort of staged reaction, most do not. This contrasts with much of the literature describing carer reactions as following a neat series of distinct emotional and behavioural stages. (Chapter Six in Part One of thesis.) To recap briefly, such papers include the following. Kapust [1982] describes the reactions of the family members of a dementia sufferer as changing over time as the dementia progresses. She suggests initial denial, followed by anger and frustration, and finally depression as the family mourn the loss of the still biologically alive dementia sufferer. Teusink and Mahler [1984] actually relate the family responses to Alzheimer's disease to the stages of family anticipatory grief suggested by Kubler Ross. They list these stages as denial, overinvolvement, anger, guilt, and finally, resolution or acceptance. Enlow [1986] also links her own reactions to the severe mental and physical impairments in her elderly institutionalised mother to the stages of death preparation suggested by Kubler Ross. None of these reports is the result of a study which specifically set out to examine or assess the reactions experienced by the relatives of dementia sufferers. Similarly, the available descriptions of "anticipatory grief" in the parents of dying children as following a clear pattern of the sequential emergence of distinct phases are all based on observational studies: no available study has actually set out to examine the validity of this notion. In any case, even the much quoted descriptions by Kubler Ross [1970] which she warns are not intended as a complete study of the psychology of the dying, conclude by

noting that "these stages do not replace each other but can exist next to each other and overlap at times" [p.236].

And what of studies of conventional grief? There is certainly a great deal of descriptive literature which describes "staging" in the normal grief reaction. However, much of this is simply regurgitation of previous accounts and is not based on the results of new research. Closer examination of this literature demonstrates that while affirming that the normal grief process is staged, the majority of authors offer themselves a let-out clause by also stating that it may not be. Consider the following examples.

"... loss of loved object leads to a behavioural sequence which, varied though it be, is in some degree predictable ... Not that either sequence runs a smooth unvarying course. On the contrary both behaviour and feeling oscillate violently, especially in the early phases ..."
[Bowlby, 1961, p.331]

" ... grief is a phasic process although the transitions from one phase to another are seldom distinct and features from one phase of grief often persist into the next."
[Parkes, 1970, p.465]

"The bereavement reaction may be described as comprising a series of phases, representing some of the processes of adaptation to loss. It must be acknowledged, however, that any such phases are not clear cut or fixed, and that the bereaved may pass backward and forward among them or may indeed become locked in one or another, partially or completely."
[Raphael, 1984, p.33]

The "contemporary formulation" of grief as comprising "multiple dimensions of distress that evolve somewhat independently over time" is "based on intensive follow-up on a small number of bereaved women" [Jacobs, 1988, p.132]. What Jacobs is describing is presumably Parkes' [1970] longitudinal study of the reactions of 22 London

widows. Jacobs and Douglas [1979] offer the following criticisms of Parkes' work - which included 94 subjects studied on the basis of psychiatric chart reviews plus 43 who were directly studied, half of whom were psychiatric patients and very few of whom were men or were elderly. Firstly, this sample is hardly representative of the general population. Jacobs and Douglas note secondly that Parkes' conclusions on the existence of the phase of despair and sadness remain in the domain of strong clinical impressions and convictions because 'it has proved difficult to demarcate using systematic, reliable observations. (They describe this as "the empirical deficiencies in this area of his work" [p.166].) Thirdly, "the various features of grief and progression of changes he described were not universal: most were recorded as occurring in 50%-75% of subjects in varying intensities" [Jacobs and Douglas, 1979, p.167].

The consensus among previous reviews therefore seems to be that it would be very difficult to find evidence of clear "staging" by examining the reactions to loss or anticipated loss in a large sample of people since their emotions and behaviours would be oscillating backwards and forwards among all the possible "phases". This, of course, is exactly what was found in the present study. Taking the sample as a whole, there was very little evidence of staging. There was slight - but significant - evidence of decreased "Disbelief/Hope" and increased "Acceptance" over time within the sample. Although these relationships were statistically significant, examination of graphical presentations of the data shows that the changes in intensity of these two components over time are certainly not dramatic. (Even the comparison of the intensities with which each grief item was experienced "nowadays" versus "earlier

on" which demonstrated statistically significant changes in the items representing shock/disbelief/denial/hope and also acceptance demonstrated that large numbers [generally between one half and three quarters] of the sample stated that their reactions in these areas had not changed over time.) Nor were the distressful components of the emotional and behavioural reactions within the present sample (ie. those apart from "Acceptance") mutually exclusive. These carers were not therefore even oscillating back and forth; they were experiencing several reaction components simultaneously. (Or possibly they were oscillating back and forth: if both angry protest and sadness were experienced "sometimes", maybe they were experienced at different times. This possibility was not examined in the present study, but the comments of the carers suggest that it is unlikely.)

Jacobs [1988] cites the only available study which actually attempted to explore hypotheses about the evolution of emotional distress following bereavement over time. Jacobs notes that these hypotheses suggest that "when one dimension of grief is prominent, other dimensions of grief are less important or less likely to be reported" [1988, p.133]. This was tested by correlating the Bereavement Items (BI- Jacobs, Kosten and Kasl et. al. [1987]) "numbness-disbelief" and "separation distress" scale scores. Although it might be predicted that the defensive effort represented by "numbness-disbelief" would be incompatible with acceptance of the loss and expressions of sadness, despair and disorganisation represented by "separation distress", the two scales actually correlated positively ($r = 0.61$). This result corresponds with that of the present study which found significant positive relationships between the four I.S. components

which represented distress, and in addition, among most of the F.A. components. It also suggests that the concept of staging in grief is neither so clear nor so simple as is conveyed by many writers.

In addition, as was noted in the previous chapter, the caregivers of dementia sufferers are not experiencing their anticipatory grief reactions in a vacuum. Any emotional or behavioural reactions of grief in this group will be constantly "contaminated" by their reactions to the tasks and other objective burdens associated with caring. Not only this, but the progressive nature of dementia is such as may spark off a series of little griefs one after another. A carer may just have begun to accept the fact that their previously fastidious relative now needs constant prompting to get washed at all, when that dementia sufferer begins to exhibit urinary incontinence. The carer may just have begun to accept the fact of the incontinence when the dementia sufferer begins to be unable to recognise them reliably and thus confuses them with someone now deceased, or orders them to leave the house. And so it goes on. Even though they may have been forewarned by reading information packs, watching TV, or attending a relatives' support group, it is likely that each additional impairment (usually perceived as "a step down") will be received with some shock: "I knew this could happen to people with dementia - but to MY mother/husband?"

Given the above, it might come as quite a surprise that any evidence of stages in the emotional reactions of the caregivers in the sample was found at all. However, 30% did fulfil the criteria which had been set for such a categorisation. The requirement had been that on the graphs representing the "pattern" of their reactions,

there should have been a definite decrease in grief components represented at the left hand end of the horizontal axis (shock/hope) plus a corresponding increase in the intensity of those represented at the right hand end (sadness/acceptance). It could be argued that this criterion of "staging" was fairly lax, given that it only required changes in the intensity of the beginning- and end-points of the carer's reactions. However, narrowing the criteria further would have eliminated almost every carer from the "stages" group.

It is interesting that those carers whose emotional and behavioural reactions had changed over time in this way were also more likely to be those who believed that their reactions had been like grief. Could it be that it is only the sub-group of the caregiving relatives of dementia sufferers who perceive the illness in terms of loss and future loss who experience anticipatory grief, and who in turn are subject to a degree of staging in their emotional and behavioural reactions as time goes on? (Or at least an increase in acceptance with a corresponding decrease in shock/disbelief/denial/hope.) There was no evidence of a predominance of "staged" reactions among the very small number of carers who were interviewed two years or less since the onset of dementia. (This is not surprising given the finding that the "stages" group tended to be those who were interviewed a greater time since diagnosis of the dementia. However, it is surprising given previous studies which have suggested that the stages of "anticipatory grief" occur over a period of a few months, after which resolution or calm acceptance is in evidence. For example, Natterson and Knudson [1960] suggest this process takes about four months in mothers of fatally ill children.)

The numbers comprising the "stages" group tended to account for those among the total sample who reported changes in the intensities with which the grief items representing shock/disbelief/denial/hope and acceptance were experienced "nowadays" versus "earlier on". In contrast, those whose reactions were not categorised as "stages" tended to account for the one half to three quarters of the total sample who stated that their reactions in these areas had not changed over time. This latter group also tended to be somewhat more likely to be those for whom the intensities of the "nowadays" grief scale items were significantly and positively related to their intensities "earlier on". Once again, however, it should be stated that this result is hardly surprising - given the criteria on which the categorisation into "stages", "unsure - stages" and "no stages" was made, these results really only serve to validate that categorisation.

A much more interesting result would have been if the pattern of inter-relationships between the "nowadays" components (either I.S. or F.A. components) had been very different across the three groups. In particular if the intensities of those components representing the traditionally prescribed initial stages of grief (shock /disbelief/denial/hope) had been significantly and negatively related to the intensities of those components representing the later stages (anger/ yearning/despair) for the group whose reactions were categorised as "stages". This result did not occur. Inspection of the results demonstrates that the pattern of inter-relationships between the grief components were not very different across the three groups. Nor were there any significant negative relationships between the intensities of the components - apart from

those between the components representing distress and "acceptance".

2. Stages?

The weight of evidence from the present study therefore suggests that there is a background of approximately a third of carers whose shock or disbelief or hope is greater earlier on in the process of their relatives' dementia and whose acceptance of the illness and the future increases over time. This was the only evidence of "staging". Against this background are at least as many carers who reported no significant changes in these "beginning-" and "end-point" components of their anticipatory grief reaction over time. There was no evidence of the phasic emergence of components representing anger or yearning or sadness. They did not emerge towards the temporal "middle" of carer anticipatory grief - rather, they tended to remain at a stable level throughout the process. There was certainly no suggestion of a wholesale progression through a series of stages in the emotional and behavioural reactions of the current sample caregiving relatives, with the end-point being that of resolution.

The present results do not wholly correspond to those of previous observational longitudinal studies or anecdotal reports of the phasic emergence of stages of grief or anticipatory grief. The results do, however, correspond to the only available attempt to investigate the inter-relationships between the components of grief. It may therefore be suggested that the emergence of the stages of anticipatory grief does not follow the clear cut pattern which may be indicated by an uncritical reading of previous reports. Indeed, the results of the present study show little

evidence for the existence of emotional or behavioural stages in the reactions of the majority of the caregiving relatives of dementia sufferers. However, it is also possible either that the present results relate only to the experiences of the caregiving relatives of dementia sufferers, or that these relatives do experience staged reactions which were not picked up because of the nature of the present study. (For a discussion of methodological issues which emerged in the present study, the reader is referred to Chapter Eighteen.)

VI. SUMMARY

This chapter has presented analyses which sought to answer whether the components of anticipatory grief in the caregiving relatives of dementia sufferers emerged in a phasic or staged fashion. Analyses were conducted on both a whole sample and an individual-by-individual basis.

Analysis of the whole sample suggested a slight but statistically significant increase in I.S. component "Acceptance", and a parallel decrease in F.A. component "Disbelief/Hope" with time. Graphical representations of the intensities of the grief components demonstrated their stability rather than their phased emergence over time. High proportions of carers reported no change in the intensities of individual grief items over time. The tendency was for the intensities of all the grief components representing distress to be positively associated with each other, and negatively associated with "Acceptance".

Analysis on an individual basis suggested that approximately one-third of the sample had experienced decreased shock, denial, hope or bargaining, accompanied by increased preoccupation, sadness or acceptance over time. This group of carers was more likely to believe that they had experienced grief. It was suggested that the experience of grief associated with the perception of losses due to dementia may have triggered a staged emergence of the components of the emotional and behavioural reactions in these caregiving relatives.

While 70% of the sample expressed the belief that they had experienced stages in their reactions over time, very few of their descriptions corresponded to the "traditional" stage model.

These results were discussed, and compared with previous accounts of the presence of stages in both anticipatory and conventional grief reactions. Empirical studies have not all yielded clear evidence of stages in the grief reaction. Close examination of previous accounts revealed that authors tend to state both that grief may and that grief may not occur in stages. Thus, the results of the present analysis did not diverge significantly from those of all previous studies. It was suggested that for the majority of caregiving relatives, anticipatory grief does not occur in the clear stages outlined in previous accounts.

CHAPTER THIRTEEN

EXAMINATION OF THE RELATIONSHIP BETWEEN THE SEVERITY OF CAREGIVER ANTICIPATORY GRIEF AND INDIVIDUAL CAREGIVER OR SUFFERER CHARACTERISTICS

I. INTRODUCTION

The analyses presented in the previous chapter suggested that time since onset or diagnosis of dementia in the sufferer had little impact on the pattern of anticipatory grief experienced by caregiving relatives. The aim of the present chapter is therefore to investigate whether certain characteristics of the carer, sufferer, or their relationship impact on the pattern of the caregiver's anticipatory grief. This can be conceptualised as an attempt to identify the carer who is "at risk" for more intense or distressing reactions to dementia in their relative. This parallels previous studies which have attempted to identify those who are at risk for more intense or prolonged grief following bereavement.

Stepwise multiple regression analyses were performed in an attempt to answer the question of whether the nature or the severity of caregiver anticipatory grief was related to individual caregiver or sufferer characteristics, or to the carer-sufferer relationship.

II. PREDICTORS OF CAREGIVER ANTICIPATORY GRIEF AT THE TIME OF THE INTERVIEW

A series of identical analyses were conducted for each separate grief component (both for the I.S. components

- initially specified, and for the F.A. components - obtained via factor analysis). In the main the variables which were entered into the regression equations were those characteristics which have been demonstrated to have an impact on the normal post-bereavement grief process. Also included were additional sufferer behaviour characteristics which have been demonstrated to have an impact upon the subjective burden of caregivers. (The codings for each of these variables as they were entered into the regression equations can be found in Appendix Eight)

The variables comprised the following:

CARER CHARACTERISTICS EQUATION

(1) Carer gender; (2) Carer age; (3) Carer religiosity; (4) Carer learning of diagnosis and prognosis; (5) Carer general knowledge of dementia; (6) Carer overall perception of dementia.

SUFFERER CHARACTERISTICS EQUATION

(1) Sufferer gender; (2) Sufferer age; (3) Sufferer living arrangements; (4) Time since onset of impairments; (5) Time since diagnosis of the dementia; (6) Overall change in sufferer perceived by carer; (7) Most important sufferer change perceived by carer; (8) Sufferer ability to recognise carer

SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION

(1) Total frequency of problems from behavioural domain "Depend"; (2) domain "Can't do"; (3) domain "Incontinence/Hygiene"; (4) domain "Apathy"; (5) domain "Disturb"; (6) domain "Demand"

CARER-SUFFERER RELATIONSHIP EQUATION

(1) Blood/role relationship; (2) Quality of premorbid carer-sufferer relationship; (3) Quality of current carer-sufferer relationship; (4) Change in quality of carer-sufferer relationship

Tables 13.1 and 13.2 show the results of the "final" round of stepwise multiple regression analyses - that

is, those which entered the variables which had been found to be significant predictors of the grief component in question via the first round of analyses. (The method of conducting two separate "rounds" of regression analyses is discussed in Chapter Nine, "Data Analysis". The full results of the "first round" of multiple regression analyses can be found in Appendix Nine). For greater ease of understanding in the case of those (mainly "dummy") variables, where it is not immediately obvious, the direction of the relationship in the equation is explained in the table, for example "(poorer) ...".

Tables 13.1 and 13.2 (over page) demonstrate that different characteristics of both carer, sufferer, and their relationship predicted the intensities of different components of grief. However, it should be noted that the predictive strength of the variables was generally small.

Examination and comparison of the two different sets of components of grief (which it will be recalled are comprised of slightly different combinations of the individual grief items) suggest the following points.

Carers who were related to younger sufferers and those who were interviewed a shorter time since they had noticed something wrong with the sufferer were most likely to be disbelieving of the diagnosis, unable to accept what had happened, and hopeful for the sufferer's future prognosis. Carers who were related to spouse or sibling sufferers were more likely to be shocked at their behaviour, while those carers who were related to more demanding sufferers and those who were themselves older, were more likely to play down the problems and bottle up their emotions.

Table 13.1

Stepwise multiple regression analyses - "predictors" of I.S. grief components at the time of the interview ("nowadays")

	<u>Adjusted R²</u>	<u>Beta</u>	<u>F-value</u>
<u>I.S. SHOCK/DENIAL</u>			
Blood/role relationship: Sufferer			**
= spouse or sibling.....	0.07	-0.27	7.89
Behaviour problem domain			***
"Demand".....	0.12	0.24	7.47
<u>I.S. HOPE/BARGAINING</u>			
None of the variables entered into any of the regression analyses were found to have significant predictive value.			
<u>I.S. QUESTIONING/ANGER/GUILT</u>			
Carer perception: Dementia			***
= horrible/worst illness.....	0.30	-0.48	42.67
Quality of current relationship.....	0.36	-0.27	28.97
<u>I.S. PREOCCUPATION/UNFINISHED BUSINESS/DESPAIR</u>			
Carer perception: Dementia			***
= horrible/worst illness.....	0.13	-0.29	15.60
Carer religiosity: Faith/belief			***
no help or no faith/belief.....	0.16	0.22	10.72
Quality of current relationship.....	0.20	-0.22	9.47
<u>I.S. ACCEPTANCE</u>			
Carer perception: Dementia			**
= just illness/old age.....	0.08	0.32	9.90
(Greater) Carer general knowledge of dementia.....	0.11	-0.20	7.22

* = p<.05 ** = p<.01 *** = p<.001

Table 13.2

Stepwise multiple regression analyses - "predictors" of F.A. grief components at the time of the interview ("nowadays")

	<u>Adjusted R²</u>	<u>Beta</u>	<u>F-value</u>	
<u>F.A. DISBELIEF/HOPE</u>				
Time since onset of dementia.....	0.04...	-0.20...	4.80	*
Age of sufferer.....	0.07...	-0.20...	4.55	*
<u>F.A. DENY</u>				
Age of carer.....	0.09...	0.30...	11.05	**
Behaviour problem domain "Demand".....	0.13...	0.22...	8.57	***
<u>F.A. PROTEST</u>				
Carer perception: Dementia = horrible/worst illness.....	0.33...	-0.53...	50.54	***
Quality of current relationship.....	0.36...	-0.19...	29.16	***
Carer age.....	0.38...	-0.16...	21.39	*
<u>F.A. YEARN</u>				
Carer religiosity: Faith/belief no help or no faith/belief.....	0.04...	0.20...	5.28	*
Carer perception: Dementia = horrible/worst illness.....	0.07...	-0.19...	4.70	*
<u>F.A. MOURN</u>				
Carer perception: Dementia = horrible/worst illness.....	0.13...	-0.28...	15.60	***
Quality of current relationship.....	0.20...	-0.27...	13.13	***
Behaviour problem domain "Demand".....	0.23...	0.19...	10.68	***

* = p<.05 ** = p<.01 *** = p<.001

Younger carers, those whose perception of dementia was that it was a very horrible or the worst possible illness, and those whose current relationship with the sufferer was poorer were more likely to experience the "Protest" items of the I.S. grief component "Questioning/Anger/Guilt" (ie. angry at others, God, themselves, and the illness).

Those carers who either found their faith or belief no help or else had no faith or belief, and those whose perception of dementia was that it was a very horrible or the worst possible illness, were more likely to experience "Yearning" (ie. looking back and wishing for the past, guilt at continuing their own lives). Those carers whose perception of dementia was that it was a very horrible or the worst possible illness, those whose current relationship with the sufferer was poor, and those caring for more demanding sufferers were more likely to experience the "Mourn" (ie. upset, crying, depression, own life meaningless) items of the I.S. grief component "Preoccupation/Unfinished Business/Despair".

Finally, those carers who perceived dementia as just what happens when you get old or as just an illness, and those who had greater general knowledge about dementia were more likely to be calm and accepting of the illness.

III. PREDICTORS OF EARLIER CAREGIVER REACTIONS TO THE DEMENTIA

Since there was some evidence (see previous chapter) of decreased disbelief/hope/denial and increased acceptance over time, it was decided to conduct

multiple regression analyses on the "Earlier on" scores for those components which might occur most prominently at either end of the grief process in some caregiving relatives. That is, for the following:

I.S. grief components - "Shock/Denial"

- "Acceptance"

F.A. grief components - "Disbelief/Hope"

"Deny"

It would not have been reasonable to enter all the variables used in the "nowadays" equations into these analyses, since not all of them could be assumed to have been present "earlier on". The variables which were entered into the multiple regression analyses for "earlier on" therefore comprised the following:

CARER CHARACTERISTICS

- (1) Carer gender;
- (2) Carer age;
- (3) Carer religiosity;
- (4) Carer learning of diagnosis: Sudden versus gradual.

(Carer general knowledge and perceptions of dementia were not included since they could have changed over the time period between "Nowadays" and "Earlier on". While it might be argued that carer - and indeed sufferer - age would also have changed over those period, it is reasonable to assume that relative ages would be roughly similar: for example, those carers who were younger "earlier on" would also be among the younger ones "nowadays".)

SUFFERER CHARACTERISTICS

- (5) Sufferer gender;
- (6) Sufferer age.

(Sufferer living arrangements and impairment variables were not included since they could have changed over the time period between "Nowadays" and "Earlier on". Obviously, time since onset and diagnosis were not included either.)

CARER-SUFFERER RELATIONSHIP CHARACTERISTICS

- (7) Carer-sufferer blood/role relationship;
- (8) Quality of premorbid carer-sufferer relationship.

(Change in carer-sufferer relationship and quality of current relationship were also removed from the equation, once again on the grounds that they might have changed over the time period between "Nowadays" and "Earlier on".)

Table 13.3 (below) shows the results of the stepwise multiple regression analyses which entered the above variables into the equation in order to assess their influence on some of the "Earlier on" components of grief.

Table 13.3
Stepwise Multiple Regression Analyses - "Predictors" of Grief Components "Earlier On" in the Illness.

	<u>Adjusted</u> <u>R²</u>	<u>Beta</u>	<u>F-value</u>
<u>I.S. COMPONENT SHOCK/DENIAL</u>			
Carer learning of diagnosis and prognosis (sudden).....	0.11...	-0.35...	13.90 **
<u>I.S. COMPONENT ACCEPTANCE</u>			
Carer learning of diagnosis and prognosis (gradual).....	0.09....	0.33...	10.37 **
Carer age.....	0.13....	0.50....	8.22 ***
Blood/role relationship: Sufferer = parent or parent-in-law.....	0.17....	0.35....	7.57 ***
<u>F.A. COMPONENT DISBELIEF/HOPE</u>			
None of the variables entered into the equation were found have significant predictive value.			
<u>F.A. COMPONENT DENY</u>			
Carer learning of diagnosis and prognosis (sudden).....	0.04....	-0.22....	4.99 *

* = p<.05 ** = p<.01 *** = p<.001

Clearly - but perhaps not surprisingly - the way in which the carer learned the diagnosis was the most significant predictor of whether they reacted with

shock or denial (after learning suddenly), or acceptance (after learning gradually) earlier on in the process of the sufferer's dementia. Additional factors which were associated with acceptance earlier on in the illness were an older carer who was looking after a parent or parent-in-law: it appears to be more acceptable and "natural" for one's elderly parents to develop dementia than one's spouse or sibling.

IV. DISCUSSION

Only one previous study has attempted to investigate the factors which identify those likely to experience more intense anticipatory grief. Welch [1982] found significantly higher mean grief scores in relatives of adult cancer patients to be associated with three factors. Firstly, with a patient who was being treated in a specialised oncology unit; secondly, with a feeling of panic that something might happen to the patient while they were at home; and thirdly, with crying about the diagnosis. Lower mean grief scores were associated with an elderly patient, and having previously lost a relative to cancer.

The risk factors for an increased intensity or poor outcome to conventional grief have been identified as follows: being younger, possibly being male, possibly a "clinging" or "dependent" personality, an unhappy relationship, death of a child (rather than a parent), the prevention of the expression of emotion or review of the past by those supporting the bereaved, and a severe early grief reaction. (See Chapter Three.)

No available study has attempted to systematically investigate the risk factors for particular aspects or

components of anticipatory grief. However, this was the approach which was taken in the present research.

1. "Predictors" of Initial Reactions to the Dementia Diagnosis

Turning to the present study, the factor which was most significantly related to whether a caregiver reacted with initial shock or denial as opposed to acceptance was the way in which they had learnt the diagnosis. As would be expected, initial shock or denial was more likely in those who learnt the diagnosis and prognosis suddenly. This group of carers had generally been given the diagnosis and prognosis by a professional - in the vast majority of cases, a doctor. Although prior to the news this group had been aware of impairment in the dementia sufferer, they had generally attributed it to a cause other than dementia which did not have the same prognostic implications (for instance, depression or general aging). In contrast, those carers who reacted with initial acceptance were those who learnt the diagnosis and prognosis gradually. Usually they had some basic background knowledge of the effects and process of dementia, perhaps from previous experience with a dementia sufferer, perhaps from the media coverage of the illness. Their observations of their dementing relative had led them to gradually realise and assimilate that what their relative was suffering from was likely to be dementia. The breaking of the news by a professional simply served to confirm these suspicions.

Additional factors which were associated with initial acceptance were being an older carer and looking after a parent or parent-in-law. Why is it more acceptable for one's parents or parents-in-law rather than one's

spouse or sibling to develop dementia? The reason is presumably that while dementia in an older generation may be accepted as in some way "natural", dementia in one's own generation is far more threatening to oneself. If dementia can occur in one's spouse or sibling, the fact that it could also occur in oneself is much more difficult to deny. The reason for the finding of a relationship between initial acceptance and being an older carer is somewhat more difficult to interpret. Possibly the older carer is more able to accept the restrictions to their own life associated with the caregiving role.

It might be possible to manipulate one of these factors which predict initial carer reactions of shock or denial as opposed to acceptance. To some extent, even greater media coverage should increase the numbers of caregiving relatives who assimilate the dementia diagnosis and prognosis gradually. The relationship is complicated by the possibility of carer denial: however great the media coverage, some carers may continue to deny the implications of their relative's obvious and increasing impairments prior to objective medical tests and confirmation. The next question would then be, is the gradual assimilation of the dementia diagnosis and prognosis a "good thing"? To some extent this parallels the notion of the effects of anticipatory grief or "anticipatory preparation" on the conventional grief reactions of those bereaved by expected deaths as opposed to those for whom bereavement is unexpected. Possibly a gradual assimilation of the diagnosis is preferable, in that it was those carers who experienced greater shock and less acceptance "earlier on" whose reactions were more likely to be categorised as "stages" (see previous chapter). This group was more likely to have experienced greater distress earlier on,

and to still be experiencing greater "Preoccupation/Unfinished Business/Despair" at the time of the interview. It was this group who were more likely to perceive themselves as having grieved. Could it be that this is because learning the dementia diagnosis and prognosis suddenly is more likely to trigger thoughts of current and future losses? It would be extremely interesting to follow the reactions of all the carers after the physical deaths of the dementia sufferers. Would the "stages" group - likely to have perceived themselves as having grieved, and to have experienced greater initial shock and less initial acceptance - manifest a different intensity or different type of conventional grief than the "no stages" group? Given that the answer to this question is unknown, and basing the case solely on the "anticipatory grief" reactions of the caregiving relatives, the argument would presumably be in favour of increasing the chances of a gradual assimilation of carer knowledge of the dementia diagnosis and prognosis. This, as previously stated, might in part be achieved by further increased media coverage. This could, for example, take the form of factual information about dementia available in public library information racks, or informed (but not necessarily "poor carer") newspaper articles.

2. "Predictors" of Caregiver Reactions at the Time of the Interview

SHOCK, DENIAL AND HOPE

Given that - as has been discussed earlier in this thesis - the initial reaction to an unwanted event or piece of news is generally the hope that it might not really be true, it is not unexpected that those carers who thought the doctors might have made a mistake or

that something more could be done, were hopeful, engaged in bargaining, or were unable to accept what has happened, also tended to be those interviewed closer to the onset of dementia. (And, of course, a significant negative relationship between F.A. component "Disbelief/Hope" and time since onset had already been found using Pearson's correlation. The multiple regression analysis simply demonstrates that the relationship continues to hold even when accounting for a number of other carer, sufferer and relationship variables.)

"Disbelief/Hope" was also associated with dementia in a younger sufferer. Once again we see the perception of this illness as not "natural" or acceptable in younger sufferers. The common perception is that being susceptible to "going senile" is the lot of only very elderly people. The late middle aged or young-old should be immune from dementia. It is certainly less threatening to believe this - and in the main, of course, it is entirely correct. Dementia in this group is thus against the rules and as such may be the cause of disbelief, or hope for a favourable outcome. Dementia in a younger sufferer may be understood in terms of its greater "grief potential". As defined by Fulton and Fulton [1970] this refers to the extent to which a person's death will trigger grief in their survivors. The authors suggest that the deaths of younger people generally have a higher grief potential than those of disengaged, elderly people. In the same way, dementia in a younger sufferer may have a higher anticipatory grief potential for their family members.

Minimising the problems to others, difficulty discussing the dementia sufferer and attempting to avoid emotion (F.A. component "Deny") were associated

with older carers. Possibly the older carer is more likely to perceive dementia as more shameful than the younger carer. In fact, some carers did discuss the notion of sweeping certain illnesses "under the carpet". Popular media coverage of dementia is a relatively recent phenomenon. While it may have helped form the opinions of younger carers concerning the illness, the opinions of older carers may be based not on the media view but - for example - on the image of a confused elderly neighbour recalled from childhood. Encouraged by media "open-ness", younger carers may be able to discuss the dementia sufferer or express their emotions with others, while older carers may not. Another possibility is that older carers may be forced into a state of some denial through a simple lack of confidants.

This denial was also associated with caring for a sufferer exhibiting behaviours from the problem domain "Demand" (wandering and demanding attention). Again, possibly these more active behaviours - behaviours of commission rather than omission - are a source of shame and sweeping under the carpet by the carer. (Although it might have been assumed that this would be more likely with sufferers exhibiting behaviours from problem domains "Incontinence/Hygiene" and "Disturb".) Possibly demanding behaviours by the sufferer were associated with some other (unmeasured) characteristic which was related to denial in the carer.

Given the above, it is not surprising that a combination of shock and denial (I.S. component "Shock/Denial") was also associated with caring for a more demanding sufferer. It was also associated with being related to a dementia sufferer who was a spouse or sibling rather than a parent or parent-in-law. Once

again, we see the fact that dementia has occurred in someone of one's own generation as less acceptable or natural than dementia in an older generation.

ANGRY PROTEST, QUESTIONING AND GUILT

I.S. grief component "Questioning/Anger/Guilt" was found to be significantly more likely in those carers who perceived dementia to be a very horrible or the worst possible illness, and in those whose current relationship with the sufferer was poorer. In fact it appears that these associations may be accounted for largely by the anger items of this component since F.A. grief component "Protest" was also found to be significantly more likely in those who perceived dementia as a horrible/worst illness, and those whose current relationship with the sufferer was poorer, as well as in younger carers. (To recap, F.A. grief component "Protest" comprised anger directed at God, at others, at the dementia, at themselves, and at formal services.)

With regard to the age of the carer, younger people have generally been identified as more "at risk" for intense or prolonged grief following bereavement [for example, Maddison and Walker, 1967; Ball, 1977; Parkes, 1986]. Subjective burden has been found to be more likely in younger caregivers of dementia sufferers [Barusch and Spaid, 1989], but no relationship between carer age and burden was found in two other studies [Gilhooly, 1984; Gilleard, Belford and Gilleard etc. al., 1984]. Greater "Protest" among younger carers in the present study could have been related to the fact that this group may have differing expectations and greater additional commitments than older carers. Younger carers may be more "socially engaged" and thus

perceive caring for a dementia sufferer as a greater restriction than a more disengaged older carer.

The association between "Protest" and poor quality of current carer-sufferer relationship is likely not to be unidirectional. A high degree of caregiver anger is unlikely to be conducive to a good relationship with the sufferer, and in turn, a poor carer-sufferer relationship may well further increase carer anger and irritability. (To recap, a poor relationship comprised questionnaire items such as [not] laughing and joking with the sufferer, feeling cross with the sufferer, that the sufferer was possessive, that there was tension in the relationship, etc.) It should be noted that there is slight overlap in these and the F.A. grief component "Protest" items, in particular, anger directed at the sufferer. This may account to some extent for the association between greater carer "Protest" and poorer current carer-sufferer relationship.

By far the most significant association, however, was with the carer perceiving dementia to be a very horrible or the worst possible illness (accounting for adjusted R^2 in the I.S. grief component "Questioning/Anger/Guilt" of 0.30, and in the F.A. grief component "Protest" of 0.33). Why might this be? The reader will recall that Beck's cognitive theory of emotional disorders was referred to in the discussion of the possible basis of this negative view of dementia. To follow up on this notion, the cognitive theory would suggest that to perceive dementia as a very horrible or the worst possible illness would in turn cause a negative affective response. Beck [1967] suggests that the mood disorder in depression is secondary to the cognitive disorder: "The affective state can be

regarded as the consequence of the way the individual views himself or his environment ... the way an individual structures his experiences determines his mood" [p.261]. Haas and Fitzgibbon [1989] explain the mechanism of cognition in the etiology of depression postulated by Beck in the following way. Certain individuals are "depression prone" because they possess schemas which influence the organisation of incoming stimuli in a negative way. These "negative schemas" are triggered by stressful stimuli. The negative schemas lead to the emergence of constellations of "negative cognitions", which in turn trigger the depressive syndrome. Thus the depressive syndrome is secondary to, and to some extent, maintained by the activation of negative cognitive schemata. While it is certainly true that negative cognitions are associated with depression, a simple correlation does not imply direction of causality. As Williams [1984] points out, there is continuing debate "between those who believe that cognitive events precede and cause the emotional disturbance, and those who believe that the emotional disturbance can be explained on other grounds ... and see cognitive distortions and negative self-talk as a product or correlate of the emotional disturbance" [p.171].

Applying this approach to produce a mechanism of "cognition in the etiology of angry protest in the caregiving relatives of dementia sufferers" would suggest the following scenario. Certain ("protest prone") individuals have a very negative perception of dementia - possibly, as suggested in Chapter Ten, by previous negative experience with a dementia sufferer or by media coverage. These negative perceptions (or schemas), usually latent, are triggered by dementia in their own relative. The negative perceptions lead to

negative cognitions (possibly such as "Oh God! I can't stand any more of this", "No-one understands what I'm going through") which in turn trigger the emotional and behavioural aspects of angry protest in these carers. Of course, the fact that the current analysis is cross-sectional rather than longitudinal means that this hypothesised direction of causality cannot be demonstrated. Carer negative perceptions of dementia could equally well be simply a product or correlate of a carer's angry protest.

It is interesting to find that other recent studies have also suggested that caregiver burden might be associated with factors such as their "cognitive style and perceived control" [Morris, Morris and Britton, 1989]. For example, Morris et. al. found that caregiver depression and strain were significantly correlated with their perceived lack of control over their own emotional reactions and over the dementia sufferers' behaviour. Morris, Morris and Britton [1988a] point out that this and similar studies suggest that "the manner in which caregivers respond to the situation may be important in determining the level of emotional disorder" [p.152]. This, of course, is basically the cognitive theory of carer distress as outlined in the discussion of the results from the present study.

YEARNING AND MOURNING

I.S. grief component "Preoccupation/Unfinished Business /Despair" was also more likely in carers who perceived dementia as a horrible or worst possible illness, and in addition in those who had no religious faith or belief or whose faith or belief had not helped them, and in those whose quality of current relationship with the sufferer was poorer. The items from this I.S. grief

component largely divide into the two F.A. components "Yearn" (comprising looking back and wishing for the past, guilt at continuing their own lives) and "Mourn" (comprising being upset, crying, depression, and believing one's own life to be meaningless). F.A. grief component "Yearn" was more likely in carers who had no religious faith or belief or whose faith or belief had not helped them, and also in those with a negative perception of dementia. A negative perception of dementia was also significantly associated with F.A. grief component "Mourn" as was a poorer quality of current carer-sufferer relationship, and caring for a more demanding dementia sufferer.

Once again, the cognitive hypothesis of causation could be invoked to account for the association between these components and the perception of dementia as a very horrible or the worst possible illness. A negative schema of dementia could be assumed to trigger not only anger-provoking cognitions but also depression- or wishful thinking-provoking cognitions.

The role of a helpful religious faith (christian throughout this sample) or other belief (such as "What's for you won't go by you") in reducing yearning is interesting. Since there was a division between the ways in which a carer's religion or beliefs may have proved helpful (spiritual or practical), two mechanisms can be postulated. The first of these is the spiritual mechanism. This would suggest that the ability to receive comfort and relief through prayer, or the belief that the dementia was a part of some grand plan and that ultimately God would see that everything worked out (ie. external attributions of control) might reduce the tendency to look back to the past, to wish for things to be as they used to be, or to feel guilt

at continuing one's own life. The practical mechanism would suggest that active involvement in church life would increase a carer's network of social and practical support, and in addition would provide an alternative focus so that their lives did not revolve entirely around the dementia sufferer. Of course, the spiritual and practical mechanisms of religion postulated to reduce carer yearning are by no means mutually exclusive, and in fact it is perhaps more likely that they would operate in tandem. A similar conclusion was reached by Strobe and Strobe [1987] in their review of the impact of the "social" and "spiritual" components of religion on the outcome of conventional grief.

The association between both a poor current carer-sufferer relationship and also a demanding dementia sufferer with F.A. grief component "Mourn" suggest that this component may have been mis-named. Rather than reflecting mourning it may well reflect reactive depression resulting from the situation of being a caregiver to a relative with dementia. Reactive depressions "are described as relatively mild and with a mood fluctuating from day to day in response to environmental events" [Kendell, 1983, p.301]. The events of caring for a dementia sufferer who wanders at night or who demands one's attention could well result in depression in the carer, as could a poor relationship with the sufferer. In contrast, "mourning" is usually associated with grief and loss. While it could be argued that a demanding dementia sufferer represents a loss of the previously well known person, so equally might the behavioural domains "Depend", "Can't do", "Apathy", etc., but they did not feature in the final regression analysis equations. Similarly, while it could be argued that a poor current

relationship represents a loss of the previous relationship, the "Change in carer-sufferer relationship" score did not feature in the final regression analysis equations.

ACCEPTANCE

I.S. grief component "Acceptance" was more likely in carers who perceived dementia as just what happens when you get old or as just an illness, and in those who had greater general knowledge about dementia.

Once again, a cognitive explanation for carer acceptance could be invoked. Dementia is presumably far more acceptable if you regard it as a natural consequence of aging, or as an illness which could happen to anyone, just like heart disease or arthritis, rather than as the very worst illness possible. The former perceptions could not be classed as "negative schemata". Thus, the cognitive model would suggest that even given the stressful stimulus of caring for a dementing relative those who hold such perceptions will not be prone to distress about the situation in the same way as those who hold extremely negative perceptions of dementia.

The association between carer acceptance and carer general knowledge about dementia may occur because those carers who have a greater general knowledge are better able to take an objective view of the situation. If you know that, as one carer explained "It's like parts of the brain dying - the part maybe that told you how to tie your shoelaces, if that part died, you wouldn't know how to do that again", you may be better able to accept it when the dementia sufferer does become unable to perform certain tasks. If you do not

know the mechanism behind the sufferer's behaviour, you may be more likely to search for explanations, for example, self-blame, or anger at the sufferer for "not trying". Alternatively, those carers who displayed a greater general knowledge about dementia may have employed intellectualisation in their effort to cope with, and come to terms with, their relative's illness.

Of note is the fact that while time since onset of the dementia was initially significantly correlated with "Acceptance" (Pearson's correlation), the relationship disappeared when the effects of additional sufferer variables were accounted for. This adds additional weight to the argument that there was no neat "end-point" to the reactions experienced by caregiving relatives - there was no evidence that with greater time they "resolved" their loss and thus reached a "stage" of acceptance.

3. Importance of the Identification of "Predictors" of the Nature and Intensity of the Emotional and Behavioural Reactions of Caregiving Relatives

As mentioned earlier in this chapter, no previous available study has attempted to systematically investigate the "risk factors" associated with different components of grief or anticipatory grief. This is despite the fact that writers have asserted that grief is not unidimensional but instead comprises a variety of different aspects. What the present study has demonstrated is that not only are the emotional and behavioural reactions of the caregiving relatives of dementia sufferers multi-dimensional but that differing factors are associated with the differing components of the reaction. To simply assess the "risk factors" for grief or anticipatory grief measured as unidimensional

concepts may lead to a confounding of these factors; for example, while younger carers in the present study were found to be more at risk for F.A. component "Protest", older carers were found to be more at risk for "Deny".

Identification of the risk factors for particular aspects of the "anticipatory grief" reaction in the caregiving relatives of dementia sufferers may in turn allow the identification of particular "at risk" carers and if possible the targeting of appropriate interventions. For example, is this carer related to a relatively young sufferer or one with recent onset dementia? In that case they may be at somewhat greater "risk" for disbelief or hope. Is this carer relatively young themselves, is their relationship with the sufferer poor or most importantly, do they speak of dementia as an awful illness, the worst thing which could have happened? In that case they may be at greater "risk" for angry protest. A parallel could be drawn here with Worden's [1983] notion of mourning as a series of tasks. Worden suggests that mourning (adaptation to loss) involves four basic tasks. These are: (1) to accept the reality of the loss; (2) to experience the pain of grief; (3) to adjust to an environment in which the deceased is missing; and (4) to withdraw emotional energy and reinvest it in another relationship. Worden states that it is essential that the grieving person accomplish these tasks before mourning can be completed [1983, p.10]. He presents the goal of grief counselling as being to facilitate the tasks of mourning in the recently bereaved in order that the bereavement process can come to a successful termination. To return to the present study, the identification and counselling of "at risk" individuals may reduce their chances of becoming stuck in a certain

aspect or component of the various emotional and behavioural reactions. Having made this assertion, it should also be said that the associations found between the majority of factors discussed in this section and the various different emotional and behavioural reactions were only very small, although statistically significant. Thus, while being a younger carer was associated with F.A. grief component "Protest", this should not be taken as suggesting that all younger carers will demonstrate angry protest.

The factor which appeared to form a common thread, associated with distress - for example, "explaining" the greatest amount of variance in F.A. grief components "Protest" and "Mourn" - is the perception of dementia held by the carer. Negative perception of the illness was associated with distress, while perceiving dementia as just what happens when you get old or as an illness just like any other illness were associated with acceptance. If the cognitive explanation of causality is correct, might it be possible to reduce carer distress by designing an intervention which would alter (or "shift") an extremely negative perception of dementia? In fact, it would probably be extremely difficult if this negative perception is really a long-lasting and entrenched attitude or assumption about dementia. In addition, given the impairments associated with dementia it may be a fairly realistic view of the illness. However, cognitive therapy techniques might aim towards establishing the types of beliefs held by those who did not perceive dementia as the worst possible illness. Since "Dementia is just what happens when you get old" is factually incorrect, it would be not only unethical but also impossible to argue the case with the majority of carers who are aware of the facts. The only remaining beliefs were generally along

the lines of, "Well, they're not in any pain" or, "They seem happy in their own world". In addition, the approach taken by some formal services, such as a local Alzheimer's Society Project which accompanies dementia sufferer on caravan holidays or out to tea may help to "normalise" and dignify the illness in the eyes of the carer.

A final observation to be made with regard to these results is that while they point to the impact which a variety of caregiver, sufferer, or their relationship variables may have on the nature and intensity of carer emotional and behavioural reactions, the only association with time is the inverse relationship between "Disbelief/Hope" and time since onset of dementia. Thus, once disbelief and hope have dwindled, it appears that the remaining caregiver reactions will to some extent be dependent upon the presence of a variety of caregiver and sufferer characteristics, but will not come and go in a predictable phasic fashion. To some extent these caregiver or sufferer characteristics parallel those which have been identified in previous studies as "risk" factors for more intense or lengthy conventional grief. These include being younger (associated with increased carer "Protest" in the present study), and dementia in a younger sufferer (associated with increased carer "Disbelief/Hope" in the present study - which parallels the more intense grief usually experienced following the "un-natural" death of a younger person). In addition, the finding that grief component intensities "earlier on" were significantly related to those of "nowadays" (see previous chapter) parallels the finding of previous studies that a severe early grief reaction is associated with increased intensity or poor outcome to conventional grief.

V. SUMMARY

This chapter has presented the results of stepwise multiple regression analyses which were employed in an attempt to identify whether the nature and intensity of caregiver anticipatory grief was related to characteristics of either the carer, the sufferer or their relationship.

Initial shock or denial was associated with the carer having learnt the diagnosis and prognosis suddenly. Initial acceptance was more likely in older carers and in those who were looking after a dementia sufferer of an older - rather than of their own - generation.

Shock, denial or hope at the time of the interview were associated with less time since onset of dementia in the sufferer, with a younger sufferer, with those carers who were looking after a more demanding sufferer or a dementia sufferer of their own generation. Protest was more likely in younger carers, those whose evaluative perception of dementia was negative, and those reporting a poor current relationship with the dementia sufferer. Yearning in the carer was associated with with lack of a helpful faith or belief and a negative perception of dementia. A demanding dementia sufferer, poor reported current carer-sufferer relationship and negative perception of dementia were associated with depression - "mourning" - in the carer. Those carers who did not hold a negative evaluative perception of dementia and who had greater general knowledge of the illness were more likely to express acceptance.

The reasons for, and the meanings of these results were discussed. In addition, the value of attempting to

identify the carer "at risk" of more intense or distressing reactions to dementia in their relative was considered.

CHAPTER FOURTEEN

EVIDENCE FOR THE PERCEPTION OF DEMENTIA SUFFERERS AS "SOCIALLY DEAD" BY THEIR CAREGIVING RELATIVES

I. INTRODUCTION

The aim of this chapter is to present evidence relating to the social death of the dementia sufferers as they were perceived by their relatives.

Most of the chapter is descriptive. The section which follows this introduction relies on the comments of the caregivers in response to the questions which made up the "Social Death of Sufferer" section of the Carers' Questionnaire. These items related to four major areas. Firstly, the degree of awareness which the caregiver believed the sufferer had of events going on around them, and of their own impairments. Secondly, the degree to which the carer believed the sufferer should maintain their dignity and independent behaviour (ie. their personhood). Thirdly, whether the carer spent time anticipating the sufferers' death and their own subsequent life. Finally, whether the carer believed that the sufferers' death would come as a blessing, and whether, in fact, they felt as though the sufferer had already died. While the items in the "social death" section of the Carer's Questionnaire may appear to the reader to be something of a rag-bag, they result from the aim of exploring different aspects of the issue. These items were chosen firstly because they seemed to reflect the differing ways in which the rather nebulous concept of social death had been discussed in previous literature. The second reason for the choice of the "social death" items in the questionnaire was that in

the preliminary interviews and the pilot study, subjects had demonstrated that caregiving relatives both understood and were prepared to respond to such items.

Factor analysis of all nine of the items on the scale identified three very clear factors which were termed "Anticipate Death", "Life Pointless" and "Sufferer Unaware" (see Chapter Eight, "Data Analysis"). To some extent these factors reflect the different aspects of social death which had been initially hypothesised. The main difference is that a separate "sufferer dignity" factor did not emerge. Instead, these items weighted on the "Life Pointless" (included personal appearance of sufferer [not] important), and the "Sufferer Unaware" (included independence of sufferer [not] important) factors. Clearly, then, the implication is that if a dementia sufferer's continued existence is unimportant, it does not really matter if they are not dressed up in their smartest clothes, so long as they are not dirty or smelly. Similarly, if a dementia sufferer ceases to be aware of their surroundings then there is not much point in trying to encourage them to continue with independent behaviours. These three factors tend to reflect previous discussions of social death.

The third section of the chapter describes the results of post-interview ratings of carer beliefs and behaviours relating to the social death of the sufferers. These suggested that social death behaviours generally occurred after social death beliefs, and some descriptive examples are presented.

The final section discusses the characteristics of the three social death factors and the post-interview ratings of social death.

II. THE SOCIAL DEATH OF DEMENTIA SUFFERERS - THEIR RELATIVES PERCEPTIONS

1. Did Caregiving Relatives Regard the Dementia Sufferer as Able to Understand their Environment?

QUESTION : Does ... seem to know and understand everything that's going on?

% of carers (N = 100)

All the time.....	3%
Often.....	13%
Sometimes.....	36%
Rarely.....	26%
Never.....	22%

The majority (over 80%) of the carers believed that the sufferer only knew and understood what was going on "sometimes" or less often. What was most interesting about their comments for this item, and in fact throughout the "social death" items was the way in which they reacted to this question. While for example, some carers gave the impression that it was only sometimes that the sufferer knew what was going on, others stressed the positive side - that at least the sufferer still sometimes knew what was going on.

Those carers who reported that the sufferer knew and understood what was going on all or most of the time tended to be those whose sufferers were less impaired. Mrs. Deans, for example, stated that her husband often understood what was going on - and indeed he could engage in activities such as answering the phone, although he would later forget having done so. Mrs. Law drew a distinction between having dementia, which she equated with forgetfulness, and being senile, by which she meant being out of touch with what was going on. Her perception of her mother was that she had dementia, but was not senile:

I'd never say senile ... I don't think she is, she's not loopy. As I say, she can carry on a conversation, but she forgets, just really forgets things - oh, she just forgets everything.

Over one third of the carers rated the sufferer as "sometimes" knowing and understanding what was going on around them. Mrs. Quinn, for instance, described her mother as follows:

Pretty bad, but at the same time I know she's not away with the fairies.

Mrs. McEwan described her husband's confusion about what was going on around him:

He sometimes knows what's going on, but he never knows when it's happening ... he'll say, "Where do I go the day?" - you know.

Mrs Shaw contrasted her husband, in long-term hospital care, with other patients; while he did not always know what was going on round about him, she believed that at least he had more contact with his environment than those who simply vegetated:

They've re-assessed him - oh, he was in a terrible ward, nearly everyone was curled up in a big easy chair like a snail, with their arms hanging over, all sleeping - he was the only person that was walking about, he had nobody to talk to - he just talks rubbish anyway, but there wasn't a soul, he was lost.

Two of the carers who described their (institutionalised) husbands as sometimes knowing what was going on were Mrs. Carr and Mrs. Owen. Both their husbands were severely impaired (in fact, Mrs. Owen's husband died about a month after the interview), and their perceptions may therefore have been over-estimations. Mrs. Owen described going to visit her husband:

We'll sit at the window and he'll watch people passing. I'll say "Oh, the trees are beautiful"

and he'll say, "Lovely", and he'll read the registration of cars.

Mrs. Carr reported:

Oh, I had a great day yesterday - he said, "Hello, Louise", and that meant he knew me ... and he said "Cheerio", and lifted his hand, and that is a wonderful day for me ... that is - every day like that is a bonus.

Half the carers believed the sufferer never or only rarely knew what was going on round about them. Often they were described as 'living "in their own world". Again, the emphasis of the comments made by the carers differed. Among those carers who did not emphasise any remaining contact was Mr. Nichol, who said of his wife:

I mean, you're sitting there ignoring her basically - you're not ignoring her, you know you've got to toilet her and things like that just to try and keep her comfortable, but it's not as if you can sit beside her and talk and try to get her to smile - I've got beyond that.

Similarly, Mrs. Young described the need to attend to her husband's physical needs, although he exhibited very little awareness:

I don't think he understands very much at all of what's going on. I mean, he knows if I'm there or I'm not there, if he feels like a cup of tea or wants a cup of coffee - just sort of physical needs ... well, of course, for company he's absolutely nil for company.

The emphasis of the comments made by Mr. Dunn was a little different. Caring for his extremely severely impaired wife, who was unable to communicate verbally, he thought she occasionally knew what was going on:

Well, she knows - she's a good eater and she knows I'm through there making her lunch or tea and things like that. She knows that's her sweets over there - she can lift that dish and take a sweet and I let her take the paper off the chocolate.

2. Did Caregiving Relatives Regard the Dementia Sufferer as Demonstrating Insight into their Condition?

QUESTION : Does ... ever talk about what's happening?
% of carers (N = 99)

All the time.....1%
Often.....10%
Sometimes.....16%
Rarely.....17%
Never.....56%

This question, although not originally intended as such, was perceived by the carers to imply insight on the part of the sufferer. In other words, whether the sufferer talked about what was happening to themselves rather than what was happening round about them. It was frequently described as a relief if the sufferer did not talk about their illness or demonstrate any insight, since the vast majority of carers wished to shield the sufferer from knowledge of their true diagnosis. Sufferers who did show some insight were usually fobbed off with variations of "it's just your age". Even those sufferers who did talk about what was wrong with them tended not to do so very often - usually only if they failed to be able to manage a task, or lost things.

Sufferers who did comment about there being something wrong included Mrs. Edwards' husband:

... when he's lost things ... he'll say, "Oh, I don't know what's come over me" - he knows there's something wrong, but he doesn't seem to understand what it is.

Mrs. Calder's husband had also demonstrated occasional insight:

Mrs. C: He says himself he knows there's something wrong - "I know I can't help it" - just now and again, when he gets upset.

H.S: How does that make you feel?

Mrs. C: I often wonder how to answer him.

Mrs. Deans was among those carers who felt (in her case, on the advice of a nurse), that it was probably preferable that her husband did not seem to have insight into his condition:

Mrs. D: I've never heard Bob once say, "What's wrong with my memory?" - I don't know if he knows, he's not one for complaining.

H.S: How do you feel about that?

Mrs. D: Confused - does he realise what is wrong with him? Sister Y. said not to say to him ... it would be even worse if he realised.

The type of reassuring response usually given to sufferers who commented about there being something wrong was exemplified by Mrs. Young:

He knows there's something wrong and he'll just sort of - look, and I say, "Don't worry".

Mr. Napier's strategy had been to tell his wife - earlier on, when she was able to talk - that she was ill, but not to tell her what was actually wrong:

She would sometimes say to me, "What's wrong with me?" - she knew there was something wrong, and I couldn't answer ... I told her, I told her straight, she just had an illness and she wasn't to worry about it.

Mrs. Cooper was unusual in stating that there was no point in explaining what was wrong to her mother, not because it would be upsetting, but because she wouldn't understand:

She knows there's something wrong with her, I mean, she'll say to me, "What's the matter with me?", I mean, she knows herself ... I just say, "No, there's nothing" - there's no' much use explaining, she doesna' know any better ... you'd be here all day trying to explain to her about it and then after that she would just forget all about it, so there's no' much use.

Among those sufferers who did not talk about their illness were those who had never shown any awareness that there was anything wrong with them, and those who

had shown a degree of insight earlier on but had ceased, due to increased impairments and/or inability to express themselves verbally. Among this latter group of sufferers was Mr. Gibson's mother:

She - a couple of years ago she used to say, "What's wrong with me?" Am I going the same way as my mother?" ... she did, she seemed to realise there was something wrong and relate it to what happened to her own mother (who actually did have dementia), which was very very hard.

Mrs. McEwan's husband was one of the group of sufferers who had never shown any insight into their condition:

He thinks there's nothing wrong ... he'll say "oh, I'm great, there's nothing wrong with me" - that's the way he goes on.

Similar beliefs had been expressed by Mrs. Innes' mother, despite the fact that she was in institutional care as a result of her dementia:

She told my aunt and I when we were down on Tuesday ... there was a woman sitting down, and she said, "Old Rosie's memory's bad, but that's one thing about me - I've got all my faculties" - you know, she genuinely thinks if she came home she could cope.

As with the previous question, some of the comments made by the carers in answer to this item exhibited an apparent over-estimation of the sufferer's understanding - or perhaps a wish to perceive the sufferer as a person with understanding. Mrs. Baird's husband was impaired to the extent that he did not reliably recognise her and could not be left safely alone. Nevertheless, her answer to the question about whether her husband talked about what was happening to himself went as follows:

He knows he's got Alzheimer's, oh aye, I've told him why he has to go to the day centre and all these different things - whether he knows actually what it is or not, but I've said to him - because we got a letter from the Poll Tax to say he's exempt from that next year, and I

was telling him, I said - we were watching the television and all these different things about the Poll Tax and I said, "Well, that's something you'll no' have to worry about", and he says, "Why?" I says, "Because you've got Alzheimer's, and it's to do with your memory", and he says, "Oh" ... he does know, although he doesn't understand what it is, he does know - he doesn't know he's got cancer, I've never told him that.

3. Did Caregiving Relatives Encourage Independence in the Dementia Sufferer? '

QUESTION : Is it important to you that ... does as much for him/herself as possible?

% of carers (N = 99)

All the time....	63%
Often.....	11%
Sometimes.....	11%
Rarely.....	2%
Never.....	13%

Three quarters of the sample of carers believed it was important that the sufferer did as much as they could for themselves most or all of the time. The reasons for this fell into two main categories: firstly, to give them dignity or independence, and secondly to "keep them going" (the rationale being that if the sufferer was not pushed towards doing what they could then they would quickly reach a "vegetative" state). The examples of what the sufferer was encouraged to do formed a consistent, but decreasing pattern with increasing deterioration. The least impaired were encouraged to continue as normal for as long as possible, dressing or washing themselves, making (supervised) cups of tea, buying the paper from the local shop, etc. This was generally replaced by being encouraged to help with simple household tasks, almost invariably dusting or drying-up. Finally, it became important that the sufferer attempt to eat unaided. Those carers who did

not think it was important that the sufferer did as much for themselves as possible tended to make the comment that there was "no point": lack of dignity, dependence and increasing impairments were simply inevitable.

Mrs. Davis' mother was one of the less impaired dementia sufferers and she continued to manage to cope in her own flat, although with large amounts of formal and informal support

I give her money for two or three days ... I feel it still gives her that bit of independence, if she's got some money ... I feel it's a wee bit of independence she's still got left ... I feel she should keep her independence as long as possible, and I try to make her get up and make a cup of tea ... I says, "You get up and make a cup of tea for me", I says, "I'll go and get bread", or something like that, I'll say, "While I'm away you get up and get the tea made".

Mrs. Deans' husband was also still reasonably able. Although she reported that he "couldn't care less", she continued to encourage him to wash and dress himself, because:

Once you can't wash and dress yourself, what is there? ... he would go down and down, and would be no use at all.

Mrs. Elliott encouraged her mother to help out with some basic household tasks, with the aim of maintaining her self-esteem and self-hood:

I like to let her do simple things that I know she can do - like washing up the dishes, like peeling the potatoes ... Well, I don't force her to do it, but it's to give her a little bit of self, that she's not just sitting in a chair, that she's contributing, she's still contributing to life - that she's not put to one side just because she is the way she is, she's not shut away, she's still part of the family unit - she's still head of the family unit.

Similarly, Mr. Lees gave his wife some housework to do, although she suffered from a moderate-severe degree of impairment:

If I'm "hoovering", for instance, I'll give her a cloth and it usually ends up she's polishing the couch, but she's working away quite happily ... all the wrong things will be getting done, but nevertheless, she's doing something.

Eating was often mentioned as an area in which the sufferer was encouraged to manage by themselves. Possibly this was because feeding a person with a spoon was perceived as treating them completely like an infant, and thus as robbing them of their dignity - whereas, however infantile it may seem, it would be simply impractical to encourage a person who needed assistance with going to the toilet to manage by themselves. Mrs. Thom, for example, said of her mother's eating:

I make a point of coming up with food that is acceptable for somebody in mammy's position to eat by herself - chips, for example ... sandwiches, she can eat that herself - if there is any meal that I can make that she can eat with her fingers then, yes, that's good ... I quite enjoy to see her getting on with it ... anything at all that she can eat without making herself look ridiculous or messing herself up then, yes, I'll let it go, and that's good.

Comments about encouraging the sufferer to do as much as possible were made about even some of the most impaired sufferers in the sample. Mr. Clark's wife was in long-term hospital care with very severe dementia. Even so, he said:

Mr. C: Well, I think it's important to try - even lifting a cup, or I try putting something in her hand - even getting her to concentrate a wee bit ... to put a sweet in her mouth.

H.S: To keep her dignity?

Mr. C: She's doing it for herself.

Those carers who reported that they rarely or never encouraged the sufferer to do as much as possible for themselves invariably commented that they had done so at one stage, but now there was "no point", because the sufferer was so severely impaired.

Mrs. Noble and her family, for example, had tried stimulating her mother's memory earlier on, when she was less impaired, but didn't bother any more:

At the beginning we sort of tried to make her remember, if you know what I mean - we sort of tried to make her remember and we kept repeating it to her, thinking it would jog it, but - well now there's nothing.

Mrs. Cooper commented that although she had once encouraged her mother to engage in activities, she didn't bother any more:

I just let her sleep, where at one time I wouldna' let her sleep, I just let her sleep.

Several carers commented that it made their own task a great deal easier if a co-resident sufferer was content to be left doing nothing at all for themselves. Mrs. Quinn, for example, described this state of affairs, although she believed that if dementia sufferers could engage in some sort of activity for themselves it would increase their quality of life. Commenting on the fact that her mother did nothing "useful", she said:

... the fact is that even the simplest things like washing dishes, she doesn't even do that properly, so therefore if she's not doing things it makes life much more easy for me, because when I go to do things then I'm doing them in a straight-forward manner ... but I think they must be leading a better life and a much happier life if they seem to have a lot of "go" about them, because the way my mother, and many people the same, they just seem to have given up all interest in everything ...

4. Was the Personal Appearance of the Dementia Sufferers Regarded as Important by their Caregiving Relatives?

QUESTION : Is it important to you that ... always looks their best?

% of carers (N = 98)

All the time.....	87%
Often.....	7%
Sometimes.....	4%
Rarely.....	1%
Never.....	1%

A good personal appearance on the part of the sufferer was extremely important to almost all the sample of carers. Most of the reasons given for this related to the sufferer; either that it was important that the sufferer looked good or "normal" in order to preserve their dignity, or else that it would make (even in some cases severely impaired sufferers) feel better if they knew they looked smart. A less common reason for attending to the sufferer's appearance was that a scruffy or smelly dementia sufferer reflected badly on the quality of care being provided and thus (for non-institutionalised sufferers), upon the carer him or herself.

One carer who commented on the need to preserve the normality and dignity of the dementia sufferer, was Mrs. Noble, commenting on her severely impaired mother:

That really is important, they'll say to me - you know how - when I go in for anything, it's not just a case of, "That'll do", it is important that it's a normal person ... she's still a person although she's an Alzheimer's case - I don't believe this - because they're that - I mean, they're still people at the end of the day.

Similarly, Mr. Dunn described why he believed his wife's appearance was important:

Mr. D: ... to keep them like human beings, that's the important thing - to keep them like human beings - she's just the same as if she was going to go out ...

H.S: You want to keep her dignity?

Mr. D: That's right, that's right.

Mr. Yates, another of the carers of an extremely impaired sufferer, described how important it was to maintain a normal appearance in his mother in order to be able to continue his caring relationship with her:

I don't like to see her looking all messed up - it's not for the sake of anybody coming in, it's just for me looking at her - sometimes when she gets up in the morning and her eyes - she looks like a mad woman - understand what I mean? ... that's the way she looks sometimes, and sometimes her eyes are not vacant, and you see her looking as if she's thinking, "Who are you?" and she gives you a smile, but I hate it when she looks like somebody out of "Wuthering Heights" - that sort of expression, it's not her at all. When you tidy her up she doesn't look so bad - that's what I'm trying to say ... it's easier.

The notion of their personal appearance contributing to the dementia sufferer's self esteem did not appear to be related to the degree of impairment in the sufferer. Mrs. Newark's mother suffered mild-moderate dementia. A continued interest in her personal appearance reassured Mrs. Newark that a "wee bit of mum" still remained:

... she's still got the pride in herself. She still puts on her lipstick and her make-up. Sometimes she does it really good, sometimes she doesn't and she'll put it on and on and on and on and on, and I'll have to say, "Come here, mum", because she's got so much rouge on, she looks just like a wee clown ... she's still got that pride in herself, and I'm glad to see her like that, for I wouldn't want to see her letting herself go ... it's still there, that wee bit of mum ... and it still makes her feel good, which is a good thing, that I know that

that's not been taken away from her anyway,
just now, anyway.

Mrs. Neary's husband was somewhat more severely impaired, however she believed his personal appearance was "definitely" still very important to him:

He's always been the type of man that always looked after himself ... and I feel if he knows that he wasna' shaved, or he wasna' washed, or he hadna' clean underwear or shirt and that on, that would upset him ...

Looking good was perceived by Mr. Clark to still be important to his severely impaired, institutionalised wife - or perhaps it would be more correct to say that he hoped it was still important to her:

It matters, oh it does - I think even they mind - getting their hair done, up there they get their hair done every fortnight or so, and it matters to them, they know this hairdresser is doing their hair and they're going to look good - because it still must be something in their mind that a woman's looks, she must look - she feels she's getting her hair cut or something ... you always feel better, she's had a bath, she's clean, she's dry, she's neat, she's got her clothes on - it's important to you as a carer ... you hope it's going through to them - you hope there's something getting registered.

The least common reason given for regarding the dementia sufferer's personal appearance as important was that it reflected the quality of care being given to them. Mrs. Nash, for instance, commented:

It's important to the carer that she looks clean and presentable - I mean, a friend of the carer's could come in and you couldn't have her sitting dirty.

Similarly, Mrs. Church said, with regard to her husband's personal appearance:

I feel people's looking at him and they know he's my husband - I must keep him looking well.

Those carers who said that they did not think it was particularly important that the dementia sufferer looked their best regarded spending a great deal of time on their personal appearance as something of a waste, since the sufferer was judged to be unable to appreciate it. However, keeping the sufferer clean was regarded as important. Mrs. Cooper, for example, said of her mother:

As long as she's clean and tidy - I mean, you don't want them to go about having smells about them or anything like that, do you? ... She doesn't notice at all - even when she's eating, she's dripping all down her as well. Let's put it this way, she's no' my mother, definitely not, because everything had to be perfect ... she couldna' care less now.

Mrs. Edgar, in response to this question, simply said, with regard to her mother's looks, "What is the point? What is the point?". The same beliefs were expressed by another carer, Mrs. Lennox, with regard to her husband:

H.S: Do you think it's important that he always looks his best?

Mrs. L: Well, no, I don't think that of him now, to look like that - I can understand what he's got and that he'll never be himself as he was - you know, as I knew him, that he'll never come back to himself, never, and I don't think I could try and change that.

H.S: It's pointless trying to make him look good?

Mrs. L: Very pointless to try that.

5. Did Caregiving Relatives Think about the Death of the Dementia Sufferer?

QUESTION : Do you ever find yourself thinking ahead to the time when ... will die?

% of carers (N = 97)

All the time.....	1%
Often.....	21%
Sometimes.....	33%
Rarely.....	24%
Never.....	22%

Three quarters of the carers reported that they had thought ahead to the death of the dementia sufferer, even if only occasionally, and a fifth did so often. Those who spent a lot of the time thinking ahead to the sufferer's death appeared to have done so in one of two ways. Firstly, carers might have thought ahead in general terms, which included the prospect of the sufferer becoming increasingly impaired, and lead to the thought that it would be preferable if they could die before that happened. Secondly, carers might have thought ahead in terms of specific practical or contingency plans.

Among those who thought ahead to the sufferer's death in fairly general terms was Mrs. Neary, caring for her husband:

The way I think about it is if instead of gradually getting worse and worse and worse, if he could just slip away in his sleep - that's the way I think about it - and wouldn't suffer a lot of pain, you know.

Miss, Law's comments, with regard to her mother, were very similar:

H.S: Do you ever think ahead to when your mum will die?

Ms. L: Yes, I do, I go right to the dying - it's terrible to say, but I've often said if she got really bad I'd rather she died than have to live like that.

Somewhat more specific thoughts were described by Mr. Yates, who imagined himself discovering that his mother had died:

If she's going to go, I'd rather she went in her home than stuck in a ward ... I've always thought about it - I don't relish the thought of coming in through that door and finding her here ...

A small number of carers commented on the fact that the dementia sufferer had now lived their allotted span (varying time periods, but specified by the media, other informative literature, or professionals), and that this had made them think particularly about the death. Mrs. Thom, for example, commented:

There seems to be a general feeling that ten years is a sort of a - well, we're now into the ten year bit, and I'm on edge ... sometimes a little learning is a dangerous thing, isn't it ... when you're in my shoes you latch onto that and you think, "Well, we can expect ten years" - now, when you're in the second year, that doesn't matter, but when you get to ten, you think - every time she sneezes, "Is this us on the final slope?" kind of thing.

Several carers tried to plan ahead for the death. During the interview, Mrs. Shaw referred to her anxieties about the event of her husband's death:

My son goes away to Australia for a month's holiday in February, and I dread that - I said to him, "What am I going to do if something happens to your father while you're away?" - because I've no relatives. He said, "That's all been taken care of".

(Clearly, Mrs. Shaw was not the only one in her family who had been thinking ahead to her husband's death.)

Among the carers who reported that they never, or only rarely thought ahead to the death of the dementia sufferer was a group who simply didn't seem to have considered it, and instead concentrated on the sufferer's day-to-day life. There was also a group who appeared to consciously stop themselves from considering it. There were two apparent motives behind this. First of these was that it made the sufferer uncomfortable to think of the death, therefore they avoided it. The second motive contained an element of almost superstitious thinking: to consider the

sufferer's death might hasten either it or else the death of the carer.

One of the carers who seemed to have never really considered the sufferer's death, or even his increasing impairment, was Mrs. Baird, looking after her husband. Instead, she accepted it in a fatalistic fashion:

H.S: Do you ever find yourself thinking ahead to when he will die?

Mrs. B: No, no, no - I just - every - one day at a time, you only live one day at a time.

H.S: You just think about him getting worse, but not -

Mrs. B: Well, I know it's inevitable, but I don't look for it, I just know maybe some day it'll no' be the same as it was yesterday sort of style, but I just take it one day at a time, and that's it - I just live one day at a time - I never look away into the future, or wait till next week, or anything, I just wait for today, and then tomorrow when it comes, and that's it - I've always found that's the easiest way to do it.

Mrs Lennox consciously avoided thinking of her husband's death if possible, giving the impression that to do so caused her some discomfort:

I've seen me thinking about that - I know that's in front of me, and then I'll say to myself, "I'm not going to think about that because I could be away before him" - that cuts me off it. I feel, "Why should I think about that?" - I'll say, "I can see this happening ...", and then I'll say, "I'm no' going to think about that - if it happens, it happens".

The discomfort which Mrs. Church felt if she considered her husband's death was the fear that her own death might precede his:

I'm feared to think about that 'cos sometimes you think like that and it happens to you afore them. You pray to God that you'll maybe get some peace one day, but it's up to him who goes first.

6. Did Caregiving Relatives Engage in Imaginal Rehearsal of Events Following the Death of the Dementia Sufferer?

QUESTION : Some people find themselves rehearsing or going through what might happen and what they might do straight after a death - for example, thinking about the funeral and imagining how it will be.

Do you ever find yourself thinking anything like this?
% of carers (N = 97)

All the time.....	1%
Often.....	14%
Sometimes.....	27%
Rarely.....	12%
Never.....	45%

Over half the sample of carers had rehearsed in imagination what might happen immediately following the death of the dementia sufferer. Those who did engage in rehearsal did so in two different ways. Some of them imagined discovering the dementia sufferer dead. Many of this group described having thought the sufferer actually had died at one time or another, because their appearance had been so corpse-like. The other group rehearsed what might happen soon after the death, for example, finding a burial plot, attending the funeral, or being "strong".

Mrs. Nash had often engaged in imaginal rehearsal of the actual death of her very seriously impaired co-resident mother-in-law:

I've got telephone numbers to contact - my daughter says, "Phone me", and I say, "I'll phone you after I've phoned the doctor". I know exactly what to do if it should arise, and I would not panic about it because there's some mornings I go up the stairs ... sometimes when I go into the bedroom and I say, "Morning, Gran", and there's nothing, and I go right over to her and I just see a wee flicker of the eyes opening up, you know, and I think, "Thank God" - I'm relieved, but in saying that, if I did go up it would not worry me, I would just have my

wee while with her and I'd come down and make my phone calls - I've got myself prepared for it.

Similar experiences were described by several other carers, including Mrs. Cooper, who looked after her mother, and Mrs. Church, who looked after her husband. Their descriptions, like almost all the others, referred to the sufferer appearing to be dead while actually asleep. Mrs. Cooper said:

At night - you see, if she sleeps over her time for sleeping, actually I start getting worried, and I go in and have a look at her, you know ... you're saying to yourself, "How am I going to get her? Is she going to be alright, or is she going to be dead?"

Similarly, Mrs. Church commented:

Sometimes I think he has died - he looks so ill in bed, you really get a fright. I think some day that might just happen like that.

The other group who engaged in imaginal rehearsal tended to think or plan for what Mrs. Edwards described as "all the things that you would have to do" after the death of the dementia sufferer. This planning might be on psychological or practical terms. Mrs. Davis, for instance, had considered how she would have to cope in herself following her mother's death:

If anything ever happens to her, my sister will go to pieces - I'll have to be the strong person. I mean, I don't mean to be morbid, but if anything should happen, my sister's the type that'll go to pieces.

Mr. Napier's rehearsal had been practical: his wife's severe dementia had caused him to consider not only her death, but his own as well:

I said to my daughter, "When I come back from my holiday I want to give you some money - I'll write out a cheque and it'll cover both our funeral expenses" ... you see, I've been doing this gradually ... I was at the lawyer and I've made a will ... also I've found out there's no more layings in Johnstone ... so this is now in my mind, too, I've now reached the stage where

I think when I come back of my holiday I'll go and search for a place for ourselves ... everything'll be prepared ... I think I'll get one in Paisley no trouble.

Another carer, Mrs. Thom, described herself as in a state of almost suspended animation while waiting for her mother's death and subsequent funeral:

Mrs. T: ... I feel now, every moment, I go about and I do things and I carry on with my day-to-day living, but I'm waiting. I always have a sense of waiting, nothing - I canna find permanence, because I know that things are so temporary.

H.S: Do you rehearse in your mind what it would be like if she did die?

Mrs. T: Well, I have thought about it, and I've come to the conclusion that I very much doubt that I could attend my mother's funeral ... I spend a lot of time not feeling real - it's a horrible feeling, and there just seems to be no tomorrow.

Yet another carer, Mrs. Edgar, felt something quite different: her mother's funeral would symbolise the release of them both from Alzheimer's, which she described as "probably the cruellest disease":

H.S: Do you ever think about what it would be like if she ever did die?

Mrs. E: Yes, because you have to, because you don't know when it's going to happen, and it takes longer than other illnesses ... it (death) can swoop down very quickly that you have to be prepared to deal with - and maybe psychologically you have to be prepared to deal with the fact that, "Oh, when that funeral's over I might be at peace, I might be able to get to sleep", you know, maybe it's a sort of selfish little thought you've got, it's not really planning the funeral, it's - "Well, at least that person will be out of their discomfort, and their humiliation, and their pain, and their embarrassment, and they'll be buried, and I'll not have to suffer anymore". I think that could be a thought of planning the funeral - it's to get them out of this situation.

Comments of those - approximately half the sample - of the carers who had not engaged in this type of imaginal rehearsal or planning demonstrate that there seemed to be no particular reason behind this: they simply hadn't done so:

- No, that's a thing I haven't thought about.
- I don't think I've ever thought in such detail as that.
- ... there'll be time enough - and he could still be here and it'll be me that'll be away.

7. Did Caregiving Relatives Anticipate their Future Lives Without the Dementia Sufferer?

QUESTION : Do you ever find yourself thinking about what the future would be like without ...?

% of carers (N = 96)

All the time.....	0%
Often.....	9%
Sometimes.....	29%
Rarely.....	19%
Never.....	43%

The majority of those carers who reported that they had thought about what the future might be like without the sufferer described anticipating a big gap in their lives. For some it was simply the loss of the presence of the sufferer who, however impaired, represented the fact that somebody else was sharing their house. For others it was the loss of their own role as caregiver.

Mr. Inglis believed that he would be lonely without his wife's presence in the house:

... I'm quite happy with her here, I mean, I'd be sitting here myself - I'd become a kind of zombie or something, wouldn't I? ... I prefer her even with her problems and her odds and ends - she's giving me as much help as I'm giving her, know what I mean?

Similarly, Mrs. Neary thought that she would miss her husband: even though his companionship was now only on

a physical rather than a social level:

H.S: Will you miss him?

Mrs. N: The person there in the house - oh, yes definitely. You know, you come in and you sit in the chair and in the summer we sit round in the back garden quite a bit, and he's always there, and even though you're upset about something ... you talk away to them, although you know that they're not taking in a word ... but they're there to talk to.

One non-resident carer, Mrs. Norden, also described her anticipation of the loss of her mother; not within her own house, but around the local area:

... because we've lived in this area - my mother's had that house forty-two years, and I lived in it before I got married, and then after I got married I came to live in the district, and I've often wondered to myself, "I wonder how I'll be able to pass that house when my mother's no' there? I wonder how I'll be able to cope with that?"

Several carers referred to an ambivalence about the future without the dementia sufferer. While relinquishing the burden of care was generally eagerly anticipated, it was mixed with anxiety about how they would manage without the sufferer. This was summed up by Mrs. Church, caring for her husband:

I feel there would be days when I'd be very grateful for peace and quietness, and then I say maybe I'd be frightened on my own - you know, although he's not well, he's always there. If he did die, I would miss him - although I don't think I would miss him, but I would.

A similar ambivalence was expressed by Mrs. Cooper with regard to her husband's death. In her case, however, the positive side was not the fact that she could stop caring, but that her husband would be in some way released:

I won't like being on my own, but then again, I'll feel more content he's at peace.

The loss of their own role in addition to the loss of the presence of the sufferer on their death was referred to by several carers. For instance, Mrs. Nash, caring for her mother-in-law, said:

It would take me a wee while to adjust without her, because I've been so used with it - as I've said, it's like a baby, and I think the geriatric chair, not having that, I'd just feel there's something missing from the living room ... it's like a job, working, I'm caring for this person, then all of a sudden I'm not - I'd be out of a job, I'd miss her.

Miss Kay anticipated a similar gap in her own life following the death of her mother:

I think I would be lost without her - I think that would shatter me, at least initially ... your whole life's concentrated on that, and if that's taken away, it must be absolutely shattering.

Some carers had tried to imagine life without the sufferer, but found it impossible; for example, Mrs. Deans:

I can't imagine what it would be like - if you're talking to a widow they say, "You can't realise what it would be like until it happens to you".

While the removal of the sufferer to long-term institutional care was in some senses a preparation for life after their death, so might respite care be. Mrs. McAdam's husband had recently been away for his first ever respite break, lasting two weeks. She described this period of respite care as "almost like a trial run, if I could put it that way", and also commented on her surprise at the way she had managed without him:

By the time it got to the second week I was feeling - not quite pleased with myself, but quite amazed that I could go out by myself, get on buses, arrange things ...

Two fifths of the sample reported that they had not thought of the future without the sufferer. For the majority the reason again appeared to be that it had not really crossed their minds. As Mrs. Lennox said:

I may have thought like that had I been a younger person, but I'm not young myself and I feel anything could happen to me before him, couldn't it?

For a few carers, anticipation of life after the death of the dementia sufferer was an unpleasant activity and therefore to be avoided. This process was described by Mrs. Owen as follows:

You put up a barrier, because you don't want it to happen.

8. Did Caregiving Relatives Agree that Death Might come as a "Blessing" to the Dementia Sufferer?

QUESTION : Would you agree that death might come as a blessing to ...?

	<u>% of carers (N = 96)</u>
Strongly agree.....	28%
Slightly agree.....	6%
Unsure.....	21%
Slightly disagree...	7%
Strongly disagree..	38%

Over one third of the sample of carers agreed, either slightly or (more usually) strongly, that the death of the sufferer would be a blessing, while almost half believed it would not. Their decisions were invariably made on the basis of the "quality" of the sufferer's life - and many of those who stated that death would not come as a blessing qualified this by saying that their decision applied to the current state of affairs; death might well be a blessing at some future date. While the decision was made on the basis of the quality of life, it did not necessarily relate to degree of

impairment: several of the carers of very severely impaired dementia sufferers believed that a sufficient quality of life remained to enable them to judge the continuation of that life to be worthwhile.

Among those carers who agreed the death of the sufferer would be a blessing was Mrs. Edgar, who commented, "there's absolutely no reason why mum is existing now". Similarly, Mr. Napier said of his wife, "she's just a vegetable now anyway → just sits there, she doesn't even speak". Another carer who "most definitely" believed there was no point in the continued existence of the sufferer was Mrs. Nash:

... especially at the stage she's at - she doesn't make a lot of sense, she doesn't know the family, she doesn't like being cleaned - oh, she would say she'd be better at rest - I mean, she's not the same person, she's just sitting there.

This notion that if they had insight into their condition then the sufferer would also agree that their death was a blessing was also raised by Mrs. Gemmell, with regard to her mother:

H.S: Do you ever think that death might come as a blessing for your mother?

Mrs. G: Yes, I have thought of that - I just look at her some days and think she's just so weary, and knowing that, I mean, my mother before she was confused used to speak about other people and say, "I would hate to be a burden to anybody - I hope I never get to that stage".

Death was often regarded as a positive event in that it would remove the impairments caused by the dementia. Mr. Clark, for example, said that his severely demented wife's death would be a blessing because "it would give her back her dignity". This was also referred to by Mrs. Young, who related her belief that "science" was to blame for unnecessarily preserving lives to her belief that her husband's death would be a positive

event:

H.S: Would you agree that death might come as a blessing to Ralph?

Mrs. Y: Oh yes, very much, very much - because if you're a feeling person, you do actually feel - science is a grand thing, but it can be carried too far, and resuscitation and things with people who would be better away - oh aye, science is great, but it can be used too often.

The belief that the sufferer's death would be a blessing not only to themselves but also to those involved in their care was mentioned by some of the carers. This was either because of the pain and sadness which resulted from viewing the continued deterioration, or else because of the strain of the caregiving task. One of those who emphasised their own sadness as one of the reasons for regarding the death of the dementia sufferer as a blessing was Mrs. Norden, caring for her mother:

I get so depressed now - just sometimes, not every time, and then I think it would be a help if she got taken, you know ... quietly, just sleeping away, you know - but you don't always get what you want right enough that way, but I feel it's sad the way her life has ended up, you know, because she was a very active person.

Mrs. McEwan also spoke of the sufferer's death in positive terms, but she emphasised the relief which it would bring her from the strain of caring for her husband:

Mrs.McE: ... you say to yourself, "Oh, my God, if he would just go to his bed some night and I woke up in the morning and discovered he was away" - that I often say, "What a relief!"

H.S: It would be a blessing?

Mrs.McE: It would be a blessing to him, it'd be a relief to him, well I wouldna' say a relief, because he doesna' know what's going on round about him, that it's no' - he doesna' know - that it's no' actually him - I'm the one that suffers, know what I mean? It's the person that looks after him is the one that suffers.

One fifth of the sample of carers were unsure of whether or not the death of the sufferer would be a blessing. This was because they were unsure whether or not the quality of the sufferer's life was currently poor enough to agree that they would be better off dead - which in turn was related to their conception of death. This internal debate was very clear in some of the comments which were made. Mrs. Innes, whose mother was in long-term hospital care, said, for example:

The girl I work beside - when she wasn't well at the weekend, I had said on Monday - she said, "You know, your mother would be better just sleeping away". I had never really thought about it till this weekend, but I don't think she's really got a life now, has she? But yet, she's happy, she doesn't moan in the hospital.

Mrs. Church also debated the question of whether or not her husband's death would be regarded as a blessing:

You don't know what death is - you don't know what you're blessing them into. He's no' happy, he's definitely no' a happy man. I don't think he gets any fun with getting up every day, he's nothing to look forward to and he doesn't take any interest in anything, so what has he got to live for really? I mean - I don't think - I don't know what Danny would think about that himself if you asked him - I don't know whether he's made his peace himself, or what he thinks ... I don't think he thinks about it at all now, I think he's past thinking about that.

During the interview Miss Kay had quite a long debate with herself during which she pointed out that while it was easy to say that death would be a blessing for a dementia sufferer, it was much harder in practice, when the sufferer was your own relative:

H.S: Do you think it might come as a blessing to your mother?

Ms. K: In theory, yes. When it comes down to your own parent, I don't know. Certainly she's not got any life at all now - and that's happening so often now. They say people are living longer, and they are, but what good is that when the quality of life is not there? In theory I definitely feel there's a case for euthanasia, but I don't know about the practicalities of

it, but again, when it comes down to your own relative, I don't know ... But if she was taken next week say, I suppose we would all say it was for the best because she definitely hasn't got a life at the moment, but she's not sort of at that more advanced stage where you'd think that somebody should help her to die ... mind you, she knows she's not right and some days she gets very tired of life and she herself would be quite happy to go.

Slightly less than half the carers were more sure that the death of the sufferer would not come as a blessing. These carers were not necessarily the relatives of less impaired sufferers. Again, their decisions were made on a somewhat indefinable quality of life which often related to the sufferer giving the appearance of being content, but sometimes also to their having some understanding of what was going on round about them. About half the carers in this group referred to their belief that the death of the sufferer would not be a blessing just yet, but that it might become so at a later stage.

Among those carers who suggested that death might become a blessing in the future was Mrs. McAdam, who looked after her husband:

... it depends how far the illness would go - if there was no quality of life at all, obviously it would be a blessing. I mean, I'm not a great one for this sort of "life at any price" ... I think nature should take it's course ... I think we're getting too clever by half ... not at the moment, but obviously if things, you know, inability to do anything, even eat, or enjoy anything ... (then death would be a blessing).

Similarly, Mr. Fergus, who cared for his very severely impaired wife believed that death would not be a blessing for her at present:

I could imagine that state of affairs, yes indeed, when life becomes intolerable, but it hasn't become intolerable to us yet -

difficult, yes, but not intolerable. Rachael's quality of life is very limited, but there is something there - it's not totally destroyed yet, although it probably will come to that situation.

Mrs. Quinn clearly had a concept of what we might regard as "social death", represented for her by severe impairments and institutionalisation. She described herself as hoping that her mother would become "dead in life" (ie. physically dead) before this situation occurred - but not just yet:

Mrs. Q: I say to my family, I say, "I don't wish my mother dead, because I love my mother, but I hope she's dead in life before she's really bad mentally with this illness" - not because I want rid of her, because I don't wish that on her.

H.S: But you think death might come as a blessing?

Mrs. Q: Yes, I do. I mean I know that there are people really bad with this illness, and I know of a few through speaking to people at the Alzheimer's Society and I hope that my mother's dead before she reaches that stage, and I'm not being hard when I say that ... as regards the future, I hope it's a slow progress, just the way it has been. I would like her dead in life before she would end up really bad and in some sort of mental institution or something like that.

Finally, some carers stated without qualification that death would not come as a blessing to the sufferer. Mrs. Elliott, for example, described her mother's life as follows:

She's still enjoying life - she may be confused at times, and disorientated at times, but she still enjoys people, company, events ... we've gone to the theatre, although you know when you go that she's not going to remember being there, but she enjoys it when she's there, and that's the important thing.

Similar statements were also made by some of the carers of more severely impaired dementia sufferers, for example, Mr. Lees commented on his wife's life: (over)

Obviously she's not got the quality (of life) that we would like for her, but she's got the quality that she likes herself ... she flitters about, she gets great pleasure from our younger son ...

Mrs. Edwards did not think that her husband's death would be a blessing either, because he appeared to be happy:

No, I wouldn't - I think as long as they're there and as long as they're quite happy with life, especially when you know the type of person they have been that lived life to the full and loved life ... you just know they're still there, and that's it, it makes you happy you're quite happy.

9. Did Caregiving Relatives Perceive the Dementia Sufferer as "Already Dead"?

QUESTION : Would you agree that in some ways it is as if ... is already dead?

	<u>% of carers (N = 97)</u>
Strongly agree.....	59%
Slightly agree.....	3%
Unsure.....	2%
Slightly disagree...	2%
Strongly disagree..	32%

The pattern of responses to this question is interesting. Carers quite definitely either did or did not agree that in some ways it was as if the sufferer was already dead. Very few were unsure. Almost twice as many carers agreed than disagreed with the statement.

Those carers who agreed that in some ways it was as if the sufferer was already dead related this to the loss of the person of the sufferer; somehow the sufferer had changed so that they were not the person they had once been. However, criteria for the loss of the person differed. Mrs. Norden said, with regard to her mother:

Yeah, that's true - I'd say my mother died five years ago, because she's never been the same,

you know, never been the same for the past five years - and for the last three years, although she knows, she knows me and everything, it's just not the same person.

Another carer, Mrs. Gemmell, described her mother in virtually the same terms:

They become a different person really - you know they're still your mother, but they're not the mother you knew - I think it's a very confused feeling - maybe you don't analyse it because you don't have time to.

Mr. Tassie described his wife as follows:

Finished, done, dead, dead - they're dead as far as you're concerned, they're dead because they're not the same person they were.

Her feelings at the moment when she realised the person within her mother had died were described by Mrs. Edgar:

... over a year ago I discovered that. That was the hardest, that was the most painful - one of the most painful things. Dad had been invited to his golf club to present some cups, and I went over to look after mum for the evening, and I was kind of looking forward to it, and I took a meal and I sat down with her - it really dawned on me that my mother was gone, that this person wasn't my mother anymore. It's hard - really the person has died and you're just left with the body, that's how I feel about her ... the realisation hit me that night - I was talking to her and she wasn't there - and I cried all the way home, I thought, "My mother is dead".

Variations on this notion of having been left with the body of the sufferer were mentioned by several carers.

Mrs. McAdam, for example, said of her husband:

He's a ghost, a shell ... and even sometimes if there's a little flash, instead of making you happy, it makes you sad.

Similarly, Mrs. Cooper described her mother as already dead in some ways, while her body remained alive:

She can walk about and she can eat and do that, but for a conversation, you'll never get a

conversation out of her ... she's there alright, but the brain's not - there's no brain there at all, I mean, she'll no' even give you a smile.

The same situation was described by Mrs. Church as a "living death" in her husband:

He's no' doing anything. It's a living death, that's a fact.

One third of the sample of carers did not agree with the statement that in some ways it was as if the sufferer was already dead. They emphasised the continued involvement - even if on a very limited level - of the person of the sufferer with the life going on round about them. Mrs. Owen for example, said of her severely impaired husband:

I feel I've still got Jimmy - while he's still aware of trees, people, grass, surroundings.

Similarly, Mrs. McAleer described her feelings about her father, also severely impaired:

No, I don't feel he's dead. No, I feel as if, "You've no' got a great future, dad, but at least you're getting looked after, you're comfortable", you know, he's all involved, he's still there.

"Involvement" was also used by Mrs Deans to justify her disagreement with the statement that it was as if her husband had died in some ways:

He's interested if someone comes in - he sits and listens to conversations, and then he might say something silly ... I would like it if he would go out, just to keep him interested.

Finally, as with the previous item, some carers suggested that although they did not feel as if in some ways the dementia sufferer had died at present, they might do so at some time in the future after continued deterioration in their condition. Mrs. Calder, for example, anxiously contrasted her "still alive" husband with another dementia sufferer whom she clearly classed

as "already dead":

Mrs. Holm - her husband's in the V. Hospital and when I see her I say, "How's Dougie?", and she'll say, "He didn't know me when I was in", and I think, "Oh God, Greg's going to get like that one of these days - how will I do?", I don't know.

III. POST-INTERVIEW RATINGS OF "SOCIAL DEATH" - BELIEVING AND BEHAVING

Following each interview, two ratings of "social death" were made. These were: firstly, the extent to which the carer believed the sufferer was socially dead; and secondly, the extent to which the carer behaved as if the sufferer was socially dead. Ratings were based on the comments, information, and impressions gained throughout the interview. Tables 14.1 and 14.2 present the results of these ratings, together with the criteria upon which the ratings were made.

Table 14.1

Post-interview ratings of belief that sufferer socially dead.

<u>% of carers (N = 96)</u>	<u>Criteria for levels of belief that sufferer socially dead. (Ordered highest to no social death.)</u>
8%.....	Sufferer life a nuisance, carer looks forward to the death.
18%.....	Sufferer life hardly worthwhile, carer thinks ahead to death.
31%.....	Some difficulty seeing life as worthwhile but never/rarely thinks ahead to death.
43%.....	Sufferer life entirely worthwhile at present (= no belief that socially dead).

Table 14.2

Post-interview ratings of behaviour as if sufferer socially dead.

<u>% of carers (N = 97)</u>	<u>Criteria for levels of behaviour as if sufferer socially dead. (Ordered highest to no social death.)</u>
2%.....	Sufferer ignored if present/carer reports no point acknowledging.*
1%.....	Carer pays only slight attention (socially) to sufferer.
40%.....	Carer attends to sufferer as required.
57%.....	Carer attempts to include sufferer as normal, acts in accordance with perceived wishes of sufferer (= no behaviour as if socially dead).

* Note that words such as "attention", or "ignores" on the above table relate to the carer's social treatment of the sufferer - thus to ignore a sufferer does not necessarily mean to fail to care for their physical needs adequately. Nowhere in this sample was there any evidence of the provision of inadequate physical care; indeed, it was generally excellent.

The relationship between believing a sufferer to be socially dead and behaving as if the sufferer was socially dead was examined. In order to do this, both scales were divided into two at the point between the (lowest) "No evidence of social death" rating, and the other (higher) ratings, which represented the presence of various levels of social death. Table 14.3 (over page) shows the numbers of carers who fell into each of the four categories which resulted from combining presence/absence of belief that sufferer socially dead, with presence/absence of behaviour as if sufferer socially dead.

Table 14.3

Relationship between belief that sufferer socially dead and behaviour as if sufferer socially dead. (Numbers of carers in each category - based on post-interview ratings.)

		BEHAVIOUR AS IF SUFFERER SOCIALLY DEAD	
		YES	NO
BELIEF THAT SUFFERER SOCIALLY DEAD	YES	37	18
	NO	4	36

(Total N = 95)

This result differs significantly from a random distribution of carers among the four categories (chi-square = 28.67, $p = <.000$ - after Yates' correction).

The results of the post-interview ratings suggest a Guttman scaling for the dimension of social death, progressing from belief to behaviour. Carers who did not believe that the dementia sufferer was socially dead were unlikely to treat them as such. Carers who did believe the dementia sufferer was socially dead may or may not have treated them as such. Carers who treated the sufferer as socially dead almost invariably believed this to be the case.

The remainder of this section illustrates the ratings made of the carers' social death beliefs and behaviours, categorised into the four groups illustrated in Table 14.3 (above). The examples which have been chosen tend to be the more extreme, in order to more clearly illustrate the dimension of social death.

1. Carers who Neither Believed that, nor Behaved as if, the Sufferer was Socially Dead.

Mrs. Owen whose severely impaired husband was receiving long-term hospital care described her feelings for him as unchanged by the dementia: "You remember the person the way they were". She spent a large portion of the interview describing how she believed one should behave towards dementia sufferers in order not to hurt their feelings, for example: .

- Make a joke of it, don't say, "That's stupid" - pass it over that way, don't make it obvious that they can't do a thing.
- You don't embarrass them by having to cut food for them - have it cut before you put it on that plate - but not too small, let them work away a wee bit themselves. Alright, so he maybe made a mess - I used to have a wee bib, and made the excuse I didn't want it going on the carpet.
- Quite a number of people make the mistake, when they're talking with anyone with Alzheimer's disease, or even if they're just forgetful, they treat them as though they were stupid - they're not stupid, they're just forgetful. They talk down to them. I don't even talk down to a child, because they've got more sense than maybe the person who's talking to them.

Mrs. Owen's husband had been hospitalised because she was physically unable to continue caring for him at home. She was extremely upset by his admission:

... I couldn't have spoken to a soul when he went into that ward - couldn't have answered them because of emotion - it's still difficult.

She visited as often as she could:

... it means two buses, it wouldn't matter if it was twenty-two, I'd still go.

When not visiting, she spent a large part of her time thinking of him, and wondering if he was alright. She did not agree that his death might come as a blessing nor that he was in any way dead already.

Mrs. Carr's situation was very similar in that her severely impaired husband was also in long-term hospital care because she was unable to cope with him at home. At the same time he remained very definitely socially alive in her eyes. Mrs. Carr believed her husband's life continued to be worthwhile:

While Willie's there my feelings will never change ... and when he, if he ever was away, my feelings would never change.

Although her husband had been near death several times, his continued survival was regarded by Mrs. Carr as very fortunate:

... they say he's the "miracle man" - I've been sent for a few times and told that he wouldn't be there next day.

She frequently took expensive new clothes into the ward for him:

They say at the hospital he should be the best dressed man in Motherwell, that's the staff - I'm always buying.

Although her husband was unable to speak, and sometimes even to recognise her when she visited, Mrs. Carr continued to attempt to act in accordance with his wishes, describing one of her major problems as follows:

One of the things is not being able to tell me what he would like - what he would want me to bring in. I've asked him, "Is there anything nice you would like me ..." - you talk away for days sometimes and don't get a word - I have forgotten what his voice is like, that's another thing that hurts.

The above two illustrations may be regarded as somewhat extreme examples of "social life" in that both carers appeared to have over-estimated the remaining abilities of the sufferers. This was not a necessary occurrence for social life. Mr. Fergus, for example was entirely realistic about his wife, Rachael's abilities, however she was also perceived as socially alive. Rachael was

also severely impaired, but continued to live at home. Mr. Fergus did not agree that her death would be a blessing, nor that she was already dead in some ways. His feelings towards her had not changed:

She's still my girlfriend - I still look at her face and I still kiss her and cuddle her - I still love the girl, we've been together a long time.

Despite her severe dementia ("Rachael needs complete assistance in all aspects of normal living - more than assistance - actually doing it for her"), Mr. Fergus attempted to involve her in the life which went on round her, as demonstrated in the following examples of his comments:

- (re. involving her socially) ... I think she enjoys it, so it's always wise and good to try and bring her in and talk to her, even though the response is nil. She can sense it, I'm sure she can ... if you touch her, you know, take her hand, don't be remote.
- I put a lot of time and effort into making Rachael look smart, and I'm quite often complemented on how she's turned out ... I take Rachael out and Rachael's beautifully dressed in her own kilt - the same tartans, we're both dressed alike and with our blouses and jackets, and her hair's done ...

2. Carers who Believed the Dementia Sufferer was Socially Dead, without Behaving as if they were.

Mrs. McEwan cared for her husband at home. She agreed that his death would be a blessing, and that in some ways it was as if he had already died. Nevertheless, she also thought that he should be involved fully in life, and demonstrated concern for his feelings. She described one way in which she did this herself:

He goes to the wee club and he tries to play bingo, and I'm watching his card, and I'm watching my own card - but I just give him it in fun, so he's no' saying, "Oh, I'm no' getting a card - she's no' bothering about mine" ...

While she did not agree that in some ways it was as if her husband was already dead, Mrs. Neary did think his death might come as a blessing:

Yes - it sounds callous right enough, when you talk about - like when I talk about it, but I wouldn't like to see him get worse and worse and worse.

Despite this, Mrs. Neary also tried to involve her husband in everyday activities:

... because I think if they're just left to sit in a chair they just vegetate - just lose interest, do nothing, you know.

She was also annoyed if other people discounted him socially:

Mrs. N: ... the only thing is, my neighbour that faces me, she used to be quite chatty, and I mean, she's been a nurse - and she hardly talks to him at all now if she sees him out on the path - she'll speak to me, but she'll no' really address him.

H.S: As if he's not really there?

Mrs. N: Exactly - and being a nurse and having nursed people like that I'd have thought she'd have known better.

Mrs. McAleer and her family cared for her severely impaired father at home. She agreed his death would come as a blessing:

I wouldn't be sad if my father died, because my father's had a good life, and he's had a long life, and I don't think my father - if he knew he had to be as dependent as he is on everybody he wouldn't want to live - you know?

However, Mrs. McAleer gave her father "as much as possible to do for himself", was concerned with his personal appearance, "because I know how particular he was with his clothes", and she was pleased that the rest of her family continued to involve him socially:

(My husband) talks to him all the time - he talks to him about football, because he loved sports and when there's anything on, we just sit him here (in front of T.V.). My husband says to him who the team is, and I says to myself, "My dad's not even taking that in" -

but then, he's still talking to him ... I think you've still got to talk to him - the girls as well ... he's spoken to a lot, because this is a very busy house, and everybody talks to him.

3. Carers who Behaved as if the Dementia Sufferer was Socially Dead, Without Believing that they were.

Mrs. Mann cared at home for her husband, who suffered from Alzheimer's disease. He was present during the interview, and Mrs. Mann said that this would not matter, since he would not understand what was going on. He became quite agitated while the 34-item Behaviour Problem Checklist was presented, and asked to see the large-print list of items which was provided for carers to refer to. Mrs. Mann agreed that it could be given to him to look through. During the interview, she tended to discount his social presence, making comments such as, "He's very inquisitive". Despite this, Mrs. Mann believed that her husband's quality of life was still sufficient to say that his death would not be a blessing, and in fact, she spoke of his pleasure at being involved in everyday family activities:

I mean now we try to make the most of each day, I mean, there's no reason why we can't have fun - we still buy him new clothes, and he'll say, "Did you buy that for me?" - like last Saturday we got him a nice new pullover and he was thrilled to bits ... he loves to go to town and have a cup of coffee and a scone, or going to the Jackanapes Restaurant on a Sunday for our lunch.

4. Carers who both Believed and Behaved as if the Sufferer were Socially Dead

Mrs. Edgar was involved in the care of her mother, who suffered from fairly severe dementia. Mrs. Edgar's father was still alive, but he was physically very frail. She had found herself wishing that her mother could die:

What scares me is the fact my mother looks so well - my father is so thin and sort of worn-out and wobbly, and yet mum is really quite good looking for 79, and healthy looking, because she's getting very good medical care ... and it scares me how long she'll live. I think - probably a year ago she was going downhill very fast, and we thought, "Well, it's going to be O.K." ... so when she sort of levelled off again, I thought "Oh no" - now this is a terrible emotion to feel in your life, because I'm a good person, there's not much badness in me - I'm going, "Oh no, May, don't slow down" - I went, "What am I thinking?", and I think this has to be the hardest emotion is to wish that person would pass away.

While continuing to care for her mother as required, Mrs. Edgar commented that it was pointless to try to make her look her best, or to try correcting her mistakes:

We treat her mostly, unfortunately, as if she's not really in our world.

Mr. Nichol, who cared for his severely impaired wife, commented that, "I suppose people would say it's like living with the living dead". His wife was entirely dependent on others:

She doesn't speak, she does nothing, she just sits there ... it's very easy really, she's just a big baby.

Mr. Nichol had solved the problem of ensuring his wife's safety when he went out for short periods of time by tying her onto the toilet:

Well, I just lock the door if I'm going out and leaving her in ... I've actually got two methods of doing it - I either lock the door, or I take her in the toilet and strap her on the pan. It's usually perhaps half an hour with the dog ... my conscience wouldn't let me (leave her any longer).

Mrs. Gemmell, caring for her mother, agreed both that her death would come as a blessing and also that in some ways it was as if she had already died, because the person she remembered had gone. Some days Mrs. Gemmell coped with the situation by treating her mother as a task rather than as a person:

I feel some days that - wrongly, I should think - that I'm just looking after an old person. It's become a kind of repetitive process some days.

Finally, among this group of examples, was Mrs. Young, caring for her husband at home, but having placed his name on the waiting list for a long-term hospital bed. Mrs. Young agreed that it was as if her husband was already dead:

That's exactly the position, that's the way I feel about it.

She also agreed that his death would be a blessing, and that if such patients did not die, then they should be institutionalised:

In my opinion, when a person has had enough, they've had enough, and they should concentrate on having places for people - I don't believe in all this business of sending in a home help ... home helps are great for just interim things, but they need to concentrate on having places to put people if they're going to have them live as long as that. I think God never destined for people to live and live and live. I think ... to have a place for them to go and just relax until it's their time.

At the end of the interview, which had lasted - with cups of coffee - over 90 minutes, Mrs. Young asked if

the interviewer would like to meet her husband. Somewhat to the interviewer's amazement, she then went to help him in from the back garden, where he had been sitting all the time (he was unable to get up and walk unaided). The interview had been conducted on 6th December, and it was a chilly morning.

IV. DISCUSSION

1. Assessing Social Death

Previously available literature has presented theoretical discussions of social death and allied concepts. However, no other study has attempted to operationalise social death in order to be able to discuss it with non-professionals and to assess the degree to which it is present within a caregiving situation. It was thus interesting to find that (given a sensitive and appropriate phrasing of the questions) the caregivers of dementia sufferers were quite prepared to discuss topics such as thinking about the sufferer's death, considering whether it might be "a blessing", and indeed, whether or not the sufferer was in some ways "already dead". Clearly, for many carers these notions were by no means foreign, nor shocking. While they might not be discussed widely, some carers had obviously given them consideration. This, to some extent, provides a positive answer to the question of whether or not dementia sufferers are perceived as socially dead by their caregiving relatives.

The remainder of this section will discuss the characteristics of social death in dementia sufferers which emerged from interviews with their caregiving relatives. It is organised into discussions of the

characteristics of each of the social death factors (ie. "Anticipate Death", "Life Pointless" and "Sufferer Unaware" - see Chapter Nine, "Data Analysis", for details of the factor analysis), followed by a discussion of the post-interview ratings of social death beliefs and behaviours.

2. Characteristics of Social Death in Dementia Sufferers as Perceived by Their Relatives

SOCIAL DEATH FACTOR "ANTICIPATE DEATH"

Three quarters of the present sample of carers had thought ahead to the death of the dementia sufferer, if only occasionally. Over half had engaged in imaginal rehearsal of what might happen immediately following the death of the dementia sufferer and about the same number had at one time or another thought about what the future would be like without the sufferer. While these items do not evaluate whether or not the anticipation of the dementia sufferer's death was as a positive or a negative event, the results demonstrate that this sample of caregiving relatives had considered the future without the sufferer.

Given that most of the dementia sufferers in the present sample would be regarded as "elderly" (mean age 75.5 years) it could be argued that their relatives might have been anticipating their deaths even if they had been cognitively intact. Death in the very old is generally perceived as "natural" [Kastenbaum, 1972]. Fulton [1987] points out that the death of elderly parents may have been anticipated by grown children for a great many years before it actually occurs. In the context of social death it may therefore be more appropriate to ask whether the anticipation of the

dementia sufferer's death is coupled with the belief that their life has no value, or with the perception that they have continued to live for too long and are now simply "lingering". Such situations may occur. They are discussed in both the next section of this chapter ("Life Pointless") and in the following chapter.

SOCIAL DEATH FACTOR "LIFE POINTLESS"

This factor is perhaps the one which most encompasses social death in its extreme form as described by previous writers, comprising as it does, the belief that in some ways it is as if the dementia sufferer is already dead, that their physical death would be a blessing, and that their physical appearance is not (has presumably ceased to be) important. Sudnow [1967], for example, chose the narrow definition of social death as the point when a patient is treated essentially as a corpse. Kalish [1967] links psychological death with the belief that a patient might as well be dead. Some cases - such as very severe dementia - may not benefit from the doctor who is able to prolong life [Foot, 1978]. It may be said of such patients that they "deserve to die", or following the event, that their death was "a blessing" [Glaser and Strauss, 1968].

While, obviously, a caregiver - at least one related to a dementia sufferer living in the community - cannot literally treat the sufferer as they would a corpse, almost 60% of the present sample "strongly" agreed that in some ways it was as if the dementia sufferer was already dead. It was interesting that the responses to this item were almost all "strongly agree" or "strongly disagree": carers were very definite about whether or not the dementia sufferer was already dead or not.

Comments related being already dead to their perception of having lost the person they had known but of having been left with the body. A third of the sample of carers agreed that the death of the sufferer would be a blessing, while almost half thought it would not be. As would be predicted by those writers who discuss life as "a good" or in cost-benefit terms, the basis on which many carers made this judgement was their perception of the quality of the sufferer's life. Running through their comments there was a clear thread relating to the existence of a definite cut-off point in the deterioration of the dementia sufferer's condition after which their quality of life would be nil or so negligible that it was not worth maintaining. The position of this cut-off point differed between carers: some who were related to extremely impaired sufferers believed that sufficient quality of life remained to make their continued existence worthwhile. This notion of a cut-off point allowed several carers to state that while they could not regard the dementia sufferer's death as a blessing at the moment, they believed that such a state of affairs would occur in the future. However, the issue of a cut-off point at which continued life becomes worthless and death is to be desired is of course widely contested. Clearly among this sample, some relatives of extremely impaired sufferers were far from seeing their lives as pointless. It is interesting that the item weighing most heavily on social death factor "Life Pointless" was whether or not a good personal appearance on the part of the sufferer continued to be important. The vast majority of caregiving relatives believed it was. Presumably, then, if the dementia sufferer's personal appearance ceases to be regarded as important by the carer, this is an extremely good indicator that their life is no longer seen as sanctified.

SOCIAL DEATH FACTOR "SUFFERER UNAWARE"

Many writers have linked social death (or allied concepts) to lack of awareness. Kalish [1968], for example, defines "psychological death" as occurring when an individual becomes unaware of his or her own existence. Harris [1985] discusses his concept of a person as involving the ability to value its own existence. Downie and Telfer [1969] regard the distinctive endowments of persons as the ability to be self determining and the ability to adopt rules. Englehardt [1987] discusses the notion of "minimal" degrees of sentience and consciousness as a qualification for personhood. Severe dementia sufferers - those who are unaware - are regarded by Wershow [1981] as having lost their personhood, thus legitimising a warehousing approach to their care within an institution. Dying geriatric patients in just such an institution were found by Kastenbaum [1967b] to be socially invisible to the staff in proportion to their degree of mental impairment. Glaser and Strauss [1966] described patients with severe senile dementia as socially dead, and because of their impairments they were unaware of their approaching physical death. Removing a person's dignity and individuality ("non-person" treatment [Goffman 1961, 1963]) has been regarded as removing their personhood, or as "dehumanising" [for example, Vail, 1964; Travelbee, 1964; Strauss, 1984].

Social death factor "Sufferer Unaware" appeared to include the dementia sufferer losing their personhood by becoming unaware of and unresponsive to their environment. Whether in addition, or in response to this state, it also included the dementia sufferer having their personhood to some extent removed from

them by the carer's decision that independent behaviours need not be encouraged.

By far the majority of carers in the present study estimated that the dementia sufferer knew what was going on only "sometimes" or less often. Similar responses were given in answer to the item concerning how much insight the sufferer demonstrated; over one half of the sample of dementia sufferers were reported to never speak of there being anything wrong with them. Of course, these are fairly objective items in comparison with the rest of the Social Death scale. While it might be possible for a carer to grossly under- or over-estimate the amount of awareness that their dementing relative possessed, this did not appear to be the case in practice. The differences lay in the emphasis placed on their responses. This was very similar to the proverbial distinction between the perception of a glass as half empty or half full. Different carers could discuss the remaining abilities of very similar dementia sufferers in very different ways. To some extent this may have been reflected in their responses to the third item comprising social death factor "Sufferer Unaware", for while acknowledgement of lack of awareness among the dementia sufferers was given by the majority of carers, most also believed it was important that the sufferer did as much as they could for themselves. This was presented as maintaining dignity and independence, and as encouraging the dementia sufferer to keep going. In other words, continued independent behaviour - on whatever level possible - was seen by caregiving relatives as endeavouring to maintain the personhood of the sufferer.

RATED SOCIAL DEATH (POST-INTERVIEW)

The rating of degree of social death was an attempt to make some sort of overall assessment of the extent of sufferer social death observed during the interview. It was based on the notion of the possibility of observing (or gathering) "non person" treatment; for example, ignoring the presence of the dementia sufferer, evidence that their care was perceived as a mechanical set of tasks, discussing them as a dementia patient rather than as an individual, no evidence that the sufferer was included in household tasks (if able) or social visits. After only a few interviews it became obvious that the criteria for rating degree of social death which had been included in the Carers' Questionnaire were unsatisfactory. (A single scale had been utilised, running from "Carer wholly positive about sufferer, attempts to include as normal, talks to sufferer, acts in accordance with perceived wishes, regards sufferer's continued life as entirely worthwhile" to "Sufferer ignored, carer regards sufferer's life as a nuisance, looks forward to death as positive event") In practice, degree of social death appeared to run along two dimensions which could be labelled "believing" and "behaving". These dimensions did not always correspond. In particular, carers often appeared to believe the sufferer was more socially dead than might be suggested by their behaviour towards the sufferer. Post-interview ratings of social death were therefore sub-divided into both social death beliefs and social death behaviours. (Noted in Chapter Eight, "Method - Study Sample, Procedures, Materials and Measures", and in Appendix Three, "Formalising the Carers' Questionnaire and Coding Frame".) The fact that these two aspects of Rated Social Death were found to form an additive Guttman-type scale (a carer was

extremely unlikely to behave as if a sufferer was a "non person" unless they believed that they were a non person who had reached a stage where they were as good as dead) is unsurprising. A carer is unlikely to leave an elderly dementia sufferer sitting alone in the garden on a wintery morning, or tied to the toilet, unless they have largely discounted that sufferer as a person. However, one fifth of this sample of carers, while apparently believing that the dementia sufferer was as good as dead, continued to behave as though they were socially alive (for example, talking to them, taking them to bingo, becoming upset when others ignored them). For this group, the dementia sufferer was still a person of whom some individual notice should be taken. It was clearly possible to maintain this behaviour while at the same time believing that the sufferer had reached a stage of impairment such that their death would be a positive event. It is possible to speculate on the reasons for this. Perhaps the physical presence of a dementia sufferer prompts an attempt to continue a lengthy or close personal relationship, even if only out of force of habit. Perhaps a carer decides to behave as though the dementia sufferer is a person of whom ritual notice should be taken as an insurance, "just in case" the sufferer is aware of more than would appear. Finally, perhaps an uncomfortable dissonance would be created by ceasing to behave towards a dementing relative as though they were socially alive while at the same time continuing to care for them on a physical basis. As Pearlin, Mullan and Semple et. al. [1990] point out, "giving care to someone is an extension of caring about that person" [p.583]. On a behavioural level, it would be possible to attempt to involve a dementia sufferer as a social person for any or all of these reasons, while at the same time thinking ahead to their death

and believing that their life has ceased to be worthwhile.

V. SUMMARY

This chapter has presented and discussed evidence suggesting that some carers perceived their dementing relatives to be socially dead - if this is defined as anticipating the death of the sufferer, believing that their continued life is pointless, or that they have ceased to be aware of their environment. The majority of carers reported having thought ahead to the death of the dementia sufferer, even if only occasionally, over half had engaged in imaginal rehearsal of events following the death, and most had considered a future life without the sufferer. Approximately one-third of the sample agreed that the death of the sufferer would come as "a blessing", while over half believed that in some ways the sufferer was "already dead". Almost every dementia sufferer was perceived as to a greater or lesser degree unaware of their environment, and as lacking insight into their condition. Despite this, most carers continued to encourage as much independent behaviour in the dementia sufferer as they were able.

A proportion of the carers who held views that could be categorised as believing the sufferer was socially dead, also behaved towards the dementia sufferer in ways that would signify the discounting of their presence as a social person. "Social death behaviours" in relation to the dementia sufferer were unlikely to occur unless "social death beliefs" were held by the carer. Factors associated with - and perhaps even predictive of - these social death beliefs and behaviours are highlighted in the next chapter.

CHAPTER FIFTEEN

FACTORS ASSOCIATED WITH SOCIAL DEATH IN DEMENTIA SUFFERERS

I. INTRODUCTION

Chapter Fourteen presented evidence which suggested that many caregivers held "social death beliefs" relating to their dementing relatives, and a smaller number also exhibited "social death behaviours". Previous literature has suggested that social death may occur as the end-point of a variety of processes. These processes include the resolution of anticipatory grief in relatives, the physical removal of the socially dead person, or their severe impairment and lack of ability to respond to others.

What were the predictors of social death in the present sample of dementia sufferers? Was social death predicted by the pattern of the emotional reactions of their caregiving relatives? Was social death predicted by certain sufferer characteristics such as "loss of person" type impairments, or institutionalisation. Or, was social death predicted by other variables altogether? To answer these questions, stepwise multiple regression analyses were performed in order to determine the association between caregiver, sufferer, or their relationship variables, and the social death of the sufferer.

II. FACTORS ASSOCIATED WITH SUFFERER SOCIAL DEATH

Since factor analysis had demonstrated a multi-dimensional structure to social death (see Chapter Nine - "Data Analysis"), separate analyses were conducted with four different measures of social death. These were as follows:

1. "Anticipate Death" | The three social death factors
2. "Life Pointless" | obtained via factor analysis
3. "Unaware" | of the social death scale.
4. Total "Rated Social Death". Post-interview ratings of believing that the sufferer was socially dead and behaving as if the sufferer was socially dead had been found to approximate a Guttman scale, progressing from belief to behaviour (see previous chapter). In view of this, the two ratings were summed to create total "rated social death".

In the "first round" six multiple regression analyses were conducted in order to eliminate the majority of possible predictor variables. The variables which were entered into the regression equations were those characteristics of carer and sufferer which it was hypothesised might be related to the onset of the social death of the dementia sufferer. (For details of the coding of the variables as they were entered into the regression equations, please refer to Appendix Eight.)

These variables comprised the following.

CARER CHARACTERISTICS EQUATION

(1) Carer gender; (2) Carer age; (3) Carer religiosity; (4) Carer general knowledge of dementia; (5) Carer overall perception of dementia; (6) Carer perception of having experienced grief.

CARER GRIEF: I.S. COMPONENTS EQUATION *

(1) "Nowadays" I.S. grief component "Shock/Denial" score; (2) "Hope/Bargaining" score; (3) "Questioning/Anger/Guilt" score; (4) "Preoccupation/Unfinished Business/Despair" score; (5) "Acceptance" score.

CARER F.A. GRIEF COMPONENTS EQUATION *

(1) "Nowadays" F.A. grief component "Disbelief/Hope" score; (2) "Deny" score; (3) "Protest" score; (4) "Yearn" score; (5) "Mourn" score.

SUFFERER CHARACTERISTICS EQUATION

(1) Sufferer gender; (2) Sufferer age; (3) Sufferer living arrangements (community vs. institution); (4) Time since onset of impairments; (5) Time since diagnosis of dementia; (6) Overall change in sufferer perceived by carer; (7) Most important change in sufferer perceived by carer; (8) Sufferer ability to recognise carer; (9) Sufferer physical changes as perceived by carer.

SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION

(1) Total frequency of problems from behaviour problem domain "Demand"; (2) domain "Can't do"; (3) domain "Incontinence/Hygiene"; (4) domain "Apathy"; (5) "Disturb"; (6) domain "Demand".

* Since the I.S. and F.A. grief components comprised some of the same items, they were entered into mutually exclusive equations. A "final" regression analysis was conducted for the results of each equation separately. Thus, the final analysis using I.S. components of grief entered those items which had emerged as significant predictors of the social death measure in question APART from the F.A. components of grief. The final analysis using F.A. components of grief entered those items which had emerged as significant predictors of the social death measure in question APART from the I.S. components of grief. Clearly the results of these equations could be expected to be very similar, since apart from the grief components, the same variables were entered into each.

CARER-SUFFERER RELATIONSHIP EQUATION

(1) Blood/Role relationship; (2) Quality of premorbid carer-sufferer relationship; (3) Quality of current carer-sufferer relationship; (4) Change in quality of carer-sufferer relationship.

The results of the six "first round" stepwise multiple regression analyses for the five different measures of social death are presented in Appendix Nine.

Table 15.1 (over page) presents the results of the "final" round of stepwise multiple regression analyses for the four different measures of social death when the I.S. components of grief were included in the equation. Table 15.2 presents the results of the analyses when the F.A. components of grief were included in the equation. In those cases where it is not immediately obvious, the direction of the relationship for those variables in the equation is explained in the table.

Tables 15.1 and 15.2 demonstrate that somewhat different combinations of "predictor" variables were related to the differing measures of social death.

Social death factor "Anticipate Death" was found to be more likely with greater time since onset of the dementia and when the dementia sufferer exhibited more demanding behaviour. When the I.S. components of grief were included in the equation it was associated with "Questioning/Anger/Guilt" but when the F.A. components of grief were included it was associated not as might be expected with "Protest", but instead with "Mourn". (This solution accounted for a greater proportion of the variance than that explained by I.S. component "Questioning/Anger/Guilt".)

Table 15.1

Stepwise Multiple Regression Analyses - Predictors of Social Death (S.D.) when I.S. Components of Grief Included in Equation

	Adjusted R ²	Beta	F-value	
<u>S.D. FACTOR ANTICIPATE DEATH</u>				
I.S. grief component				**
"Questioning/Anger/Guilt".....	0.10	0.30	11.39	
Time since onset of dementia.....	0.15	0.28	10.09	***
Problem behaviour domain				***
"Demand".....	0.25	0.25	9.76	
<u>S.D. FACTOR LIFE POINTLESS</u>				
Carer perception: Has definitely grieved.....	0.20	0.39	25.12	***
Quality of current relationship.....	0.29	-0.26	21.02	***
Problem behaviour domain				***
"Depend".....	0.35	0.26	18.75	
I.S. grief component				***
"Hope/Bargain".....	0.38	-0.22	16.45	
Carer perception: Dementia = horrible/worst illness.....	0.41	-0.18	14.70	***
<u>S.D. FACTOR SUFFERER UNAWARE</u>				
Behaviour problem domain				***
"Can't do".....	0.25	0.36	34.73	
Behaviour problem domain				***
"Depend".....	0.29	0.24	21.09	
(Greater) Carer general knowledge of dementia.....	0.32	-0.20	16.64	***
<u>RATED SOCIAL DEATH</u>				
Quality of current relationship.....	0.18	-0.30	22.16	***
Problem behaviour domain				***
"Depend".....	0.25	0.21	17.18	
Quality of premorbid relationship.....	0.30	-0.28	15.51	***
Sufferer (unable to) recognise carer.....	0.34	0.20	13.64	***

** = p<.01 *** = p<.001

Table 15.2

Stepwise Multiple Regression Analyses - Predictors of Social Death (S.D.) when F.A. Components of Grief Included in Equation

	<u>Adjusted R²</u>	<u>Beta</u>	<u>F-value</u>
<u>S.D. FACTOR ANTICIPATE DEATH</u>			

F.A. grief component "Mourn".....	0.15	0.39	18.85

Time since onset of dementia.....	0.24	0.31	16.43
Problem behaviour domain			***
"Demand".....	0.26	0.19	12.85
<u>S.D. FACTOR LIFE POINTLESS</u>			
Carer perception: Has			***
definitely grieved.....	0.20	0.35	25.12
Quality of current			***
relationship.....	0.29	-0.25	21.09
Problem behaviour domain			***
"Depend".....	0.35	0.25	18.75
Quality of premorbid			***
relationship.....	0.37	-0.18	15.54
<u>S.D. FACTOR SUFFERER UNAWARE</u>			
Behaviour problem domain			***
"Can't do".....	0.25	0.37	34.73
Behaviour problem domain			***
"Depend".....	0.29	0.21	21.09
(Greater) Carer general			***
knowledge of dementia.....	0.32	-0.20	16.64
F.A. grief component			***
"Protest".....	0.35	0.18	14.10
<u>RATED SOCIAL DEATH</u>			
Quality of current			***
relationship.....	0.18	-0.30	22.16
Behaviour problem doamain			***
"Depend".....	0.25	0.21	17.18
Quality of premorbid			***
relationship.....	0.30	-0.28	15.51
Sufferer (unable to)			***
recognise carer.....	0.34	0.20	13.64

*** = p<.001

Social death factor "Life Pointless" was more likely when the carer perceived him or herself to have grieved, and dementia as a very horrible or worst possible illness. It was more likely when the current relationship between carer and sufferer was poor, and when the sufferer exhibited a greater number of dependent behaviours. When the I.S. components of grief were included in the analysis, lack of "Hope/Bargaining" was found to be associated with "Life Pointless". When the F.A. components of grief were included, none emerged as significantly associated with this social death factor, although a poor premorbid carer-sufferer relationship did.

Dementia sufferers who were perceived by their carers to be unaware of their environment were likely to be those who displayed more behaviours of omission, and more dependent behaviours. Their carers were more likely to have greater general knowledge about the mechanisms and effects of dementia and also to be experiencing anger at the sufferer, the illness, themselves, or God.

Finally, those sufferers who received high rated social death scores (ie. whose carers both believed that, and behaved as if the sufferer were socially dead) were likely to display greater dependency problems. They were less likely to be able to recognise their caregiving relative. Both the premorbid and current carer-sufferer relationships were likely to have been poor.

III. DISCUSSION

1. Factors Associated With Social Death in Dementia Sufferers

SOCIAL DEATH FACTOR "ANTICIPATE DEATH"

Kastenbaum [1969] suggests that a person may become classified as socially dead because they have NOT died but have instead lived beyond their prime. Natterson and Knudson [1960] and Natterson [1973] describe the final phase in the reactions of mothers of fatally ill children as being a time when separation from the child became easier and wishes for the death of the child could be expressed. Gosling [1980] describes the problems of the "Not-Officially-Bereaved" who have to continually pick up the pieces of their relationship each time the patient fails to die. Rush [1974] notes that lengthy terminal illnesses are associated with an exhaustion of the emotional resources of family members who then wish the patient would die so that they could resume their lives. In sum, previous literature appears to associate the anticipation of a person's death with living too long - either surviving through an unexpectedly lengthy "living-dying interval", or else perhaps simply getting too old.

In correspondence with previous anecdotal reports, anticipation of the dementia sufferer's death in the present study was also associated with living too long. The longer someone with dementia survives from the time when their impairments first become obvious, the more likely are their relatives to think about that sufferer's death, or what their own lives will be like following its occurrence. Given the comments of some of the carers, this may be partly related to the

information which they receive with regard to the allotted life span of someone with dementia: as that deadline approaches they begin to think increasingly about the sufferer's death. For others it is probably simply that a consequence of an increasingly lengthy period as a caregiver is the thought "When/How is this going to end?".

It is interesting that the only sufferer impairment variable to be significantly associated with "Anticipate Death" was the behaviour domain "Demand". This was the behavioural factor which accounted for the least variance among those extracted from the 34-item Problem Checklist. This, plus an inspection of the item content suggests that it is far less of an index of overall sufferer impairment than the behaviour domains "Depend" and "Can't do". Thus, thinking ahead to the sufferer's death appears to be prompted by trying, demanding sufferer behaviours rather than simply by their increasing impairment and inability to perform the activities of daily living.

This is also suggested by the carer grief components which were associated with social death factor "Anticipate Death", particularly if, as was suggested earlier in this thesis, F.A. grief components "Mourn" is regarded as reflecting carer reactive depression. The impression one receives is that if a carer is related to a dementia sufferer who has been ill for a very long time and who exhibits trying, demanding behaviours, and if that carer is feeling fed up and depressed, then they are more likely to be thinking ahead to the time when the situation will change. This is represented by the death of their dementing relative.

SOCIAL DEATH FACTOR "LIFE POINTLESS"

Dementia sufferers who were perceived by their carers to be living pointlessly were likely to be those who displayed more dependent behaviours. Their carers were more likely to have given up any hope for the sufferer's future, and to believe both that they had experienced grief and that dementia was a very horrible or the worst possible illness. The quality of the current carer-sufferer relationship was likely to be poor, and possibly also their premorbid relationship. The direction of several of these relationships is difficult to decide, and the best assumption may be that they are not unidirectional. Take the association between social death factor "Life Pointless" and the carer's belief that they have grieved. Comments on the theme of the loss of the sufferer were made by those who endorsed the "sufferer already dead" item of "Life Pointless". They were also made by those carers who perceived themselves as having experienced grief. But to ask which of these variables "comes first" is much like the proverbial chicken-and-egg question. Those who advocate the resolution of anticipatory grief as the main route to social death might suggest that the perception of having grieved comes first. To others the social death factor "Life Pointless" might appear to be the loss which leads to the perception of having grieved. Much the same argument could be applied to the association between "Life Pointless" and a negative perception of dementia. Is it because you perceive dementia to have resulted in the loss of the sanctity of your relative's life that you also perceive it as a very horrible or the worst possible illness? Or does the fact that you perceive dementia in such negative terms lead you to regard your relative's life as already as good as lost? The same could be said for the

association between "Life Pointless" and poor quality of current carer-sufferer relationship. If the relationship is poor so you never laugh, you feel the sufferer is possessive, you are constantly having silly arguments, and you wish you could get away from them, then you may well regard the continuation of the dementia sufferer's life as not worthwhile. But perhaps also if you regard yourself as having already lost the person of the dementia sufferer, their death as a blessing, and their personal appearance as no longer important, then it would be very difficult to maintain a high quality, relaxed and cheery relationship with them.

One of the variables associated with "Life Pointless" where we can assume directionality is sufferer problem behaviour domain "Depend". As was noted earlier, "Depend" was the first factor to be extracted via principal components analysis from the 34-item Problem Checklist (ie. it accounted for the greatest amount of variance), and inspection of its item content suggests that it is mainly a measure of very obvious physical disabilities which can arise as a result of dementia. It thus appears that increasing sufferer dependency may represent the index upon which a carer is most likely to measure quality of life, and loss of the person of the dementia sufferer. It is interesting to question why the behavioural domain which was assumed to be most representative of loss of the person, namely "Apathy" (comprising sitting around doing nothing, unable to occupy self doing useful things, and unable to hold a sensible conversation) did not emerge as significantly associated with "Life Pointless". Possibly this arises because apathetic dementia sufferers are often perceived as gently fading away and not as particularly distressed by their continued life. They may be the

sufferers who are perceived as "happy in his/her own wee world". Given this, their lives may still be worth living. However, another - rather simpler - possibility is that in practice almost all the present sample were reported to sit around doing nothing, unable to occupy themselves and unable to hold a sensible conversation. Thus there was very little variation across the scores for this measure, in which case a statistically significant relationship with other variables would be impossible.

While none of the F.A. grief components emerged as significantly associated with "Life Pointless", I.S. component "Hope/Bargaining" was negatively related to this social death factor. Perhaps giving up of all hope with regard to the possible recovery or even the arrest of deterioration in the dementia sufferer's condition represents the acceptance that they are already as good as dead. Or perhaps it is the acceptance of this state of affairs that leads to the loss of all hope in the carers.

When the F.A. components of grief were included in the analysis, poor quality of premorbid carer-sufferer relationship emerged as significantly associated with social death factor "Life Pointless". It may be more difficult for a carer who has memories of a good relationship with the sufferer before the onset of dementia to believe that their death would now come as a blessing, that in some ways it is as if they are already dead and that their personal appearance has ceased to be of any importance now, whatever their actual degree of impairment.

SOCIAL DEATH FACTOR "SUFFERER UNAWARE"

While it had been thought that some of the carer estimations of degree of sufferer awareness may not have been entirely correct, sufferer impairment variables were found to be significantly associated with this social death factor. "Sufferer Unaware" was more likely when the dementia sufferer scored highly on the behavioural domains "Can't do" (which included being unable to wash and unable to dress without help, unable to read papers, etc., unable to follow TV or radio) and "Depend" (which included being unable to manage stairs, walking outside, getting in and out of a chair/bed without help, unsteady, falling, needing help at mealtimes). These variables clearly reflect degree of not only mental impairment, but also physical disabilities which would be all too obvious to the caregiving relatives.

"Sufferer Unaware" was also significantly associated with greater carer general knowledge about dementia. Possibly - as has been suggested earlier, and in another context - carer general knowledge about the mechanism and effects of dementia increase their objectivity about what is happening to the sufferer. If you know that parts of the brain are ceasing to function, you may be less likely to think that maybe the sufferer is more aware or is able to do more for themselves "than they are letting on they can": you know they simply cannot.

While none of the I.S. grief components was significantly associated with "Sufferer Unaware", F.A. component "Protest" was. It is difficult to explain why this is so. An angry carer would clearly not produce an unaware or unresponsive dementia sufferer - although

possibly they would be more likely to perceive the sufferer in such terms. In that case, perhaps the relationship runs in the other direction: an unaware, unresponsive dementia sufferer who is judged as incapable of engaging in independent behaviour and who needs assistance with everyday activities plus physical help to get around, may result in an angry, protesting carer. (However, it is worth noting here that multiple regression analysis did not suggest that any of the problem behaviour domains exhibited by the dementia sufferer were significantly associated with F.A. grief component "Protest".)

RATED SOCIAL DEATH

The Rated Social Death Scale comprised both social death beliefs plus social death behaviours (see previous chapter), thus to attain an extremely high Rated Social Death Scale score a carer would have to give evidence of both maximal social death beliefs and behaviours. The Carers' Questionnaire items tapping social death largely related to carer beliefs. The difference then, between Rated Social Death and the 9-item Social Death Scale (from which the three social death factors emerged) is that RATED social death includes social death BEHAVIOURS. The one variable which was associated with Rated Social Death but not with any of the social death factors was the sufferer's ability to recognise the carer. This suggests that it is only once a dementia sufferer ceases to recognise them, that their carer is able to discount them as a person. This makes intuitive sense: how much easier it would be to ignore a person if you were sure that they did not know who you were. Calkins [1972] also suggests the importance of recognition as a significant influence on whether or not people are treated as

socially dead. (She discusses the case of an "extremely brain damaged" woman whose husband was unable to treat her as socially dead and construct a life without her simply because she could still recognise him.)

The other sufferer variable found to be associated with Rated Social Death was behaviour domain "Depend". As discussed earlier, this presumably represents the fact that it is the more impaired dementia sufferer who is most likely to receive non person treatment from his or her carer.

Both poor current and premorbid carer-sufferer relationships were associated with higher Rated Social Death. Again, as previously discussed, the effect of premorbid carer-sufferer relationship presumably represents the fact that a bank of good memories of the past relationship makes it difficult to discount the dementia sufferer as a person now. A poor current carer-sufferer relationship may result from, or lead to behaviour towards the dementia sufferer as if they were a non person; most probably the relationship does not run along in just one direction.

2. Main Roads to Social Death?

Previous writers have implied that there may be one or more main road(s) to social death. The most frequent suggestion is that social death may result from a resolution of anticipatory grief . The scenario drawn is of the family members of a dying patient passing through all the phases of grief and reaching a stage of deatthexis and resolution before the patient's physical death. Another suggestion is that social death may be facilitated by the physical removal of the patient to an institution: that once out of sight a dying patient

also becomes out of mind. Yet another hypothetical main road to social death is severe impairment in the patient. Perhaps coma, a vegetative state, inability to recognise or communicate meaningfully with others, or completely helpless dependence leads to the suggestion that such patients are no longer leading worthwhile lives and also allows others to treat them as non persons.

Do the results of the present study allow us to back any of the above routes as the main road to the social death of dementia sufferers?

None of the three social death factors, nor Rated Social Death was associated with carer I.S. grief component "Acceptance". Indeed, "Anticipate Death" was associated with I.S. grief component "Questioning/Anger/Guilt" and with F.A. component "Mourn". However, "Life Pointless" was associated with lack of "Hope/Bargaining". This suggests that while social death was not necessarily related to the resolution of carer anticipatory grief, it may have been related to complete acceptance of the dementia as represented by the giving up of all hope or bargaining for their improvement or maintenance. In addition, since "Life Pointless" was associated with a carer's belief that they had definitely experienced grief, social death may have been related to the acknowledgement of, and reaction to loss due to dementia in the sufferer.

Whether or not the dementia sufferer lived in an institution rather than the community had no significant impact on any of the measures of social death. For this sample, then, removal of the body of the dementia sufferer did not increase the likelihood that they would cease to exist as a person in the eyes

of their carer. Caution should be taken in generalising from this result to all caregiving relatives of dementia sufferers. It should be remembered that the response rate for participation in the study was low (for example, 38% from one psychogeriatric in-patient ward). It could be argued that those relatives of institutionalised dementia sufferers who agreed to take part in the study were those whose dementing relative was least likely to have become socially dead. It is possible that this was also true for the community carers.

For the present sample, the clearest of the previously suggested routes towards social death was the impairment of the dementia sufferer. Social death factor "Anticipate Death" was associated with behaviour domain "Demand"; "Sufferer Unaware" was associated with "Depend" and "Can't do"; "Life Pointless" was associated with "Depend"; and finally, Rated Social Death was associated with "Depend" and sufferer inability to recognise the carer. It thus appears that for dementia sufferers, a major road to social death is the fact that their own deterioration leads to the judgement that such beliefs or behaviours have become quite legitimate. Given negative carer perceptions of dementia or a poor carer-sufferer relationship, the impairments of the sufferer may incur for him or her the status of being socially dead.

IV. SUMMARY

Factors associated with the social death of dementia sufferers were presented in this chapter. Stepwise multiple regression analyses were employed to identify these factors.

Anticipation of the death of the sufferer was associated with greater time since onset of dementia, with demanding sufferer behaviours, and with depression or anger in the carer. Perception of the continuation of the sufferer's life as pointless was more likely in carers whose evaluative perception of dementia was negative, who believed themselves to have experienced grief, and who expressed fewer reactions of hope or bargaining. Perceiving the sufferer's life as pointless was also associated with poor current and premorbid carer-sufferer relationships, and with dependent sufferer behaviours. Reported sufferer lack of awareness was associated with greater sufferer impairment, greater carer general knowledge of dementia, and greater carer protest. Behaving towards the sufferer as if they were socially dead was more likely when the sufferer did not recognise the carer, when the sufferer exhibited more demanding behaviours, and when the current and premorbid carer-sufferer relationships were reportedly poor.

These results were discussed against the background of previous literature concerning social death; in particular whether social death results from the resolution of carer anticipatory grief, from the physical removal of the dementia sufferer, or from the nature or degree of their impairments.

CHAPTER SIXTEEN

FACTORS ASSOCIATED WITH CAREGIVER SUBJECTIVE BURDEN

I. INTRODUCTION

Subjective burden was assessed in a variety of different ways, both during the interview and via written questionnaires (completed by those of the carers who were willing) after the interview.

The current chapter seeks to identify factors associated with caregiver subjective burden. These factors include characteristics of the carer, the sufferer, and their relationship. In addition, the analysis examines whether anticipatory grief and social death were linked to a carer's coping and well-being. In particular, did certain aspects of the carers' emotional reactions impact to a greater degree on their perceived burden and ability to cope than other aspects? And did caring for a socially dead dementia sufferer increase or decrease subjective burden?

II. CAREGIVER SUBJECTIVE BURDEN - DESCRIPTIVE RESULTS

Results demonstrated clear evidence of subjective burden in the caregiving relatives of dementia sufferers. Of the 68 subjects who completed the GHQ-28, 33 (49%) scored above the cut-off point of 5, and thus qualified as a "GHQ case". With regard to life satisfaction, 31% of carers described themselves as currently "mostly dissatisfied" or worse. "Quite a lot" or "enormous" strain resulting from caring for the dementia sufferer was reported by 20% of carers with

regard to their physical health, by 49% with regard to mental health, by 53% with regard to social life, and by 23% with regard to finances. (Both these and further results describing the extent of carer subjective burden can be found in Appendix Ten.)

III. FACTORS ASSOCIATED WITH CARER WELL-BEING AND ABILITY TO COPE

Stepwise multiple regression analyses were performed in order to determine the predictors of caregiver subjective burden.

Separate analyses were conducted for each one of the following five measures of subjective burden:

ASSESSED DURING INTERVIEW (All subjects)

- "Strain scale" (4 items);
- Carer's overall rating of how well they were coping;
- Carer's overall rating of current life satisfaction;

ASSESSED FOLLOWING INTERVIEW

- General Health Questionnaire (GHQ-28);
- Affect Balance Scale (ABS).

In the "first round" six multiple regression analyses were performed for each of the five measures of subjective burden. The variables which were entered into the equations were those which it was hypothesised might influence caregiver burden. (For details of the coding of the variables as they were entered into the regression equations, please refer to Appendix Eight.)

These variables comprised the following: (over page)

CARER CHARACTERISTICS EQUATION

- (1) Carer age; (2) Carer gender; (3) Carer work outside the home; (4) Carer given up work to care; (5) Number of professionals carer had spoken to with regard to sufferer and dementia; (6) Carer general knowledge of dementia; (7) Carer overall perception of dementia; (8) Carer perception of having experienced grief; (9) Carer religiosity
- | | | |
|---|--|---|
| (10) Carer use of "negative coping techniques"..... | | Assessed via post-interview questionnaire - only entered into equations for GHQ and ABS, also assessed via questionnaire. |
| (11) Carer use of "positive coping techniques | | |

CARER I.S. COMPONENTS OF GRIEF EQUATION

- (1) "Nowadays" I.S. grief component "Shock/Denial" score; (2) "Hope/Bargaining" score; (3) "Questioning/Anger/Guilt" score; (4) "Preoccupation/Unfinished Business/Despair" score; (5) "Acceptance" score.

SUFFERER CHARACTERISTICS EQUATION

- (1) Sufferer age; (2) Sufferer gender; (3) Sufferer living arrangements (community vs. institution); (4) Time since onset of impairments; (5) Time since diagnosis of dementia; (6) Overall change in sufferer perceived by carer; (7) Most important change in sufferer perceived by carer; (8) Sufferer ability to recognise carer; (9) Sufferer physical changes as perceived by carer; (10) Speed at which carer perceives changes had occurred in sufferer.

SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION

- (1) Total frequency of problems from behaviour problem domain "Depend"; (2) domain "Can't do"; (3) domain "Incontinence/Hygiene"; (4) domain "Apathy"; (5) domain "Disturb"; (6) domain "Demand".

SUFFERER SOCIAL DEATH EQUATION

- (1) Social death factor "Anticipate Death" score; (2) "Life Pointless" score; (3) "Unaware" score.

CARER-SUFFERER RELATIONSHIP EQUATION

- (1) Carer-sufferer blood/role relationship; (2) Quality of premorbid carer-sufferer relationship; (3) Quality of current carer-sufferer relationship; (4) Change in quality of carer-sufferer relationship.

The results of the "first round" stepwise multiple regression analyses for the five caregiver subjective burden measures can be found in Appendix Nine.

Table 16.1 (over page) presents the results of the "final round" of analyses. Explanations of the direction of the association with caregiver subjective burden are given where necessary. The results of the analyses are summarised in the paragraphs which follow.

Those carers who reported greater "strain" (physical and mental health, social life, and financial strain) were likely to be experiencing more intense "Preoccupation/Unfinished Business/Despair" and to have no employment outside the home. They were more likely to be caring for sufferers who were incontinent and who showed no concern for personal hygiene.

Those carers who believed themselves to be coping badly at the time of the interview were more likely to have a poor relationship with the sufferer and to regard themselves as having definitely grieved.

Carers who reported that their life satisfaction was poor were likely to be experiencing more intense "Questioning/Anger/Guilt" and "Shock/Denial". They were not likely to be working outside the home. Their relationship with the sufferer was more likely to be poor.

Carers who completed the GHQ-28 and received a higher score (indicating greater likelihood of psychiatric "caseness") were likely to use a greater number of negative coping techniques (such as blaming themselves, putting off practical solutions, taking their minds off the problem by drinking, pills, smoking, etc.). They

Table 16.1

"Predictors" of Five Different Measures of Subjective Burden in the Caregiving Relatives of Dementia Sufferers.

	Adjusted R ²	Beta	F-value
<u>STRAIN SCALE SCORE</u>			
I.S. grief component "Preocc/ Unfinished Business/Despair".....	0.28	0.46	40.49 ***
Problem behaviour domain "Incontinence/Hygiene".....	0.35	0.26	27.76 ***
Carer (not) working outside the home.....	0.38	-0.21	21.63 ***
<u>PERCEIVED POOR CURRENT COPING</u>			
Quality of current relationship.....	0.15	-0.36	18.63 ***
Carer perception: Has definitely grieved.....	0.22	0.27	14.73 ***
<u>PERCEIVED POOR LIFE SATISFACTION</u>			
I.S. grief component "Questioning/Anger/Guilt".....	0.24	0.31	31.98 ***
Carer (not) working outside the home.....	0.32	-0.24	24.60 ***
Quality of current relationship.....	0.38	-0.27	21.25 ***
I.S. grief component "Shock/Denial".....	0.41	0.21	18.60 ***
<u>GHQ SCORE</u>			
Carer use of "negative coping techniques".....	0.25	0.23	22.21 ***
Time since onset of impairments.....	0.44	-0.29	18.12 ***
Problem behaviour domain "Depend".....	0.52	0.28	18.70 ***
Quality of current relationship.....	0.54	-0.30	18.70 ***
Number of professionals with whom carer has had contact.....	0.58	-0.23	16.31 ***
Carer perception: Has definitely grieved.....	0.60	0.24	15.30 ***
<u>ABS SCORE</u>			
Quality of current relationship.....	0.30	0.44	28.47 ***
I.S. grief component "Questioning/Anger/Guilt".....	0.36	-0.28	18.94 ***

*** = p<.001

were likely to have had contact with a smaller number of professional people with regard to the dementia sufferer. They were more likely to regard themselves as having definitely grieved. These carers were more likely to be looking after a sufferer with a greater number of dependency problems and whose impairments were of relatively recent onset. The relationship between carer and sufferer was more likely to be poor.

Finally, carers who completed the Affect Balance Scale and received a higher score (indicating greater life satisfaction) were likely to have a better relationship with the dementia sufferer and to be experiencing less intense "Questioning/Anger/Guilt".

IV. DISCUSSION

1. "Predictors" of Caregiver Subjective Burden

Given the inter-correlations between the five different measures of carer subjective burden (see Appendix Ten) it is to be expected that, as was found, they tended to be associated with the same "predictor" variables. The discussion of these associations will commence with those variables found to be related to the GHQ-28 scores for the following reasons. Firstly, the high R^2 (0.60) suggests that this regression analysis resulted in a equation with high "goodness-of-fit"; secondly, the GHQ is the measure of subjective burden which has been employed most frequently in previous studies of the caregivers of dementia sufferers; and thirdly, simply because it includes the largest number of variables in the final equation.

"PREDICTORS" OF CARER GHQ-28 SCORE

A high GHQ score (indicating greater psychiatric morbidity) was more likely when the carer used a greater number of "negative coping strategies". "Negative coping strategies" included such strategies as criticising/blaming oneself, trying not to think about what's happening, or taking feelings out on someone/something. Their association with a high GHQ score among caregiving relatives is very interesting because it corresponds with MacCarthy and Brown's [1986, 1989] finding of a relationship between coping style and psychological adjustment in Parkinsonian patients. They found that the use of "Positive coping" (described as active problem solving, seeking social support, and re-orientation) was significantly related to positive well-being, but had no relationship with depression. In contrast, the use of "maladaptive coping" (acting out/distraction and denial/distancing) was positively associated with depression. They therefore concluded that "depressed patients have used actively and potentially adaptive coping strategies just as often as those who are in better psychological health. However, the depressed patients have been making more efforts to cope by using strategies which appear to be maladaptive in addition to the strategies associated with positive well-being" [MacCarthy and Brown, 1986, p.12]. The reader will recall that the carer coping strategies questionnaire (termed "Coping with the Effects of Giving Care") in the present study was based on that used by MacCarthy and Brown - and clearly, very similar results were obtained with regard to the effects of the types of coping strategies employed. The use of "negative coping strategies" was associated with a high GHQ score, while the use - or lack of use - of "positive coping strategies" had no

impact on GHQ score. MacCarthy and Brown [1989] appear to assume directionality of association, since they suggest that interventions to modify coping behaviour may benefit the mental and physical health of Parkinsonian patients. If we assume that "negative coping strategies" lead to high GHQ scores then we could also conclude that the caregiving relatives of dementia sufferers might benefit from an intervention designed to limit their use of such strategies. However, the possibility remains that the relationship acts in the opposite direction, and that it is as a result of GHQ "caseness" that certain carers tend to engage in certain behaviours such as putting off trying practical solutions, even when they can think of them, or trying to take their minds off thing by smoking, drinking, eating, or taking pills to relax.

GHQ score was inversely related to the number of different professionals to whom the carer had spoken with regard to the sufferer. All carers had spoken to one or more professionals; however, those who had spoken to greater numbers had generally done so via some sort of support group. Because of the sources from which the sample was drawn, almost all the caregiving relatives who were interviewed had the opportunity to attend a group, run either by one of the psychogeriatric day units, the Alzheimer's Society, or the social services. This would suggest that contact with additional professional staff via the route of a relatives' support group may have the function of protecting carer well-being. What is interesting about this result is that the variable was NOT the number of professionals with whom the carer was currently in contact, but rather the TOTAL number with whom they had spoken over the course of the dementia sufferer's illness. Thus, it does not necessarily relate to the

amount of current formal support, but suggests that a continued and available supply of support is helpful. As has been noted already, the present study suggested that the amount of carer general knowledge about dementia was positively associated with the number of different professionals to whom the carer had spoken. Previous studies have suggested that providing carers with information about dementia may reduce subjective burden [Toner, 1987; Chiverton and Caine, 1989]. Might this also be the mechanism of maintaining good carer well-being in the present study? Presumably not, since degree of carer general knowledge about dementia did not emerge as a significant "predictor" of GHQ score in the current analysis. Possibly, then, it is simply the expression of interest and support from a variety of professionals throughout the dementia sufferer's illness that reduces the likelihood of high GHQ scores among caregiving relatives. (The impact of the amount of relief from caring [ie. formal respite services] on subjective burden was not included in the present analysis. This was not an oversight. Relief from caring /provision of support services was only of relevance to carers of community dwelling dementia sufferers. To restrict analysis to this sub-sample was not the intention of the present study, since the emphasis throughout was on caregiver anticipatory grief and sufferer social death, and not on sufferer living arrangements. In addition, to remove the carers of institutionalised dementia sufferers from the sample would have reduced the size of the sample, thereby making multiple regression analysis a less applicable statistic.)

The final carer variable associated with high GHQ score was the belief that they had definitely experienced grief. Carers who believed they had experienced grief

tended to be both currently experiencing, and to have previously experienced, greater degrees of distress and less acceptance (as measured by the various components-of-grief scales) than those who believed they had not experienced grief. To some extent the content of the GHQ-28 overlapped with the individual grief scale items (for example, GHQ item "edgy and bad tempered" and grief item "anger/irritability with others", or GHQ item "life entirely hopeless" and grief item "life lost its meaning"). Therefore this result presumably results from the fact that both a higher GHQ and a carer's belief that they have grieved reflect distress.

The finding that high GHQ score was associated with less time since the onset of impairment, while perhaps not what might be initially hypothesised (based on some sort of build-up of burden model) does in fact accord with two other studies which have related carer burden to duration of impairment. Machin [1980] suggested her finding that some supporters had found the first few months as caring most difficult occurred because that represented the time when they were getting used to their role and lifestyle as a caregiver. Gilhooly [1984] found a positive association between the morale and mental health of community caregivers and the duration of caregiving. She attributed this to either the fact that carers learn to adjust and cope with time, or else to the "survival effect".

A higher GHQ score was also associated with a greater frequency of sufferer problem behaviours from domain "Depend". This problem behaviour domain reflects very obvious physical disabilities requiring vigilance and/or active intervention on the part of the carer (for example, a sufferer's inability to get in and out of a chair, negotiate stairs, or feed themselves without

help). The majority of previous studies have found an association between sufferer impairment and carer subjective burden. However, the finding has usually been that it is disturbed or "aberrant" behaviours which create greater burden - and indeed, Whittick [1985] states specifically that neither the level of the dementia sufferer's physical disability nor disturbances of gait were associated with carer GHQ scores. The question therefore arises as to why behaviour domain "Depend" but not - for example - "Demand" or "Disturb" emerged as significantly associated with GHQ score in the present study. Possibly the reason is that "Depend" is the behavioural domain which most clearly reflects overall degree of sufferer impairment. However, this seems unlikely since firstly, carer estimates of the overall degree of sufferer change did not emerge from the analysis as significantly associated with carer GHQ score; and secondly, it has been suggested that caring may actually become easier as a dementia sufferer deteriorates from moderate to severe impairment and thus (usually) becomes more apathetic. The reason why disturbing or demanding sufferer behaviour was not found to be associated with GHQ score may be an effect of the methodology of the current analysis, which included institutionalised dementia sufferers. While they may exhibit disturbed or demanding behaviours, these may not impact upon the carers in the same way as they would if the sufferers were living in the community. This may have confounded the results.

Finally, a high GHQ score was associated with a poor current carer-sufferer relationship. A distressed carer is unlikely to be able to maintain a "good" or relaxed relationship with the dementia sufferer. In addition, there is the possibility that distressed carers may be

more likely to evaluate their relationship with the sufferer as poor. These may not be the only reasons for the association: after all, a poor carer-sufferer relationship is unlikely to be conducive to high carer well-being.

"PREDICTORS" OF CARER AFFECT BALANCE SCALE SCORE

The other self-completion measure of well-being, the Affect Balance Scale (in which high scores represent greater "happiness" or well-being) was also associated with the quality of current carer-sufferer relationship and in addition with I.S. grief component "Questioning/Anger/Guilt". Higher ABS scores were associated with less "Questioning/Anger/Guilt". Clearly, those carers who are currently less distressed in this way are more likely to be happy; not a remarkable finding. Of more interest, perhaps, is one variable which did not emerge as significantly related to ABS score. While MacCarthy and Brown [1986, 1989] found that the use of "positive coping" bore no relationship to depression in Parkinsonian patients, it was significantly related to positive well-being as measured by the Positive Affect Scale of the ABS. While the results of the present study correspond with those of MacCarthy and Brown in finding the use of "negative" (or "maladaptive") coping strategies to be related to psychiatric morbidity, the relationship between positive coping strategies and carer well-being was not found in the present study.

"PREDICTORS" OF SINGLE-ITEM CARER LIFE-SATISFACTION SCORE

The single item measure which probably came closest to assessing the same "happiness" factor as the ABS was the carer life satisfaction item. Poor life

satisfaction was again associated with poor quality of current carer-sufferer relationship, and, like the ABS, with the degree of I.S. grief component "Questioning/Anger/Guilt". Unlike the ABS, the life satisfaction item was also associated with whether or not the carer worked outside the home and the degree of I.S. grief component "Shock/Denial". Poorer Life Satisfaction was more likely when the carer was experiencing more intense "Shock/Denial". I.S. grief component "Shock/Denial" reflects not only shock at sufferer dementia or behaviours, but also the attempt to avoid emotional expression. That it was associated with poor life satisfaction (unhappiness) in the carer could be regarded as adding weight to the notion that emotional catharsis is beneficial to mental health. In other words - as was in fact expressed by several carers - "bottling up" your emotions is a bad thing. The fact that being in paid employment was associated with higher life satisfaction may seem surprising since it might be assumed that employment would increase the stress on the carer. It is interesting to find that in another study, there was also a positive relationship between carer morale or good mental health and employment, although the correlation approached but did not reach statistical significance [Gilhooly, 1984]. Thus, outside employment may well be associated with more benefits than costs for caregiving relatives. These benefits presumably include the social support available from work mates, and the change which employment makes from caring - it quite literally gets the carer out of the house. The fact that a carer is able to take paid employment also means that they are able to leave the dementia sufferer. This in turn means that (in the case of co-resident carers) the dementia sufferer is still capable enough to be left alone or else there are other family members who can act as

"sitters" - both factors which might be assumed to be associated with higher carer life satisfaction.

"PREDICTORS" OF SINGLE-ITEM CARER COPING SCORE

The other single item measure of carer well-being was their perception of how well they were currently coping. Poor coping was more likely when the carer believed that they had definitely experienced grief and when the current carer-sufferer relationship was poorer. Poor relationship was thus found to be a "predictor" of high carer GHQ score, low ABS score, low current life satisfaction, and with carer estimates of poor current coping. Clearly, then, quality of current carer-sufferer relationship was linked to carer well-being or subjective burden. Carer belief of having experienced grief was also associated with high GHQ score. The same mechanism of association could probably be assumed in the case of carer coping: both the belief that grief has been experienced and poor current coping being associated with greater distress throughout the dementia sufferer's illness.

"PREDICTORS" OF CARER "STRAIN SCALE" SCORE

The final measure of carer subjective burden was the 4-item "Strain scale". Unlike the two life satisfaction measures (single item Life Satisfaction and ABS score) which were associated with carer I.S. grief component "Questioning/Anger/Guilt", a higher carer score on the "Strain scale" was associated with I.S. grief component "Preoccupation/Unfinished Business/Despair". It is very difficult to say why this might be so, since examination of the individual ABS items shows them to correspond in part to both these grief components (for example, ABS includes "so restless you couldn't sit

long in a chair" but also "depressed or very unhappy"). It will be recalled that these two I.S. grief components were highly correlated, and were associated with broadly similar "predictor" variables (perception of dementia as a horrible or worst illness, and poor current carer-sufferer relationship). For some reason the depressed or preoccupied carer was more likely to report that caring had affected their health, social life and finances, while the angry or questioning carer was more likely to report poorer life satisfaction.

Greater overall strain was more likely in carers related to dementia sufferers who more frequently exhibited problem behaviours from domain "Incontinence/Hygiene". This problem domain relates to incontinence and lack of personal hygiene skills. Not only does it relate to a rather unpleasant set of caregiver tasks, but also to the loss of the previously "clean" dementia sufferer. In this, the present study agrees with many previous studies of caregiver well-being, since incontinence has frequently been identified as associated with increased subjective burden in carers [for example, Rabins, Mace and Lucas, 1982; Levin, Sinclair and Gorbach, 1984; Argyle, Jestice and Brook, 1985].

There was a relationship between employment and lower carer strain. This could be attributed (as discussed with regard to its role in increasing carer life satisfaction) to the social outlets, distraction from caregiving, and either less impaired sufferer (capable of being left alone) or the availability of another "sitter". Since the "Strain scale" also included financial strain, there is the possibility that paid employment also reduced carer strain by providing them with additional finances.

2. Importance of the Identification of Factors Associated with Increased Subjective Burden in Carers

One of the initial aims of the present study was to examine whether anticipatory grief and social death were linked to a carer's coping and well-being. The evidence is that three of the I.S. grief components were associated with subjective burden. In some respects, this should not come as a surprise, since these grief components represent carer distress, while the two components which were not found to be associated with subjective burden ("Hope/Bargaining" and "Acceptance") are those least associated with active carer distress. Since (as was discussed in an earlier chapter) there was very little evidence of clear staging of caregiver emotional reactions, we cannot use the notion of anticipatory grief to suggest that there may be certain "stages" when caregiving relatives experience a greater degree of subjective burden.

None of the social death factors was associated with subjective burden. This may mean that factors such as thinking ahead to the sufferer's death or believing their life to be pointless have no impact on burden. Alternatively it could mean that social death impacts upon different carers in different ways, and that these individual differences cancel each other out. For example, it is possible that while one carer may find it less stressful (less guilt provoking or frustrating) to care for a socially dead dementia sufferer (as suggested by Howell [1984]), another carer may actually find it more stressful to care for someone whose personhood is absent (as suggested by Hermann [1984]). The present results do not therefore resolve this debate.

One of the main aims of identifying factors associated with increased subjective burden is that by doing so one is also identifying the "at risk" carer - that is, the carer who is suffering (greater) distress. The majority of factors which both this and previous studies have identified as associated with increased burden are - unfortunately - not remediable. However, certain of the variables highlighted in the present study might be modified. These include the possibility of increasing the 'availability of a variety of different professional staff to talk with the carer about the sufferer and their dementia throughout the process of the illness: expressions of continued professional interest in the carer may be just as helpful as the provision of general information about dementia. In addition, the use of "negative" (or "maladaptive") coping strategies could be examined and possibly modified. This would require focused sessions on either an individual or a small group basis. Even the sufferer impairment variables ("Depend" and "Incontinence/Hygiene") which were found to impact upon some of the measures of carer subjective burden in the present study, while not "curable" may be open to some sort of intervention to make them easier to cope with: aids to mobility, railings, stair-lifts, showers, regular and readily available incontinence pads and sheet laundry services may ease the burden on community carers.

Some of the factors which have emerged as significantly associated with carer burden in previous studies did not emerge in the present analysis. These included disturbing or demanding sufferer behaviours (possible reasons for this have been discussed), female carers, and poor premorbid carer-sufferer relationship. With regard to the premorbid relationship, given that

premorbid and current relationship were significantly associated, it may be that by including quality of current relationship in the regression analysis effectively reduced the significance of premorbid relationship in statistical terms. It might therefore have been more interesting to remove "quality of current relationship" from the analysis in order to examine for the effects of premorbid relationship on carer subjective burden. However, an alternative possibility is that previous studies have found poor premorbid carer-sufferer relationship to be significantly associated with carer burden simply because it is a "predictor" of a poor current relationship. (Quality of the current carer-sufferer relationship emerged as a variable associated with the nature and degree of a carer's emotional and behavioural reactions, sufferer social death, carer subjective burden, and - as indicated in the chapter which follows - carer attitudes to continued community care. Because of its clear importance, factors associated with the quality of current carer-sufferer relationship were examined. The results of this analysis are presented and discussed in Appendix Twelve.)

V. SUMMARY

This chapter presented the results of stepwise multiple regression analyses designed to identify factors associated with caregiver subjective burden.

Caregiver burden had been assessed in five different ways (4-item "Strain Scale", single-item carer coping measure, single-item carer life-satisfaction measure, GHQ-28, and Affect Balance Scale). These five measures

of burden tended to be associated with the same factors. Increased carer subjective burden was associated with a carer's use of "negative coping strategies", with the belief that they had definitely experienced grief, with those grief components most representative of carer distress, with a carer who did not work outside the home, and with a carer who had had contact with fewer "professionals". Increased carer burden was also more likely when the quality of the current carer-sufferer relationship was poor, when less time had passed since the onset of impairments in the sufferer, and with sufferer dependency or incontinence/hygiene problems. (This represents a summary of the results. Not every one of the five measures of subjective burden was associated with every one of the factors listed here.)

In the discussion of these results it was noted that the association between anticipatory grief and subjective burden occurs because both variables represent carer distress. It was also noted that no social death factors were associated with carer subjective burden. The value of identifying factors associated with the carer "at risk" of increased subjective burden was discussed.

CHAPTER SEVENTEEN

FACTORS ASSOCIATED WITH THE INSTITUTIONALISATION OF DEMENTIA SUFFERERS

I. INTRODUCTION

Previous chapters which examined the relationship of a variety of factors to caregiver emotional reactions (or "anticipatory grief") and sufferer social death did not find evidence that institutionalisation of the dementia sufferer made a significant impact on either of these areas.

This chapter seeks to find out whether the opposite applies. Does the state (or "stage") of a caregiver's emotional reactions, or the extent of sufferer social death impact upon caregiver willingness to institutionalise the dementia sufferer? Or do other variables predict caregiver willingness to institutionalise?

The living arrangements of the 100 dementia sufferers at the time of the interviews with their carers were as follows:

- 61 lived in the carer's home;
- 16 lived in their own home;
- 23 lived in long-term care.

The present chapter focuses on the carers of dementia sufferers living in the community. It uses stepwise multiple regression analyses in order to identify those factors which increased the willingness of a carer to place the dementia sufferer into long-term care. (Descriptive results with regard to caring for a dementia sufferer within the community, and measures of

willingness to institutionalise can be found in Appendix Eleven.)

II. FACTORS ASSOCIATED WITH CARER WILLINGNESS TO INSTITUTIONALISE RELATIVES WITH DEMENTIA

Analyses were conducted on the following two measures of willingness-to-institutionalise:

- Total "Carer Willingness to Institutionalise" score.

The two 5-point scales of "How likely is it that your relative will enter long-term care within the next year?" and "How likely would you be to take a place tomorrow?" had been found to form a Guttman distribution (see Appendix Eleven). The scores on these two scales were therefore summed to create a total "Carer Willingness to Institutionalise" score.

- Post-interview ratings of "Attitude to Continued Caring".

(These two measures were significantly related: $r = 0.669$, $p < .000$)

In the first round, seven multiple regression analyses were conducted. The variables within each area which were entered into the regression equations were those which it was hypothesised might impact upon carer willingness to institutionalise. (For details of the coding of the variables as they were entered into the regression equations, please refer to Appendix Eight.) These variables comprised the following:

CARER CHARACTERISTICS EQUATION

(1) Carer age; (2) Carer gender; (3) Carer work outside the home; (4) Number of professionals carer had spoken to with regard to sufferer and dementia; (5) Carer general knowledge of dementia; (6) Carer overall perception of dementia; (7) Carer perception of having experienced grief; (8) Carer estimate of current coping ability; (9) Carer estimate of current life satisfaction.

CARING SITUATION EQUATION

(1) Hours per week relief from caring; (2) Satisfaction with help from relatives; (3) Satisfaction with help from professionals.

CARER I.S. COMPONENTS OF GRIEF EQUATION

(1) "Nowadays" I.S. grief component "Shock/Denial" score; (2) "Hope/Bargaining" score; (3) "Questioning/Anger/Guilt" score; (4) "Preoccupation/Unfinished Business/Despair" score; (5) "Acceptance" score.

SUFFERER CHARACTERISTICS EQUATION

(1) Sufferer age; (2) Sufferer gender; (3) Sufferer living arrangements; (4) Time since onset of impairments; (5) Time since diagnosis of dementia; (6) Overall change in sufferer perceived by carer; (7) Most important change in sufferer perceived by carer; (8) Sufferer ability to recognise carer; (9) Sufferer physical changes as perceived by carer.

SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION

(1) Total frequency of problems from behaviour problem domain "Depend"; (2) domain "Can't do"; (3) domain "Incontinence/Hygiene"; (4) domain "Apathy"; (5) domain "Disturb"; (6) domain "Demand".

SUFFERER SOCIAL DEATH EQUATION

(1) Social death factor "Anticipate Death" score; (2) "Life Pointless" score; (3) "Sufferer Unaware" score.

CARER-SUFFERER RELATIONSHIP EQUATION

(1) Carer-sufferer blood/role relationship; (2) Quality of premorbid carer-sufferer relationship; (3) Quality of current carer-sufferer relationship; (4) Change in quality of carer-sufferer relationship.

The results of the seven "first round" stepwise multiple regression analyses for the two measures of willingness-to-institutionalise can be found in Appendix Nine.

Table 17.1 presents the results of the "final round" stepwise multiple regression analyses for the two measures of willingness-to-institutionalise. Where necessary, the direction of the relationship for those variables in the equation is explained.

Table 17.1
 "Predictors" of the Willingness of Community Caregivers
 to Institutionalise Dementia Sufferers

	<u>Adjusted R²</u>	<u>Beta</u>	<u>F-value</u>
<u>UNWILLING TO INSTITUTIONALISE</u>			
Hours per week relief from caring.....	0.07...	-0.30....	8.69 **
Carer estimate of current coping ability (good).....	0.14...	-0.26....	9.04 ***
<u>POSITIVE ATTITUDE TO CONTINUED CARING</u>			
Quality of current relationship.....	0.20....	0.28...	26.71 ***
Carer estimate of current coping ability (good).....	0.25...	-0.24...	17.64 ***
Social death factor "Life Pointless".....	0.29...	-0.24...	14.67 ***

** = p<.01 *** = P<.001

The above results demonstrate the following points.

Those carers who were least likely to be considering institutionalisation of the dementia sufferer (ie. long-term care unlikely even within a year), were likely to be receiving fewer hours relief from caring each week, and more likely to believe that they were currently coping well with the situation.

Those carers who were rated as having the most positive attitude to continued caring were more likely to have a good current relationship with the dementia sufferer, and more likely to believe that they were currently coping well with the situation. Finally, they were less likely to believe that the sufferer's life was pointless (ie. that the sufferer was already dead in some ways, that their physical death would be a blessing, and that their physical appearance was no longer important.)

III. DISCUSSION

1. Factors Associated with Carer Willingness to Institutionalise

Given that total "Carer Willingness to Institutionalise" score (likelihood that dementia sufferer would enter long-term care within a year plus likelihood that an institutional place would be accepted tomorrow) and post-interview ratings of "Attitude to Caring" were highly and significantly correlated, the variables associated with each will be considered together in this discussion.

The association between believing that one is coping badly with the current (community care) situation and increased willingness to relinquish the task makes "logical" sense. Previous studies have investigated the effects of carer well-being or subjective burden rather than coping on preference for institutional care, with the balance of results suggesting that subjective burden increases desire to institutionalise [for example, Levin, Sinclair and Gorbach, 1984; Morycz, 1985; Colerick and George, 1986]. It was poor coping

rather than poor life satisfaction which emerged as a "predictor" variable in the present study. This could reflect the fact that a carer may still wish to continue caring despite feeling stressed or unhappy themselves. On the other hand, if they actually feel that they have ceased to be able to cope adequately with the caregiving task, this may act as a much more compelling reason for believing that institutional care had become the only option.

Present results suggested that those carers who received more relief from caring might be more willing to institutionalise their dementing relative. This, of course, runs counter to the notion of the provision of community support or respite services in order to maintain a dementia sufferer within the community. However, as Gilhooly [1990] points out, a number of other studies have also suggested that such a notion may actually be something of a myth. In fact, the present results are similar to the findings of Colerick and George [1986] who reported that caregivers who subsequently institutionalised a dementia sufferer received more social support than those who kept the sufferer in the community. Possibly the reason for such results is that the carer who is not coping well with looking after their relative either mobilises additional support from other quarters - or they are recognised as vulnerable and thus have additional formal or social support thrust upon them. An additional - or alternative - reason for the finding that greater relief from caring is associated with increased willingness to institutionalise may be that once carers receive substantial relief from caring they not only "get a taste for it", but their guilt at relinquishing care diminishes. Thus, institutional care becomes more attractive: it is perceived as having more

benefits and fewer costs. The final reason for the association may be that, as suggested by Colerick and George [1986], the belief that no additional assistance is necessary to meet the "caregiving challenge" means that a carer is both accepting of their role and also that they believe themselves to be successful in that role. In other words, if you do not believe you need respite from caring on a day basis, you are unlikely to believe that institutionalisation of the dementia sufferer is necessary. '

The association between poorer current carer-sufferer relationship and rated negative attitude towards caring does not come as a surprise. It would be difficult to be positive about the continued care of a person with whom one never laughed, often argued, frequently felt tension, or often wished to get away from. Previous studies have not examined the association between the quality of current relationship and willingness to continue care, but have stressed the power of a good premorbid relationship in predicting low preference for institutional care.

When discussing institutionalisation, many community carers commented that they would not feel able to place their relative in long-term care unless the dementia sufferer ceased to recognise them and became unaware of their surroundings. At such a point they seemed to believe it would somehow become legitimate to relinquish care because such a degree of impairment meant that the sufferer would not know where they were nor who was looking after them. This would mean that they would not know that they were no longer at home nor that their spouse or child was no longer caring for them. This in turn would decrease the guilt of the caregiving relative. These carers were expressing the

idea that institutionalisation may be appropriate for the socially dead dementia sufferer. It was interesting to find that the statistical analysis bore this out. Those carers who were rated as having a negative attitude towards continued care were more likely to have endorsed items from social death factor "Life Pointless". That is, they were more likely to believe that in some ways the dementia sufferer was already dead, that their physical death would come as a blessing, and that their physical appearance had ceased to be particularly important. It must be difficult to be positive about caring for someone about whom you hold such beliefs.

2. Institutionalisation, Anticipatory Grief and Social Death

Previous chapters noted that the fact of the dementia sufferer living in institutional as opposed to community care was not significantly associated with either the pattern of carer anticipatory grief, the social death of the dementia sufferer, or the subjective burden of the carer. Reasons for these findings included the possible bias of the sample towards the carers of more "socially alive" institutionalised sufferers, and also the possibility that it is the more distressed carers whose sufferers become institutionalised while the less distressed carers "survive" with their dementing relative in the community.

The results in the present chapter demonstrate that neither the pattern nor the intensity of carer anticipatory grief were significantly associated with their willingness to institutionalise a dementing relative. Indeed carer perceived current coping ability

was the only well-being variable to emerge as a "predictor" of willingness to institutionalise. However, one aspect of sufferer social death, the belief that their continued existence had become pointless, was found to be related to increased carer willingness to institutionalise. Presumably while the dementia sufferer's death would come as a blessing for the group of caregiving relatives who hold such beliefs, institutionalisation - the removal of the sufferer's physical presence and the need for continued care and vigilance - may well be perceived as the next best alternative. This would be entirely consistent with comments such as those of one carer who spoke of "just putting in the time" until her husband could be admitted for long-term care at the local psychiatric hospital.

IV. SUMMARY

Stepwise multiple regression analyses were employed in order to identify factors associated with preference for institutional care among relatives who were caring for a dementia sufferer in the community.

Increased willingness to institutionalise was associated with the receipt of greater amounts of relief from caring, and with carers who perceived themselves to be coping badly with the current situation. Negative rated attitude to continued community care was more likely when the current carer-sufferer relationship was poor, when the carer perceived him or herself to be coping badly, and when the carer held the beliefs which comprised social death factor "Life Pointless".

The reasons for these findings were discussed. It was noted that institutionalisation of the dementia sufferer had not been found to impact upon carer anticipatory grief nor upon sufferer social death. However, while neither the pattern nor the intensity of a carer's emotional and behavioural reactions impacted upon their preference for institutional care, increased sufferer social death - the fact that their continued life was perceived as pointless - increased carer preference for institutional care.

CHAPTER EIGHTEEN

FINAL DISCUSSION - RESULTS, METHODOLOGICAL ISSUES, AND RECOMMENDATIONS

I. INTRODUCTION

Each of the preceding "results" chapters has aimed to both present and discuss the findings of the present study. This chapter therefore limits itself to a brief final discussion of the results which were obtained, within the context of both previous "stress and caregiving" studies and also the initial aims of the present study. This discussion also forms a summary of the main findings of the study. This is followed by a section which discusses the methodological issues which emerged during the completion of the study. The final section of this chapter presents recommendations concerning both the direction of future research and the most useful support which might be offered to caregiving relatives.

II. DISCUSSION OF RESULTS

The demographic details of the carers and their relatives with dementia, and also the behavioural characteristics of the dementia sufferers in the present study bear a very close resemblance to those of previous studies. A quarter of the present sample of dementia sufferers were institutionalised; in line with estimates of between one-fifth and a quarter of the moderately and severely demented as living in institutional care [Kay and Bergmann 1980 - cited in Gilleard, 1984]. The majority of carers were women,

looking after either their husbands, or aged parents - often widowed mothers who may still have been surviving in their own homes. The male carers in the present study tended to be looking after their wives in the marital home. The average age of the dementia sufferers was 75 years, while that of the carers (60 years), means they were the "young-old". With regard to the behaviours which were reported to occur, and those which were actually regarded as "a problem" in the present sample of dementia sufferers, the similarity to the findings of the "Edinburgh" research studies [Gilleard, 1984] is striking. The outcome of the factor analysis of the checklist in the present study was also broadly similar to that obtained by Gilleard, Boyd and Watt [1982]. Since not only was the same assessment tool (34-item Problem Checklist) used in both instances, but also the caregiver samples were drawn from broadly the same geographical area, these results should not come as a surprise. In fact, they serve to validate the findings of the "Edinburgh" studies and the use of the 34-item Problem Checklist.

The similarity between the characteristics of the carers and their relatives with dementia in the present study and those quoted in previous studies is important. It means that the present results can be generalised to other samples of caregiving relatives with greater confidence.

The first three aims of the present study were to establish the following: firstly, whether the nature of the reaction experienced by the caregiving relatives constituted anticipatory grief; secondly, whether the reaction occurred in stages with the end-point being that of resolution; and thirdly, whether the nature or intensity of the reaction was related to particular

characteristics of the carer, the sufferer, or their relationship. Among this particular sample of caregiving relatives living in Clydeside in 1989-90, knowledge about the diagnosis and the prognosis of dementia was generally good. Dementia was clearly acknowledged as an illness which would result in the continued deterioration and eventual death of the sufferer. It was perceived by this sample of caregiving relatives not only as a "terminal illness", but also as an illness which had already brought losses in the sufferer. The emotional and behavioural reactions of these carers could be related partly to the caregiving task, but for the majority of carers, partly also to acknowledgement of the present and future losses brought about by dementia. As such, a part of their emotional and behavioural reactions could be described as "anticipatory grief". In the simple description of the reactions of the caregiving relatives the results of the present study are similar to previous accounts of anticipatory grief. However, while the present study found that a proportion of caregiving relatives did experience a degree of staging in their reactions, this was by no means general. This means either that stages exist in the reactions of the caregiving relatives of dementia sufferers but that they were not picked up in the present study, or else that carers' reactions do not usually emerge in a predictable sequence of stages. It should be noted that none of the previous accounts of distinct phases in the reactions of the families of dementia sufferers was devised to critically evaluate the validity of this notion. Rather, they are based on having run a relatives' support group, or are an application of the previous descriptive literature to the relatives of dementia sufferers. This older literature was based on observations of the relatives of very different groups

of terminal patients; in particular, the parents of dying children, in whom one could assume that the anticipatory grief period would be both more salient and more depressing than in the relatives of dementia sufferers.

Although time was not found to be significantly associated with particular components of a carer's reaction, apart from decreased "Disbelief/Hope", a variety of other variables were. These included characteristics of both the carer, the sufferer, and their relationship. The nature of these variables (for example, age of carer and sufferer, sufferer behaviour, nature and quality of carer-sufferer relationship, etc.) corresponds with the notion that a carer's emotions and behaviours should be regarded as reactions to the whole situation. This includes the practical tasks of caregiving, in addition to the losses resulting from dementia in their relative. A particularly important variable was that of the evaluative perception of dementia held by the carer; greater distress being associated with its perception as a "horrible/worst illness". The fact that a carer's cognitions may contribute towards their responses to dementia accords with the recent interest in the role of the cognitions in the emotional disorders (for example, Beck, Emery and Greenberg [1985]). However, this is an area which has received little attention among the "stress and caregiving" research.

The fourth and fifth aims of the present study were to establish whether dementia sufferers are perceived as socially dead by their caregiving relatives, and if so, whether the staging of carer anticipatory grief is linked to the social death of the sufferer. The study demonstrated that it is possible to operationalise and

assess degree of social death. The concept of social death as discussed in previous literature emerged as multi-dimensional in the present study. The three dimensions identified comprised anticipating the death of the sufferer, perceiving the continuation of their life as pointless, and reporting that the sufferer was unaware of their environment and their impairments. The factor "Life Pointless" (comprising the beliefs that the sufferer's death might come as "a blessing", that in some ways they were "already dead", and that their physical appearance was no longer important) appeared to be the most "useful" dimension, in that it came closest to measuring the belief that the dementia sufferer was "as good as dead". It is of interest that this was the only social death factor to be associated with a carer's perception that they had definitely grieved (which was in turn associated with greater carer distress). "Life Pointless" was also associated with lack of I.S. component "Hope/Bargaining". Thus, a carer's belief that their dementing relative's life is pointless appears to have been related to the acknowledgement of, and response to, the loss of the person of the dementia sufferer. Since clear "stages" had not been identified in the reactions of caregiving relatives, it was not possible to relate sufferer social death to a particular phase of carer anticipatory grief. Indeed, the factor most consistently associated with sufferer social death was the degree of their impairment.

The two final aims of the present study were to establish whether carer anticipatory grief and sufferer social death were linked to caregiver subjective burden and/or to the institutionalisation of the dementia sufferer. The study found that whether the dementia sufferer lived in institutional or community care had

no impact on either carer anticipatory grief or sufferer social death. Turning from the factors "predictive" of carer anticipatory grief and sufferer social death to the impact that these variables may have themselves, the "usefulness" of the social death factor "Life Pointless" continued. It was the only social death factor associated with increased preference for institutional care. None of the components of the carer emotional and behavioural reactions had a significant impact on their preference for institutional care. None of the dimensions of social death as assessed in the present study had any impact on carer coping ability or subjective burden. That emotional and behavioural reactions representing distress did impact on carer subjective burden is to be expected since to some extent they are all measures of different aspects of the same concept.

A final comment should be made not about carer anticipatory grief, sufferer social death, or the variables to which they were related, but about the associations between all these factors. The caregiving relatives of dementia sufferers live in the real world. Caregiving relatives are individuals, subject to their own perceptions, beliefs and general knowledge; they exist in a variety of social circumstances; they receive a variety of support in the task of caring; they look after dementia sufferers with differing degrees and patterns of impairment; they have different recollections of the premorbid relationship with their dementing relative. As a result of all these variables acting in concert, each carer will react to their relative's dementia as an individual, they will each develop individual strategies of coping, and they will each develop different sets of beliefs about the worth or otherwise of the sufferer's continued existence. The

aim of "stress and caregiving" studies is to clarify these relationships. However, it is possible that by doing so, many previous studies may have focussed on only a tiny part of the carers' lives. As a result they may have presented the experiences and subjective burden of caregiving relatives in an excessively simplistic form, thus encouraging others to believe that "If X, then Y" in these subjects. One point which emerges clearly from the present study is that these relationships are very complex.

III. DISCUSSION OF METHODOLOGICAL ISSUES

Issues which emerged during the collection and analysis of the present study data concerned the following: the representativeness of the study sample; the problems of collecting retrospective data in a cross-sectional survey; the possibility that the majority of the carers had experienced a set of staged reactions very soon after becoming aware of the dementia diagnosis and prognosis; the applicability of 34-item Problem Checklist results to institutionalised sufferers; the validity of the data; and finally, the recording of the data. These will each be discussed in turn.

1. How Representative was the Present Study Sample?

Among a number of methodological problems identified by Barer and Johnson [1990] in a critical review of the recent caregiving literature are two which concern the choice of subjects. One is that a range of meanings is attributed to the term "caregiver" - with the result that studies employ diverse ways of identifying caregivers. This criticism should not apply to the present study, since as defined by its title, all

subjects were the (primary) caregiving relatives of a dementia sufferer. The second of Barer and Johnson's criticisms is that most of the samples which they reviewed were selected from self-help groups, community agencies, and other formal sources, thus raising questions as to the representativeness of their findings. Barer and Johnson comment that since most samples of caregivers are self-selected, most caregiver studies do not have representative samples, and "little, if anything, is known about the myriad of anonymous informal caregivers who have no contact with, or even awareness of, informal institutions" [1990, p.28]. Unfortunately the authors do not go on to recommend a method of overcoming this difficulty.

The response rates for participation in the present study represented fewer than 50% of the carers who were initially contacted. The range in response rates varied between the different caregiver sources from a minimum of 20% to a maximum of 69%. It is difficult to explain this low response rate. Possibly carers were not particularly interested in research which was presented as concerned with how they had been feeling, rather than with a treatment for dementia itself. Whatever the reasons, this low response rate raises the possibility of sample bias of two different origins.

Bearing in mind the comments of Barer and Johnson [1990], the first potential source of bias is that the caregivers of dementia sufferers who are in contact with formal services may differ in some way from those who are managing to cope without formal assistance. Gallagher, Rose and Rivera et. al. [1989] for example suggest that caregivers who are in contact with services may be more distressed, and that it is this distress which pushes people to seek help. This

increased distress may result from different coping strategies among these carers, different patterns or levels of sufferer impairment, or perhaps other factors. The notion is of a great untapped well of unknown caregivers existing in the community - but is this actually the case? Eagles, Beattie and Blackwood et. al. [1987] conducted a community survey of the mental health of 274 elderly couples (both aged over 65 years); 5.7% of the total sample of 548 subjects were classified as "demented" via their score on the Mental Status Questionnaire. The mean age of the "demented" subjects (almost 77 years) was significantly greater than that of the "non-demented" subjects. The authors comment that the obtained overall prevalence rate of 5.7% is lower than most estimates of the community prevalence of dementia. However, Pollitt, O'Connor and Anderson [1989] describe a project which surveyed 2,616 people aged 75 years or over living in the community in Cambridge. O'Connor, Pollitt and Roth et. al. [1989] report that 145 were identified as demented. On the assumption that this represents the number identified as demented out of the total sample (the authors do not state whether this is the case), this represents approximately 5.5% of those aged over 75 years and living in the Cambridge community who were demented. (This represents dementia at all levels: about half the sub-sample were classified as "mildly demented", approximately 40% as "moderately demented" and 10% as "severely demented".) Pollitt, O'Connor and Anderson [1989] were surprised to find that the relatives of "mildly demented" individuals did not see themselves as carers, nor the elderly person as demented. This suggests firstly that previous numerical estimates of dementia within the community as a great iceberg of struggling family carers with only a small tip of those carers in contact with the formal services may be an

over-estimation. Secondly, since the result suggests that the majority of relatives of mildly demented individuals do not perceive themselves to be carers, the assumption could be made that once a relative does perceive the sufferer's impairment to be "a problem" they will probably contact the formal services. In sum, the possibility that the caregivers of dementia sufferers who are in contact with formal services are different from those who are managing to cope without formal assistance may be exaggerated.

However, there was a second potential source of bias in the present sample. This was that of the potential subjects contacted, fewer than half agreed to become involved in the main study. Why? Was this group more distressed and therefore wanting to talk to someone about their problems? Were the carers less distressed and therefore better able to cope with the additional hassle of spending time talking to the investigator? Were they caring for more "socially alive" dementia sufferers because the relatives of the more socially dead sufferers did not wish to spend time discussing them? Were they more likely to be actively involved in relatives' support groups and therefore possibly both more knowledgeable about dementia, and in addition experts at discussing their problems? Since the characteristics of the non-participants remain unknown, it is clearly impossible to answer these questions. An encouraging factor is that the demographic composition of the present caregiver sample and the impairments exhibited by their dementing relatives were both very similar to those reported in previous studies of the caregivers of dementia sufferers. However, all this means is that the present study sample is comparable with those of previous studies - but not that any of the study samples are necessarily comparable with

caregivers as a whole. This problem is insurmountable: the potential bias it produces must be considered when reading the results of research into the characteristics or problems of caregiving relatives, but it may be difficult if not impossible to eliminate.

2. When was "Earlier On" in the Present Study?

Or: "The Problems of Collecting Retrospective Data in a Cross-Sectional Study".

Clearly, the ideal way of collecting information about any changes in a caregiving relative's emotional and behavioural reactions over time would be to conduct a longitudinal study. This would involve a series of interviews which, in the ideal world would commence at the moment the carer realised there may be something wrong with the dementia sufferer. This ideal world scenario is probably impossible, although a longitudinal survey of caregiver reactions would not be. However, the problem which arises with such a method is that given the lengthy time-course of dementia from onset to the sufferer's death, the study would have to be extended over several years.

The time constraints meant that a longitudinal study was out of the question in the present case. One way of investigating for the possibility of a stage-like shift in the carers' emotional and behavioural reactions over time was clearly to compare carers who represented greater or lesser lengths of time since onset or diagnosis of the dementia. However, it was recognised that individual differences between carers might obscure any evidence of "staging". The decision was therefore taken to ask carers for the intensity with

which they experienced each grief item both "nowadays" and "earlier on - sooner after ... got ill".

Clearly, this technique is fraught with difficulties, relating to the fact that "earlier on" for one carer will not mean the same thing as "earlier on" for another carer. (Given this, it is interesting that no carer ever asked "When was earlier on?", but instead unhesitatingly stated that a certain aspect of their reactions had increased, 'decreased, or stayed about the same throughout the illness.) Thus, to compare the change in the pattern of one carer's reactions between "earlier on" and "nowadays" is not necessarily comparing like with like. Differences due to the consideration of different time periods may cancel out any significant results when analysing the sample as a whole. Clearly, "earlier on" for a carer only 6 months after the dementia diagnosis is going to mean something different from "earlier on" for a carer 6 years after diagnosis. While analysis of the data on a subject-by-subject basis to some extent eliminates this difficulty, there is still the problem of comparing the "picture" of changes in carer reactions over time between two carers who may vary greatly in both the time since they became aware of the dementia diagnosis and prognosis and also in their perceptions of how long ago "earlier on" was.

An additional problem is that a carer's current feeling state may well have coloured their recall of their emotional and behavioural reactions earlier on in the illness. This is noted by Whyte, as follows: (over)

"The difficulties in interpreting subjective data are increased when the informant is recollecting past feelings or attitudes. Recollections of past feelings are generally selected to fit more comfortably into one's current point of view."
[Whyte, 1982, p.115]

Perhaps this was the reason for the highly significant relationships between the intensities of almost all the "earlier on" and "nowadays" grief items.

Of course, these difficulties were recognised at the time when the decision to ask about reactions "earlier on" was made. What was also recognised was that there was no other way of collecting such data in a cross-sectional study.

3. Were Most of the Caregiving Relatives Interviewed Too Late?

It might be argued that given what we know about the duration of grief or anticipatory grief, to expect to collect data relating to a pattern of stages in a carer's reaction at - say - 6 years following the diagnosis of dementia is quite unrealistic. The argument would suggest that a pattern of stages would only be evident within the first months following carer knowledge of the dementia diagnosis and prognosis.

In order to overcome this difficulty, it would be necessary to collect a sample of carers a very few months after they learnt the dementia diagnosis and prognosis. Given what has already been noted about the low response rate and the difficulties in collecting a sample of 100 caregiving relatives over a wide geographical area, it would be an extensive undertaking to try to identify a sample of similar size shortly after the diagnosis of their relatives' dementia. In

addition, there is the problem that for many carers, diagnosis did not represent the point at which they realised what was wrong with the sufferer - however, it would plainly be extremely difficult to collect a sample before the "official" diagnosis.

While this might be regarded as presenting a considerable problem in the methodology, the results of the present study suggest that even had all 100 carers in the sample been interviewed a relatively short time after the diagnosis, there would still have been no significant evidence of a pattern of stages in their reactions. There are two reasons for this. Firstly, the argument that stages in the carers' reactions occur during the first few months would presumably have to go on to suggest that those carers interviewed a somewhat greater time after diagnosis would all have resolved their anticipatory grief. This was not the case in the present sample. Secondly, there was no greater evidence of staging in the pattern of reactions reported by the small sub-sample of carers who were interviewed two years or less since the dementia diagnosis.

4. The Applicability of 34-item Problem Checklist Results to Institutionalised Dementia Sufferers

The 34-item Problem Checklist was administered to all carers. Those related to institutionalised dementia sufferers were asked to recall the sufferer's behaviours just prior to institutionalisation. This may have created two sources of error. Firstly, carers may not have recalled either the frequency of certain behaviours or their problem status (ie, "severity") accurately. For example, there was the possibility that the problems created by the dementia sufferer might

have been inflated in an attempt to justify the subsequent institutionalisation of the sufferer. The second source of error is that these results were included in the analysis, despite the fact that the profile of the dementia sufferer's behaviours or impairments, or (more likely) their problem status for the carer may have changed since admission. It is possible that the results of analyses which assessed the relationship between the problem domains and various other factors might have been rendered invalid by the inclusion of institutionalised dementia sufferers. The alternatives would have been to either eliminate the 34-item Problem Checklist results of all institutionalised sufferers from the analysis and use mean-substitution to plug the many gaps which would have resulted, or to completely eliminate institutionalised sufferers and their caregiving relatives from the analyses. Since one of the main aims of the study was to investigate the effect of institutionalisation on anticipatory grief and social death, this option was not considered viable.

Given the above, it was decided to include the Problem Checklist results in the analysis. It is interesting to note that the pattern of both the frequency and problem status of sufferer behaviours in the present study was very similar to that obtained when the Problem Checklist has been applied to purely community samples. This suggests that the inclusion of institutionalised sufferers and their relatives may not have greatly affected the Problem Checklist results. In addition, it might be assumed that following institutionalisation the problem status (ie "severity" scores) of the dementia sufferer's behaviours would be much more open to change than the problem frequencies. (This was particularly the case since the majority of sufferers

had entered long-term care when already quite severely impaired, thus there was little opportunity for their problem behaviours to change greatly following institutionalisation.) However, the problem severity scores were not used in any of the analyses in the present study, apart from the demonstration that "pure severity" score may be a useful measure of the degree of carer subjective burden (see Appendix Ten). It was hoped that these factors might act to reduce the possible confounding effects of the decision to include the Problem Checklist results of institutionalised dementia sufferers in the present analysis.

5. The Validity of the Data

The interview methodology of the present study yielded data which relied exclusively on self reports. A potential difficulty which thus arises is the assessment of the validity of the data, since what people will say when they are being interviewed or filling in questionnaires may not be the same as what they actually think or do. Whyte [1982] points out that an informant's reporting of evaluative data is dependent upon the following: their current emotional state; their values; their attitudes towards the topic being discussed; and their opinions or ideas about the topic. For example, Zarit [1989] notes that we know distressed and depressed people will often estimate the magnitude of events inaccurately. If a distressed caregiver reports that the care receiver is disruptive "all the time", are they depressed by the frequency of these disruptive behaviours, or are they reporting that these behaviours occur all the time because they are depressed?

In addition, the data was collected by a single interviewer, who had also devised the study and the Carers' Questionnaire. One of the criticisms which has been levelled at Kubler Ross' methodology is that since she collected the data upon which her stage theory of anticipatory grief reactions in dying patients and their relatives is based, the material might be influenced by her own professional orientation. [Kastenbaum, 1977]. In other words, perhaps Kubler Ross (consciously or unconsciously) collected data which fitted her theory: she saw what she wanted to see. It was recognised that exactly the same criticism could be levelled at the present study.

A number of steps were taken in an attempt to increase the validity of the present study. These included the more general "rapport" techniques of interviewing the carer without the sufferer being present, assuring the carer of the confidentiality of their responses, and commencing with low threat/low personal disclosure items. In addition, three methods were adopted in order to reduce the chances of interviewer bias impacting upon the responses. The first of these was to provide the carers with "prompt" cards to guide their responses. (Successful in the case of the 34-item Problem Checklist - probably because their attention was drawn to the prompt card by the necessity of turning over the pages in order to follow the topic of discussion. Not successful in the case of the card representing the frequency with which each grief item was experienced - probably because the prompt card did not hold the carers' attention, since they were far more interested in describing their own reactions.) The second method of reducing potential interviewer bias which was introduced following the failure of the frequency prompt card and was also used for items not

related to frequency was to check a carer's response wherever possible: "So that doesn't happen at all?"; "So you aren't sure about that?", etc. The third method of reducing potential interviewer bias was to operationalise any post-interview ratings using behavioural criteria wherever possible. An additional advantage of this method is that should other investigators wish to make use of the Carers' Questionnaire - or items from it - they will be able to make ratings based on the same objective criteria rather than imposing, for example, their own subjective notion of "social death behaviours".

Clearly, the most effective way of validating the rating of the Carers' Questionnaire would have been for another - disinterested - person to listen through a random selection of the taped interviews and make ratings. This was recognised at the outset, and a request was made to the University of Glasgow to provide money to pay someone to do this. Unfortunately, since no finances could be made available, a validity study of this type could not be conducted.

Finally, it should be said that the results obtained from both the pilot and main studies tend to favour the placing of an "unbiased" judgement upon the interviewer-investigator. The aim of the present study was investigative, with no specific hypotheses about the presence or form of anticipatory grief reactions nor social death beliefs and behaviours among caregiving relatives. The results obtained do not fit any neat pattern such as might be expected by the consistent (conscious or unconscious) operation of a set of specific expectations.

6. Recording of Data

There is some disagreement in the literature over the best way of recording the voluminous data which results from an interview. Whyte [1982] considers the use of a tape-recorder. Despite its obvious advantage of yielding the fullest recording of the interview, Whyte lists numerous disadvantages that he believes may place a serious obstacle in the way of an interviewer using a tape recorder getting him or herself established, particularly in the early stages. These include a tape recorder's expense, both in financial terms plus the time required to transcribe the interview, and in addition, the formality which it introduces into the situation, resulting in informants talking "for the record". Whyte also criticises the alternative of taking notes during the course of the interview. He believes notes may again add to the formality of the interview, as well as inhibiting the informant who cannot receive immediate verbal or non-verbal feedback from the interviewer who is engaged in producing a verbatim record of their most recent statement rather than being alert and able to pick up productive leads. A third method mentioned by Whyte is to make notes on the interview after it has finished. The obvious disadvantage of this technique is the difficulty which the interviewer may have in recalling the interview without distortions or a significant loss of information in the reconstruction. Clearly this method would not have been applicable to the present study.

In contrast to this rather depressing list of the disadvantages of data recording techniques, Zito [1975] makes the following comment: (over page)

"People soon forget the tape recorder; they are not distracted by mysterious note-taking on the part of the interviewer; generally, once they begin talking, the only problem the researcher faces is how to turn them off one question and onto the next."
[Zito, 1975, p.61]

Interviews in the present study were tape recorded and in addition, short notes were made onto the Carers' Questionnaire. The experience of the interviewer accorded with that of Zito in that neither the tape recorder nor the note-taking appeared to interfere with the carers' replies - particularly in view of the spontaneous comments by many that they had forgotten about the presence of the tape recorder. Of course, the possibility remains that some carers did modify their replies "for the record" because of the tape recorder; however, this should be balanced against the wealth of - particularly qualitative - data which was made available by transcription of the tapes.

IV. RECOMMENDATIONS

Bearing in mind the discussions of both the results and the methodology of the present study, recommendations can be made concerning both the direction of future research and the most useful support which might be offered to caregiving relatives.

1. Recommendations for Future Research

In order to overcome the difficulties associated with the collection of retrospective data, further research on the nature and pattern of anticipatory grief reactions should be conducted on a longitudinal rather than a cross-sectional basis. This would apply not only

to research focussing on the reactions of the caregiving relatives of dementia sufferers, but to all anticipatory grief research. Given the strength of the concept of anticipatory grief reactions as "staged", plus the fact that the studies on which this notion are based are either descriptive observational or anecdotal reports, further longitudinal research to critically evaluate the existence of stages in "anticipatory grief" reactions among different groups of subjects is recommended.

The present study demonstrated that a range of degrees of anticipatory grief was present among the caregiving relatives of dementia sufferers. This finding was paralleled by the fact that while three-quarters of those asked believed that they had definitely experienced grief, the rest were either unsure or believed that they had not experienced grief. Given this variety of caregiver reactions during the life of the dementia sufferer, it would be interesting to re-assess their reactions following the sufferer's death. Such a follow-up study would increase knowledge concerning the impact which anticipatory grief has on conventional grief. Once again, this approach could be employed among different groups of subjects.

"Social death" proved to be an interesting area of the present study, in particular the dimension "Life Pointless". Given the relationship which was demonstrated between this factor, a carer's belief that they had definitely grieved, acceptance of the dementia and increased preference for institutional care, further refinement of both the concept and the ways in which it might be assessed are recommended.

2. Recommendations for the Formal Psychological Support of Caregiving Relatives

Within this thesis suggestions have been made with regard to two areas in which changes may be made to reduce carer distress. The first of these was the amount of information about dementia made generally available via the media. It was suggested that further increasing the amount and availability of this information might in turn increase the proportion of carers who gradually realise the dementia diagnosis and its implications themselves, rather than by learning it suddenly from another person. In the present study, gradually realising the probable diagnosis and prognosis was associated with less distress and less likelihood that a carer would believe they had experienced grief. The second area in which it was suggested that intervention might reduce carer distress was that of the evaluative perception of dementia. It was suggested that a cognitive therapy intervention to shift a carer's perception of dementia from "a very horrible/worst illness" to "an illness like any other illness" might in turn reduce carer distress. However, it was also recognised that such a shift in a carer's cognitions would be difficult to achieve.

The interviewer initially had reservations and anxieties about discussing topics such as the death of the sufferer, whether it might come as "a blessing", and whether carers perceived the sufferer as "already dead" in some ways. In the majority of cases these reservations proved groundless. Having established the confidence of a carer it was generally possible to talk with them about "social death". Not only that, but several carers appeared keen to discuss the topics which it encompassed, and were relieved to hear that

they were not the only one to have thought about the "bad" event of the sufferer's death or the worth of their continued life. Given this, plus the association between social death factor "Life Pointless" and a carer's perception that they had experienced grief, that dementia was "a horrible/worst illness", and increased preference for institutional care, it is suggested that it might be beneficial to raise at least this aspect of "social death" with certain carers.

Another factor which the present study found to be associated with increased preference for institutional care was a carer's perception that they were coping badly with the current situation. The simple question "How are you coping just now?", therefore aids in the identification of carers for whom institutional care of their dementing relative may be desired. Given the finding that increased relief from caring was associated with increased rather than reduced preference for institutional care, the provision of greater formal or informal support may not be an acceptable alternative to institutionalisation for such carers.

Rando [1984] cautions against trying to understand an individual grief reaction by trying to force it into a theoretically prescribed stage rather than relating it to the individual's personality and experiences. The results of the present study suggest that this should also be the case for those providing support to the caregiving relatives of dementia sufferers. Unfortunately, a reading of the literature which so often describes the emotional and behavioural reactions of carers in terms of stages (generally those of Kubler-Ross [1970]) may encourage the uncritical application of these stages to every carer. Rather, an

understanding of the characteristics of the individual carer, as well as those of their dementing relative, and of their relationship with that relative is recommended in order to fully understand the reactions of each individual carer.

V. SUMMARY

In the first section of this chapter, the findings of the present study were briefly discussed within the context of both previous "stress and caregiving" studies, and also the aims of the study.

The following methodological issues raised by the present study were discussed: the representativeness of the sample; the problems of collecting retrospective data in a cross-sectional survey; the possibility that the majority of the carers had experienced a set of staged reactions very soon after becoming aware of the dementia diagnosis and prognosis; the applicability of 34-item Problem Checklist results to institutionalised sufferers; the validity of the data; the recording of the data.

Recommendations were made for the following areas of research. Firstly, for future research on anticipatory grief reactions to be conducted on a longitudinal basis. Secondly, for follow-up research with regard to the reactions and perceptions of caregiving relatives both prior to, and following the death of the dementia sufferer. Thirdly, for research to further investigate and refine the dimension of social death which has been termed "Life Pointless" in the present study. Recommendations were also made for the increased availability of general information about dementia, for

the discussion of possible "taboo" topics - such as aspects of social death - with caregiving relatives, and for the identification of carers with a high preference for institutional care. The final recommendation was for the need to understand the reactions of each caregiving relative as those of an individual.



**CARING FOR A RELATIVE
WITH DEMENTIA:
Anticipatory Grief and
Social Death
VOLUME TWO
(Of Two Volumes)**

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SUMMARY

This exploratory study has as its background the effects of dementia, not only on the sufferers themselves, but also on those who love them. The end-result of dementia may be a sufferer who is completely unable to exist independently, unable to communicate meaningfully, or to recognise once familiar persons.

The first area of investigation was whether the reactions experienced by caregiving relatives constitute "Anticipatory Grief" in response to the "loss" of the person of the dementia sufferer. The study examined the nature of the emotional and behavioural reactions of caregiving relatives, the possibility that they may emerge in some sort of predictable stage-like sequence, and the ways in which different types of reaction may be associated with different characteristics of the carer, the sufferer, or their relationship. The second main area of interest in the study was the possibility that dementia sufferers may become "Socially Dead". That is, that they may in some senses be discounted as persons by their caregiving relatives. The study examined whether the relatives of dementia sufferers did perceive them in a way that could be described as "socially dead", and it investigated variables associated with the social death of dementia sufferers. The third main area within the study was to investigate the impact which carer "anticipatory grief" and sufferer "social death" might have on carer well-being and their preference for institutional care for the sufferer.

The study derived its data from semi-structured interviews with 100 relatives of patients with a

primary diagnosis of dementia. At the time of the interview, the dementia sufferer lived with the carer in 61 cases, in their own home in 16 cases, and in long-term institutional care in 23 cases. The interviews were based on a "Carers' Questionnaire" which had evolved via preliminary unstructured exploratory interviews with carers, followed by a pilot study employing an initial draft of the questionnaire.

The study demonstrated that caregiving relatives generally acknowledged dementia to be an illness which would result in continued deterioration and death in the sufferer; that is, as a terminal illness, bringing both current and future losses.

The emotional and behavioural reactions which previous studies have labelled "anticipatory grief" were experienced - to varying degrees - by the caregiving relatives of dementia sufferers. While partly simply a response to the burdens of the caregiving situation, they could also be attributed in part as the response to the loss of the person of the dementia sufferer. The majority of carers believed they had experienced grief, and the underlying structure of their reactions was similar to that of conventional grief. The results of the study showed that taken as whole, there was considerable stability in the emotional and behavioural reactions of the caregiving relatives of dementia sufferers over time. Against this background, there was a sub-group of approximately one-third of the sample of carers whose shock, or disbelief, or hope was greater earlier on in the process of their relatives' dementia, and whose acceptance of the illness and the future had increased over time. There was, however, no evidence of a phasic emergence of a variety of discrete stages in the carers' reactions, nor of an end-point of

resolution or acceptance. The different components of the emotional and behavioural reactions of caregiving relatives were associated with different caregiver and sufferer characteristics. Initial shock was associated with learning the diagnosis and prognosis suddenly. Current carer shock, denial or hope were associated with sufferers who were younger, were spouses or siblings, and were demanding, with carers who were older, and with less time since onset of the dementia. Protest, questioning and guilt were more likely in younger carers, those who perceived dementia as a horrible/worst illness, and those reporting a poor relationship with the sufferer. Reactions of yearning or preoccupation were more likely in carers who perceived dementia as a horrible/worst illness, and who were not helped by a religious or other belief. Carer depression was associated with demanding sufferer behaviour, perceiving dementia as a horrible/worst illness, and reporting a poor relationship with the sufferer. Finally, carer acceptance was more likely when they perceived dementia as the consequence of aging or as just an illness, and when they had greater general knowledge regarding dementia.

While not labelling it as such, some carers did perceive their dementing relative in terms which could be regarded as "socially dead". Three factors comprised the underlying structure of social death. Factor One, "Anticipate Death", relating to thinking in a variety of ways about the sufferer's death, had occurred for between half and three-quarters of the sample. "Anticipate Death" was associated with variables suggesting that the dementia sufferer had lived too long, and that the carer was fed up (angry or depressed) with the situation. Factor Two, "Life Pointless", relating to elements of social death such

as believing that the sufferer's death would be a blessing, had occurred - to varying degrees - for at least half the sample. This was the only social death factor to be associated with a carer's belief that they had experienced grief. It was also related to a lack of carer hope or bargaining behaviours (perhaps representing the acceptance of the inevitability of the sufferer's decline), with increased sufferer dependency, with the carer's perception of dementia as a horrible/worst illness, and their reporting a poor relationship with the sufferer. Social Death Factor Three, "Sufferer Unaware", relating to sufferer lack of awareness of, and response to, their environment, was endorsed by the vast majority of the caregiver sample. It was associated with increased impairment in the sufferer (perhaps representing "loss of the person".)

Those carer emotional and behavioural reactions most clearly representing distress were associated with increased subjective burden. Belief that they had experienced grief was associated with a reduction in a carer's perceived coping ability. None of the social death factors was linked to carer subjective burden or coping. Finally, with regard to institutionalisation, there was no evidence that placement in long-term care triggered either the social death of dementia sufferers or anticipatory grief in their relatives. Among community carers, preference for institutional care was not directly related to any of the anticipatory grief reactions. It was, however, associated with social death factor "Life Pointless". This suggests that if a carer perceives the continuation of their dementing relative's life as meaningless, then the removal of the physical presence of the sufferer to institutional care may be more acceptable, or even welcomed.

APPENDICES

APPENDIX ONE

PRELIMINARY INVESTIGATIONS

"This is not always done, but some researchers ... spend time at this early stage in conducting informal interviews with people in order to find out from them what the key issues are. ... The researcher could not draw any general or valid conclusions from such discussions, but they should provide useful guidelines as to what should be followed up in the main inquiry."
[McNeill, 1985, p20.]

I. PRELIMINARY DISCUSSIONS WITH PROFESSIONALS

Following the initial background reading, discussions were held with some of the professionals involved in the support of this group of caregivers. They included the leader of a local Alzheimer's Society Project, and the Officer in Charge of a large council owned residential home for the elderly. The discussions concerned the relevance of the concepts of an "anticipatory grief" process, and "social death", to the relatives of people with dementia.

All those consulted agreed on the following:

1. That the notion of a process which could be regarded as anticipatory grief may well be applicable to the caregiving relatives of dementia sufferers.
2. That in their experience it was an area which, with sensitive handling, this subject group would be able to discuss.

II. AIMS OF PRELIMINARY INTERVIEWS WITH CAREGIVING RELATIVES

In the light of the discussions with professional staff, it was decided to conduct exploratory interviews with a small number of caregiving relatives in order to determine the following points.

Firstly, whether they would be willing to discuss their emotional reactions with a strange interviewer.

Secondly, whether they were able to describe reactions which could be regarded as constituting anticipatory grief.

Thirdly, whether the notion of "social death" made sense to them - although clearly it could not be discussed as such, but rather in terms of the loss of the person they once knew.

Finally, to allow the interviewer to become familiar with this topic, and more comfortable while discussing it.

III. SAMPLE - PRELIMINARY INTERVIEWS

Description of Sample

All subjects during the preliminary interview stage were the primary caregiving relatives of dementia sufferers who attended the Psychogeriatric Day Unit at Stobhill General Hospital. Stobhill is situated in the north of Glasgow with a catchment area covering predominantly working class areas (for example, Springburn, Possil Park), but also some middle class areas (for example, Bishopbriggs, Lenzie). The major psychiatric hospital for the administrative unit is Woodilee Hospital, Lenzie, approximately 7 miles from the centre of Glasgow. The relatives of some of the caregivers interviewed received respite care in the psychogeriatric unit there.

Permission to conduct the preliminary interview study was received from the Unit Division of Psychiatry (see Appendix Five for letter of application).

IV. PROCEDURE - PRELIMINARY INTERVIEWS

1. Contacting the Sample

The names and addresses of 14 relatives caring for a dementia sufferer were supplied by the psychogeriatric day hospital staff. This represents under 50% of the day hospital attenders. Names were supplied by the staff if firstly, they felt from their personal knowledge that a relative may be willing to participate in the study, and secondly, they actually had an address for the caregiving relative. (If a dementia sufferer lives alone, the day hospital may just have a contact telephone number for the primary caregiver. It was not felt appropriate to make an initial approach to these caregivers by telephone on the grounds that they might feel either coerced to agree to participate or on the other hand might immediately decline).

The 14 caregiving relatives were approached by letter which introduced the interviewer as a clinical

psychologist working at Stobhill Hospital, and continued as follows:

I am conducting a research project with people caring for elderly, confused persons. It is to investigate how they feel about their situation, and how they cope with their problems. I understand that you are one of these carers. I therefore wonder if you might be willing to participate in my research? It would involve a discussion concerning both the problems which crop up, and the ways you have been feeling as you give care. I should add that the doctors from Stobhill who work with the elderly patients know about this project, and are happy for it to go ahead.

It was felt that it was unfair to ask potential subjects to decide whether or not they wished to participate in the study without a fairly full explanation of the contents of the interview. The caregivers were provided with a form to complete and return in a stamped addressed envelope if they wished to participate in the study. They were informed that following this the interviewer would contact them to arrange a convenient time to visit.

Eight (57%) of the 14 caregiving relatives agreed to participate.

2. Conduct of Interviews

Interviews were conducted between December 1986 and February 1987. Each interview lasted between 45 and 70 minutes.

Interviews were arranged in the caregivers' own homes, generally at times when the dementia sufferers were not present. (In one case during the preliminary interviews the sufferer was present during the interview. The caregiver was asked whether they felt quite comfortable talking in the presence of the sufferer, since the discussion would include their problems and feelings. The caregiver described their relative as suffering dementia to such a severe degree as to preclude their understanding of the nature on the interview.)

At the outset of each interview the interviewer introduced herself as a clinical psychologist with some experience of the behaviour of confused elderly people and the potential difficulties which it could present to their caregivers. However, the caregivers were told that she had no individual knowledge or experience of their own particular relative, nor any direct input to any of the hospital or other day facilities which their relative might attend. The carers were also assured of the confidentiality of their responses.

At this initial stage a completely unstructured interview was employed. This gave the subjects the opportunity to describe their experiences as caregiving relatives of dementia sufferers without having to fit their responses into any preconceived and imposed framework.

There were two reasons for this format. Firstly, the interviewer's own ideas as to how best to formulate questions within the topic areas of anticipatory grief or social death were not sufficiently fixed to approach subjects with a set interview schedule or questionnaire. Secondly, it was felt that the unstructured interview format would yield most information at this preliminary stage.

Prior to approaching the first subject a list of topics which the interviewer hoped to discuss, was compiled. The aim of the topics chosen was to allow the carer to talk about the issues of change and loss which had resulted from the sufferer's dementia. Descriptions of the history and the nature of the problems they faced would be encouraged. The occurrence of emotions associated with grief would be discussed, plus factors (such as role changes, or attitudes towards institutionalisation) which might be related to grief. The list looked like this:

- Practical problems.
- Illness - prognosis, time scale, why has it happened?
- Thoughts of future - death, loss.
- When did it start?
- When was loss recognised?
- Grief - Sadness, crying, memorialisation, pining, searching.
 - Disbelief, denial.
 - Anger ... displaced? Anxiety, insomnia.
 - Guilt, ambivalence.
- Role change.
- Institutionalisation.
- Disengagement/enmeshment?
- Isolation.
- Relationships.
- Previous coping history.
- Neurotic disorders.
- Visits to doctor, medication.
- Alcohol.

This list was re-read immediately prior to each interview at this preliminary stage, but was not physically referred to during the interview.

In order to build up rapport and increase the confidence of the subjects, the preliminary interviews commenced with requests for basic demographic details of carer and dementia sufferer. This was followed by

asking the carers to describe the practical problems encountered while looking after their relative, and then to describe the onset of the dementia - allowing the subjects to tell the story of what they noticed first of all and how a diagnosis was eventually obtained. The aim of commencing with such topics was to allow the informants to become familiar with the interview situation and the interviewer without having to discuss emotional issues, unless they raised them spontaneously.

3. Recording of Interviews

All preliminary interviews were tape-recorded and later transcribed in full.

In each case the interviewer asked permission from the carers to tape the interview before producing the tape recorder, with the aim of minimising the pressure on them to acquiesce. It was explained that the reason for using a tape recorder was to allow the interviewer to concentrate on the discussion, rather than having to sit, head down, constantly scribbling notes. Subjects were also reassured as to the confidentiality of the completed tapes, which would only ever be reviewed by the interviewer.

For the preliminary interview a small portable battery powered cassette recorder with a built-in microphone was used - placed on the floor or a chair between the interviewer and the respondent.

V. PRELIMINARY INTERVIEWS - PRESENTATION AND DISCUSSION OF RESULTS

1. Practical Problems

All caregivers were able to discuss the practical problems of looking after a relative with dementia, and it did prove a useful topic with which to establish rapport. However, since this study was not principally concerned with practical problems they will not be covered at great length in the following account, although some examples are given.

As Gilhooly [1990] points out, "If one looks closely at the sorts of problems carers report, one finds that most caregiving tasks involve 'surveillance'" [p.15]. For example, Mr. Tierney, co-resident caregiver to his mother, described the practical problems of her care as follows:

Mr. T: My biggest problem is that I'm self-employed
and my mother's condition deteriorated

gradually and the more that happens the more I've got to look after her which means I can't work - that's the first problem.

Later, Mr. Tierney continued on the subject of the restrictions to his life caused by having to care for his mother:

Mr. T: .. I can't go out, I can't really leave my mother alone - she just keeps wandering away.

H.S: So you find that your life just revolves around her completely?

Mr. T: Basically, unless I can get her taken off my hands for a few hours - my wife will maybe take her to her mother's - someone has to really just be there, you know ...

Mrs. Moore described having to "constantly hover" around her husband:

Mrs. M: You are persistently repeating and repeating what he's got to do. See this morning there changing his socks - he sleeps with his socks on - well, eh, I leave his clothes out for him but quite often I've to help him now because he puts things backsides forwards on now - underpants and what have you and even his socks. Now, five times this morning within a matter of minutes I'd to tell him to take off his boots and put on a change of socks. You know, things like that. But in the morning my time's taken up attending to him. ... And I've to just kin' of hover about to get him organised. I can't leave him now.

Mr. Thomas was unemployed and cared for his mother-in-law. She lived with him and his wife, who worked full time:

Mrs. T: Really we couldn't have my mother here if Bill wasn't in the house - you know, our roles are kind of reversed, you know that way.

H.S: So there needs to be someone full time?

Mr. T: Oh, there needs to be - all the time

Mrs. T: She must have someone.

They described night time surveillance:

Mr. T: There's plenty of times she'd put the light out, then she'd get into her bed - but she couldn't find this bed, so she'd have to put the light on to find where her bed is - so confused.

H.S: So is she up several times in the night?

Mr. T: Yes

Mrs. T: Yes

H.S: I mean, is she actually keeping you awake?

Mrs. T: Yes

Mr. T: Well, luckily I can get up because I'm not

- working, but if I was working -
- Mrs. T: You see, what we do is we don't get up if we think she's going to find her way back to her bed. She sometimes gets utterly confused - she gets up, she goes to the toilet, she goes back to the bedroom, she's not sure of her bedroom, she puts on the light ... I mean this can go on three times - we can listen to the light going off and on then eventually we've got to get up, you know, we try and get her to do it on her own.
- Mrs Thomas described "watching her all the time":
- Mrs. T: Once she's up and you get her undressed - you see, I'll go in and I'll have the towels over the radiator, and I maybe go to get clean underwear and I leave her and tell her "Get undressed", and when I come back she'll maybe have it all back on, you've got to keep, you know, watching her all the time -
- Mr. T: My whole life revolves round my mother-in-law now, you know
- H.S: I was going to say that
- Mr. T: You see, I can't get out now at all, and we we can't get out, we can't get out together.

Although caregivers may have had a large number of practical activities-of-daily-living tasks to carry out for the dementia sufferer, they did not tend to present them as a problem. For example, Mrs. Urquhart, caregiver to her husband described the list of things which she had to do for him:

- Mrs. U: .. Normally I shave him, I cut his hair about once a month, I wash his hair, and I bath him, and this weather he's rather dodging the baths but - it's so cold in that bathroom - and I cut his toenails, I cut his fingernails and generally look after him, but those are the kind of practical things. ... I help him on with his clothes, he can put on his own pyjamas himself most times but I've seen him coming in and he can't get a sleeve in or something, or he puts them back to front ...

Similar tasks were described by Mrs. Taylor, caregiver to her husband:

- Mrs. T: .. normally he just leaves me for to do everything. He can't dress himself nor undress himself. He can't go to the toilet by himself and the nurse comes in once a fortnight to give him a bath.

Disruptive or aggressive behaviours were more distressing to the caregivers than the practical tasks of caring for the dementia sufferer. An extreme example

of this was Mrs. Davies, caregiver to her husband. They lived by themselves. Mrs. Davies described her husband as engaging in "foul talk", and "he says I'm not his wife, in bad temper". He had broken pottery and the front door chain. He had set the kitchenette on fire due to careless smoking. She was frightened of him and barricaded her bedroom door at night.

Mrs. Taylor described how upsetting she found her husband's uncharacteristic bad language:

Mrs. T: .. and a thing that never happened before - I don't mean not happened before, I don't know whether this is a regular thing for people of his state - he never swore, we had four of a family, he never swore in front of the family, I don't know if he did it at his work, but he never swore in front of the family. Now if he gets frustrated or confused or angry with me he swears - not dirty swears but swearing, and that's very - that's not him.

H.S: How does that make you feel when he does that?

Mrs. T: Makes you feel awful, it really makes you feel awful.

Mrs. Urquhart also described physical aggression and bad language from her husband, however, she was not frightened by it:

Mrs. U: An odd time he gets a bit aggressive - he's lifted his hand to me before - but I'm not afraid of him because I know if he - he's off balance now - I can, usually I can dominate him, but it, it kind of leaves you shaken just the same and he calls me for everything that you can think of, all the foul names ...

The small number of subjects interviewed in this preliminary study, and the reliance on qualitative data precludes firm conclusions. However, these results concerning the particular aspects of the dementia sufferers' behaviour which caregivers found most burdensome or stressful are in line with the findings of previous studies. These indicate that having to give assistance with the more straightforward activities of daily living such as dressing, is generally well tolerated by caregivers in comparison with having to cope with disturbed or demanding behaviour (for example, Grad & Sainsbury [1968]; Machin [1980]; Greene, Smith and Gardiner et. al. [1982]; Gilleard, Boyd and Watt [1982]; Argyle Justice and Brook [1985]; Morris, Morris and Britton [1988a]; Pruchno & Resch [1989]).

2. Knowledge of the Illness and Prognosis

This was an important area from which to gain information from the subject. A caregiver cannot be assumed to be a potential subject for an anticipatory grief process unless they are aware of the nature of their relative's illness and its inevitable downhill course towards death.

The caregivers were aware that their relatives were suffering from an illness, that it affected the brain and that it was going to get worse, although not all mentioned dementia as such. This finding simply reflects the information given to caregivers by the doctors at Stobhill and Woodilee Hospitals, plus the local G.P.s, and thus can certainly not be generalised to all the caregiving relatives of dementia sufferers.

Mrs Urquhart described being given the diagnosis of her husband's dementia:

Mrs. U: Well, it was Dr. Q. that came up, and she pinpointed it immediately, and then when he went up to Stobhill for scans etc. they told me it was arteriosclerosis, which is a form really, of senile dementia, so I knew then.

Similarly, Mrs. Moore received the results of her husband's physical tests from the hospital:

Mrs. M: .. and then they referred me to the Southern General for tests and what have you, and three weeks after that they sent for me and told me that there was nothing they could do, the brain cells were too badly damaged.

Mrs. Smith described her mother as suffering from "deterioration of the brain", the doctor "told me she'd get worse, and she has - I preferred the truth".

Mrs. Thomas was clearly aware of her mother's prognosis:

Mrs. T: .. there's no way my mother's going to get better - it's not as if she's got like an illness that you say that they're going to come out with a cure and she's going to get better - that won't happen and we've both accepted that, so the only way that we could perhaps get the freedom that we want is if my mother were to die, but I mean none of the two of us wish that - it's a funny situation, you know, just the way that you feel about it ...

Similarly, Mr. Tierney described his awareness of the inevitable downhill course of his mother's illness:

H.S: So when you think about the future - do you make plans about the future?

Mr. T: I can't ... I think that there is no point in making plans because you don't know how long or how soon - how long it's going to take till she deteriorates to some sort of unsatisfactory level - an uncontrollable level or something like that.

3. Evidence of Emotional Reactions which could be regarded as "Anticipatory Grief"

In line with the concept of anticipatory grief as a process involving a series of different stages, this section reviews the evidence for a process involving "denial and isolation", "anger", "bargaining", "depression", "acceptance" and "hope" (as described by Kubler Ross [1970]).

There was some evidence of denial by the caregivers following the diagnosis of dementia in their relative. For example, despite the prognosis given to her by the doctor (see previous page), Mrs. Smith had decided her mother should come and live with her because "I hoped bringing her here she'd come round".

Mr. Tierney described clear denial with regard to his mother's dementia; initially it was his own, and now it was that of his four brothers who saw very little of their mother.

H.S: When did you first notice this starting - when did it all begin?

Mr. T: Oh, about a year and a half ago - my wife noticed it two years ago and she kept telling me about - "your mother needs help", and I obviously didn't want to bring the professionals in for as long as possible.

And later,

Mr. T: They (his brothers) refuse to admit that there is anything wrong with her - I think it's the case of a horror of what's happened. My brother won't accept it ...

Mrs. Tierney confirmed this:

Mrs. T: Well, I've nursed senile dementia, so I sort of knew sort of signs of it, er, although I didn't say to any of the family that that was it - you know I just said I thought there was something wrong with their mother - but none of the family wanted to know, and they still don't want to know.

One caregiver, Mrs. Moore, described hope which had led to a feeling of anger and resentment with the medical profession who had diagnosed the arteriosclerotic

dementia many years ago but then had been unable to do any more to help her husband.

H.S: Did you ever believe when it - you know, soon after it happened, that maybe the doctors had made a mistake and he would get better?

Mrs. M: Well, that's what I often say - often think back when he didnae - right enough he told me in the S. Hospital then that they couldn't operate, the brain itself was too badly damaged - but I really didnae think it was going to be like this. You know what I mean? Well, as I say, I believe in miracles, mind you, maybe I shouldnae, but, as I say, you live in hope that maybe something'll change, you know what I mean? And then, as I used to say, the way medicine's changed in years and years and years back, that I mean I think it's a shame that they didnae keep up looking after him and keeping him going back and forward - that maybe something has happened that could have helped him -

H.S: Right - in between?

Mrs. M: And I just feel that was all wrong, you know what I mean? Maybe something could have been done years ago to help him and that's why I feel very bitter.

Other caregivers also expressed anger at their perceived abandonment by professionals, although recognising that they could not have done anything medically to cure their relative. For example, Mrs. Urquhart described the lack of help with her husband:

Mrs. U: You know you get very little help from outside services - he used to go to the day centre twice a week and they've cut him down to once a week.

Mr. and Mrs. Tierney also raised this theme while discussing the care of Mr. Tierney's mother:

H.S: What have the doctors been like?

Mr. T: I've had no contact from - no contact - in fact I've phoned - last week I phoned to find out if and when I'd be contacted by them to be given some sort of opinion of her, and it sounded as if it was some sort of staff nurse I spoke to - it was just a chap and he said "Well, we don't find any problem with her, she's very forgetful but she's quite cheerful" We've had no official contact with Dr. C. - you are the first person that's actually come and done anything with us.

And later, Mrs. Tierney continued:

Mrs. T: .. and we're saving the government a lot of money looking after his mother - if we were well off we wouldn't bother about it, but there you are -

H.S: It's a bit like they've abandoned you, isn't it?

Mrs. T: Well, that's the feeling you get - this is the impression you get, that no-one wants to know.

Some caregivers felt resentful of the illness and the situation which they were in. For example, Mrs. Moore:

Mrs. M: .. as I say, I just don't know how it happened to me, I just don't.,

H.S: Some people,, when they're questioning things like that feel quite angry that things like that have happened.

Mrs. M: Oh bitter, bitter, very bitter. Oh bitter. Ah've even spoke to wir Catholic priest.

On the other hand, some caregivers appeared to have accepted their relatives' dementia without questioning, for example, Mrs. Urquhart:

H.S: Do you ever sit and wonder "Why on earth did this happen to us?", or do you just accept it?

Mrs. U: I just accept it - I canna say - well, in the first place I'm not a religious person, never have been, so therefore I don't say "Why has somebody done this to us?". It's just a fact of life, it's happened to him and that's it - it could have happened to me.

Expressions of sadness and loss were frequently made; both the loss of the person whom they had known plus the loss of a life with that person since the onset of their dementia, or in the future. This was described on several occasions during the discussion by Mrs. Moore, for instance:

Mrs. M: .. he doesn't really know where he is at all, he'll fall asleep and when he wakens up he's quite confused again, you know what I mean? You see him looking about an' that.

H.S: Many people find these situations very sad.

Mrs. M: Oh yes, compared to what he was, oh aye, compared to what he was. I mean he worked all the hours that God sent, he did, he did indeed he was a busy man. He was never in his own house, never in his own house. It's dreadful, dreadful.

H.S: It makes you feel very sad to see the way he's changed?

Mrs. M: Oh, it's dreadful, it's changed wir whole life.

H.S: Do you sometimes think about the way things

could have been?
Mrs. M: Well, I often wonder how - what would have happened when he retired, you know, things like that.

Later she continued on this theme of loss,
H.S. So you can't do all the nice things that you should have been able to?

Mrs. M. We should be - that's right enough, that's right. When you, you read about retired people an' that, you know, how they're all going on holiday the-gether and they're enjoying life an' things like that, I mean, we don't, we don't. And I mean you havenae got it to look forward to. It's different an illness you could say "Well, everything's all past, we'll be better" - you know what I mean? An' "we'll get back to wir usual" - I mean you've no future, you havenae got a future, you don't know when it's going to finish, you don't know when it's going to end, how it's going to end, you know what I mean?

Similarly, Mrs. Smith described herself thinking of her mother and feeling as follows:

Mrs. S: Sad, when you think of what she was, so smart looking ... I'd lost her, even before she lived here - you can't have a conversation with her. ... Once in the hospital, she looked so old, I burst out crying.

Mrs. Urquhart also described sadness at the loss and what she perceived as the pointlessness of her husband's continued existence:

Mrs. U: He's just a vegetable really.

H.S: And how does it make you feel to see him like this?

Mrs. U: Well, I feel sometimes very sad about it, knowing the person he was and I see him like that, it's sad to see him because he was a very active, hard working man, friendly with everybody, ... and sometimes when I watch him going into the van on a Monday and he has to be helped in, and he's so helpless, then I feel "What a sad end", and I often say to myself he'll eventually have to go into W. Hospital and he'll just turn like a vegetable really, and I'd rather see him dead.

4. Evidence of the "Social Death" of the dementia Sufferers

This section details what might be regarded as differing degrees of social death in the dementia sufferer as described of their caregiving relatives.

There did seem to be a fairly striking variation in the viewpoints of different caregivers with regard to issues such as the loss of the person of the dementia sufferer, the worth of their continued existence and thoughts of their death, and the importance of attempting to involve them in activities and social situations.

At one end of the continuum Mrs. Taylor, who looked after her husband, appeared to regard him in exactly the same way as she always had done, attempted to continue to treat him as her husband, and to make sense of behaviours which others might regard as simply confused. For example, just prior to the interview her husband had refused his breakfast:

Mrs. T: We're sixty-two years married and I've made porridge all my life for him before he went to his work and this morning I went in and he said "I don't want that, what's that?" ... but that's not his usual, he usually eats up his breakfast and asks for more. I don't know what - he's maybe a wee bit difficult this morning, but I know he was frightened last night, and he'll turn round and he'll, I think he's afraid of being left on his own, he'll turn round and try and cuddle me, and if I lie in bed and put my hand over the top of him and he knows I'm there he's quite good and he sleeps good all night.

Later Mrs. Taylor described her belief that she could still communicate meaningfully with her husband:

Mrs. T: He can't seem to communicate with other men or other people. I think I'm the only one he can communicate with.

She did not seem to have considered her husband as a dying man:

H.S: Do you ever think ahead to the death of your husband?

Mrs. T: I don't think about that at all - I think he'd miss me an awful lot.

H.S: If you were to die first?

Mrs. T: What I do for him ... well, I really just imagine that, because he seems to be pretty happy.

She pointed out those aspects of her husband which she perceived as having remained unchanged,

Mrs. T: .. he gives a lovely smile yet, he really does, he gives a lovely smile -

H.S: So he's still got the same old smile?

Mrs. T: Oh aye, dimples in his cheeks and his chin, and a good complexion, not all scruffy - tidy.

Contrast this with the comments of Mrs. Urquhart, caring for her husband, who had a similar (moderate-severe) degree of dementia as Mrs. Taylor's husband:

Mrs. U: When he first went like this I used to make him get up out of his bed every day, but it became such an effort, it was taking more out of me, it was a fight to get him up, so now I've decided, well if he wants to lie in bed, he can lie in bed.

She did not regard him as the same person any more:

Mrs. U: .. he's not the same person - his whole personality's changed.

H.S: I was going to ask you that - do you still think of him as your husband?

Mrs. U: To be quite truthful - and it's a horrible thing to say, I wouldn't care if he died tomorrow - I've begun to get a kind of hatred to him - I just treat him as a person that's there, I've got to attend to him, but I've absolutely no feelings.

For Mrs. Urquhart it was as if her husband had died:

H.S: I suppose in a way it's almost as if the person that you used to know has already died.

Mrs. U: Exactly, that's - it is. He's just not the same person, no way is he the same person, but as I say, it's a hard thing to say, but I'd rather see him dead and know he was dead than to think that he's got to go into W. Hospital and become like some of the cases I've seen.

Similarly, Mrs. Moore described how her feelings towards her husband had changed as a result of his dementia:

H.S: So, it sounds as if the Frank Moore that you used to know has really changed and gone?

Mrs. M: Oh, completely, completely. ... he's no' got an interest in anything at all. ... he's a different man if you know what I mean, a different man altogether.

H.S: So you don't think of him really as the same man?

Mrs. M: Oh no, he is not. No, not a bit, not a bit, not a bit.

Later, Mrs. Moore considered the prospect of "the shutters coming down", by which she meant the time when her husband would stop recognising her completely. She thought that sometimes this already happened, and certainly he was unable to recognise any of his other relatives:

Mrs. M: Sometimes I wonder now if he knows me at times you know what I mean? I often question that, often question it - that if I wasnae here, would it bother him? You know what I mean? Would it worry him at all or would he miss me?

You know, I often think that myself.

H.S: How does it make you feel when you think ahead to a time when you say the shutter might come down and he'd have no recall?

Mrs. M: I don't know at all, I don't know ... you just take day to day and day to day ... it's just terrible, it's just an existence. And I mean, as I say, he's in a world of his own. Sometimes I don't think he'd miss me at all, you know what I mean?

She continued on the same theme:

Mrs. M: See, he disnae - he canna follow nothing. He can't read, he doesn't understand a thing on the television, but he just sits looking at it anyway, or else he shuts his eyes and sleeps ... it's jist, it's a terrible thing to say, but he's jist like a robot. You know what I mean? Like a robot, a programmed robot.

Mrs. Moore thought ahead to her husband's death:

Mrs. M: .. the only thing I hope is that he goes before me, that's all, you know what I mean? That he goes before me. I could cope with that. I believe I could cope with that, rather than the other way round, I don't know, it's an awful thought. Mind you, it's always in my mind, you know what I mean?

In some ways she seemed to regard him as already dead:

Mrs. M: .. as I say, you're more or less - I think of myself as on my own, you know what I mean? In the house - it's no as if a man in your life you can discuss business - I mean, I've to do everything businesswise, you know what I mean?

H.S: So it's as if little by little he's gone, and now you're by yourself?

Mrs. M: Actually, that's it, exactly.

And later, she continued this theme of the loss of the person, and its incongruity in the context of having to continue physically caring for her husband:

Mrs. M: I don't know how to explain it - we're close and we're not close, if you know what I mean.

H.S: In what ways are you close still?

Mrs. M: Well, wi' me working with him.

H.S: Right.

Mrs. M: You know what I mean? But otherwise we're not, you know what i mean? Because we can't discuss nothing - no conversation nor nothing, you know what I mean? Actually I'm just always telling him what to do. I mean, I cannae say to him, eh, a paper an' that "what do you think of this in the paper?" ... I mean, you've nothing, you've nothing like that at all, you know what I mean? ...

H.S: It's almost as if he died?

Mrs. M: It really is, it is, that's a fact, that's a

fact. You're living with a stranger, you're really living with a stranger, if you call it living, an' it's no' living, believe me, it's not, it's not.

Between these examples which could be categorised as "no social death" (Mrs. Taylor) versus "definite social death" (Mrs. Urquhart and Mrs. Moore), there appeared to be some caregivers who were aware that their relative could very easily become socially dead were it not for their active intervention to prevent it. Mr Tierney described this situation with regard to his mother:

Mr. T: I know that eventually I'm going to have to stop treating her as a person and that's what I was unwilling to do - that's why I treat her - tell her to do this, tell her to do that ... I make her work for it, to do something for herself, for her sake.

And later:

Mr. T: .. gradually I'm going to have to take over entirely. I mean, I've already had to take over her pension - that is something I've fought off for a long time because I thought it gave her dignity to go for her pension, and I insisted she walked it, so she had to go out and get her pension, because in my opinion, it gave her a certain dignity.

Mr. Tait also used this tactic with his wife, who suffered from a mild degree of dementia.

Mr. T: And to keep her mind active she goes across the road to the pakis' and up to the shops at Glasgow Cross, but she forgets some of the messages.

H.S: Right, so she does that on her own does she?

Mr. T: Oh, she does that on her own - I mean, I let her do it, to keep the mind active, because if I was taking it away she would just be dormant.

Mr. and Mrs. Thomas also discussed this theme of preserving the "personhood" of Mrs. Thomas' mother. She suffered a severe degree of dementia, which it could be argued might make the task of preventing her social death more difficult:

H.S: How do other people cope with your mum - like your friends?

Mrs. T: Well, see they come in at first and start to talk, but they're not getting anywhere, so eventually they just ignore -

Mr. T: After five or ten minutes -

Mrs. T: It's as if she's not there ... I feel sorry for my mother because she's cut off, you know,

she's cut off, and eventually we just forget about her, it's as if she's not there ...

Mr. T: .. But to totally ignore her, you're not treating her as a person then, you're treating her as part of the furniture ...

H.S: So you feel it's very important to treat her as a person.

Mrs. T: Oh yes.

Mr. T: Oh yes.

Mrs. T: Oh yes, aye - I mean there's no way I would pack my mother up to her bed just because I had somebody coming to the house, I don't think that's a nice thing to do and I don't think it's a fair thing to do, because my mother contributes to the house just as much -

Mr. T: I don't think your mother contributes -

Mrs. T: No, but she's a member of the household, of course she is.

Mr. T: I know that.

Later:

Mr. T: .. and you don't want to sedate them with sleeping pills all the time because it takes away any personality - I mean, she was like a semi coma and she was neither a person one way or - and you've got to try and get a balance where she still keeps some of her identity.

Contrast this last statement with Mrs. Urquhart's comment that she preferred it when her (socially dead) husband would stay in his bed for most of the day.

5. Future Institutionalisation of the Dementia Sufferer

In the main, the caregivers had considered the future institutionalisation of their relative. For example, Mrs. Smith had "thought about it lately" for her 85 year old mother: "my family say 'Why don't you, she wouldn't know the difference'". In contrast, Mrs. Moore's son was completely opposed to the institutionalisation of his father, even respite care: "if he phones up - he works away a lot from home ... he'll say 'Is my dad in that place?' you know, 'Is my dad in that place?' - he'll no' even say the name."

For many caregivers the main reason for continuing to look after the dementia sufferer themselves was the guilt which they believed would be unbearable if they were to institutionalise their relative. However some felt that institutionalisation might be possible if the dementia sufferer reached the stage of being completely unaware of their surroundings or who it was that was looking after them. For example, Mr. and Mrs. Thomas:

Mr. T: I think if we put Nora's mother in anywhere she wouldn't last at all.

Mrs. T: No.

Mr. T: I'm quite convinced really, and you'd feel - and I mean we've done very well as far as I'm concerned, but even at that we'd still feel very guilty - ...

Mrs. T: .. I think if it got to the stage where my mother was incontinent and she didn't know who we were - but she still knows who we are, and to me, as long as I can keep my mother I will keep her, you know.

Mrs. Urquhart also felt very guilty when she considered the possibility of the institutionalisation of her husband, although she realised that "realistically" it might have to happen:

Mrs. U: When the doctor said to me, he says, "eventually he'll have to go in", he says, "not only for himself, but for your health", and I says, "well you know I feel awfully guilty" - and I really do feel guilty, but then again, to be realistic, my life is going to be nothing, and I'm going to be down. If anything happens to me he'll have to go, because I'm the only one he's got.

Institutionalisation was often regarded as the inevitable result of very severe dementia. At this stage, if a caregiver cannot cope any longer, the responsibility for institutionalisation might be abdicated to professionals, thus reducing the guilt somewhat. For example, the doctor's decisions had obviously influenced Mrs. Taylor:

Mrs. T: .. I was asking the doctor whether there were any chance of us getting into a home together and she says "Well", she says, "there's a big waiting list, but I actually don't think Mr. Taylor's fit for a home, I think it will have to be hospital at the end of the day", she says, "because he can't look after himself" ... and I know now that maybe if I can't cope with him he's just got to go into hospital.

H.S: How does that make you feel, thinking about him going into hospital?

Mrs. T: I'm not very happy about it, because we've been a long time married and we've been a long time together, you know, but if it's better for - and I, really, some days I'm exhausted.

Mr. Tierney raised the notion that the institutionalisation of his mother would be akin to her having died:

H.S: How do you think you'd feel if she were to go in?
Mr. T: I suppose initially I'd be upset, but my mother's seventy, and I feel that her life in hospital wouldn't be any different than if she was in the house. You have to accept these things. I would accept it, I'd just feel very similar as if she'd died or something - I mean, I wouldn't put her out my mind but I'd have to accept it just as if that was what'd happened.
H.S: As if she'd just gone out of your lives?
Mr. T: Exactly.

6. Carer Wellbeing

The caregivers interviewed in this preliminary stage exhibited a range of mental health. At one end of the continuum Mrs. Taylor did not believe her health to have been affected in any way by having to care for her husband. She appeared to be content and to accept the situation:

H.S: Do you think having to look after him and do so much has affected your own health?
Mrs. T: No, I don't think so. ... not compared to some folk - when you go to hospital and you see that ward and you see some of the poor souls you realise how lucky you are, you really do. ... I don't mind working for him.

Later she described this contentment with her life,
Mrs. T: I just take it in my stride and think it's part of my job, it's not heavy ... I've got an automatic washing machine ... no, I'm very lucky what I've got, dear. I mean I know I've got enough to keep us fed and warm for the rest of our lives, I think that I don't think I've anything to complain about.

At the other end of the wellbeing continuum was Mrs. Davies, who cared for her husband:

Mrs. D: I think I will die before him, I just don't feel well, every new upset I lose weight ... I'm not a crier, but I've been weepy recently ... I can't relax ... I'm too tired to go shopping.

Mrs. Moore also believed that her general wellbeing had been affected by the task of caring for her husband:

H.S: Do you think it's affected your health having to look after him like this?
Mrs. M: Oh well, I think so. I think so. I think nature wise and everything, I mean, it's bound to affect people ... I've got the patience but yet sometimes I lose my cool, if

you know what I mean. I can get irritable and frustrated too, but, eh, I just say, "well, I've got to carry on", you know what I mean? Got to carry on.

She got depressed:

H.S: Do you get weepy when you're on your own?

Mrs. M: Very much, I was just going to say that, ... and do you know, quite often I used to say "I would like to be taken in for a week somewhere masel just for a rest, or even a sleep", you know what I mean? Just taken away from everything and just taken away somewhere for a week masel. Quite often I say that, even to some institution or that ...

Other relatives described an improvement in their own wellbeing over time as they had come to accept the situation. For example, Mrs. Smith "used to cry" about her mother's dementia, but "not so much now". Although she smoked more than she used, and suffered sciatica as a result of having to bath her mother, "I can relax, I sit and knit at night - I've had it so long with her, I can close my mind". She tried "to see the bright side - if you didn't laugh at it, it would get to you".

7. Opinion of the Interview

No caregiver expressed a negative opinion of the interview, and the majority seemed to regard it as positive, because someone was taking an interest in them, despite the fact that it had touched upon potentially sensitive topics, For example, Mr. and Mrs. Tierney concluded:

Mr. T: It's nice to talk to somebody else about it, isn't it? I've never spoke to Dr. C. at all - I think you were here when Dr. C. -

Mrs. T: But again, he didn't talk about it.

Similarly, Mrs. Moore said:

Mrs. M: And it's nice to talk to somebody about it, because as I say, I don't have that many people to talk to at all, you know what I mean? As regards his illness an' that, but if it helps somebody else or helps you, that's the main thing you know.

H.S: Well, do you think it does help you, because I noticed some of the things we talked about made you quite sad?

Mrs. M: Aye.

H.S: Do you mind that - talking about sad things?

Mrs. M: No, no, no.

H.S: Sometimes it's quite a relief, isn't it, to get it off your chest.

Mrs. M: It is, aye, it is right enough, because, eh,

when the nurse used to come over she would say "Now, don't hold nothing back, just - if you want to cry, cry", oh, many a time I do that - in the room so he doesnae see me.

VI. CONCLUSIONS FROM THE PRELIMINARY INTERVIEWS

These interviews, admittedly with a very small number of subjects did allow the questions which had been posed at the outset to be answered in a positive fashion.

Firstly, some caregiving relatives would agree to participate in a study which they were aware would involve a discussion of their emotional reactions. In addition, those who did agree were then able to discuss these issues, and in fact some appeared to benefit from doing so.

Secondly, reactions were described which could be regarded as constituting anticipatory grief.

Thirdly, issues of the social death of their dementing relative could be discussed with caregivers in terms of loss of the person, thoughts of the death of the person, and the importance of involving the person in social and other activities.

Finally, as a result of the above, it was possible for the interviewer to feel comfortable when discussing these topics with caregiving relatives.

The next stage was to compile a formal "Carers' Questionnaire" in order to investigate these topics more systematically and to gather quantitative data with regard to the emotional reactions, the behaviours, and the beliefs of the caregiving relatives of dementia sufferers.

APPENDIX TWO

PILOT STUDY

(INCLUDES DEVELOPMENT OF CARERS' QUESTIONNAIRE - PILOT VERSION)

I. INTRODUCTION

Following the preliminary investigations the next stages were as follows. Firstly, to construct a "Carers' Questionnaire" which would allow for a more structured collection and analysis of both qualitative and quantitative data. Secondly, to pilot this questionnaire on a group of caregiving relatives. This appendix describes these stages of the research.

The first section of this appendix describes the construction of the "Carers' Questionnaire - Pilot Version". In order that the reader can follow the thinking behind the construction of the questionnaire, brief sections providing the rationale for the inclusion of each of the various topics are included. (Further details of the studies or interactions described can be found in the introductory part of the thesis.) Details of the sources of those items which have been culled from other questionnaires or studies are also included.

The rest of this appendix describes the piloting of the carers' questionnaire and details the results which were obtained in the two major areas of the carers' emotional reactions (or "anticipatory grief"), and the sufferers' social death. The final section presents a brief discussion of these results.

II. CONSTRUCTION OF THE CARER'S QUESTIONNAIRE : PILOT VERSION

Following the aims of the study (see Chapter Seven), the framework of hypothesised relationships used to construct the pilot questionnaire was as shown in Figure A2.1 (overpage).

This section describes how the questionnaire items were devised. It should be noted that the order of the items in the questionnaire itself is not the same as the ordering of the items presented here. Here the items are presented in logical sequence. In the questionnaire itself items were ordered with two considerations in mind. The first of these was the necessity of building

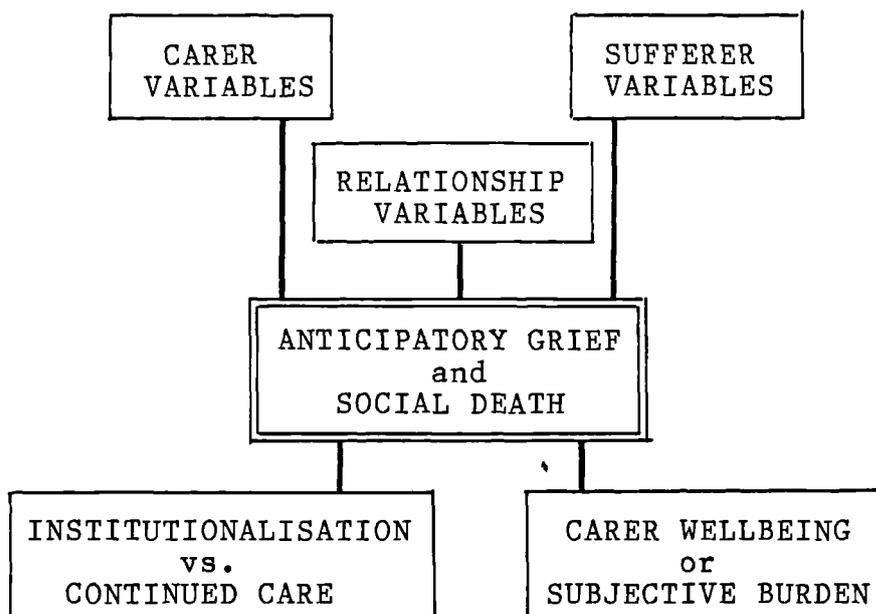


Figure A2.1 Framework of Hypothesised Relationships used to Construct the Carers' Questionnaire.

up the rapport and the confidence of the subjects. The second consideration was to allow for as near a natural flow from one item to another as might be possible within the constraints of the topics to be covered. (The pilot version of the "Carer's Questionnaire" can be found in the Appendix Four.)

The Carers' Questionnaire (pilot version) items were devised as follows:

1. Carer Variables

BASIC DEMOGRAPHIC CHARACTERISTICS:

Not only are these important in order to simply describe the nature of the sample of carers, but also because of the possibility that demographic characteristics may impact upon carer emotional reaction (or "anticipatory grief"), and also upon the "outcome" variables of carer wellbeing or willingness to institutionalise.

The evidence of the majority of studies is that the intensity of conventional grief is significantly inversely related to the age of the bereaved person (see Stroebe and Stroebe [1987] for a summary). One study found a significant inverse relationship between age and the subjective burden of the caregivers of dementia sufferers [Barusch and Spaid, 1989], and a greater preference for institutionalisation has been

found in younger carers [Gilhooly, 1986; Colerick and George, 1986].

Studies of the relationship between gender of the bereaved and the intensity of conventional grief have yielded conflicting results. However, being a female carer of a dementia sufferer has been related to increased subjective burden [Zarit, 1982; Gilhooly, 1984; Gilleard, Belford and Gilleard et. al., 1984; O'Connor, Pollitt and Roth et. al., 1989], and also to increased preference for institutional care [Colerick and George, 1986].

There is some evidence that effective social support can improve bereavement outcome [Maddison and Walker, 1967; Parkes and Weiss, 1983], however little investigation of the relationship between socioeconomic status and bereavement outcome has been conducted. Studies of carer willingness to institutionalise have found that it is greater when carers have other commitments such as employment or other dependants [Gilhooly, 1986; Colerick and George, 1986].

Questionnaire items in this area therefore included the following:

- Carer sex.
- Carer age.
- Carer marital status.
- Carer work/socio-economic status (SES): current or most recent occupation; whether paid employment had relinquished in order to care; and if required, spouse's or father's occupation (since SES of females is not based directly on their own occupation).

CARER AWARENESS OF PROGNOSIS AND THEIR UNDERSTANDING OF DEMENTIA:

Grief of any kind cannot take place unless a loss is recognised. It therefore follows that if anticipatory grief exists in the caregiving relatives of dementia sufferers, it will not occur unless the carer is aware of the nature of the disorder and the prognosis (ie. that dementia means inevitable deterioration and eventual death).

Awareness of the prognosis will depend not only on the information which caregivers receive, but also on whether they are able to understand and assimilate this information. Previous studies [Gilhooly, 1980; Gilleard and Watt, 1982 - both cited in Gilleard, 1984] found many carers of dementia sufferers to have a very hazy knowledge of the illness and its prognosis; possibly no professional had explained it clearly to them, or

possibly they were under strain through caring, or too shocked by the explanation to take it in. Awareness of the prognosis might be aided by the chance to discuss the course of the deterioration and the realities of the prognosis with others. Such others might include not only "professionals", but also other caregivers and the carer's own family and friends. This might be regarded as encouraging the carer to become socialised into the bereaved role - the definition given to "anticipatory bereavement" by Gerber [1974]. Gerber points out that if the responses of others to the carer's plans and knowledge with regard to the dying person's future are sensitive and positive, the thoughts are more likely to be accepted; if such plans are considered bad taste or premature, they may be denied.

Knowledge and understanding of what the future holds might also be increased by previous contact with dementia - whether through family, friends, or professional experience. An example of this, although in a very different diagnostic area is given by Burton [1975]. She reports that some parents of second born children with cystic fibrosis admitted to deliberately endeavouring from the outset to reduce their emotional bonds with this child and hoping it would die quickly: reactions which resulted as an attempt to reduce their own distress, and resulted from their previous contact with cystic fibrosis.

Questions on carer knowledge and awareness therefore covered the following areas:

- Discussion of the sufferer with "a professional", and if so, with whom?
- Discussion of the sufferer with other people, and if so, with whom?
- Ability of the carer to give a formal diagnosis of the sufferer's illness.
- Carer knowledge of what was going to happen to the sufferer in the future.
- Previous contact by the carer with other dementia sufferers, and knowledge of the outcome of their illness.

CARER RELIGIOUS BELIEFS:

No available study has investigated the impact of religious beliefs on the subjective burden or willingness to institutionalise of the caregivers of dementia sufferers. However, this area has been studied in relation to conventional grief, although results have been either non-significant or conflicting. Church-going has been found to relate to better outcome

[Bornstein, Clayton and Halikas et. al., 1973], but in another study it was found to have no impact on adjustment [Bowling and Cartwright, 1982]. Religious beliefs were believed to have been helpful by the majority of widows interviewed by Parkes [1986].

Carers were therefore asked:

- Whether they had a faith or belief which helped them to cope with the situation, and if so, how it had done so.

CARER COPING STRATEGIES:

Psychological stress has been defined as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" [Lazarus and Folkman, 1984, p.19]. Vitaliano, Russo and Carr et. al. [1985] note that the appraisal process may be influenced by a person's beliefs or personality. Having perceived a situation as potentially harmful, a person goes on to use some sort of coping strategy to reduce the potential harm. Examples of such coping strategies include the following: denial, selective ignoring, seeking information, motor activity, avoidance, learning specific behavioural procedures, wishful thinking, blaming others, and seeking comfort from others [Felton and Revenson, 1984].

The particular strategies which a person uses to cope with stress are believed to affect their psychological, physical and social well-being [Folkman and Lazarus, 1980]. For example, Felton and Revenson [1984] found that when it came to coping with a variety of chronic illnesses, the strategy of information seeking (ie. an active, confrontative approach) was related to decreased negative affect, whereas wishful thinking (ie. a strategy of avoidance) was related to difficulties in adjustment. MacCarthy and Brown [1986, 1989] found that in people with Parkinson's disease, "positive coping" was significantly related to positive wellbeing, while "maladaptive coping" was positively associated with depression.

In the present study, carer coping strategies were measured as follows:

- "Coping with the Effects of Giving Care":
A modification of the "Coping Checklist" used by MacCarthy and Brown [1986 - a slightly different version of the checklist and analysis are presented in their 1989 paper] was employed. This checklist had

in turn been adapted from that of Folkman and Lazarus' "Ways of Coping Checklist". MacCarthy and Brown's scale comprised 28 brief descriptions of cognitive and behavioural strategies for coping with the consequence of major stress. The wording of the items was not specific to coping with Parkinson's disease, or even with illness in oneself. Their factor analysis yielded four factors which they collapsed into two composite scales: "Positive coping strategies" (comprising "Active problem solving/re-orientation" and "Seeking social support" factors) and "Maladaptive coping strategies" (comprising their "Acting out/distraction" and "Denial/distancing" factors). Those items which MacCarthy and Brown found had loadings of greater than 0.5 on any of the four factors were included in the coping measure used in the present study. (This originally resulted in 16 items, which were further reduced to 15 by combining the two "acting out/distraction" items "Increased smoking, drinking or taking pills" and "Tried to take my mind off things by eating".)

The "Coping with the Effects of Giving Care" scale in the present study comprised the following topic areas:

Positive coping strategies

- Stepping back from the situation, trying to feel detached and objective.
- Telling self that it wasn't really all that bad.
- Carrying out practical things.
- Engaging in independent activities.
- Trying to work out the problems and making future plans.
- Keeping feelings to self.
- Trying to work out problems with family and friends.
- Trying to find others who'd experienced similar problems
- Asking others for practical advice and information.

Negative coping strategies

- Trying to take mind off problems by smoking, drinking, eating, or pills.
- Criticising or blaming self.
- Taking feelings out on someone/something.
- Preparing for the worst.
- Putting off practical things.
- Trying not to think about what was happening.

The items were presented in random order in the questionnaire. Carers were instructed to mark how often they had used each strategy in order to help them cope with the situation over the past few months (on a 5-point scale: "never" - "all the time").

2. Sufferer Variables

BASIC DEMOGRAPHIC CHARACTERISTICS:

As with the carer demographic information, these variables may also impact upon carer emotional reactions or carer wellbeing, or their willingness to institutionalise the dementia sufferer.

Kastenbaum [1972] suggests that the deaths of elderly people are perceived as "natural". Kalish [1969] describes the deaths of elderly people in Western society as least disturbing. Fulton and Fulton [1970] cite as one of their criteria for a "low grief potential" death the fact that the deceased is an elderly person. However, there are no reports of a significant relationship between the age of a dementia sufferer and either the subjective burden or the willingness to institutionalise of the carer.

Because almost all studies of grief have focussed solely on widows, there are none available which examine the impact of gender of the deceased on the intensity of grief experienced by the bereaved. The only report of a significant relationship between sufferer gender and caregiver subjective burden is that of Gilhooly [1984], who found greater morale in those caring for a female dementia sufferer.

Questionnaire items in this area therefore comprised the following:

- Sufferer sex.
- Sufferer age: years.
- Sufferer marital status.
- Previous occupation of sufferer.

SUFFERER IMPAIRMENT AND CHANGES SINCE ONSET OF DEMENTIA:

Two major aspects of the impairments of the dementia sufferer might be hypothesised to impact upon carer anticipatory grief and sufferer social death.

First of these aspects is the overall degree of impairment. It might be assumed that degree of impairment would be related to anticipatory grief and sufferer social death - but not necessarily so. As Gilleard [1984] notes, a distinction should be made between a carer noting the disabilities of a sufferer and going on to label them as problems. In addition, there is the possibility that carers might attempt to deny or "normalise" all problems - described by Calkins [1972] as the "gradual aging" pattern of deterioration. By this Calkins was referring to the situation where

the sufferer's deterioration was perceived by their family as simply reflecting the fact that he or she was slowly growing older and less able to help themselves. It was not perceived as a disease process. Thus it was clearly important to utilize both an objective and a more subjective carer assessment of sufferer impairment in the present study.

The second major aspect of sufferer impairment, besides the overall amount, is the exact nature of the impairments. Dementia sufferers do not all display the same characteristics. Not only might certain types of impairments be more disturbing, upsetting, or noticeable to the carer, but also some may be perceived as making the sufferer less of a person than they once were. (For example, Greene, Smith and Gardiner et al's [1982] finding that personal distress in the carer was related mainly to the amount of apathetic and withdrawn behaviour shown by the dementia sufferer, whereas negative feelings held by the carer towards the sufferer were related to sufferer mood disturbance.)

Sufferer impairment measures therefore comprised the following:

- 34-item Problem Checklist [Gilleard, 1984]. This measure was devised by Gilleard because of the need to assess behavioural disabilities and disturbances separately from their status as problems. It was originally devised by asking the supporters of psychogeriatric day hospital attenders to identify the problems they were currently facing. It was later revised to include the following: firstly, additional items reflecting inactivity and disengagement; and secondly, to include not only ratings of the occurrence of a certain behaviour but also of their "problem" status for the supporter. In this format it was used in the "Edinburgh" studies cited by Gilleard [1984]. It has also been used since in other community studies of dementia [O'Connor, Pollitt and Roth et. al., 1989; Morris, Morris and Britton, 1988b; Whittick, 1988].

The problem checklist comprises 34 items covering the following areas:

- "dependency" (for example, "Unable to dress without help")
- "disturbance" (for example, "Temper outbursts")
- "disability" (for example, "Incontinent - soiling")
- "demand" (for example, "Demands attention")
- "wandering" (for example, "Wanders about the house at night")
- "inactivity/disengagement" (for example, "Unable to take part in family conversation").

For each item, subjects are asked the frequency with which it occurs (scored as "not present" = 0, "occasionally occurring" = 1, "frequently/continually occurring" = 2). For those situations which occurred at least occasionally, subjects are asked how much of a problem they find it (scored as "no problem" = 0, "a small problem" = 1, "a great problem" = 2).

- Sufferer physical changes: 3-point scales asking whether the carer thought the sufferer looked the same as they used to, and whether they looked physically well. If the carer did believe the sufferer looked different or unwell, they were asked in what way.
- Sufferer overall changes: A 10-cm. line visual analogue scale (endpoints "no change" and "completely changed") to be marked by the carer according to how much the sufferer had changed overall from "how they used to be". (It was assumed that this would be a more subjective assessment of sufferer change than the 34-item problem checklist.) In addition, the carer was asked what they felt were the most important changes in the dementia sufferer.
- Speed of sufferer changes: A 3-point scale ("suddenly" - "very gradually") asking how quickly the carer perceived the changes to have occurred in the dementia sufferer.

DURATION OF SUFFERER IMPAIRMENT:

If we regard anticipatory grief as a series of stages through which the subject passes, as suggested by Kubler Ross [1970], then it might also be assumed that the stage of a carer's grief would to some extent be dependent upon the length of time since he or she was made aware of the prognosis (again, assuming the carer is aware of the prognosis). On this assumption, the longer the sufferer has been impaired, the more likely the carer's grief is to have been resolved. In the caregiving literature, there are some reports of improved ability to cope and carer wellbeing with a greater duration of having been in the caring role [Machin, 1980; Gilhooly, 1984].

Questions were therefore constructed to cover the following:

- The time at which the carer first noticed something wrong with the dementia sufferer.
- The time at which the carer first found out what was actually wrong with the dementia sufferer.

REACTIONS OF OTHERS TO THE SUFFERER:

If the carer sees friends or visitors responding to the sufferer as if they were still a worthwhile person, this may reinforce such beliefs in themselves. On the other hand, if visitors ignore the sufferer - treat him or her as if "socially dead", this may make the carer see the deterioration which has occurred. (Of course, carers may not agree with the treatment meted out to the dementia sufferer by others.)

Items therefore covered the following areas:

- Others' awareness: Do people who don't see the sufferer very often notice the changes (rated on a 3-point scale, "often" - "never"). Do they notice changes more or less than the carer? Why did the carer think this was?
- Others' behaviour: How do other people treat the sufferer? Is this the right way to behave with the sufferer? How does it make the carer feel when others behave in this way to the sufferer?

PREVIOUSLY EXPRESSED WISHES OF THE SUFFERER:

Wishes of the sufferer expressed prior to the onset of the dementia, or life-long agreements about caring may influence the reactions of the carer. Previous - often unspoken - agreements to continue caring to the end may lead to increased guilt in a carer who is having difficulty coping, or considering institutionalisation.

Questionnaire items in this area therefore covered the following:

- Previously expressed wishes about how the sufferer wanted to end their days.
- Previous discussion about the possibility of caring for the sufferer, and any decisions that were made.
- Whether or not the carer believed the sufferer would expect them to be caring.
- Whether the carer felt obliged to care.
- Why the carer did care for the sufferer.

- A post interview rating of "Why is the carer caring?" was included, with the five categories of "Love", "Repayment", "Duty", "No choice", and "Can't care any longer". This scale was culled from Hirschfeld [1978]. She investigated the factors influencing willingness to institutionalise, the most important of which was "mutuality". One of the four variables which comprised mutuality was the "Amount of emotional satisfaction the carer gained from the caregiving situation". This was categorised in the

following terms of decreasing satisfaction:
"Continuing love and affection", "Repayment for all
impaired member did and was", "Out of duty", "Lack of
acceptable choice", and "Unable to continue care for
the impaired member at home" [p.88].

3. Carer-Sufferer Relationship Variables

BLOOD/ROLE RELATIONSHIP:

The few reports on the impact of blood/role relationship on grief intensity suggest that long-expected or "natural" deaths (for example, very elderly parents) may impact less than those which appear to go against the natural order of things (for example, one's children). Clearly, the intensity of grief following the loss of a person with whom one has had a relatively close blood/role relationship (for example, one's spouse) will generally be greater than the loss of someone with whom one has had a relatively distant or no blood/role relationship (for example, the Prime Minister).

Reports on the subjective burden of the caregivers of dementia sufferers have presented conflicting results as to the impact of blood/role relationship; not only whether it has any effect at all, but also if it does, the direction of the relationship. However, spouse caregivers have been found to be far less likely to relinquish the care of a dementia sufferer to an institution than other relatives - instead accepting their continued role as caregiver and perceiving their spouse as continuing to occupy a place in their lives [Gilleard, 1984; Colerick and George, 1986]. Gilhooly [1986] found close blood/role relationship to be associated with low preference for institutional care.

A questionnaire item therefore asked:

- What relationship does the sufferer have to the carer?

QUALITY OF RELATIONSHIP:

Quality of premorbid relationship may be related to anticipatory grief. A poor previous relationship has been shown to reduce the chances of a good long-term outcome to bereavement and to increase the chances of bitterness, resentment, or guilt in the survivor [Maddison, 1968; Parkes and Weiss, 1983; Bowling and Cartwright, 1982]. In addition, previous disengagements (which is not necessarily the equivalent of poor quality of relationship) may weaken social and emotional commitments and thus reduce the emotional

impact of the sufferer's dementia on the carer. (Caroff and Dobroff [1974] note that the disengagement of an elderly person will reduce the effect of their death on the life of the family.)

Some studies have also found a poor premorbid relationship to be related to greater subjective burden in the carers of dementia sufferers [Wheatley, 1979; Gilleard, Belford and Gilleard et. al, 1984]. The amount of change (or loss) between the quality of the premorbid relationship and that of the current relationship has also been associated with caregiver subjective burden [Morris, Morris and Britton, 1988b; Motenko, 1989].

Quality of relationship was therefore assessed as follows:

- An "Interaction Scale", based on that of Machin [1980] and modified by Gilleard, Belford and Gilleard et. al., 1984, was devised. Machin's original [1980] scale comprised 10 questions concerning both positive and negative aspects of the interaction between aged parents and their adult children. The 10 topic areas were as follows: laughter, anger, comfort, possessiveness, positive aspects of caring for an elderly person, conflict of duty, interference, tension, advice, and upsets. Each item was scored on a 5-point scale ("all the time" - "never"). The scale was shortened by Gilleard, Belford and Gilleard et. al. [1984] to only the following 6 areas: laughter, anger, possessiveness, interference, tension, and upsets. (ie. they removed 3 of the "positive" aspects of interaction, and one of the "negative" aspects from the scale.) These authors administered their shortened version of the interaction scale twice: the first time prefacing each item with "Nowadays", and the second time prefacing each item with "Before the onset of the illness". In this way information was available about the quality of both past and present carer-sufferer interactions. For the present study the interaction scale was further modified by the addition of 3 items which it was hypothesised might reflect the social death or loss of the person of the dementia sufferer (so the total number of scale items was 9). The areas covered by the 3 new items were as follows: trying to ignore the sufferer; positive aspects of the relationship; and wishing to get away from the sufferer. Each of the 9 items was scored on a 3-point scale ("Often"/"Many" - "Never"/"None"). The scale was administered for current ("Nowadays") and premorbid ("Before the onset of the illness") interaction.

- The overall quality of the carer-sufferer relationship was also assessed via a 10-cm. line visual analogue scale (endpoints "very poor" and "excellent") to be marked by the carer and based on that used by Zarit [1982]. This scale was also administered twice; once for current and once for premorbid relationship.
- Previous separations between carer and sufferer: How often did the carer see the sufferer prior to the onset of dementia? Was the sufferer a quiet or isolated person ("keep themselves to themselves")? Had co-resident sufferers been away for periods of time since the onset of the dementia?

THE CURRENT CAREGIVING SITUATION:

Poss [1981] suggests that a family's adjustment work towards the acceptance that one member is dying may be complicated by various factors. These include the demands made upon their time and energy by the dying person, so draining their resources that they have little left to spend on their own adjustment to the situation. A further complicating factor can be the demands of other family members apart from the dying person.

Informal relief from caring and the receipt of emotional support has been related to reduced carer subjective burden [Zarit, Reever and Bach-Peterson, 1980; Brody, Hoffman and Kleban et. al., 1989]. However, the impact of formal services on carer wellbeing or preferences for institutional care has generally been found to be fairly minimal. Horowitz [1981, cited in Gilleard, 1984] found that carer strain was significantly related to expressed satisfaction or dissatisfaction with formal service provision but not to the absolute levels of support provided.

With regard to the taking on of new roles, Bowling and Cartwright [1982] note that some bereaved people may regard the learning of new tasks as a challenge - maybe it is the first time they have felt important or responsible for others in their lives. On the other hand, being faced with the responsibility for a dementia sufferer, or practical tasks you have never tackled or even thought of before may be anxiety-provoking. This role change may be especially difficult if the carer was previously very dependent upon the sufferer, or not much fitter physically.

Questionnaire items in this area therefore included the following:

- Members of carer's household.
- Caring time: how much time spent with the sufferer each day (hours), amount of informal support.
- Relief from caring: how much relief from caring each week (hours); expressed satisfaction with amount of relief from caring; with help from relatives; and with help from professionals (3-point scales: "completely" - "not at all satisfied").
- Role change: Amount of change in responsibilities previously held by dementia sufferer (rated on 3-point scale: "not had to take over anything" - "for many things"); for what things; how does the carer feel about this?

4. Carer Anticipatory Grief Variables

Lindemann [1944] described the anticipatory grief reaction as a process of working through all the phases of grief - depression, heightened preoccupation with the departed, a review of all the forms of death which might befall him or her, and anticipation of the modes of readjustment which might be necessitated by it. The early descriptions of the emotional reactions of the relatives of dying child patients included the following:

- Withdrawal; unworthiness; preoccupation with thoughts of earlier times; anxiety; guilt about responsibility; feelings of concern, loss, and emptiness; gradual detachment [Richmond and Waisman, 1955].
- Disbelief; shopping around for alternative diagnoses; guilt about responsibility; anger and hostility towards physicians; clinging; hope [Bozeman, Orbach and Sutherland, 1955].
- Denial and guilt; tension and anxiety; withdrawal; weeping; clinging; guilt about responsibility; concern to comfort the patient; calm acceptance [Natterson and Knudson, 1960].
- Feelings of unreality; isolation of affect; denial; motor activity; search for meaning; "anticipatory mourning", with somatic changes and preoccupation; detachment [Chodoff, Stanford and Friedman et. al, 1964].
- Intellectualisation; frenzied activity; depression; irritability; anger, hostility and guilt [Binger, Ablin and Feurstein et. al., 1969].
- Acknowledgement; grieving; reconciliation; detachment; memorialization [Futterman, Hoffman and Shabsin, 1972; Futterman and Hoffman, 1973].

The best known model of the stages passed through by the relatives of dying patients, that of Kubler Ross [1970], suggests the following order: "Denial and Isolation"; "Anger"; "Bargaining"; "Depression"; and finally, "Acceptance".

Lebow [1976] suggests six "adaptational tasks" which the family members of dying patients should be encouraged to complete in order that they are "better fortified in dealing with the final impact of death and bereavement" [p.459]. These tasks are as follows:

1. To remain involved with the patient and communicate openly with them.
2. To remain separate from the patient thus building the basis for a future life without them.
3. To adapt to the necessary role changes.
4. To bear and express the affects of grief.
5. To face the reality of the loss.
6. To say goodbye, thus acknowledging the loss.

This list is greatly enlarged upon by Rando [1986], who points out the importance of becoming aware of and then resolving any "unfinished business" which might remain between the relative and the dying patient. "Unfinished business" basically means getting things settled: tying up loose emotional ends and rectifying past misunderstandings.

The stress made by all three of the above authors is on open communication between a dying person and their family members. The opposite of this (a context of "closed awareness" and "conspiracy of silence" - Glaser and Strauss [1966]) is generally regarded as maladaptive. The problem for the relatives of dementia sufferers is obviously that "open communication" may not be possible.

No previous questionnaire-based research has investigated the notion of anticipatory grief as a series of stages. The only questionnaire available to the author at this time was the "Texas Inventory of Grief" - TIG [Faschingbaur, Devaul and Zisook, 1977]. This is a brief (7-item), paper and pencil measure of the extent of unresolved conventional grief. Items include the following areas: needing to cry; getting upset; preoccupied with thoughts; inability to accept the death; pain in the same area as the deceased; feeling like the deceased; anniversary reactions. Each item is rated by respondents on a 5-point scale ("completely true" - "completely false"). The authors found that the TIG forms completed following "recent" deaths had a significantly higher mean score than forms for deaths that had occurred more than two years previously. The TIG was modified by Welch [1982] as a measure of "anticipatory grief" for use with the family members of patients with cancer. Her scale comprised 12 items covering the following areas: difficulty getting along with other people; difficulty working; wishing to get involved in the sick person's interests; irritability; difficulty sleeping; crying; getting

upset; missing the sick person the way they used to be; preoccupation with thoughts of the sick person; hiding tears; believing the illness to be unfair; and inability to accept the fact of the fatal illness. Rando [1980, 1983] used a different strategy to retrospectively measure the extent of anticipatory grief. Following their child's death, parental "anticipatory grief" was operationalised as the numerical sum of eight behaviours which they might have engaged in during the terminal illness (for example, "Discussing their child's dying with their child"; "Making funeral preparations"; "Starting to partially disengage themselves emotionally from their child"). A further scale available to the author for reference was the "Impact of Event Scale" [Horowitz, Wilner and Alvarez, 1979]. The revised version of this scale comprises 15 items which assess the current subjective distress for any life event (not necessarily bereavement). The scale comprises two subsets: the "intrusion subset" (for example, "I thought about it when I didn't mean to"; "I had dreams about it"), and the "avoidance subset" (for example, "I tried not to talk about it"; "My feelings were kind of numb"). Each item is measured on a 4-point frequency scale ("not at all" - "often"). The scale has been demonstrated by the authors to be a sensitive reflection of change in subjective distress about an event, and to distinguish between different groups of distressed people (persons attending a stress clinic vs. medical students engaged in cadaver dissection).

In view of the previous dearth of questionnaire-based research in this area, it was decided to base a series of items aimed at tapping any anticipatory grief reactions of caregiving relatives on previous observational research; in particular the stages suggested by Kubler Ross [1970]. In an attempt to uncover any (possibly "staged") changes in carer reactions over time it was decided to ask subjects whether or not each of the "anticipatory grief" items had changed over the time since they had been involved in caring for the sufferer. (In addition, there was the possibility of comparing the reactions of carers who had been interviewed a greater or lesser time since they had been made aware of the dementia diagnosis and the consequent prognosis.)

Caregiver emotional reaction items therefore comprised the following:

- Initial reactions: How they felt when they became aware of the diagnosis and prognosis; whether they had understood the information; and whether they had believed it.

- "Anticipatory grief" items (each scored on a 3-point scale "often" - "never") which comprised the following:-
 - Shock/Denial: feeling shocked or numb; minimising the problems; and difficulty talking about the sufferer.
 - Over-involvement: ability to accept help from others; making sacrifices in order to care; putting the needs of the sufferer first.
 - Questioning/Blame/Anger/Guilt: wondering why the dementia happened; blaming others for the dementia; anger about the dementia; anger about having to care; anger directed at the sufferer; anger directed at "professionals"; guilt at anger.
 - Hope/Bargaining: hoping the sufferer might get better; bargaining about cures.
 - Mourning (including preoccupation and unfinished business): thinking back to how the sufferer used to be; feeling sad about the dementia; crying; preoccupation with thoughts about the sufferer; wishing the sufferer could have done certain things they weren't ever able to; wishing the sufferer and the carer could have done certain things together which they weren't ever able to; wishing to say certain things to the sufferer.
- Current feelings: Carers were asked to describe their current feelings towards the sufferer.
- Staging: Whether the carer believed their feelings had passed through a series of stages, and if so, what they thought these had been.
- In addition, post-interview ratings (3-point scales: "no evidence" - "great evidence") based on impressions gained and comments passed by the carers during the interview were included for the following reactions:
 - Evidence of denial (for example, focussing on well-functioning remote memory rather than impaired current functioning);
 - Evidence of overprotectiveness;
 - Evidence of anger;
 - Evidence of mourning;
 - Evidence of ambivalence towards dementia sufferer;
 - Evidence of conspiracy of silence.

5. Sufferer Social Death

No available questionnaire has attempted to assess social death. It is a somewhat vague concept, given wider or narrower definitions by different authors. Social death has been related to the following:

- The "trimming" of individual characteristics [Goffman, 1961].
- "Non-person" treatment [Goffman, 1963; Glaser and Strauss, 1966].
- Treatment as if a corpse [Sudnow, 1967].
- Being "as good as dead" [Kalish, 1967].
- The absence of behaviours normally directed towards a living person [Kastenbaum, 1969].
- The withdrawal of others from the person [Fulton and Fulton, 1970; Pattison, 1987].
- Dehumanisation, treatment of someone as less of a person than they really are, as a task, or as a stereotyped "patient" [Nursing literature, for example, Travelbee, 1964; 1971].
- Someone who ceases to be "a person" - that is, unable to value it's own life [Harris, 1985], unable to be self determining or adopt rules [Downie and Telfer, 1969], lacking "minimal" sentience and consciousness [Englehardt, 1987], lacking "good" in their life [Foot, 1978], lacking the ability to set or achieve goals [Kohl, 1978].
- The inability of the person to recognise significant others [Calkins, 1972].
- The belief that death is "a blessing" [Glaser and Strauss, 1966].
- The belief that the person should have died some time ago [Kastenbaum, 1969].

Clearly, these are not issues about which it would be possible to question carers directly: a carer could not be bluntly asked, "Do you treat the sufferer as if they were a corpse?", "Do you believe the sufferer has the ability to be self determining or adopt rules?", or "Do you think the sufferer should have died some time ago?". Even if not thoroughly shocked by such questions, a carer's answer would be highly likely to be biased towards "desirability".

A set of 8 basic questions were therefore devised as an attempt to assess and prompt discussion of the degree of the sufferer's social death as perceived by the carer. The questions covered the following areas:

- Does (the sufferer) know what's happening?
- Does (the sufferer) talk about what's happening?
(These two questions were designed to reflect the amount of awareness that the carer believed the sufferer has of their surroundings - ie. did the carer believe the sufferer possessed "minimal" consciousness and contact with the environment?)

- Is it important to you that (the sufferer) looks smart?
- Is it important to you that (the sufferer) does as much for him/herself as possible?
(These two questions were designed to reflect the degree of carer belief of the continued importance of the sufferer's dignity - ie. did the carer believe the sufferer should still be treated as a person?)
- Do you ever find yourself thinking about the time when (the sufferer) will die?
- Some people find themselves rehearsing or going through what will happen and what they will do after the death, for example, thinking about the funeral and imagining how it will be. Do you ever find yourself thinking anything like this?
(These two questions were designed to reflect the anticipation of the sufferer's actual death by the carer - ie. did the carer imagine the future when the sufferer really would be a corpse?)
- Do you ever find yourself thinking that death might come as a blessing to (the sufferer)?
- Do you ever think that in some ways it is as if (the sufferer) is already dead?
(These two questions were designed to reflect the perception of the sufferer's life as having lost any positive value, and of their being "as good as dead" already.)

Each of the 8 items was rated on a 3-point scale ("often" - "never", or "very important" - "not at all important", as appropriate). Carers were prompted to enlarge upon their answers ("Why?", "How does that make you feel?"). They were also asked whether their beliefs or perceptions had changed over the time that they had been caring or as the sufferer's condition had become increasingly impaired.

- In addition, a post-interview rating of "Degree of Social Death" using a 10cm. visual analogue scale (endpoints "Absent - sufferer totally alive socially" - "Complete - sufferer totally dead socially") was included. The ratings were be subjective, based on impressions drawn during the interview, and related to the carer appearing to believe that the dementia sufferer was no longer a social person with feelings of their own (for example, commenting that there was no point visitors trying to talk to the sufferer), or treating the sufferer as no longer a social person (for example, ignoring the sufferer if they were present).

6. Carer Preference for Institutional Care

Gilleard [1984] found that attitudes and expectations about continuing the caring role were predictive of future behaviour as a carer. In his study the community carers of dementia sufferers were simply asked whether they felt able to continue caring as they were, and also whether, if there were further deterioration, they would consider long-term institutional care. Gilhooly [1986a] rated "Preference for Institutional Care" herself on a 7-point scale ("extremely strong preference for institutional care" - "unprepared to consider institutional care under any circumstances"). She based this rating on a number of questions about home and institutional care, willingness to continue caring, and comments made throughout her interview with the carer. Preference for institutional care was assessed by Zarit [1982] by asking the community caregivers of dementia sufferers to mark on a 10cm. line visual analogue scale the likelihood that they would "put your spouse in a nursing home or convalescent hospital within the next year" (end-points "won't happen" and "extremely likely").

It was decided to use 10cm. visual analogue scales to rate carer preference for institutional care in the present study. Two scales were used, to assess the following:

- How likely it was that the carer would be placed in institutional care within the next year.
- How likely the carer would be to accept an institutional place of care for the sufferer if it was offered the following day.

It was considered that the "institutionalisation tomorrow" item would tap those carers who were really keen to give up caring and were only continuing to do so because they had no choice.

Carers were encouraged to discuss the reasons behind their preferences.

7. Carer Wellbeing and Subjective Burden

Previous studies of carer wellbeing (or subjective burden) have employed a wide variety of measures, by far the most popular of which has been the General Health Questionnaire - GHQ. (For example, the "Edinburgh" studies cited in Gilleard [1984], Toner [1987], Whittick [1988], Eagles, Beattie and Blackwood et. al. [1987], O'Connor, Pollitt and Roth et. al. [1989].) Measures of subjective burden used in other studies have included the following scales.

- A 14-item "Strain scale" comprising factors hypothesised as being likely to produce strain in a supporter, such as "Do you fear accidents or dangers concerning the elderly person, for example, fire, gas, falling over?"; a single measure of life satisfaction; a single measure of degree burden resulting from looking after the elderly person [Machin, 1980].
- The Kutner Morale Scale; the Beck Depression Inventory - BDI [Newbigging, 1981].
- A Brief Symptom Inventory [Zarit, 1982].
- The Kutner Morale Scale; the OARS Multidimensional Functional Assessment Questionnaire's "Mental Health" scale [Gilhooly, 1984].
- A checklist of psychiatric symptoms; the Affect Balance Scale - ABS; a single measure of life satisfaction; psychotropic drug use [George and Gwyther, 1986].
- A single measure of strain; the BDI [Morris, Morris and Britton, 1988b].
- The Center for Epidemiologic Studies Depression Index - CES-D; the ABS [Pruchno and Potashnik, 1989].

A variety of carer wellbeing measures were therefore used in the present study, including single item measures. Not only have these been used in previous studies, but they have a common sense value. Bradburn and Caplowitz [1965] ask how we can ask a person to rate himself in terms of subjective feelings of wellbeing or distress. They answer this as follows:

"Believing that the best first approach to the problem of measurement is a direct one, we asked the straightforward question, 'Taking all things together, how would you say things are these days - would you say you are very happy, pretty happy, or not too happy?'" [p.7].

They considered the answer to this question to be a respondent's best estimate of current overall sense of wellbeing or distress.

Carer wellbeing items therefore included the following:

- A "Strain scale": A 4-item scale rating the effect which looking after the sufferer had had on the carer's physical health, mental health, social life, and finances. (Rated on 3-point scales, "not at all" - "a great deal".) The items which comprised this scale were culled from Grad and Sainsbury [1965, cited in Gilleard, 1984]. They developed an overall family burden rating based on separate ratings of strain on mental health, social life, physical health and financial resources, each rated as "no burden - some burden - severe burden".
- Carers were encouraged to expand on the way in which

each of these areas of their life had been affected by looking after the dementia sufferer.

- A single measure of carer coping: Carers were asked to mark their position along a 5-point scale labelled, "Taking everything into account, how well do you think you are coping just now?" ("very well" - "very badly"). They were also asked whether their ability to cope had changed over the time they had been caring.
- A single measure of life satisfaction: Carers were asked to mark their position along a 7-point scale labelled "How do you feel about your life as a whole right now?" ("delighted" - "terrible"). (The "Delighted - Terrible" scale was devised by Andrews and Withey [1976 - see Ford, 1979]. The "D-T" scale has a short-term test-retest reliability of 0.7 and a long-term figure of 0.4.) Carers were also asked whether their life satisfaction had changed over the time they had been caring.
- General Health Questionnaire - GHQ-28 [Goldberg and Hillier, 1979]:
The GHQ was designed as a self-administered screening test with the aim of detecting psychiatric disorders among respondents in community settings. Its focus is on psychological components of ill-health. It represents a set of items each asking whether the respondent has recently experienced a particular symptom or behaviour on a 4-point scale ("less than usual" - "no more than usual" - "rather more than usual" - "much more than usual"). The GHQ scoring system for responses on each item is 0-0-1-1 (ie. a respondent scores if they have experienced the particular item rather or much more than usual). The respondent is classed as a "GHQ case" if they score above a pre-determined threshold score. The GHQ comes in a variety of lengths from GHQ-12 to GHQ-60, each named according to the number of items they contain.

The GHQ was originally designed with the purpose of selecting current emotional disturbance in the community which might be confirmed by interview. A major problem is that it is likely to miss chronic illness, since sufferers are likely to endorse the no-scoring reply of "no more than usual" for many questions. A number of factor analyses and validation studies have been carried out, and attempts made to improve its sensitivity and specificity by altering the sub-scales or scoring techniques (for example, Goldberg and Hillier [1979]; Tarnopolsky, Hand and McLean et. al. [1979]; Finlay-Jones and Murphy

[1979]; Benjamin, Decalmer and Haran [1982]; Hobbs, Balinger and Greenwood et. al. [1984]). Despite its disadvantages, the GHQ has been used in studies of psychiatric morbidity in a variety of settings and as previously noted has been the favourite method of assessing subjective burden in the caregivers of dementia sufferers.

The GHQ-28 was selected for use in the present study. It has the advantage of being relatively quick (usually a very few minutes) to complete, although, as Goldberg points out, this might be "offset by the disadvantage that it must also be less reliable and less valid, since information is discarded as the questionnaire is shortened ... " [1978, p.13]. Using a threshold score of 4/5 the GHQ-28 has been shown to have a sensitivity of 88%, a specificity of 84.2%, and an overall misclassification rate of 14.5% [Goldberg and Hillier, 1979]. These authors also subjected the scale to factor analysis, thus producing four sub-scales: "somatic symptoms", "anxiety and insomnia", "social dysfunction", and "severe depression".

The GHQ-28 has been employed in previous studies of the subjective burden of the caregivers of dementia sufferers (for example, Toner [1987]; O'Connor, Pollitt and Roth et. al. [1989]).

- Affect Balance Scale - ABS [Bradburn and Caplowitz, 1965; Bradburn, 1969]:
The ABS consists of five positively worded items (for example, feeling "particularly excited or interested in something") and five negatively worded items (for example, feeling "very lonely or remote from other people"). The responses to each set of items are summed to produce the "Positive Affect Scale" - PAS, and the "Negative Affect Scale" - NAS. Total or "global" affect balance is the result of the PAS score minus the NAS score.

The scale arose from a USA pilot study designed to measure, on a mass scale, fluctuations over time in behaviour related to mental health [Bradburn and Caplowitz, 1965]. It was found that individuals' feeling states varied along two dimensions, one indicative of positive affect and the other indicative of negative affect. Contrary to expectations, the two dimensions were independent of one another (ie. an individual's score on one affect dimension could not be predicted via their score on the other affect dimension). However, both dimensions were related in the expected direction to overall self-ratings of happiness or subjective wellbeing,

and the best predictor of the overall self-rating was the discrepancy between the two scores.

The ABS has been validated on elderly samples by Moriwaki [1974]. Her study demonstrated that ABS scores successfully discriminated between a group of elderly psychiatric outpatients in comparison with a group of normal elderly subjects. In addition, different criteria correlated with each subscale: PAS was positively related to morale and avowed happiness, while NAS was positively related to poor mental health and greater role loss. Finally, the global ABS was significantly correlated with two other adjustment scales (Roscow Morale Scale and Nine-Item Mental Health Scale).

Ford [1979] points out that the ABS is particularly sensitive to changing social experiences. As such the long-term reliability is not really an issue.

The actual scoring of each ABS item has varied among studies. In their original study, Bradburn and Caplowitz [1965] gave each item a score on a 4-point (0-3) scale. The scoring used by Moriwaki [1974] was a simple "Yes-No", with a constant of 5 added to the global ABS score to eliminate the possibility of negative scores. Hall [1976] quotes a British study which also used "Yes-No" scoring. In the present study a 3-point scale was used to score each item ("never" = 0, "sometimes" = 1, "often" = 2). A constant of 10 was added to eliminate negative scores in the global ABS thus produced.

- Finally, a post-interview rating of "Carer coping" was included, based on a 10cm. visual analogue scale (endpoints "extremely badly" - "extremely well").

8. Carers' Opinion of Interview

Although it was clear that there would be social pressure to express approval, it was also believed to be important to attempt to collect feedback on the interview from the carers. Since the interview contained items which might cause sadness or otherwise upset the carers it was necessary to check whether they believed any of the topics had been too intrusive or should not have been discussed. If required, the feedback could be used to modify the construction of the questionnaire.

- Items in this area therefore comprised the following:
- A single rating of "How you felt about the interview overall". (Using the 7-point "Delighted - Terrible" scale.)

- Feedback on particular items: Were there any questions which should not have been asked? Which subject was hardest to talk about? Were there any questions which the carer was pleased to have been asked?

III. PILOT STUDY - AIMS

The main aim of the pilot study was to test the feasibility of conducting semi-structured interviews with the caregiving relatives of dementia sufferers, based on the pilot version of the "Carers' Questionnaire". Although the preliminary investigations had proved that it was possible to discuss topics such as their emotional reactions to the loss of the person of the dementia sufferer in an unstructured interview, it was not clear how easy it would be to do so using a questionnaire. It was also not clear how easy it would be to rate their comments and descriptions. Finally, it was not known how long an interview based on the Carers' Questionnaire would take to complete.

The aims of the pilot study were, then, to answer the following questions.

1. Does the nature of the emotional reaction experienced by the caregiving relatives of dementia sufferers constitute anticipatory grief?
2. Does it occur in stages?
3. Do dementia sufferers become socially dead?
4. Are particular carer, sufferer, relationship, or anticipatory grief variables related to the social death of dementia sufferers?

IV. PILOT STUDY - METHOD

1. Sample

The sample consisted of 20 relatives (mean age 57 years, range 32-86 years) of patients with a primary diagnosis of senile dementia. At the time of the interview the dementia sufferer lived with the relative in 11 cases, in long-term care (either social services or hospital) in 8 cases, and had died 2½ years previously in 1 case.

The sample was drawn from the psychogeriatric day hospital and in-patient ward records of Dykebar Hospital (N = 13) and from the records of the Alzheimer's Disease Project - a study of dementia sufferers in and around Glasgow (N = 7). Dykebar Hospital is situated in Paisley, with a catchment area

covering the largely working-class towns of Paisley, Renfrew, Johnstone and Barrhead and surrounding village areas. The Alzheimer's Disease Project is a research project into the nature and mechanisms of dementia, undertaken by the University of Glasgow in conjunction with Gartnavel Royal Hospital. Subjects are drawn from an area to the north and west of Glasgow, including the middle class area of Bearsden, the working class area of Clydebank, and the town of Dumbarton.

Ethical permission to conduct the study was received from Dykebar Hospital (see Appendix Five), as was permission to conduct research under the "umbrella" of the Alzheimer's Disease Project.

2. Procedure

CONTACTING THE SAMPLE

The names and addresses of 10 carers whose relative was currently attending the psychogeriatric day hospital at Dykebar and 10 carers whose relative had previously attended but was now in long-term care (or in one case, had died) were supplied by day hospital staff. The names and addresses of 9 carers whose relative was part of the Alzheimer's Disease Project were supplied by project staff.

These carers were contacted by letter, explaining the nature of the research project in the same way as had been done in the letter to the potential subjects of the preliminary interviews. However, rather than ask the carers to express interest in the study before arranging an appointment to visit, a tentative appointment was enclosed in the initial letter. (For the relatives of non-institutionalised dementia sufferers the appointment was sent for a day on which it was known the sufferer attended a day facility, thus ensuring that they would not be present during discussions.) The carers were provided with a form to complete and return in a stamped addressed envelope if they did not wish to be involved or if the suggested appointment was unsuitable. (See Appendix Five for sample appointment letter.)

Twenty of the 29 potential subjects agreed to participate. This constitutes a response rate of 69% (65% of those known to Dykebar Hospital and 78% of those known to the Alzheimer's Disease Project.)

CONDUCT OF INTERVIEWS

Interviews were conducted between October 1987 and March 1988. The interviews took 1½-2½ hours to

complete. In 10 cases the interview was split into two separate sessions for the convenience of the carer.

As with the preliminary interviews, the pilot interviews were conducted in the carer's own home at a time when the dementia sufferer was not present. The interviewer assured the carers of her impartiality, and of the confidentiality of their responses.

A semi-structured interview format, based on the pilot version of the "Carer's Questionnaire" was employed, in order to yield both qualitative and quantitative data. This format allows for a fixed list of questions for each subject, although their order may be altered depending on the direction taken by the interview, and their exact phraseology altered if necessary (although obviously without changing their meaning in any way).

The format of the questionnaire was such as to commence with basic demographic and descriptive data prior to the discussion of any potentially emotional issues.

Questions were presented to subjects verbally. Ratings were made by the interviewer according to the nature of their replies and comments. If not immediately obvious, replies would be clarified: "So would you say that happens all the time or just some of the time?" etc. During the presentation of the 34-item Problem Checklist, subjects were provided with a card-backed sheet with the criteria for reporting "frequency" and "problem" in large print, and strung above this 34 small pages each with one of the problems listed on it. Carers could therefore turn over the pages to follow the verbal presentation of the problems by the interviewer, while at the same time referring to the criteria for answering the questions.

Eight times during the interview the subject was required to mark their answer on a scale themselves (5 visual analogue scales and 3 verbal rating scales). Each of these scales was printed on a separate sheet of paper and slotted into the appropriate place in the questionnaire. They could therefore be presented to the subject to complete without having to reveal further questions or any comments noted verbatim on the questionnaire by the interviewer.

As with the preliminary interviews, the pilot interviews were recorded using a portable cassette recorder (after having gained permission from the carers).

During the interviews short notes were made on the questionnaire - although these were sometimes limited

to marking response categories (for example, male vs. female, marital status, presence of problem behaviours, degree of agreement with certain statements), or to noting brief details (for example, carer age, number of dependants). The experience of the interviewer was that neither the tape recorder nor brief note-taking interfered with the respondents' replies.

SELF-COMPLETION QUESTIONNAIRES

Three questionnaires - the GHQ-28, ABS, and "Coping with the Effects of Giving Care" - were given to those of the 19 carers of living dementia sufferers who were willing to fill them in (N = 16). For each, the interviewer went over the instructions for completion with the carer, to ensure that they were correctly filled in. It was suggested that if the carer found any questionnaire difficult or too time consuming then it should be abandoned. Carers completed the questionnaires on their own. If the interview was split into two parts, the interviewer collected the questionnaires at the second half of the interview. If all the interview had been completed in one session, the interviewer arranged to call back in person a few days later. This ensured that any difficulties or misunderstandings about the questionnaires could be resolved. (In fact, none occurred.)

POST-INTERVIEW RATINGS AND TRANSCRIPTIONS

Following each interview, the tape recording was reviewed. Any relevant comments or sections of conversation were transcribed opposite the appropriate page of the questionnaire. This technique allowed the interviewer to complete the ratings on any sections of the questionnaire which had been discussed but not noted down during the interview itself and also to make post-interview ratings of the caregiver's behaviour and emotional state.

Post-interview ratings were made by the interviewer using verbal and visual analogue scales.

3. Data Analysis

The numbers of subjects comprising the pilot study was small. Since the analysis was largely based on current emotional reactions, behaviours, or beliefs, the data obtained from the carer whose demented wife had died could not be included. Thus the maximum number of subjects for analysis was 19.

Quantitative analysis was therefore kept simple - particularly since it was conducted using a pocket

calculator. (Since the intention at this stage was not to conduct sophisticated analyses but largely to try out the Carers' Questionnaire, the coded data was not subjected to computer analysis.) The analyses of the results to be presented here were largely comparisons of groups of carers. Chi-squared tests of significance were employed to analyse absolute numbers of carers falling into the various different groups. The other statistic used was Student's t, to analyse the differences in the means of certain variables between groups of carers.

In order to simplify the comparison of data across different groupings of subjects without constantly going back to the original completed questionnaires, the following procedure was adopted. Several sheets of 1cm. squared graph paper were glued together. The names of each subject were listed along the top of the resulting long sheet of graph paper. Each variable name was listed down the left-hand edge of the sheet. Thus each square of the graph paper represented one variable for one subject. The results were filled into the appropriate squares and the paper was then cut into strips - one strip for each subject, with all their results listed down in a ribbon. It was thus possible to compare subjects by groups of age, sex, length of time since the dementia diagnosis, etc., simply by lining the graph paper ribbons into the required grouping (rather like a computer "SELECT IF..." command). The groups of 2m. X 1cm. ribbons of graph paper were fixed flat on the floor by attaching them to the carpet using drawing pins.

The aim of the pilot study was to examine the data for suggestions of "staging" in the emotional reactions of caregiving relatives, and for the "social death" of the dementia sufferers. Analysis for evidence of emotional stages was conducted in two ways. Firstly, carers' current reactions were compared with reactions which they reported had occurred "earlier on". If the reactions of the carers had changed over time this would be evidence of some sort of alteration in emotions over time. If those reactions which are generally regarded as occurring early on in the (anticipatory) grief process (such as shock or denial) had tended to decrease, while those reactions which are generally regarded as occurring towards the end of the (anticipatory) grief process (such as depression) had tended to increase, then this would be stronger evidence in favour of a "traditional" stage theory of anticipatory grief (for example, Kubler-Ross [1970]). The second way in which the possibility of changes in emotional reactions over time was investigated was by comparing the current reactions of carers interviewed a

shorter time since the dementia diagnosis with those interviewed a longer time since the diagnosis. (Time since diagnosis rather than time since onset was chosen because the study aimed to examine reactions to the knowledge of a dementia diagnosis rather than to caring in general.)

A small amount of qualitative data is presented in the form of carers' comments and examples.

V. PILOT STUDY - RESULTS

1. Descriptive Results

CARERS

- There were 6 male and 14 female carers, mean age 57 years (S.D. = 13 years, range = 32-86 years).
- The marital status of the carers was as follows:
 - 14 married
 - 3 widowed
 - 2 separated
 - 1 divorced

SUFFERERS (the 19 who were still alive)

- There were 7 male and 12 female sufferers, mean age 77 years (S.D. = 9.7 years, range = 59-97 years).
- The marital status of the sufferers was as follows:
 - 13 widowed
 - 6 married.
- The relationship of the sufferer to the carer was as follows:
 - 13 parents
 - 6 spouses.
- The living situation of the sufferers was as follows:
 - 11 co-resident with carer
 - 8 in long-term institutional care.
- Of the 11 dementia sufferers living in the community the average number of days spent in day care per week was 2.67 (S.D. = 1, range = 2-5, mode = 2).

SUFFERER IMPAIRMENT AND CHANGES

The average time since onset of the dementia was 76.1 months (S.D. = 29.7 months, range 36-132 months). The average time since the dementia had been diagnosed was 35.1 months (S.D. = 32.1 months, range 2-132 months).

Table A2.1 (over page) presents those problem checklist items which were reported to occur (whether "occasionally" or "frequently/continually") by over 50% of the 11 community carers.

The fact that a certain behaviour or impairment might be exhibited by a sufferer did not necessarily mean that it constituted a problem for their carer. Table A2.2 (over page) presents those problem checklist items which when they did occur were reported to be a problem (either "some" or "great") by over 50% of the 11 community carers.

Tables A2.1 and A2.2 demonstrate that the majority of the most frequently occurring behaviours were related to either apathy, disinterest, or inability to communicate, or else to the need for surveillance. However, although apathetic behaviours occurred frequently, they were not generally regarded as "a problem" by the caregivers. In contrast, behaviours which when they did occur, constituted a problem, were those more likely to be actively disruptive to the carer's life or to require physical assistance or interventions from the carer. For example, although "Cannot be left alone for even one hour" occurred in only 63% of the dementia sufferers (ie. 7 of the 11), when it did occur it was regarded as "a problem" by 86% of the community carers (ie. 6 of the 7). However, "Unable to hold a sensible conversation" occurred in all the sample of dementia sufferers, however it was regarded as "a problem" by fewer than half of the carers (and thus does not appear in Table A2.2).

Table A2.1

Frequency of occurrence of problem checklist items: co-resident carer-sufferer dyads

<u>Problem</u>	<u>Reported by % carers</u>
Unable to dress without help.....	100%
Disrupts personal and social life.....	100%
Forgets things that have happened.....	100%
Unable to hold a sensible conversation.....	100%
Unable to occupy self doing useful things....	100%
Unable to take part in family conversation....	90%
Unable to read newspapers ^ magazines.....	90%
Unsafe outside alone.....	81%
Shows no concern for personal hygiene.....	81%
Sits around doing nothing.....	81%
No, interest in news of family / friends.....	81%
Unable to follow TV / radio.....	81%
Unable to wash without help.....	72%
Physically aggressive.....	72%
Temper outbursts.....	72%
Falling.....	72%
No concern for personal appearance.....	72%
Uses bad language.....	63%
Cannot be left alone for even one hour.....	63%
Needs help at mealtimes.....	54%
Vulgar habits.....	54%
Creates personality clashes.....	54%
Unsteady on feet.....	54%
Always asking questions.....	54%

Table A2.2

Proportion of co-resident carers reporting behaviours or impairments to constitute a problem if they occurred

<u>Problem</u>	<u>Reported by % carers</u>
Unable to get in & out of bed without help...	100%
Cannot be left alone for even one hour.....	86%
Demands attention.....	80%
Unable to manage stairs.....	75%
Vulgar habits.....	67%
Unable to walk outside.....	67%
Unsteady on feet.....	67%
Falling.....	62%
Wanders about the house at night.....	60%
Unsafe outside alone.....	55%
Unable to wash without help.....	50%
Noisy shouting.....	50%
Incontinent - wetting.....	50%

The majority of carers believed there had been some physical changes in the dementia sufferer, but that these had not been great. In line with this, the majority of sufferers were regarded as looking either fairly or very well (see Tables A2.3 and A2.4 below).

Table A2.3

Number of carers reporting physical changes in the dementia since the onset of dementia

	<u>Number of carers</u>
Great physical change.....	3
Some physical change.....	12
No physical changes.....	4

Table A2.4

Distribution of carers with regard to reports of the current physical appearance of the dementia sufferer

	<u>Number of carers</u>
Sufferer looks unwell.....	2
Sufferer looks fairly well.....	6
Sufferer looks very well.....	11

The mean "overall change" of the dementia sufferer as rated by the carers using the 10cm. visual analogue scale was high (mean = 8.5cm - that is 85% along the line in the direction of "completely changed", S.D. = 1.6).

Table A2.5 (below) shows that the majority of carers described the speed at which the changes in the dementia sufferer had occurred as having been slow.

Table A2.5

Distribution of carers with regard to ratings of the speed at which the changes in the dementia sufferer had occurred

	<u>Number of carers</u>
Changes very sudden.....	4
Changes fairly sudden.....	3
Changes gradual.....	12

CARER-SUFFERER RELATIONSHIP

Both methods of estimating the quality of the relationship yielded a significantly poorer rating for the present as compared with the premorbid situation. (See table A2.6 below.)

Table A2.6
Difference between estimated quality of present and premorbid carer-sufferer relationship

	Present		Premorbid		t-value
	Mean	SD	Mean	SD	
Interaction Scale	9.8	(3.4)	15.1	(2.5)	6.8**
Overall Rating	6.0	(1.7)	8.0	(2.1)	2.4*

** = $p < .001$ * = $p < .05$, $df=15$

CARER WELLBEING OR SUBJECTIVE BURDEN

The mean GHQ-28 score of the 16 carers who completed the questionnaire was 6 (range = 0-25, S.D. = 7.1). Seven of these carers (44%) scored above the GHQ-28 threshold of 4/5 and therefore qualified as GHQ "cases".

SATISFACTION WITH THE INTERVIEW

The carers ratings of the interview were generally positive (3 "delighted", 12 "pleased", 3 "mostly satisfied", and 1 "mixed" - the remaining one carer was not asked owing to an omission on the part of the interviewer).

Obviously, there was considerable social pressure on the carers to give a positive rating, due to the presence of the interviewer. However, their comments also tended to be positive. They were usually pleased that "someone had shown some interest". Sometimes, "it was a relief to talk about it". Although some topics might have been difficult to discuss, this was not due to carer reticence but because it can be hard to describe personal thoughts or feelings: "they weren't difficult to talk about - some were difficult to explain".

2. Stages of "Anticipatory Grief"

STAGES - CHANGES IN CARERS' EMOTIONS OVER TIME

For each of the carer emotional reaction items a rating had been made of how often that item was currently experienced ("never" - "sometimes" - "often") and also whether it had changed over time (increased, decreased, or stayed the same). These two pieces of information were used to estimate how often each emotional reaction had been experienced earlier on in their caring history. (The assumption was made that any change had been one step on the rating scale. Thus, for example, if an item was rated as currently occurring "sometimes" and it was reported by the carer to have increased, it was assumed that it had occurred "never" earlier on. If an item was rated as currently occurring "all the time" and it was reported by the carer to have increased, it was assumed that it had occurred "sometimes" earlier on.) For ease of computation, both the "current" and the "earlier on" ratings were then collapsed into two categories - whether or not the emotional reaction item currently occurred or had occurred in the past for each carer. It was then possible to calculate the proportion of the total number of subjects who reported they were currently experiencing a certain emotional item and to compare this with the proportion who reported they had experienced it earlier on in their caring history. It was also possible to calculate these proportions for certain groups of emotional items. Figure A2.2 presents the results of these calculations as a histogram. It shows the proportions of caregiving relatives reporting the occurrence of emotional reactions at the time of the pilot interview and at an earlier stage in their caring history. The emotional reactions relate to the carer's questionnaire (pilot version) items as follows:

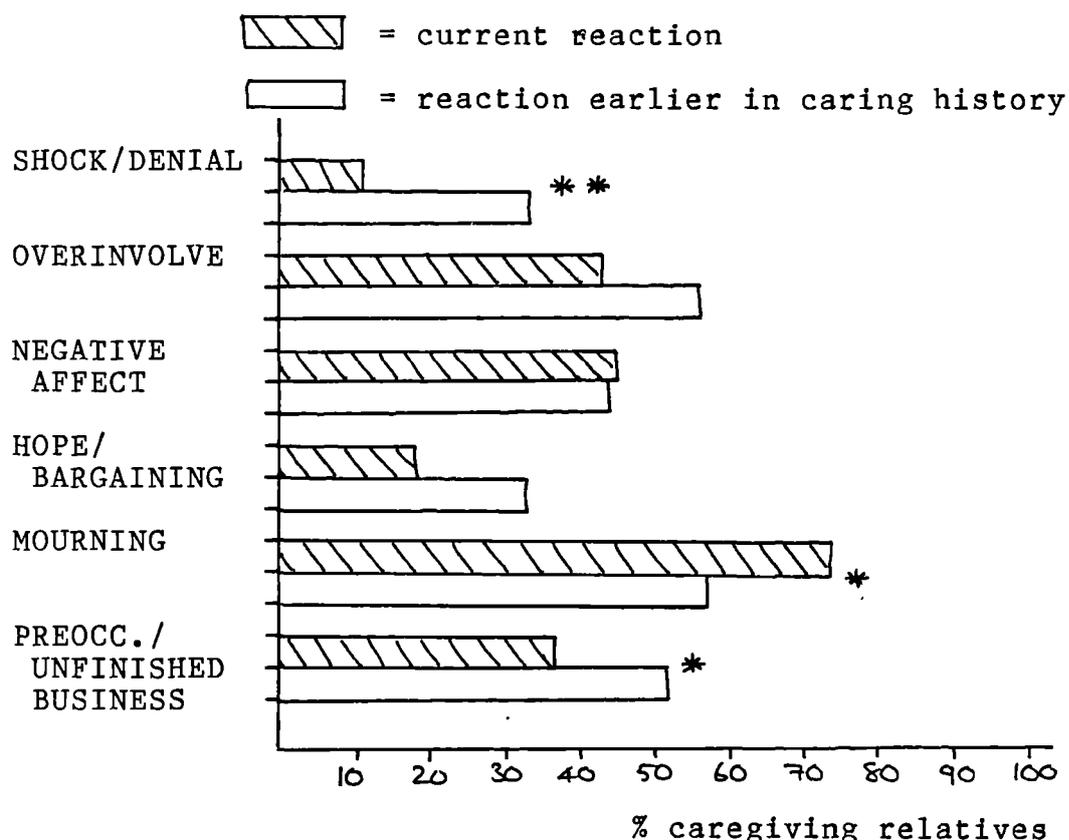
- SHOCK/DENIAL - feeling shocked or numb
 - minimising the problems to others
 - difficulty talking about the sufferer

- OVERINVOLVE - difficulty accepting help from others
 - putting sufferer's needs first

- NEGATIVE AFFECT
 - wondering why dementia happened
 - blaming others for dementia
 - anger about the dementia
 - anger about having to care
 - anger at sufferer
 - anger at professionals
 - guilt at own anger

- HOPE/
BARGAINING
 - hoping sufferer might get better
 - bargaining about cures etc.

- MOURNING - looking back to how sufferer used to be
 - feeling sad
 - crying
- PREOCCUPATION- preoccupied with thoughts about sufferer
 /UNFINISHED - wishing sufferer could have done certain
 BUSINESS things
 - wishing sufferer and carer could have
 done certain things together
 - wishing to say things to sufferer.



** = difference between reporting of emotional reaction currently versus earlier on in the caring history significant at $p < .05$ level (chi-square = 6.85, $df = 1$).
 * = difference approaching significance: $p < .10$ (chi-square = 3.45 for "mourning" and 3.17 for "preoccupation/unfinished business").

Figure A2.2 "Stages of Anticipatory Grief" - proportions of caregiving relatives reporting the occurrence of each emotional reaction/behaviour currently and earlier on in their caring history

Figure A2.2 demonstrates that the caregivers of dementia sufferers reported significantly greater "shock/denial" earlier on in the illness (ie. sooner after having received news of the diagnosis). They were also somewhat more likely to have experienced greater preoccupation or thoughts of unfinished business, but less actual sad reminiscing earlier on in the illness. Although greater "overinvolvement" and "hope/bargaining" was reported earlier on in the illness in comparison with currently, these differences did not reach significance. There had been no reported change in the overall amount of "negative affect" over the time of the illness and caring for the dementia sufferer.

The following comments which were made by the carers during the pilot interviews exemplify the different areas of their emotional reactions or "anticipatory grief" which have been identified above.

SHOCK/DENIAL:

- I never knew about dementia - I was shocked because I thought she would get back to normal.
- I avoided TV programmes about dementia - I didn't like what I was seeing.
- We tried to behave like normal, all the things we'd always done - trying to ignore it - thinking, "Surely she'll enjoy it the way she always did",

OVERINVOLVE:

- It was difficult at the beginning - I didn't want to get mum involved with the hospital.
- People said, "You'll be glad to get her away", but I wasn't, I was always thinking about her.

NEGATIVE AFFECT (questioning, anger, blame):

- I often wonder about it - am I getting punished for something?
- An inner anger that it was happening.

HOPE/BARGAINING:

- Being realistic, you know it won't improve, but you hope for some miracle, while she's still living.
- The doctor explained there was no cure, but when I saw the other patients I thought "He's not so bad" - wondered if a mistake had been made.

MOURNING:

- The more it goes on, the less others remember her as she was. I keep thinking, "If you only saw her before" - it's just not her now.
- Compared with what he was, it's so sad to see. Better a sudden death than a living tragedy.
- Sometimes all the laughter goes out of you.

PREOCCUPATION/UNFINISHED BUSINESS:

- She's always on my mind. (institutionalised sufferer)
- Many a time I think, "If she was alright now ..."
- Things we used to do together, like opera, I think, "She would love this".
- I tell her things - I hope it gets through.

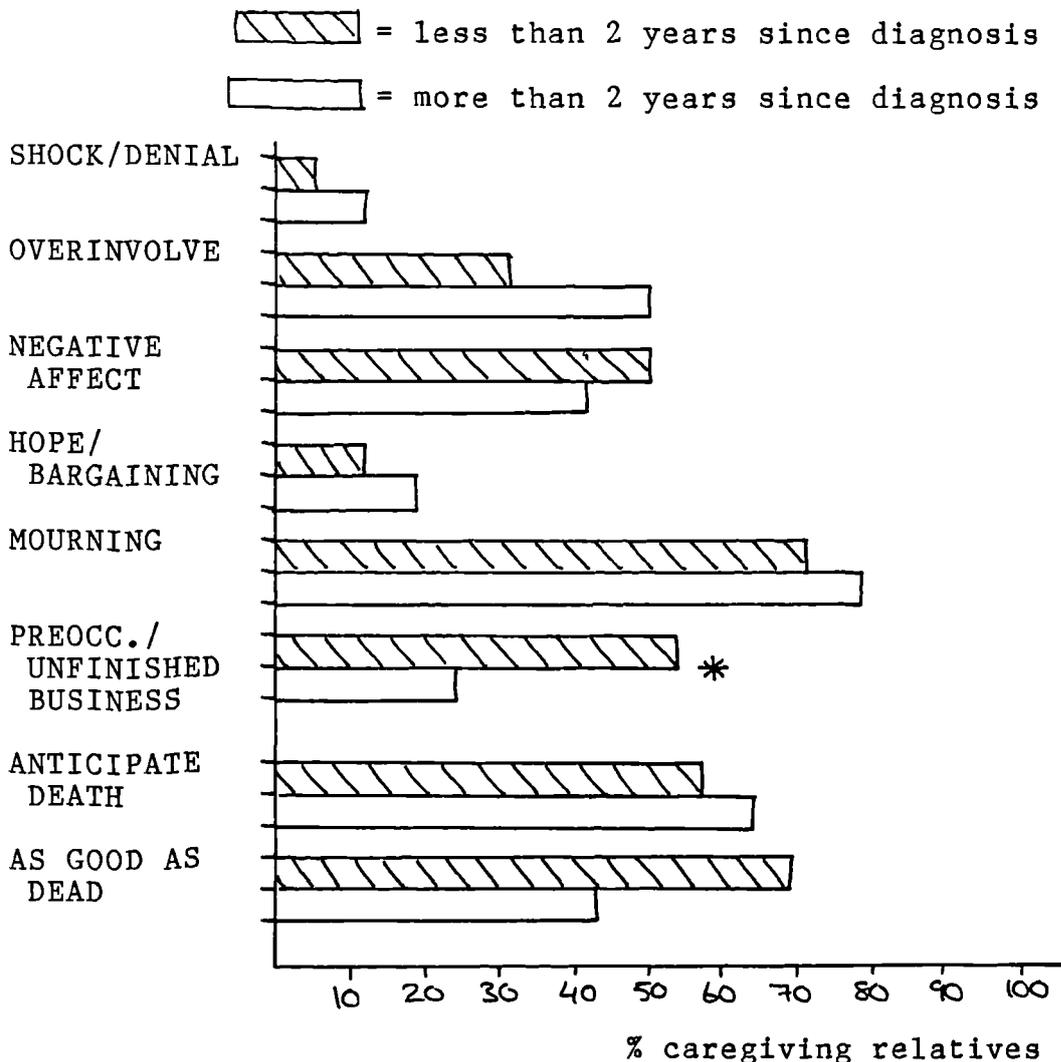
STAGES - CROSS-SECTIONAL COMPARISON OF CARERS A GREATER AND A LESSER TIME FOLLOWING DIAGNOSIS OF THE DEMENTIA

The 19 carers whose dependants were still alive were divided into two groups of roughly equal numbers, depending on length of time since they became aware of the dementia diagnosis. The division fell at less than or more than 2 years. The average time since diagnosis for those relatives (N = 8) seen closer to the diagnosis was 15.5 months (range 2-24 months), and for those relatives (N = 11) seen a greater time after becoming aware of the diagnosis it was 68.2 months (range 26-132 months).

The same computational methods as had been used to calculate proportions of carers reporting certain emotional reactions currently vs. earlier on were used. The proportions of the 8 carers seen nearer to the diagnosis who experienced certain emotional reactions were compared with the proportions of the 11 carers seen over 2 years since receiving the diagnosis of their relative's dementia. The emotional reactions/behaviours comprised the six previously described ("shock/denial", "overinvolve", "negative affect", "hope/bargaining", "mourning", and "preoccupation/unfinished business"). Two further carer behaviours/beliefs were added, as follows:

- ANTICIPATE - thinking ahead to the sufferer's death
- DEATH - rehearsing events following the death
- AS GOOD - believing death might come as a blessing
- AS DEAD - believing sufferer already dead in some ways

Figure A2.3 (over page) presents the results of these calculations as a histogram. It shows the proportions of caregiving relatives seen either under or over 2 years following the dementia diagnosis who reported certain emotions, behaviours, or beliefs, at the time of the interview.



* = difference between groups significant at $p < .02$ level (chi-square = 6.56, df = 1)

Figure A2.3 "Stages of Anticipatory Grief" - proportions of caregiving relatives under and over 2 years following dementia diagnosis currently reporting the occurrence of each emotional reaction/behaviour/belief

Relatives interviewed less than 2 years following the diagnosis were significantly more likely to be preoccupied with the dementia sufferer, or to have unfinished business. (Their preoccupation cannot be explained by a greater responsibility for the

sufferers: 3 of the 8 carers (38%) in the "short time" group had an institutionalised sufferer compared with 5 of the 11 carers (45%) in the "long time" group.) The other differences between the two groups of carers which can be seen in the histogram did not reach statistical significance.

The "short time" and "long time" groups were also compared on the following variables using t-tests:

- overall change in sufferer rating
- willingness to institutionalise within 1 yr. rating
- current "Interaction Scale" score
- overall present relationship rating
- GHQ-28 score.

The only difference which approached significance between the two groups was the overall present interaction rating (mean score = 5.4 in "short time" group and 7.0 in "long time" group, with higher scores representing better rated present interaction: $t=1.84$, $df = 15$, $p<.10$).

3. Social Death

Relatives whose dependants were still alive were divided into two groups depending on degree of social death of the sufferer as estimated by the interviewer in the post interview rating of "social death". The division fell at less than/more than 5cm. along the 10cm. visual analogue scale. On this basis there were 6 subjects rated as caring in a "high social death" (high S.D.) situation and 13 subjects rated as caring in a "low social death" (low S.D.) situation.

All six of the high S.D. caring situations involved a female carer related to a parent (5 mothers and 1 father) with dementia (distribution significant at $p<.05$ level, using Fisher's Exact Probability Test). The dementia sufferers in a high S.D. situation were significantly older (mean = 83.8 years vs. 74.3 years for sufferers in a low S.D. situation, $t = 2.18$, $df = 17$, $p<.05$). There was no significant difference in the ages of the two groups of carers.

With regard to the impairment of the sufferers, there were no significant differences between the high and low S.D. groups for either time since onset or time since diagnosis of the dementia. Carers in a high S.D. situation were somewhat more likely to estimate the overall change in the sufferer as greater on the visual analogue scale ($t = 1.77$, $df = 16$, $p<.10$), and to report the occurrence of a greater number of problem behaviours or impairments on the 34-item Problem Checklist ($t = 1.88$, $df = 12$, $p<.10$). In particular, they were more likely to report the occurrence of the

following items:

- Demands attention (t = 1.87, df = 12, p<.10)
- Disrupts personal and social life (t = 1.82, df = 12, p<.10)
- No interest in news of family or friends (t = 2.24 df = 12, p<.05)

Carers in a high S.D. situation were also more likely to report that the following checklist items constituted "a problem" for them if they were exhibited by the sufferer:

- Cannot be left alone for even one hour (t = 2.99 df = 12, p<.02)
- Wanders at night (t = 1.81, df = 12, p<.10)
- Always asking questions (t = 2.82, df = 12, p<.02)

There was also a suggestion that carers in a high S.D. situation were less likely than those in the low S.D. situation to regard the fact that the sufferer was unable to hold a sensible conversation as a strain. However, this difference did not reach statistical significance.

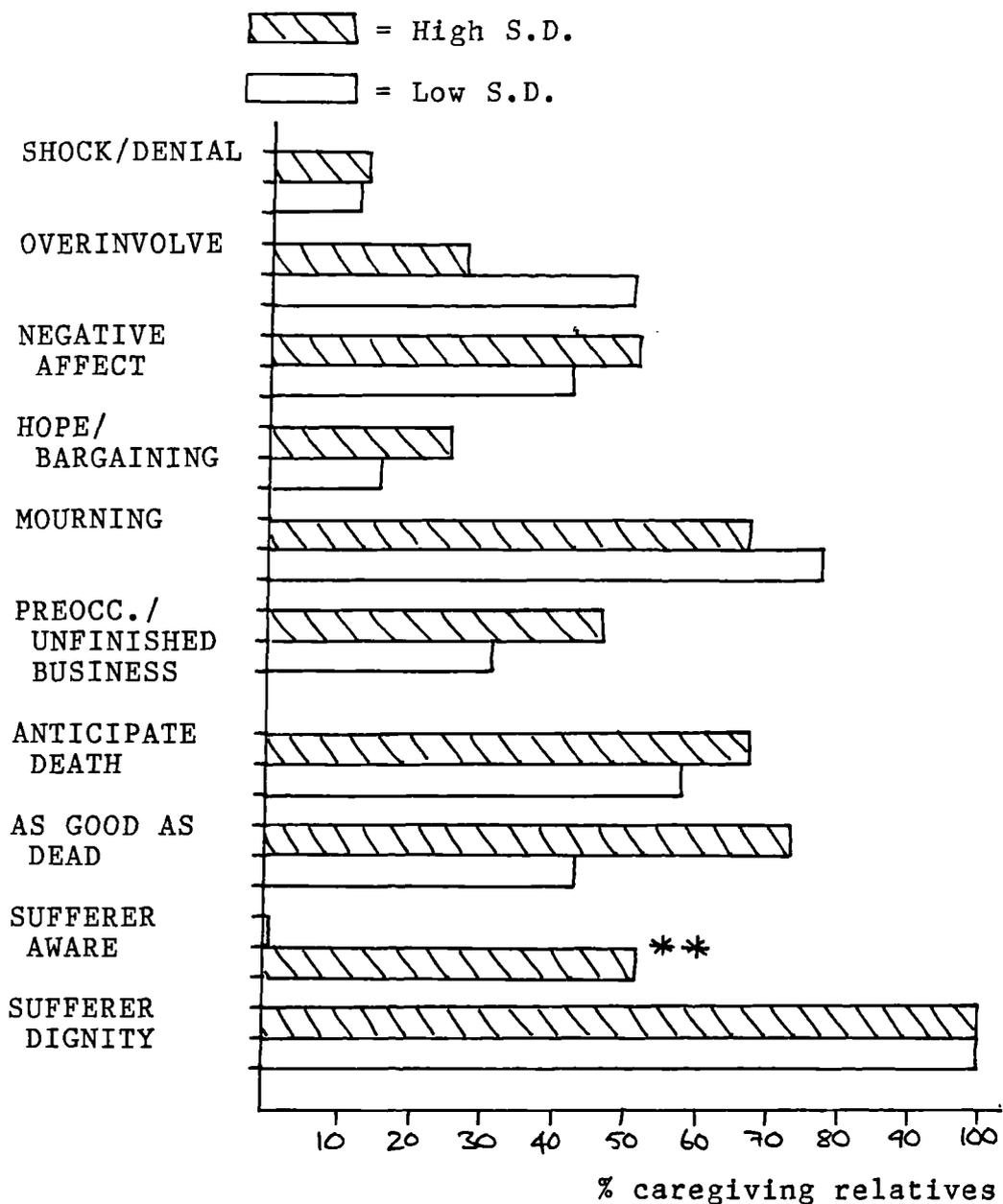
With regard to the emotional reactions or behaviours and "social death" beliefs of the two groups of carers, Figure A2.4 (over page) presents the proportions of the high vs. the low S.D. groups of carers who reported the occurrence of the following:

- The six previously described reactions of "shock/denial", "overinvolvement", "negative affect", "hope/bargaining", "mourning", and "preoccupation/unfinished business".
- The two previously described carer behaviours or beliefs of "anticipate death" and "as good as dead".
- Plus two further carer beliefs, relating to four of the carer's questionnaire items:

SUFFERER - believing the sufferer knows what's going
AWARE on
- reporting the sufferer talks about what's
going on

SUFFERER - believing the sufferer should look their
DIGNITY best
- believing the sufferer should engage in as
much independent activity as possible.

The only one of the differences (as displayed in the histogram over page) between the two groups which reached statistical significance was that none of those carers in the high S.D. group reported the dementia sufferer had awareness of, or talked about what was going on in his or her environment, whereas half of those carers in the low S.D. group thought that the sufferer had some awareness.



** = difference significant at $p < .01$ level (chi-square = 7.42, df = 1).

Figure A2.4 Proportions of caregiving relatives rated as caring in high S.D. and low S.D. situations currently reporting the occurrence of each emotional reaction/behaviour/belief

The living situation of the dementia sufferers in the two groups was as follows: 3 (50%) of those in a high S.D. situation and 8 (61%) of those in a low S.D. situation were co-resident with the carer. The remainder were in long-term institutional care. (This distribution does not differ significantly from the expected - Fisher Exact Probability Test). There was no significant difference between the two groups in willingness to institutionalise those sufferers still living in the community within the coming year.

Although carers in the high S.D. group reported poorer current and previous relationships than those in the low S.D. group, these differences did not reach statistical significance.

There were no significant differences between the two groups with regard to carer subjective burden, whether assessed via the single measures of carer coping, or of life satisfaction, or the GHQ-28, or the ABS. However, the carers in high S.D. situations reported a significantly greater use of negative coping techniques than those in low S.D. situations ($t = 2.95$, $df = 14$, $p < .02$). There was no difference between the two groups in the use of positive coping techniques.

Below are examples of comments made by relatives in the two social death groups.

HIGH SOCIAL DEATH:

- Life isn't worth living for her or me. I was looking forward to my retirement, but I'm stuck with her.
- It would be a blessing to me if she got worse.
- I never thought I'd want her to go into a home - I do now.
- It's like sitting with a stranger - it's not my mother.
- It's like a six year bereavement, with feelings you live every day. I could cope if it was a proper bereavement.
- I dread how long she's got to live in this limbo. I feel she's had her life - what's the point?

LOW SOCIAL DEATH:

- I like to see her still able to do things, so she's not completely useless.
- I worry, "What if I die first?" - I mean, she'd be in a home on her own.
- If I don't treat her with respect, I feel guilty.
- She's still mine, we've looked after each other all our married lives.
- She can look charming, dignified - not like the others in the hospital.
- Her life has got value - value in the person.

4. Comments of Mr. Laird, whose wife had died 2½ years prior to the interview

Mr. Laird described his reactions to his wife's dementia as follows: "she was a living grief, but I never wanted her away".

His main reactions had been initial hope, followed by sadness. The hope had been because he had wondered if the doctor (who told him his wife's confusion could not be attributed to "thin blood" as Mr. Laird had thought) was mistaken. He was shocked: "You sit down and you wonder, 'Why is this happening to me?'" This decreased with time: "I accepted it".

Mr. Laird had found accepting help from others in caring for his wife difficult throughout her illness. However, she was hospitalised a week before her death because he could no longer cope with the task of caring. Although he questioned the illness, he did not experience anger, and he attributed this to his religious faith (he was involved in the Salvation Army). Mr. Laird had often spent time reminiscing about how his wife had been prior to the onset of the dementia, and this had made him sad, particularly when "she had little lucid moments - I'd been accepting she'd changed, and then she gave a little reminder of how she had been".

Although Mr. Laird believed he had experienced grief prior to his wife's death, he commented that he did not think this had made any difference to his post-death grief, "because you don't believe it till the last minute and someone says she's gone".

Throughout his wife's illness, Mr. Laird had worked to preserve her dignity. He had not anticipated her death, and although "other people said so - that it would be a blessing to me - I wanted her for as long as I could." (Had his wife still been alive, Mr. and Mrs. Laird would have been rated as comprising a definite low S.D. caring situation.)

VI. PILOT STUDY - DISCUSSION OF RESULTS

The discussion of the pilot study results will be fairly brief to avoid the occurrence of repetitions in the discussion of the results of the main study.

Despite the small numbers of subjects in the pilot study, the characteristics of the sample parallel the findings of larger surveys. The majority of carers were female, and although the range of their ages was wide

the mean age was in the area of "old middle age". Married sufferers were cared for by their spouses, and widowed sufferers by their children. The predominance of apathetic behaviours and the need for constant surveillance of the dementia sufferers is in agreement with the findings of previous studies, as is the fact that it was active sufferer behaviours or those requiring some sort of direct intervention from the carer that constituted "a problem" to the caregivers. Despite the changes in the sufferers' behaviour or personality characteristics, the majority were not perceived to have changed greatly with regard to their physical appearance. The finding that the present relationship between dementia sufferer and caregiving relative was significantly poorer than that which existed prior to the onset of the illness is as would be expected. It is in line with previous studies which highlight the decline in the ability of the person with dementia to reciprocate in a relationship. That over 40% of the sample of carers could be categorised as GHQ "cases" is suggestive of the presence of subjective burden which results from being the relative of a dementia sufferer. This result also parallels the results of the majority of other studies which have employed the GHQ and found evidence of increased psychiatric disturbance in carers.

With regard to the emotional reactions of the carers, results confirm the presence of those emotions typically associated with bereavement. There was evidence of significantly greater "shock/denial" and "preoccupation/unfinished business" earlier on (ie. sooner after the dementia diagnosis), with increased mourning behaviours (reminiscing and sadness) with time. There was also a trend (non-significant) towards greater "hope/bargaining" earlier on. Emotions such as anger and guilt had remained fairly stable over time in this sample of carers. The pilot study did therefore identify a reaction which to some extent parallels the "traditional" stage model of (anticipatory) grief (for example, Kubler-Ross [1970], Parkes [1970]). It could be argued that this reaction should not be termed "anticipatory" grief since the loss of the person could be seen to have already taken place with the progressive downhill course of dementia. However the fact is that the reaction was occurring while the sufferer was still alive.

Those carers who were interviewed a greater time since the diagnosis also reported a significantly better "overall relationship" with the sufferer than those seen sooner after the diagnosis. This is difficult to explain. Similar proportions of sufferers in each group were in institutional care. Possibly the improved

relationships relate to the increase in vegetative behaviours and the reduction of actively disruptive behaviours as the dementia develops over time - however, there was no significant difference in the "overall change in sufferer" ratings between the two groups.

The "degree of social death" had been rated after completion of the interview. Ratings were subjective, based on impressions drawn during the interview and relating to the carer appearing to believe that, or treating the sufferer as if they were no longer a social person with feelings which should be taken into account. In view of the comparative lack of initial assumptions about the nature of high vs. low S.D. situations, comparison of the characteristics which differ between the groups is interesting. Social death was significantly more likely to occur in a parent-child dyad, but did not appear to be related to institutionalisation of the dementia sufferer. Possibly it is harder to regard the person with whom you have shared your married life to have "died" in a social sense than it is to so regard an aged parent - whom you would have been expecting to die in a physical sense before yourself anyway. These feelings appear stronger than the effects of the physical removal of the dementia sufferer to institutional care. There was evidence of greater sufferer impairment in a high S.D. situation. More active behaviours (ie. those which might emphasise the fact that the sufferer was still alive) were somewhat more likely to be regarded as problems by these carers - while there was a suggestion that inability of a dementia sufferer to hold a sensible conversation (an essentially human attribute) may cause more of a problem to low S.D. carers. While the differences between the impairment of the sufferers in the two S.D. groups as measured using the 34-item problem checklist may have been statistically significant, they were not particularly striking. In contrast, there was a significant and striking difference between the proportions of the sufferers in each group who were regarded as having an awareness of their environment (none in the high S.D. group vs. half of those in the low S.D. group). This may have resulted either from the investigator having - unconsciously - used sufferer awareness as an indication of social death while making the post-interview ratings, or from the fact that caregiving relatives find it easier to behave towards a non-aware sufferer as though they were also a non-person. There was little evidence of a different pattern of current emotional reactions between the two groups, and certainly none of a resolution of the anticipatory grief of those in the high S.D. group. Since the ratings of "degree of social

death" had been made on the basis of the loss of the sufferer as a social person, it is perhaps not surprising that there was a trend towards greater anticipation of the death of the sufferer, plus beliefs that when it did occur it would be a blessing and that in some ways it was as if the sufferer was already dead in the high S.D. group. It might be predicted that the loss of the social person of the sufferer would affect the carer-sufferer relationship. Although the trend of the results was towards a poorer current relationship in the high S.D. group, this was not significant. The trend was also towards ratings of a poorer premorbid relationship in the high S.D. group. Perhaps it is easier for a poor premorbid relationship to turn into a high S.D. situation with the onset of dementia in one of the parties. Or perhaps a high S.D. situation colours the perceptions of the quality of the premorbid relationship currently held by the carers. While degree of social death was not related to the subjective burden of the carers, it was related to the increased use of "negative" or maladaptive coping techniques such as denial or distraction. Given that this was a cross-sectional study, the direction of the relationship cannot be assumed - indeed it is possible that it did not simply run in one direction. Perhaps the perception of one's dementing parent as socially dead results in the increased use of strategies such as eating, smoking, criticising, putting off solutions, or denial in an attempt to cope, which in turn increase the perception of the sufferer as increasingly socially dead.

Perhaps the most important of the results from the pilot study was the one which has not been discussed so far. This is that it was feasible to conduct interviews with the caregiving relatives of dementia sufferers based on the "Carers' Questionnaire". In addition, it was possible to rate the somewhat vague concepts of "anticipatory grief" and "social death" on scales which allowed quantitative data analysis to be conducted.

While the findings of the pilot study are interesting, the small sample size and basic rating scales used precluded more than very limited statistical analysis. It was impossible, for example, to examine for the effects of more than one variable at a time - in an area which is renown for the confounding effects of a multiplicity of variables acting in concert. In addition, the method of assuming the carers' emotional reactions earlier on in the history of their relative's dementia by asking about changes in comparison with current reactions proved unwieldily, and in view of the assumptions which had to be made about the amount of change, could well have resulted in invalid data.

It is thus difficult to draw firm conclusions from the pilot study data. However, the conclusions which could be drawn were that it would be both worthwhile, and feasible, to conduct a study with a larger sample using a modified version of the Carers' Questionnaire.

APPENDIX THREE
FORMALISING THE CARERS' QUESTIONNAIRE
AND CODING FRAME

I. MODIFICATIONS TO THE "CARERS' QUESTIONNAIRE"

This section describes the modifications which were made to the Carers' Questionnaire as a result of having used it in the pilot study. Modifications were made in an attempt to improve upon the conduct of the interviews and also to increase the ease with which the data collected could be analysed. (The Carers' Questionnaire as used in the present study can be found in the Appendix Four.)

1. Main Considerations

PRODUCTION OF QUANTITATIVE DATA

The aim of the main study was use a computer-based statistical package to analyse the data. Therefore it was necessary to collect more extensive and "analysable" quantitative data than that available via the pilot version of the Carers' Questionnaire.

The first general modification was therefore to attempt to code responses to more of the items on the questionnaire than had been the case for the pilot version. This would in turn make completion of the coding frames easier, since for the majority of items the response codes could be simply copied, rather than re-considered.

The second modification with regard to the production of quantitative data was to extend the majority of the ratings from 3- to 5-point scales. This would permit sufficient variance to develop without creating scales which were too complex to complete with ease.

INCREASING THE "SMOOTH FLOW" OF THE INTERVIEW

The pilot version of the Carers' Questionnaire had required the carers to mark their responses to 8 paper-and-pencil items during the interview. This had proved quite disruptive, entailing the interviewer walking back and forth with the questionnaire, explaining the way to use a visual analogue scale, etc. It was therefore decided to eliminate the need for the carers to complete these scales themselves, while retaining most of the items in a form that could be rated by the interviewer based on the comments of the carers.

ELIMINATING INTERVIEWER BIAS FROM THE RATINGS

It was recognised that a major criticism of the Carers' Questionnaire could be that the majority of the ratings were made by the interviewer based on the discussion with the carer. While attempts were made to clarify responses and check that appropriate ratings had been made, an unscrupulous interviewer - or simply an interviewer with a high investment in a certain set of ideas - could consciously or unconsciously complete the ratings in order to create a certain set of desired results. Since the vast majority of the ratings on the modified Carers' Questionnaire were 5-point scales with the verbal tags of "all the time - often - sometimes - rarely - never", a prompt card listing the verbal tags in large print was made. The aim was to reduce the subjective element of the interviewer by providing the carer with the prompt card on which they could base their responses. (In fact, this did not prove feasible, as is discussed in Chapter Eighteen of the thesis.)

ELIMINATION OF ITEMS WHICH SHOWED NO VARIATION BETWEEN SUBJECTS

Certain of the items in the pilot version of the questionnaire were endorsed at the same level by all of the carers. These included the carer experiencing guilt following episodes of anger at the dementia sufferer, and the belief that they had taken over a great many or all of the responsibilities previously held by the sufferer. While this result may be of interest in itself, it also means that these items could not be used to differentiate between subjects. These items were therefore eliminated from the Carers' Questionnaire.

POST-INTERVIEW RATINGS

The post-interview ratings in the pilot study had proved unsatisfactory in several respects. Firstly, although the majority concerned caregiver "anticipatory grief" variables they did not correspond in an exact fashion with the anticipatory grief topics or individual items discussed during the interview. For example, while there was a rating of "anger" there was not one of "questioning" or "self blame". The results of these ratings were therefore not made use of. Secondly, the fact that the ratings were to be made on 10cm. visual analogue scales by the interviewer who had also devised the ratings, meant that the results which emerged were not only subjective, but also idiosyncratic. For example, what was meant by "overprotectiveness", "social death", or "conspiracy of silence"? Without the addition of some sort of explicit

rating criteria ("operational definitions") no other investigators could either understand the basis on which the rating decisions were made, or make reliable use of the post-interview ratings themselves. Thirdly, certain of the items - such as "conspiracy of silence" proved extremely difficult to rate.

As a result of the above, it was decided firstly to tie the interviewer rating items to specific parts of the questionnaire, such as amount of "shock/denial", or "attitude towards caring". Secondly, it was decided to replace the use of 10cm. visual analogue scales with ratings based on explicit behavioural criteria which could be observed directly during the interview.

2. Specific Modifications to the Carers' Questionnaire

CARER VARIABLES:

Basic demographic characteristics

Very few modifications were made here, apart from a slight increase in the detail of some of the codings.

- Carer sex: to be coded directly on the questionnaire, rather than indirectly via the carer's name.
- Carer marital status: For married carers, the employment status of their spouse was added as follows: "married - spouse working; married - spouse unemployed; married - spouse retired".
- Carer SES: The question on father's occupation was eliminated. A 4-item written questionnaire titled "Living Arrangements" was added for those carers who were willing to complete it. This required the respondent to mark the nearest description to their home (from 8 categories - for example, "Detached; maisonnette; high rise over 5 floors"); to code details of the rental of their home; or to code whether they were owner-occupiers; and to code their weekly family income (in £50 categories - for example, "Under £50; £50-£100").

Carer awareness of prognosis and their understanding of dementia

Again, since the questions in this area had proved to be usable during the pilot study, few modifications were made. The following items were altered.

- Discussion of the sufferer with "a professional" was altered to discussion with "anyone other than a friend or relative", since it was possible that the carers would only perceive certain formal support personnel as "professionals". (For example, while

doctors are almost universally regarded as professionals by lay people, can the same be said for health visitors, or Alzheimer's Society staff?) The coding list of possible professionals was augmented to include day hospital nurses and ward nurses - frequently important sources of caregiver information who had been omitted previously.

- Addition of two items: Did the carer believe the sufferer's problems were caused by a physical illness. Did the carer think the sufferer would get better. (Both coded on 3-point scales: "Yes - carer unsure - no".) These items were culled from the "Perceptions of the Disorder" section of the questionnaire compiled by Gilhooly for use with the community caregivers of dementia sufferers [personal communication; Gilhooly, 1984; Gilhooly, 1986a].
- Addition of a post-interview rating of carer's knowledge and perception of disorder: A 4-point scale with explicit criteria for the rating in each category of decreasing knowledge with regard to the causes of the dementia sufferer's impairments and changes. To fall in the highest "knowledge" category a carer would have to acknowledge that the sufferer had an illness and to give it an appropriate diagnostic term, they would have to understand that the changes in the sufferer's behaviour and capabilities were the result of changes in the brain, and they would have to understand that the condition was characterised by progressive deterioration over a number of years. In contrast, to fall in the lowest "knowledge" category a carer would have to be unable to give an appropriate diagnostic term to explain the sufferer's impairments, they would have no obvious knowledge of why the sufferer had become impaired, and they would not display awareness that the condition was characterised by progressive deterioration.

Carer religious beliefs

Modifications to the questionnaire were made as follows:

- The coding of the religious faith or belief scale was increased from 3 to 4 categories by splitting "faith/belief but it is no help or no faith/belief" into the two categories of "faith/belief but it is no help", and "no faith/belief".
- Addition of item: "What faith or belief?" The aim of this was to distinguish carers who had a religious faith from those with - often fatalistic - beliefs such as "What's for you won't go by you".

Carer coping strategies

No modifications were made to the "Coping with the Effects of Giving Care" questionnaire which had been used in the pilot study.

SUFFERER VARIABLES:

Basic demographic characteristics

Minor modifications were made as follows:

- Sufferer sex: To be coded directly rather than indirectly via the sufferer's name.
- Sufferer marital status: For married dementia sufferers, the employment status of the spouse was added as follows: "married - spouse working; married - spouse unemployed; married - spouse retired".

Sufferer impairments and changes since onset of dementia

Modifications to the questionnaire were made as follows:

- 34-item problem checklist: Items and ratings were not altered, but the spacing of the layout was increased to improve the ease of completion of the checklist.
- Sufferer physical changes: The rating scales for these two items were modified from 3- to 5-point scales.
- Sufferer overall changes: The rating for this item was changed from a 10cm. visual analogue scale to be completed by the carer to a 5-point scale ("no change" - "complete change") to be completed by the interviewer based on the response to the question given by the carer.
- Speed of sufferer changes: The rating scale for this item was modified from 3 to 5 points ("extremely fast/sudden" - "extremely gradual").

Duration of sufferer impairment

No modifications were made to the two items in this area.

Reaction of others to the sufferer

Modifications to the ratings of these items were made as follows:

- Others' awareness: The rating of the question concerning how much change people who don't see the sufferer very often perceived was changed from a 3- to a 5-point scale with the more logical endpoints of

amount of change ("very big change" - "no change") rather than frequency. The rating of whether or not others noticed more changes than the carer was changed from a simple "yes/no" to a 3-point scale ("others notice more change" - "notice about the same" - "notice less change").

- Others' behaviour: Behaviour towards the sufferer which had not been coded in the pilot version of the questionnaire was rated on a 3-point scale ("over-attentive" - "sometimes include" - "always ignore"). Whether or not the carer regarded others' behaviour as appropriate, which had also not been coded previously, was rated on a 3-point scale ("yes" - "unsure" - "no").

Previously expressed wishes of the sufferer

The position of these items within the questionnaire was altered. In the pilot version they had formed an independent section. In the modified version they were included within a larger section on "Caring - Current Situation and Attitudes of Carer" which also included the carer's satisfaction with help received and their attitudes towards institutionalisation. The items comprising this subject area remained the same, however, modifications were made to their ratings.

- Previous discussion about the possibility of caring for the sufferer: The rating was changed from a 3-point frequency scale to the more meaningful 3-point scale of "yes" - "unsure" - "no".
- Whether the carer felt obliged to care: The rating was changed to a 3-point strength of obligation scale ("strong obligation" - "some obligation" - "no obligation"). Carers were asked in addition to explain why they felt obliged or not obliged to care.
- The post-interview rating of "Why is the carer caring" was removed.

CARER-SUFFERER RELATIONSHIP VARIABLES:

Blood/role relationship

- This item, which had previously not been coded was now coded into 8 categories of roughly decreasing strength of blood/role ties.

Quality of relationship

Modifications were made as follows:

- Interaction Scales (both present and premorbid) : The previous 3-point frequency rating scales ("often -

never") were replaced by 5-point scales ("all the time - never").

- The visual analogue ratings of overall quality of present and premorbid carer-sufferer relationships were removed.
- Previous separations between carer and sufferer: The two items concerning how often carer and sufferer had seen each other prior to the onset of the dementia, and whether the sufferer had "kept themselves to themselves" were removed. The item concerning respite breaks of co-resident sufferers was retained, but included within the section on "Caring - Current Situation and Attitudes of Carer".

Current caregiving situation

As noted above, the majority of topics in this area were rationalised and grouped together rather than being scattered throughout the questionnaire as they had been in the pilot version.

The following modifications were made to the items which had previously formed this section.

- Members of carer's household: Item retained and augmented by requesting the ages of each member (so numbers of dependants besides the dementia sufferer could be calculated if required).
- Caring time: These items were retained.
- Relief from caring: Amount of relief from caring each week was retained. Expressed satisfaction with amount of relief from caring was removed since it tended to duplicate the other two expressed satisfaction items. These items, expressed satisfaction with help from relatives and with help from "professionals" were retained, but the rating scales were altered from 3- to 5-points ("completely satisfied" - "completely dissatisfied").
- Role change: These items were removed.
- Overinvolvement: The three items of ability to accept help, making sacrifices in order to care, and putting the needs of the sufferer first, were transferred from the "Carer Anticipatory Grief" section of the pilot version to the more appropriate "Caring" section of the modified Carer's Questionnaire. The rating of the sufferer vs. carer needs item was altered from 3- to 5-points ("great deal more important than self" - "great deal less important than self").

CARER ANTICIPATORY GRIEF VARIABLES:

This was the area of greatest modification between the pilot and the final versions of the Carers' Questionnaire. Since the items had proved intelligible to the pilot subjects and had all been endorsed by one or more subjects, the majority were retained. The section was enlarged by the addition of new items, but at the same time it was simplified somewhat into five distinct scales, which aimed to represent traditional "stages" of anticipatory grief. The overinvolvement items were removed to the more appropriate section on "Caring". A new set of items aiming to represent acceptance or resolution of caregiver anticipatory grief was added. This was principally so that the possibility of an association between sufferer social death and the resolution of carer anticipatory grief could be tested.

In the year between the construction of the pilot version of the Carers' Questionnaire and the modifications described here, a number of instruments for the assessment of the psychological distress of bereavement had become available to the author - but no more for the assessment of anticipatory grief.

The Texas Inventory of Grief (TIG - Faschingbaur, Devaul and Zisook [1977]) which was referred to during the construction of the pilot version was extended by the same authors into the Texas Revised Inventory of Grief (TRIG - Zisook, Devaul and Click [1982], Zisook and Devaul [1984], Faschingbaur [1988]). The TRIG consists of three parts, to be completed by subjects themselves. Part I, "Past Behaviour", comprises 8 items (for example, "I found it hard to work well after this person died", "I was angry that the person who died left me"). Part II, "Present Feelings", comprises 13 items (for example, "I still cry when I think of the person who died", "I feel it's unfair that this person died"). Items in parts I and II are rated on 5-point scales ("completely true" - "completely false"). Part III, "Related Facts", comprises 5 items (for example, "I attended the funeral of the person who died"), and scored true/false.

Jacobs, Kasl and Ostfeld et. al. [1986a] describe an attempt to "systematically assess the psychological manifestations of grief within the theoretical framework of attachment theory" [p.25]. They aimed to assess the three areas of "numbness-disbelief", "separation anxiety" and "sadness and despair". The authors developed a set of 6 "numbness-disbelief" items (for example, feeling stunned or dazed, experiencing disbelief), and 12 "separation anxiety" items (for

example, feeling a need to call the deceased's name, dreaming of the deceased). The 20-item Center for Epidemiologic Studies Depression Scale (CES-D) was used to assess manifestations of sadness and despair because it was discovered that it bore a close resemblance to the items which the authors had developed independently. The resulting 38-item Bereavement Items (BI) scale was presented to subjects as part of a structured interview. Subjects were required to report how often each item had occurred over the past week, since "the frequency of occurrence in the past week was the measure of intensity of the experience assessed by each item" [1986a, p.27]. Ratings for each item were made on a 4-point scale ("never/rarely during the week" - "very often = 5-7 days per week"). Factor analysis of the scale produced four factors which could be understood within the framework of attachment theory. These were labelled "sadness, loneliness and crying"; "numbness and disbelief"; "perceptual set and searching"; and "distressful yearning" [Jacobs, Kosten and Kasl et. al., 1987].

The Grief Experience Inventory (GEI - Sanders, Mauger and Strong [1979]) is a fairly lengthy (135 true/false items) self completion questionnaire. The items "were culled from the literature on bereavement and were actual statements made by individuals experiencing grief themselves or researchers' descriptions of grief as they observed it in others" [1979, p.2]. The item analysis procedure identified the following nine "bereavement scales":

- "Despair" (for example, "Life has lost its meaning for me");
- "Anger/Hostility" (for example, "I find that often I am irritated by others");
- "Guilt" (for example, "I sometimes feel guilty at being able to enjoy myself");
- "Social Isolation" (for example, "I feel cut off and isolated");
- "Loss of Control" (for example, "I have frequent mood changes");
- "Rumination" (for example, "I yearn for the deceased");
- "Depersonalisation" (for example, "Concentrating upon things is difficult");
- "Somatisation" (for example, "I experienced a dryness of the mouth and throat"); and
- "Death Anxiety" (for example, "I often think about how short life is").

The authors of the GEI have been described as drawing eclectically on several theoretical approaches, and as conceptualising grief as a multidimensional, evolving experience. The GEI itself has been described as "by

far the most extensive assessment of bereavement" [Jacobs, 1988, p.131].

None of the above questionnaires could be applied directly to the caregivers of dementia sufferers because they were designed to assess "conventional" rather than "anticipatory" grief. However, it was possible to alter the wording of the majority of items to make them appropriate to Scottish caregivers (for example, "I yearn for the deceased" could be altered to "Do you ever wish or yearn for ... to be the way he/she used to be?"). The most extensive questionnaire, the GEI was clearly far too long to administer to carers in an interview situation, while the other two (TRIG and BI) were more limited in scope. It was therefore decided to use these three questionnaires as a base of ideas upon which to extend the anticipatory grief section of the Carers' Questionnaire.

A major problem with the anticipatory grief section of the pilot version of the Carers' Questionnaire which had emerged during the analysis of the data was that attempting to assess the changes in the experience of each emotional item over time by asking whether the frequency of occurrence had changed (increased, decreased, or stayed the same) was not feasible. (See discussion of pilot study results - Appendix Two.) It was therefore decided (as with the present and premorbid "Interaction" scales) to administer each item twice. Subjects would be asked to rate the frequency of occurrence of each item for both "nowadays" and "earlier on". In this way directly comparable information would be available about the intensity of each anticipatory grief item currently and at an earlier stage in the dementia process.

The items in this area were therefore modified as follows:

- Initial reactions: Two items were added with regard to what the carer had first noticed to be wrong with the sufferer, and how they had come to learn the actual diagnosis. (In fact, these useful "story-telling" questions had been used in the pilot interviews but not noted in the Carers' Questionnaire.) Three point ratings were introduced for the items concerning the carer's initial understanding and belief of the dementia diagnosis and prognosis ("yes - understood [believed] completely" - "was unsure" - "no - didn't understand [believe] at all"). An item was added with regard to whom - if anyone - the carer had initially been able to discuss the dementia diagnosis and prognosis with.

- "Anticipatory grief" items:
 - Shock/Denial: Feeling shocked or dazed; thinking "this can't really be happening"; minimising the problems; avoidance of emotion; and difficulty talking about the sufferer.
 - Hope/Bargaining: Hoping the sufferer might get better; wondering whether the doctors have made a mistake; consulting the media for news of a cure; and bargaining about cures.
 - Anger/Guilt/Questioning: Wondering why the dementia happened; wondering if something more could be done to help the sufferer; blaming self for the dementia; guilt at enjoying self; anger/irritability directed at others; anger at the dementia; anger directed at the sufferer; anger directed at God; and anger directed at "professionals".
 - Grief - Preoccupation/Mourning/Despair: Preoccupation with thoughts about the dementia sufferer; thinking back to how the sufferer used to be; wishing the sufferer could be the way they used to be; wishing the sufferer could have done certain things they weren't ever able to; wishing to say certain things to the sufferer; getting upset about the sufferer; crying; feeling depressed; and feeling life has lost it's meaning.
 - Acceptance: Thinking calmly about the sufferer's dementia; thinking calmly about the sufferer's future; and accepting what has happened to the sufferer.

Each of these items was rated for frequency of occurrence, both "nowadays" and "earlier on", using 5-point scales ("all the time" - "never"). Thus, as well as comparing the frequency of each item "nowadays" vs. "earlier on", it would be possible to total the scores in each area to produce scale scores (for example, a "Shock/Denial" scale score) for both "nowadays" and "earlier on".

- For each of the 5 anticipatory grief areas (ie. "Shock/Denial"; "Hope/Bargaining"; "Anger/Guilt/Questioning"; "Grief - Preoccupation/Mourning/Despair"; and "Acceptance") the carers were asked, "If we were to think more generally about feeling shocked (hopeful, calm, etc.) - has there been a particular time when you felt this most strongly?". If so, they were asked when this had been.
- Interviewer ratings of change in the intensity of experience of each of the 5 anticipatory grief areas: Based on the responses to the above item ("increased" - "present but no change" - "decreased" - "never present").

- Interviewer ratings: The intensity of each of the 5 anticipatory grief areas apparent during the interview, not necessarily only during the questioning on that particular anticipatory grief area. Each of these were rated on 4-point scales with explicit criteria for making each rating. (For example, to receive the highest "Acceptance" rating, the carer would have to be able to talk freely of the illness and the problems, to discuss the sufferer's future realistically, and not demonstrate grief or distress. To receive the lowest "Acceptance" rating, the carer would have to demonstrate extreme denial or grief/distress throughout the interview, and be unable to discuss either the present or the future for the sufferer.)
- Current feelings, Staging: These two items were retained as used in the pilot version.
- Post-interview ratings based on 10cm. visual analogue scales were eliminated.

SUFFERER SOCIAL DEATH VARIABLES:

Very few changes were made to this area of questions, although the rating of each item was altered from 3- to 5-point scales ("all the time" - "never", or "strongly agree" - "strongly disagree").

The following modifications were made to this area of questions:

- Anticipation of sufferer death: One item, thinking about what the future would be like without the dementia sufferer, was added.
- Whether each one of the social death perceptions or beliefs had changed over time was eliminated and replaced by a single item, as follows: "If we were to think more generally about considering ...'s death and thinking about whether his/her life is worthwhile and about whether you think he/she can take notice of what's going on - has there been a particular time when you felt this more strongly?". If so, when had this been?
- Interviewer ratings of change in carer perceptions of sufferer as socially dead over time added: A 4-point scale based on the responses to the above item ("increased" - "present but no change" - "decreased" - "never present").
- Interviewer rating of social death apparent throughout the interview added: Rated on a 4-point

scale with explicit criteria for marking each rating. (For example, to receive the highest "Social Death" rating, the sufferer would be completely ignored if present, or the carer would say there was no point in acknowledging, the carer would appear to regard the sufferer's life as a nuisance, see no point in the sufferer continuing to exist, and would look forward to the death as a positive event. To receive the lowest "Social Death" rating, the carer would be wholly positive about the sufferer, always attempt to include them as normal, talk to the sufferer, act in accordance with the perceived wishes of the sufferer, and regard the sufferer's continued existence as entirely worthwhile.)

- The post-interview rating of degree of social death, using a 10cm. visual analogue scale was eliminated.

CARER PREFERENCE FOR INSTITUTIONAL CARE VARIABLES:

The position of these items within the questionnaire was altered so that rather than standing alone they were placed more appropriately within the "Caring - Current Situation and Attitudes of Carer".

Modifications were made as follows.

- The ratings of the two items concerning likelihood of entering institutional care within a year, and tomorrow if it was offered, were modified from visual analogue scales to be completed by the carer to 5-point scales ("extremely likely" - "extremely unlikely") to be completed by the interviewer on the basis of the responses of the carer to these items.
- Interviewer rating of carer's attitude to continued community caring added: Rated on a 4-point scale with explicit criteria for marking each rating. (For example, to receive the highest "Attitude to Continued Caring" rating, the carer would be entirely positive, enjoy the role and being with the sufferer, they would not perceive themselves as having made sacrifices, would put the sufferer's needs before their own, may speak of caring out of love, and would be planning to care as long as needed. To receive the lowest "Attitude to Continued Caring" rating, the carer would be entirely negative, dislike all aspects of the role and being with the sufferer, would perceive themselves as having made sacrifices, would put their own needs before those of the sufferer, and would only be caring because no other option was available.)

CARER WELLBEING AND SUBJECTIVE BURDEN VARIABLES:

No modifications were made to any of the assessments of subjective burden apart from the following minor changes.

- Strain Scale: The ratings were altered from 3- to 5-point scales of the effects of caring for each of the 4 items on this scale ("enormously" - "not at all").
- Single measures of Carer Coping and Life Satisfaction: Ratings of these items were retained as previously, but to be completed by the interviewer based on the answers given by the carer, rather than by the carers marking their responses themselves. Five point ratings were introduced for the responses to whether each of the items had changed over the time they had been caring ("improved a great deal" - "got a great deal worse").
- The post-interview rating of Carer Coping using a 10cm. visual analogue scale was eliminated.

CARER'S OPINION OF INTERVIEW VARIABLES:

No modifications were made to this section, apart from altering the administration of the "Opinion of the Interview" rating so as to be completed by the interviewer based on the answers given by the carer, rather than by the carers marking their response themselves.

II. CODING FRAME TO THE CARERS' QUESTIONNAIRE

The majority of ratings on the Coding Frame to the Carers' Questionnaire obviously corresponded to those within the questionnaire itself. However, some additional ratings were added to the coding frame. Some of these (for example, "Carer's Perception of Dementia") were added as a result of hypotheses formed by the investigator after a number of interviews had been conducted. Thus, to some extent, the coding frame represents yet another evolutionary stage of the Carers' Questionnaire. (The coding frame can be found in the Appendix Four.)

Ratings added to the coding frame therefore comprised the following.

SUFFERER CHANGES:

- Most important change in dementia sufferer as perceived by carer: The answers which the carers had given in response to this item were coded into one of

ten possible categories. These were: Appearance; Cognitive; Personal hygiene; Disruptive behaviour; Apathetic behaviour; No communication; No recognition; Emotional; Other; and No single change.

- Does sufferer recognise carer: This potentially important item had been omitted from the Carers' Questionnaire. It was often mentioned spontaneously by carers as a problem or as an important change in the dementia sufferer. After the completion of a few interviews the question of recognition was introduced if the topic was not spontaneously raised by the carer. Responses were rated as "yes" - "carer unsure" (ie. sufferer sometimes appeared to recognise them, but sometimes did not) - "no".

CARER'S RECALL OF ONSET OF DEMENTIA:

- Rating of carer's overall perception of dementia: After a number of interviews it became clear that different carers perceived the concept of dementia in their relative in different ways. General comments about the illness were frequently made during discussions of the sufferer's behavioural problems, the carer's own knowledge of dementia, or their story of the onset and diagnosis. There appeared to be three main ways of perceiving dementia. The following categorical ratings of perception of dementia were therefore included: "Just what happens when you get old"; "An illness, just like any other illness"; "A very horrible/worst possible illness"; "Other".

ANTICIPATORY GRIEF: ACCEPTANCE:

- Intellectual and emotional acceptance: No ratings or discussions of acceptance had been included in the pilot interviews. Early in the main study interviews it became apparent that carers distinguished between two types of acceptance. These were intellectual and emotional acceptance. They did not always correspond. Accepting the dementia sufferer's diagnosis and prognosis in one's head (intellectually) is not necessarily the same thing as accepting it in one's heart (emotionally). Coding frame ratings for changes in carer perceptions of acceptance over time and for evidence of acceptance during the interview were therefore sub-divided into both intellectual and emotional acceptance.

SOCIAL DEATH OF THE SUFFERER:

- "Have your feelings been like grief?" This question had not been included within the Carers' Questionnaire because of fears that it might contaminate other responses. (For example, there was the possibility that if the carers were aware that many of the emotional and behavioural items which

comprised the questionnaire were included because they were generally associated with the grief reaction they might attempt to respond in a way which they believed would gain the approval of the interviewer. They might, for example, be more likely to say they had cried, because grieving people are likely to cry.) About a quarter of the way through the interviews it dawned upon the investigator that such contamination could not occur if carers were asked whether their feelings had been like grief AFTER the anticipatory grief and social death items had been discussed. Following this point, the item was included in the interviews, although without featuring in the Carers' Questionnaire. Responses were rated as "yes" - "carer unsure" - "no".

- Social death beliefs and behaviours: After only a few interviews it became apparent that the criteria for rating degree of social death which had been included in the Carers' Questionnaire were unsatisfactory. In practice, degree of social death appeared to run along two dimensions, which could be labelled "believing" and "behaving". These dimensions did not always correspond. In particular, carers often appeared to believe the sufferer was more socially dead than might be suggested by their behaviour towards the sufferer. Coding frame ratings of social death were therefore included for both carer beliefs and behaviours.

CURRENT FEELINGS TOWARDS DEMENTIA SUFFERER:

- The answers which the carers had given in response to this item were coded into one of seven possible categories. These were: As always; Changed - protective; Changed - pity; Changed - annoyed/angry; Changed - no/very reduced feelings; Changed - other; Carer unsure.

STAGES:

- Rating of "classic" anticipatory grief pattern: The responses to the item on staging ("Are you able to describe stages in your reactions as a caregiver?") were rated for their correspondence to the pattern of emotional reactions generally referred to as constituting stages of (anticipatory) grief. That is: initial shock; hope; distressing anger, guilt, or questioning; preoccupation and sadness; and finally acceptance and resolution. Responses were rated as follows. "Yes - definitely" (spontaneously describing changes in two or more reactions which corresponded to the "classic" pattern - for example, reduced shock/disbelief/numbness plus increased sadness with time); "Yes - somewhat" (spontaneously describing changes in one reaction which corresponded to the

"classic" pattern - for example, increased intellectual and emotional acceptance"); and "No - definitely not".

- Rating of rough carer grief stage: Based on impressions gained during the interview, a coding was made in one of four possible categories. These were: "Does not think in terms of loss - no evidence of grief having begun"; "Earlier - shock, hope, anger prominent"; "Later - sadness prominent"; and "(Almost) over - calm acceptance".

CARING - CURRENT SITUATION AND ATTITUDES OF CARER:

- Rating of principal sacrifice made by carer: The responses to the items on sacrifices ("Have you had to make sacrifices in your own life in order to care for ...?" "If YES - what sacrifices?") were coded into one of five possible categories. These were: Social; Job; Financial; Health; Other.
- Reasons for caring: The responses to the "Why do you care for ...?" item were coded into the same five categories as had been used in the pilot version of the Carers' Questionnaire. These were: Love; Repayment; Duty; No choice; and Can't care any longer. (Culled from Hirschfeld [1978].)

QUALITY OF CARER-SUFFERER RELATIONSHIP:

- An overall rating of the quality of both the current and the premorbid carer-sufferer relationship was added to the coding frame. This was to be based on impressions gained throughout the interview and not necessarily just on comments made during the specific items concerning quality of relationship. Both current and premorbid relationships were to be rated on 5-point scales ("excellent" - "extremely poor").

CARER RELIGIOUS FAITH OR BELIEF:

- The answers which the carers had given in response to the "How does your faith or belief help you to cope?" item were coded into one of three categories. These were: "Spiritual" (for example, gaining comfort from prayer); "Practical" (for example, receiving visits from the minister or increasing one's network of support); and "Both".

OPINION OF INTERVIEW:

- The responses given to the opinion of the interview item were re-rated from seven to three categories. These were: "Positive" (previously delighted or pleased); "Neutral" (previously mostly satisfied or mixed); and "Negative" (previously mostly dissatisfied, unhappy, or terrible).

APPENDIX FOUR

CARERS' QUESTIONNAIRE: PILOT VERSION, FINAL VERSION,
AND CODING FRAME

I. CARERS' QUESTIONNAIRE - PILOT VERSION

<p align="center" style="border: 1px dashed black; padding: 5px; margin: 0 auto;"> CARER'S QUESTIONNAIRE [PHASE 1] </p> <p>Subject Number</p> <p>Subject Name</p> <p>Address</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>Date of Interview</p> <p>Interviewer</p>	<p>A. CAREER DETAILS</p> <p>1. CAREER AGE</p> <p>What is your age?</p> <hr/> <p>2. CAREER MARITAL STATUS</p> <p>What is your marital status?</p> <p> <input type="checkbox"/> Married <input type="checkbox"/> Single <input type="checkbox"/> Widowed <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Co-habiting </p> <hr/> <p>2. CAREER WORK/SES</p> <p>3.1.1 Are you working?</p> <p> <input type="checkbox"/> Yes - full-time <input type="checkbox"/> Yes - part-time <input type="checkbox"/> No </p> <p>3.1.2 If part-time - did you change from full-time work in order to care for</p> <p> <input type="checkbox"/> Yes <input type="checkbox"/> No </p> <p>3.2 If not working - did you give up a job in order to care for</p> <p> <input type="checkbox"/> Yes <input type="checkbox"/> No </p> <p>3.4 That has been your main occupation in the past?</p> <p>3.5 If married - what is your spouse's occupation at present/what was your spouse's occupation in the past?</p> <p>3.6 What was your father's main occupation?</p>
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6: CAREER EDUCATION
 4.1] That age were you when you finished full-time education?
 4.2] Did you get any exams?
 No - left school with no qualifications?
 CSE/O Grades
 Highers/A Levels
 Degree
 Higher Degree

8: SUFFERER DETAILS
 5: SUFFERER AGE
 How old is?

6: SUFFERER MARITAL STATUS
 What is the marital status of?
 Married
 Single
 Widowed
 Separated
 Divorced
 Co-habiting

7: SUFFERER JOB/SES
 What was the previous occupation of?

C: GENERAL CARING SITUATION
 R: CAREE-SUFFERER RELATIONSHIP
 That relationship does have to yourself?

9: HOUSEHOLD
 9.1] Does anyone else live in the household?
 Yes
 No
 9.2] If yes - who?

10: CARING TIME
 10.1] Roughly how many hours do you spend with each day?
 hours
 10.2] Are you the only carer?
 Yes
 No
 10.3] If shared caring - who else helps?
 10.4] If shared caring - do they help as much as you?

D: SUFFERER CHARACTERISTICS
 11: PROBLEM CHECKLIST
 I am going to read you a list of common problems - for each one please tell me whether it has occurred and, if so, how often
 [Give respondent frequency rating card - go through complete problem list]
 Now I would like to ask you about those problems you have experienced. For each one please tell me how severe you find this problem is
 [Give respondent severity rating card - go through complete problem list]

	Frequency	Severity
11.11	Unable to dress without help	_____
11.21	Demands attention	_____
11.31	Unable to get in and out of a chair without help	_____
11.41	Uses bad language	_____
11.51	Unable to get in and out of bed without help	_____
11.61	Disrupts personal and social life	_____
11.71	Unable to wash without help	_____
11.81	Physically aggressive	_____
11.91	Needs help at mealtimes	_____
11.101	Vulgar habits (e.g. spitting, table manners)	_____
11.111	Incontinent - soiling	_____
11.121	Creates personality clashes	_____
11.131	Forgets things that have happened	_____
11.141	Temper outbursts	_____
11.151	Falling	_____
11.161	rude to visitors	_____
11.171	Unable to manage stairs	_____
11.181	Not safe if alone in the home alone	_____
11.191	Cannot be left alone for even one hour	_____
11.201	Carriers about the house at night	_____
11.211	Carriers walk outside the house	_____
11.221	Unable to hold a sensible conversation	_____
11.231	Noisy, shouting	_____
11.241	Incontinent	_____
11.251	Shown no concern for personal hygiene	_____
11.261	Unsteady on feet	_____
11.271	Always asking questions	_____
11.281	Unable to take part in family conversations	_____
11.291	Unable to read newspapers, magazines, etc.	_____
11.301	Sits around doing nothing	_____
11.311	Shows no interest in news about friends and relatives	_____
11.321	Unable to watch and follow television (or radio)	_____
11.341	Unable to occupy him/herself doing useful things	_____

12.1 Does look the same as he/she used to?

Just the same

Somewhat the same

Not the same

12.2 If different from previously - what are the changes in the way looks?

.....

12.3 SUPERER OVERALL CHANGES

12.3.1 Does look physically well?

looks physically very well

looks fairly well

looks unwell

12.4 If looks unwell - what looks to be wrong with?

.....

13. SUPERER OVERALL CHANGES

13.1 Overall, compared with how he/she used to be, how much is changed now?

.....

13.2 What are the most important changes?

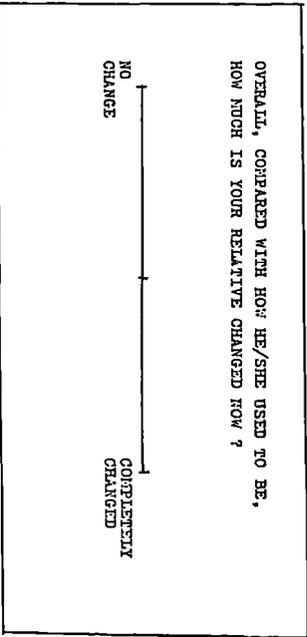
.....

13.3 How quickly have the changes occurred?

Suddenly

Fairly gradually

Very gradually



2. REACTIONS FROM OTHERS

14. OTHERS' AWARENESS

14.1 Do people who don't see very often notice the changes in him/her?

- often
- sometimes
- never

14.2 Do other people notice the changes in more often than you do?

- Yes
- No

14.3 Why do you think this is?

15. OTHERS' BEHAVIOUR

15.1 How do other people behave when they're with?

15.2 Is this the right way to behave with?

15.3 How does it make you feel?

<p>16. DISCUSSION WITH OTHERS</p> <p>16.1 Do you, or did you, talk aboutwith other people?</p> <p>16.2 If yes - who?</p> <hr/> <p>F. CAREER AWARENESS</p> <p>17. KNOWLEDGE - PERSONAL</p> <p>17.1 Have you discussed with a professional?</p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>17.2 If yes - who?</p> <p><input type="checkbox"/> CP <input type="checkbox"/> Psychiatrist <input type="checkbox"/> Physician/geriatrician <input type="checkbox"/> Health visitor <input type="checkbox"/> G.P.N. <input type="checkbox"/> Other (specify)</p> <p>17.3 What did they tell you was wrong with</p> <p>17.4 If no discussion with professional - do you know what is wrong with?</p> <p>17.5 What does this mean?</p> <p>17.6 Do you know what is going to happen to</p>	<p>17.7 How do you know?</p> <hr/> <p>18. KNOWLEDGE - GLOBAL</p> <p>18.1 Do you, or did you, know anyone else who has, or had, the same thing wrong with them as</p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>18.2 If yes - who?</p> <p>18.3 If yes - what happened to them?</p> <hr/> <p>G. CAREER'S INITIAL REACTIONS</p> <p>19.1 When did you first notice something was wrong with</p> <p>19.2 When did you first find out what was <u>ACTUALLY</u> wrong?</p> <p>19.3 Did you <u>understand immediately</u> what that meant?</p> <p>19.4 Did you believe it?</p> <p>19.5 How did it make you feel at the time?</p>
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<p>19.6 Were you able to discuss it with?</p>	<p>21.6 Has this changed?</p>
<p>R SHOCK/DENIAL</p>	<p>I OVER-INVOLVEMENT</p>
<p>20.1 Do you ever feel shocked or numb about what's happening to?</p>	<p>22.1 How easy do you/would you find it to accept help from others in caring for?</p>
<p>Often Sometimes Never</p>	<p>Very easy Moderately easy Difficult</p>
<p>20.2 Has this changed over the time that has been ill?</p>	<p>22.2 If not easy to accept help - why not?</p>
<p>21.1 Do you ever try to pretend the problems you feel with are less than they really are?</p>	<p>22.3 Has this changed?</p>
<p>Often Sometimes Never</p>	<p>23.1 Have you had to make any sacrifices in your own life in order to care for?</p>
<p>21.2 Has this changed?</p>	<p>Many sacrifices Some sacrifices No sacrifices</p>
<p>21.3 How difficult do you find it to talk about?</p>	<p>23.2 If so - what sacrifices?</p>
<p>Very difficult So-so Easy</p>	<p>23.3 How does this make you feel?</p>
<p>21.4 If yes - why?</p>	
<p>21.5 Who do you talk to?</p>	

<p>24: <u> </u> MORE IMPORTANT THAN SELF</p> <p>24.1 Is being able to care for more important than your own needs?</p> <p><input type="checkbox"/> Yes: is MORE important than own needs</p> <p><input type="checkbox"/> is EQUALLY important to own needs</p> <p><input type="checkbox"/> No: is LESS important than own needs</p> <p>24.2 Has this changed?</p> <p>_____</p> <p>_____</p>	<p>26.3 Has this changed?</p> <p>_____</p> <p>_____</p>
<p>25: <u> </u> QUESTIONING/BLAME/ANGER/GUILT</p> <p>25: <u> </u> QUESTIONING</p> <p>25.1 Do you wonder why this happened to?</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Never</p> <p>25.2 If yes - why do you think it did happen?</p> <p>_____</p> <p>_____</p>	<p>27: <u> </u> ANGER</p> <p>27.1 Do you ever get angry about what happened to?</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Never</p> <p>27.2 Has this changed?</p> <p>_____</p> <p>_____</p> <p>27.3 Do you ever get angry about having to look after?</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Never</p> <p>27.4 Has this changed?</p> <p>_____</p> <p>_____</p>
<p>25.3 Has this changed?</p> <p>_____</p> <p>_____</p>	<p>27.5 Do you ever get angry with?</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Never</p> <p>27.6 Has this changed?</p> <p>_____</p> <p>_____</p>
<p>26: <u> </u> BLAME</p> <p>26.1 Do you ever blame anyone for what happened to?</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Never</p> <p>26.2 If yes - who?</p> <p><input type="checkbox"/> Self</p> <p><input type="checkbox"/> themselves</p> <p><input type="checkbox"/> Professionals</p> <p><input type="checkbox"/> Others (specify)</p>	<p>27.7 Do you ever get angry with any of the professionals or social services?</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Never</p> <p>27.8 Has this changed?</p> <p>_____</p> <p>_____</p>

<p><u>28.1</u> <u>GUILT</u></p> <p>28.1.1 Some people in your situation end up feeling guilty about any angry or resentful feelings they may have. Do you ever feel guilty?</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p>	<p>30.2.1 If you - what do you bargain?</p> <p>30.3.1 Has this changed?</p>
<p>28.2.1 What do you feel guilty about?</p> <p>28.3.1 Has this changed?</p>	<p><u>31.1</u> <u>HONOURING</u></p> <p><u>31.2</u> <u>LOOKING BACK</u></p> <p>31.1.1 Do you ever spend time thinking about how used to be?</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p> <p>31.2.1 Has this changed?</p>
<p><u>29.1</u> <u>HOPE</u></p> <p>29.1.1 Do you ever find yourself hoping that might get better?</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p> <p>29.3.1 Has this changed?</p>	<p><u>32.1</u> <u>SAD</u></p> <p>32.1.1 Do you ever find yourself feeling sad about what's happened to.....?</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p> <p>32.2.1 If yes - what's the saddest part of it?</p>
<p><u>30.1</u> <u>BARGAINING</u></p> <p>30.1.1 Some people in your situation find themselves bargaining, e.g. If only would get better, or if only someone would find a cure for then I would never get angry with anyone again, or I would believe in God, etc. Do you ever find yourself making bargains like this?</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p>	<p>32.3.1 Have these feelings changed?</p>

<p>23. GNY</p> <p>33.1 Do you ever cry about what's happened to?</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p> <p>33.2 Has this changed?</p>	<p>35.3 Has this changed?</p>
<p>14. PREOCCUPATION</p> <p>34.1 Do you ever find yourself preoccupied with thoughts about?</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p> <p>34.2 If yes - what are these thoughts about?</p> <p>34.3 Has this changed?</p>	<p>35.4 Do you ever find yourself wishing that you and could have done certain things together that you haven't been able to?</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p> <p>35.5 If yes - what things?</p> <p>35.6 Has this changed?</p>
<p>35. WISHED BUSINESS</p> <p>35.1 Do you ever find yourself wishing that could have done certain things that he/she hasn't been able to?</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p> <p>35.2 If yes - what things?</p>	<p>35.7 Do you ever find yourself wishing that you could SAY things to that you haven't been able to?</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p> <p>35.8 If yes - what things?</p> <p>35.9 Has this changed?</p>
	<p>36. CURRENT FEELINGS</p> <p>What is your most important feeling towards just now?</p>

<p>36.3] Use this changed?</p>	<p>36.3] Use this changed?</p>
<p>37.1] Does know what's happening?</p>	<p>36.4] Is it important to you that does as much for him/herself as possible?</p>
<p><input type="checkbox"/> Yes - complete knowledge <input type="checkbox"/> Some knowledge <input type="checkbox"/> No - no idea</p>	<p><input type="checkbox"/> Very important <input type="checkbox"/> Moderately <input type="checkbox"/> Not at all important</p>
<p>37.2] Has this changed?</p>	<p>38.5] Why is it important/not important?</p>
<p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p>	<p>38.6] Has this changed?</p>
<p>37.3] Does ever talk about what's happening?</p>	<p>39.1] Do you ever find yourself thinking ahead to the time when dies?</p>
<p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p>	<p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p>
<p>37.4] If yes - what does say about what's happening?</p>	<p>39.2] Some people find themselves rehearsing or going through what will happen and what they would do after the death, for example, thinking about the funeral and imagining how it will be. Do you ever find yourself thinking anything like this?</p>
<p>38.1] Is it important to you that looks smart?</p>	<p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p>
<p><input type="checkbox"/> Very important <input type="checkbox"/> Moderately <input type="checkbox"/> Not at all important</p>	<p>39.3] If yes - how do these thoughts make you feel?</p>
<p>38.2] Why is it important/not important?</p>	
<p>38:] <u>SUFFERER DIGNITY</u></p>	<p>39:] <u>ANTICIPATING ACTUAL DEATH</u></p>

<p>39.4] Has this changed?</p> <p>39.5] Do you ever find yourself thinking that death might come as a blessing to</p> <p>39.6] <u>If yes</u> - how does that thought make you feel?</p> <p>39.7] Has this changed?</p> <p>40: <u>SOCIAL DEATH</u></p> <p>40.1] Do you ever think that in some ways it is as if is already dead?</p> <p>40.2] <u>If yes</u> - in which ways does it seem as if is already dead?</p> <p>40.3] <u>If yes</u> - what things make you think about this?</p> <p>40.4] <u>If yes</u> - how do these thoughts about it seem as if in some ways is already dead make you feel?</p>	<p>40.5] Has this changed?</p> <p>41: <u>INSTITUTIONALISATION</u></p> <p>41.1] How likely are you to place in a hospital or a home within the next year?</p> <p>41.2] Why/why not?</p> <p>41.3] Would you take a place at if it was offered to you tomorrow?</p>
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HOW LIKELY ARE YOU TO PLACE YOUR RELATIVE IN A HOSPITAL OR A HOME WITHIN THE NEXT YEAR ?

NOT AT ALL LIKELY
HAPPEN

EXTREMELY LIKELY

WOULD YOU TAKE A PLACE AT DINNER IF IT WAS OFFERED TO YOU TOMORROW ?

YES DEFINITELY

NO DEFINITELY

41.41 Why/why not?

N STAGES

42: Some people see the way that a person in your situation feels as like passing through a series of different stages - starting with the time when they first realize that has a problem. Are you able to see and describe stages in your reactions as a caregiver?

0 CAREER-SUPPORTER RELATIONSHIP

43: CURRENT RELATIONSHIP

43.1 Howdays do you and laugh and joke together?

Often
 Sometimes
 Never

43.2 Howdays do you ever feel cross or angry with?

Often
 Sometimes
 Never

43.3 Howdays do you ever feel that is possessive of yourself?

Often
 Sometimes
 Never

43.4 Howdays do you ever feel that interferes too much (e.g. in your life, family affairs, running the house, etc.)

Often
 Sometimes
 Never

43.5 Howdays do you ever feel any tension or strain in the relationship?

Often
 Sometimes
 Never

43.6 Howdays do you ever have upsetting disagreements or arguments with?

Often
 Sometimes
 Never

43.7 Howdays do you ever try to ignore?

Often
 Sometimes
 Never

43.8 Howdays are there many positive things about your relationship with?

Many positive things
 Some
 None

PLEASE RATE THE OVERALL QUALITY OF YOUR PRESENT RELATIONSHIP :

VERY POOR ----- EXCELLENT

43. 9] Howdays do you ever wish you could get away from

Often
 Sometimes
 Never

43.10] Please rate the overall quality of your present relationship with

44: PRETORRID RELATIONSHIP

44. 1] Before the onset of the illness did you and laugh and joke co-
sely?

Often
 Sometimes
 Never

44. 2] Before the onset of the illness did you ever feel cross or angry with
.....?

Often
 Sometimes
 Never

<p>44.3 Before the onset of the illness did you ever feel that was pos- sive of yourself?</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p> <p>44.4 Before the onset of the illness did you ever feel that interfered too much (e.g. in your life, family affairs, running the house, etc.)</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p> <p>44.5 Before the onset of the illness did you ever feel any tension or strain in the relationship?</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p> <p>44.6 Before the onset of the illness did you ever have upsetting disagreements or arguments with?</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p> <p>44.7 Before the onset of the illness did you ever try to ignore</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p> <p>44.8 Before the onset of the illness were there many positive things about your relationship with</p> <p><input type="checkbox"/> Many positive things <input type="checkbox"/> Some <input type="checkbox"/> None</p>	<div style="border: 1px solid black; padding: 10px; text-align: center;"> <p>PLEASE RATE THE OVERALL QUALITY OF YOUR RELATIONSHIP BEFORE THE ONSET OF THE ILLNESS :</p> <p>VERY POOR ————— EXPLOSIVE</p> </div>
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44. 9] Before the onset of the illness did you ever wish you could get away from?
 Often
 Sometimes
 Never

44.10] Please rate the overall quality of your relationship with before the onset of the illness.

45: ROLE CHANGE

45. 1] Have you had to take over responsibilities for jobs (e.g. finances, organising travel, social activities, etc.) which used to do before the onset of the illness?
 Yes - for many things
 For a few things
 No - not had to take over anything.

45. 2] If yes - what things?

45. 3] If yes - how does this make you feel?

46: PREVIOUS SEPARATIONS

46.1] Before you started to care for how often did you see him/her?
 Often
 Sometimes
 Never

46.2] If yes - exactly how often?

46.3] Before the onset of the illness was the sort of person who kept themselves to themselves?
 Yes - always kept themselves to themselves
 Sometimes
 Never

46.4] Since you started to care for has he/she been away (e.g. to restive, hospital, etc.)
 Often
 Sometimes
 Never

46.5] If yes - exactly how often?

46.6] If yes - how do you feel when goes away?

47: REASONS FOR CARE

47.1] Before the onset of the illness did have any particular wishes about how he/she would like to end his/her days?
 Yes
 Maybe
 No

<p>47.21 If yes - what were they?</p>	<p>48.21 If yes - in what way has your physical health been affected?</p>
<p>47.31 Before the onset of the illness did you discuss the possibility of caring for him/her with?</p> <p><input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Never</p>	<p>48.31 Has looking after affected your mental health?</p> <p><input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> A great deal</p>
<p>47.41 If yes - what did you decide?</p>	<p>48.41 In what way has your mental health been affected?</p>
<p>47.51 Why do you care for?</p>	<p>48.51 Has looking after affected your social life?</p> <p><input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> A great deal</p>
<p>47.61 Would agree that it is right for you to be looking after him/her?</p> <p>Yes: would definitely agree that I should be looking after <input type="checkbox"/> I might agree <input type="checkbox"/> No: would not agree</p>	<p>48.61 In what way has your social life been affected?</p>
<p>47.71 Do you feel under any obligation to look after?</p> <p><input type="checkbox"/> Strong obligation <input type="checkbox"/> Some obligation <input type="checkbox"/> No obligation whatsoever</p>	<p>48.71 Has looking after affected your finances?</p> <p><input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> A great deal</p>
<p>0 CAREER STRAITS/BENEFIT/SATISFACTION</p>	
<p>48.81 In what way have your finances been affected?</p>	
<p>47.81 Has looking after affected your physical health?</p> <p><input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat <input type="checkbox"/> A great deal</p>	

49: RELIEF FROM CARING

49.1 Overall, how much relief from caring do you get each week?
 hours

49.2 How satisfied are you overall with the amount of relief you get from caring each week?

- Completely
- Moderately
- Not at all satisfied

49.3 How satisfied are you with the amount of help you get from relatives?

- Completely
- Moderately
- Not at all satisfied

49.4 How satisfied are you with the amount of help you get from professionals (G.P., nurse, home help, etc.)?

- Completely
- Moderately
- Not at all satisfied

50: FAITH

50.1 Do you have a faith or any other belief which helps you to cope?

- faith/belief which is a great help
- faith/belief which is some help
- faith/belief but it is no help/no faith/belief

50.2 If yes - how does it help?

51: COPING

51.1 Taking everything into account, how well do you think you are coping just now?

- Very well
- Pretty well
- Just about O.K.
- Pretty badly
- Very badly

51.2 Has this changed over the time you've been caring?

52: LIFE SATISFACTION

52.1 How do you feel about your life as a whole right now?

- Delighted
- Pleased
- Mostly satisfied
- Mixed
- Mostly dissatisfied
- Unhappy
- Terrible

(Give card to respondent)

52.2 Has this changed?

R. OPINION OF INTERVIEW

53.1 Overall, how did you feel about this interview?

TAKING EVERYTHING INTO ACCOUNT, HOW WELL DO YOU THINK YOU ARE GOING JUST NOW?

- | | |
|--------------------------|-----------------|
| <input type="checkbox"/> | VERY WELL |
| <input type="checkbox"/> | PRETTY WELL |
| <input type="checkbox"/> | JUST ABOUT O.K. |
| <input type="checkbox"/> | PRETTY BADLY |
| <input type="checkbox"/> | VERY BADLY |

HOW DO YOU FEEL ABOUT YOUR LIFE AS A WHOLE RIGHT NOW?

- | | |
|--------------------------|-------------------------|
| <input type="checkbox"/> | DELIGHTED |
| <input type="checkbox"/> | PLEASED |
| <input type="checkbox"/> | MODERATELY SATISFIED |
| <input type="checkbox"/> | MIXED |
| <input type="checkbox"/> | MODERATELY DISSATISFIED |
| <input type="checkbox"/> | UNHAPPY |
| <input type="checkbox"/> | TERRIBLE |

PLEASE RATE HOW YOU FELT ABOUT THE INTERVIEW OVERALL :

<input type="checkbox"/>	DELIGHTED
<input type="checkbox"/>	PLEASED
<input type="checkbox"/>	MOSTLY SATISFIED
<input type="checkbox"/>	MIXED
<input type="checkbox"/>	MOSTLY DISSATISFIED
<input type="checkbox"/>	UNHAPPY
<input type="checkbox"/>	TERRIBLE

53.3] Here there any questions which you felt I should not have asked?

53.3] Which subject was hardest for you to talk about?

53.4] Here there any questions which you felt very pleased that I asked about?

53.5] Please rate how you felt about the interview overall.

<input type="checkbox"/>	Delighted
<input type="checkbox"/>	Pleased
<input type="checkbox"/>	Mostly satisfied
<input type="checkbox"/>	Mixed
<input type="checkbox"/>	Mostly dissatisfied
<input type="checkbox"/>	Unhappy
<input type="checkbox"/>	Terrible

5 POST-INTERVIEW NOTES/FEELINGS

54.1 EVIDENCE OF DENIAL DURING INTERVIEW?

e.g. Does carer focus on abilities rather than disabilities?
 Does carer focus on well functioning remote memory rather than recent?
 Does carer have difficulty talking about disabilities/death/injure etc?

54.1] Rate denial No evidence of denial

<input type="checkbox"/>	Some
<input type="checkbox"/>	Great

54.2] Give examples

<p>55. EVIDENCE OF OVERPROTECTIVENESS DURING INTERVIEW?</p> <p>55.1) Rate overprotectiveness <input type="checkbox"/> No evidence of overprotection <input type="checkbox"/> Some <input type="checkbox"/> Great</p> <p>55.2) Give examples</p>	<p>58.2) Give examples</p> <p>59. EVIDENCE OF CONSPIRACY OF SILENCE DURING INTERVIEW?</p> <p>59.1) Rate conspiracy of silence <input type="checkbox"/> No evidence <input type="checkbox"/> Some <input type="checkbox"/> Great</p> <p>59.2) Give examples</p>
<p>56. EVIDENCE OF ANGER DURING INTERVIEW?</p> <p>56.1) Rate anger <input type="checkbox"/> No evidence of anger <input type="checkbox"/> Some <input type="checkbox"/> Great</p> <p>56.2) Give examples (Anger at what? Anger obvious but denied?)</p>	<p>60. EVIDENCE OF SOCIAL DEATH DURING INTERVIEW?</p> <p>60.1) Rate degree of social death <input type="checkbox"/> ABSENT <input type="checkbox"/> Sufferer totally alive socially <input type="checkbox"/> Sufferer totally dead socially</p> <p>60.2) Give examples</p>
<p>57. EVIDENCE OF MOURNING DURING INTERVIEW?</p> <p>57.1) Rate mourning <input type="checkbox"/> No evidence of mourning <input type="checkbox"/> Some <input type="checkbox"/> Great</p> <p>57.2) Give examples (Crying?)</p>	<p>61. WHY IS GRIEF CALLED?</p> <p>61.1) Pain reason <input type="checkbox"/> Love <input type="checkbox"/> Repayment <input type="checkbox"/> Duty <input type="checkbox"/> No choice <input type="checkbox"/> Can't care any longer</p>
<p>58. EVIDENCE OF AMBIGUITY DURING INTERVIEW?</p> <p>58.1) Rate ambivalence <input type="checkbox"/> No evidence of ambivalence <input type="checkbox"/> Some <input type="checkbox"/> Great</p>	

61.2 Give examples

62: GREEN COPING

62.1 In general, how well do you believe the caret to be coping right now?

Extremely badly

Extremely well

62.2 Give examples

THE GENERAL HEALTH QUESTIONNAIRE

Health GHO 28
David Goldberg

Please read this carefully. We should like to know if you have had any medical complaints and how your health has been in general, over the past few weeks. Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past. It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

Have you recently

	Better than usual	Same as usual	Worse than usual	Much worse than usual
A1 - been feeling perfectly well and in good health?				
A2 - been feeling in need of a good tonic?				
A3 - been feeling run down and out of sorts?				
A4 - felt that you are ill?				
A5 - been getting any pains in your head?				
A6 - been getting a feeling of tightness or pressure in your head?				
A7 - been having hot or cold spells?				
B1 - lost much sleep over worry?				
B2 - had difficulty in staying asleep once you are off?				
B3 - felt constantly under strain?				
B4 - been getting edgy and bad-tempered?				
B5 - been getting scared or panicky for no good reason?				
B6 - found everything getting on top of you?				
B7 - been feeling nervous and strung-up all the time?				

Have you recently

	More so than usual	Same as usual	Rather less than usual	Much less than usual
C1 - been managing to keep yourself busy and occupied?				
C2 - been taking longer over the things you do?				
C3 - felt on the whole you were doing things well?				
C4 - been satisfied with the way you've carried out your task?				
C5 - felt that you are playing a useful part in things?				
C6 - felt capable of making decisions about things?				
C7 - been able to enjoy your normal day-to-day activities?				
D1 - been thinking of yourself as a worthless person?				
D2 - felt that life is entirely hopeless?				
D3 - felt that life isn't worth living?				
D4 - thought of the possibility that you might make away with yourself?				
D5 - found at times you couldn't do anything because your nerves were too bad?				
D6 - found yourself wishing you were dead and away from it all?				
D7 - found that the idea of taking your own life kept coming into your mind?				

A B C D TOTAL

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HOW HAVE YOU BEEN FEELING RECENTLY?

Please think about how you have been feeling recently. Below are a number of statements about different feelings. For each one please put a tick in the box which best describes how you have been feeling over the past few months.

1. Particularly excited or interested in something:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often

2. So restless you couldn't sit long in a chair:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often

3. Proud because someone complimented you on something you had done:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often

4. Very lonely or remote from other people:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often

5. Pleased about having accomplished something:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often

6. Bored:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often

7. On top of the world:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often

8. Depressed or very unhappy:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often

9. That things were going your way:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often

10. Upset because someone criticised you:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often

THANK YOU

COPING WITH THE EFFECTS OF GIVING CARE

Please think about how you have tried to deal with the problems which you have experienced because you care for someone who is confused.

Please decide whether you have used each strategy, and if so, how often, and then put a tick in the box which best describes how often you have chosen to cope in that way during the past few months.

1. Tried to keep my feelings to myself:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Rarely
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often
<input type="checkbox"/>	All the time

2. Criticised or blamed myself:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Rarely
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often
<input type="checkbox"/>	All the time

3. Turned my attention to other activities that I could do on my own, such as reading, hobbies, watching TV:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Rarely
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often
<input type="checkbox"/>	All the time

4. Thought about practical things to do which might help but not of doing anything about it:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Rarely
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often
<input type="checkbox"/>	All the time

5. Tried to find other people who had experienced the same problems:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Rarely
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often
<input type="checkbox"/>	All the time

6. Tried to step back from the situation, tried to feel more detached and objective:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Rarely
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often
<input type="checkbox"/>	All the time

7. Tried to work out problems calmly with family or friends:

<input type="checkbox"/>	Never
<input type="checkbox"/>	Rarely
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often
<input type="checkbox"/>	All the time

8. Tried not to think about what was happening:

- Never
- Rarely
- Sometimes
- Often
- All the time

9. Took my feelings out on someone or something: for instance, shouted, nagged or stomped; threw things about, broke things:

- Never
- Rarely
- Sometimes
- Often
- All the time

10. Tried to take my mind off things by smoking, drinking, eating, or taking pills to relax:

- Never
- Rarely
- Sometimes
- Often
- All the time

11. Prepared for the worst:

- Never
- Rarely
- Sometimes
- Often
- All the time

12. Asked professionals, friends, or relatives for practical advice and information:

- Never
- Rarely
- Sometimes
- Often
- All the time

13. Tried to work out just what the problems were and what makes things better or worse, so that I could work out a plan for the future:

- Never
- Rarely
- Sometimes
- Often
- All the time

14. Carried out one or more practical things which I hoped would help:

- Never
- Rarely
- Sometimes
- Often
- All the time

15. Told myself that what was happening wasn't really all that upsetting or difficult - things could be far worse:

- Never
- Rarely
- Sometimes
- Often
- All the time

Now that you have done through the list, please go back over it and put a cross by those items which you have found to be most helpful when you were trying to deal with the problems you have experienced.

THANK YOU

II. CARERS' QUESTIONNAIRE - FINAL VERSION

<div style="border: 1px solid black; width: fit-content; margin: 0 auto; padding: 2px; text-align: center;">CARER'S QUESTIONNAIRE</div> <p>Subject Number</p> <p>Subject Name</p> <p>Address</p> <p>Phone</p> <p>Interview Date</p> <p>Interviewer</p>	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 5%; text-align: center;">4</td> <td style="width: 35%;">CARER DETAILS</td> <td style="width: 60%;"></td> </tr> <tr> <td style="text-align: center;">1:</td> <td>CARER SEX</td> <td><input type="checkbox"/> MALE <input type="checkbox"/> FEMALE</td> </tr> <tr> <td style="text-align: center;">2:</td> <td>CARER AGE</td> <td>What is your age?</td> </tr> <tr> <td style="text-align: center;">3:</td> <td>CARER MARITAL STATUS</td> <td>What is your marital status? <input type="checkbox"/> Married - spouse working <input type="checkbox"/> Married - spouse unemployed <input type="checkbox"/> Married - spouse retired <input type="checkbox"/> Single <input type="checkbox"/> Widowed <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Co-habiting</td> </tr> <tr> <td style="text-align: center;">4:</td> <td>CARER WORK</td> <td>Are you working? <input type="checkbox"/> Yes - full time <input type="checkbox"/> Yes - part time <input type="checkbox"/> No - unemployed <input type="checkbox"/> No - retired <input type="checkbox"/> No - housewife</td> </tr> <tr> <td style="text-align: center;">4:2</td> <td colspan="2">If YES - what do you do?</td> </tr> <tr> <td style="text-align: center;">4:3</td> <td colspan="2">If NO - what has been your main occupation in the past?</td> </tr> <tr> <td style="text-align: center;">4:4</td> <td colspan="2">If PART TIME - did you change from full time work in order to care for</td> </tr> <tr> <td></td> <td></td> <td><input type="checkbox"/> Yes <input type="checkbox"/> No</td> </tr> </table>	4	CARER DETAILS		1:	CARER SEX	<input type="checkbox"/> MALE <input type="checkbox"/> FEMALE	2:	CARER AGE	What is your age?	3:	CARER MARITAL STATUS	What is your marital status? <input type="checkbox"/> Married - spouse working <input type="checkbox"/> Married - spouse unemployed <input type="checkbox"/> Married - spouse retired <input type="checkbox"/> Single <input type="checkbox"/> Widowed <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Co-habiting	4:	CARER WORK	Are you working? <input type="checkbox"/> Yes - full time <input type="checkbox"/> Yes - part time <input type="checkbox"/> No - unemployed <input type="checkbox"/> No - retired <input type="checkbox"/> No - housewife	4:2	If YES - what do you do?		4:3	If NO - what has been your main occupation in the past?		4:4	If PART TIME - did you change from full time work in order to care for				<input type="checkbox"/> Yes <input type="checkbox"/> No
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4:4	If PART TIME - did you change from full time work in order to care for																											
		<input type="checkbox"/> Yes <input type="checkbox"/> No																										

<p>8: SUPERER DETAILS</p>	<p>4:5 IF NOT WORKING - did you give up a job in order to care for? <input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>6: SUPERER SEX <input type="checkbox"/> MALE <input type="checkbox"/> FEMALE</p>	<p>4:6 IF MARRIED - what is your spouse's occupation at present / what was your spouse's occupation in the past? ?</p>
<p>7: SUPERER AGE How old is? ?</p>	<p>5: CARER EDUCATION</p> <p>5:1 What age were you when you finished full time education?</p> <p>5:2 Did you get any exams? No - left school with no qualifications <input type="checkbox"/> CSE / O grades <input type="checkbox"/> Highers / A levels <input type="checkbox"/> Degree <input type="checkbox"/> Higher degree</p>
<p>8: SUPERER MARITAL STATUS</p> <p>What is the marital status of? <input type="checkbox"/> Married - spouse working <input type="checkbox"/> Married - spouse unemployed <input type="checkbox"/> Married - spouse retired <input type="checkbox"/> Single <input type="checkbox"/> Widowed <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Co-habiting</p>	
<p>9: SUPERER WORK</p> <p>What was the previous occupation of? ?</p>	

<p>12:22 Unable to walk outside the house.....</p> <p>12:23 Unable to hold a sensible conversation.....</p> <p>12:24 Noisy, shouting.....</p> <p>12:25 Incontinent - wetting.....</p> <p>12:26 Shows no concern for personal hygiene.....</p> <p>12:27 Unsteady on feet.....</p> <p>12:28 Always asking questions.....</p> <p>12:29 Unable to take part in family conversations.....</p> <p>12:30 Unable to read newspapers, magazines, etc.....</p> <p>12:31 Sits around doing nothing.....</p> <p>12:32 Shows no interest in news about family and friends.....</p> <p>12:33 Unable to watch and follow television / radio.....</p> <p>12:34 Unable to occupy him/herself doing useful things.....</p>	<p>13:3 Does look PHYSICALLY WELL?</p> <p><input type="checkbox"/> Looks very well</p> <p><input type="checkbox"/> Looks fairly well</p> <p><input type="checkbox"/> Looks all right</p> <p><input type="checkbox"/> Looks rather unwell</p> <p><input type="checkbox"/> Looks extremely unwell</p> <p>13:4 If looks UNWELL - what looks to be wrong with?</p>
<p>13: SUPERFER PHYSICAL CHANGES</p> <p>13:1 Does LOOK the same as he/she used to?</p> <p><input type="checkbox"/> Exactly the same</p> <p><input type="checkbox"/> Almost the same</p> <p><input type="checkbox"/> Somewhat the same</p> <p><input type="checkbox"/> Hardly the same</p> <p><input type="checkbox"/> Not at all the same</p> <p>13:2 IF DIFFERENT from previously - what are the changes in the way looks?</p>	<p>14: SUPERFER OVERALL CHANGES</p> <p>14:1 Overall, and taking everything into account, how much is changed compared with how they used to be?</p> <p><input type="checkbox"/> No change - exactly as they always used to be</p> <p><input type="checkbox"/> Slight change - but almost the same as they always were</p> <p><input type="checkbox"/> Moderate change - somewhat the same as they always were</p> <p><input type="checkbox"/> Great change - only slightly like they always used to be</p> <p><input type="checkbox"/> Complete change - nothing like they used to be</p> <p>14:2 What would you say are the most important changes?</p> <p>14:3 How quickly have the changes occurred?</p> <p><input type="checkbox"/> Extremely fast / sudden</p> <p><input type="checkbox"/> Fairly fast</p> <p><input type="checkbox"/> Moderately fast</p> <p><input type="checkbox"/> Fairly gradual</p> <p><input type="checkbox"/> Extremely gradual</p>

<p>E REACTIONS FROM OTHERS</p>	<p>16:3 How does it make you feel?</p>
<p>15: OTHER'S AWARENESS</p> <p>15:1 How much of a change do people who don't see very often notice in him/her?</p> <p>Very big change <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Fairly big change <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Moderate change <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Slight change <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>No change <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>15:2 Do other people notice any more or less of a change in than you do?</p> <p>Others notice more change <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Others notice about the same <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Others notice less change <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>15:3 Why do you think this is so?</p>	<p>17: DISCUSSION WITH OTHERS</p> <p>17:1 Do you talk about with friends or relatives?</p> <p>Yes <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>No <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>17:2 If YES - who?</p>
<p>16: OTHER'S BEHAVIOUR</p> <p>16:1 How do other people behave when they're with</p> <p>Over - attentive <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Sometimes include <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Always ignore <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>16:2 Is this the right way to behave with</p> <p>Yes <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>Career unsure <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>No <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p>	

F		CAREER AWARENESS - KNOWLEDGE AND PERCEPTIONS OF DISORDER
18: KNOWLEDGE - PERSONAL		
18:1	Have you discussed with anyone other than a friend or relative? <input type="checkbox"/> Yes <input type="checkbox"/> No	
18:2	IF YES - who? <input type="checkbox"/> GP <input type="checkbox"/> Psychiatrist <input type="checkbox"/> Physician / Geriatrician <input type="checkbox"/> Day hospital nurse <input type="checkbox"/> Home nurse <input type="checkbox"/> C.P.N. <input type="checkbox"/> Health visitor <input type="checkbox"/> Other (specify) *	
18:3	What did they tell you was wrong with?	
18:4	IF NO DISCUSSION with professional - do you know what is wrong with??	
18:5	What does this mean?	
18:6		Do you think that?s problems are the result of a physical illness? <input type="checkbox"/> Yes <input type="checkbox"/> Career unsure <input type="checkbox"/> No
18:7		Do you think will get better? <input type="checkbox"/> Yes <input type="checkbox"/> Career unsure <input type="checkbox"/> No
18:8		Do you know what is going to happen to?
18:9		How do you know?
19: KNOWLEDGE - GLOBAL		
19:1 Do you, or did you, know anyone else who has, or had, the same thing wrong with them as??		
<input type="checkbox"/> Yes <input type="checkbox"/> Career unsure <input type="checkbox"/> No		
19:2 IF YES - who?		

<p>19:3 IF YES - what happened to them?</p> <p>19:4 RATE carer's knowledge and perception of disorder</p> <p>Carer acknowledges illness and names dementia. Clearly aware of brain changes causing behavioural changes, progressive nature and rough time scale</p> <p>Carer correctly names as illness dementia, some awareness that affects brain and that prognosis downhill</p> <p>Carer may name dementia, but little obvious knowledge that it is an illness or of prognosis</p> <p>Carer cannot name dementia and has no obvious knowledge of reasons for sufferer's current condition or of prognosis</p>	<p>G CARER'S RECALL OF ONSET</p> <p>20:1 When did you first notice SOMETHING was wrong with?</p> <p>20:2 What did you notice to begin with?</p> <p>20:3 When did you first find out what was ACTUALLY wrong?</p> <p>20:4 How did you learn that?</p> <p>20:5 Did you understand immediately what that meant?</p> <p>20:6 Did you believe it?</p> <p>20:7 How did it make you feel at the time?</p>
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<p>20:8 Were you able to discuss it with anyone at the time?</p> <p>20:9 If YES - who with?</p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p>Relative <input type="checkbox"/></p> <p>Friend <input type="checkbox"/></p> <p>Professional <input type="checkbox"/></p>	<p># STAGE I - SHOCK, DENIAL.</p> <p>21:1 HOWADAYS do you ever feel shocked or dazed about what's happening to?</p> <p>All the time <input type="checkbox"/></p> <p>Often <input type="checkbox"/></p> <p>Sometimes <input type="checkbox"/></p> <p>Rarely <input type="checkbox"/></p> <p>Never <input type="checkbox"/></p> <p>21:2 EARLIER ON - sooner after they became ill, did you ever feel shocked or dazed about what was happening to?</p> <p>All the time <input type="checkbox"/></p> <p>Often <input type="checkbox"/></p> <p>Sometimes <input type="checkbox"/></p> <p>Rarely <input type="checkbox"/></p> <p>Never <input type="checkbox"/></p> <p>21:3 NOWADAYS do you ever find yourself thinking "this can't really be happening to?"</p> <p>All the time <input type="checkbox"/></p> <p>Often <input type="checkbox"/></p> <p>Sometimes <input type="checkbox"/></p> <p>Rarely <input type="checkbox"/></p> <p>Never <input type="checkbox"/></p> <p>21:4 EARLIER ON - sooner after they became ill, did you ever find yourself thinking "this can't really be happening to?"</p> <p>All the time <input type="checkbox"/></p> <p>Often <input type="checkbox"/></p> <p>Sometimes <input type="checkbox"/></p> <p>Rarely <input type="checkbox"/></p> <p>Never <input type="checkbox"/></p>
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<p>21:5</p> <p>NOWADAYS do you ever try to pretend to other people that the problems which has are less than they really are?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>21:9</p> <p>NOWADAYS do you ever find it's difficult to bring yourself to talk about what's wrong with with other people?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>
<p>21:6</p> <p>EARLIER ON, did you ever try to pretend to other people that the problems which had were less than they really were?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>21:10</p> <p>EARLIER ON, did you ever find it was difficult to bring yourself to talk about what was wrong with with other people?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>
<p>21:7</p> <p>NOWADAYS do you ever try to avoid getting emotional when you think about what's happened to?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>21:11</p> <p>If we were to think more generally about feeling shocked and not wanting to believe what's happening to and trying not to feel emotional about it - has there been a particular time when you felt this most strongly?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Career unsure</p> <p><input type="checkbox"/> No</p>
<p>21:8</p> <p>EARLIER ON, did you ever try to avoid getting emotional when you thought about what was happening to?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>21:12</p> <p>If YES - when?</p> <p><input type="checkbox"/> Increased</p> <p><input type="checkbox"/> Present but no change</p> <p><input type="checkbox"/> Decreased</p> <p><input type="checkbox"/> Never present</p>
<p>21:7</p> <p>NOWADAYS do you ever try to avoid getting emotional when you think about what's happened to?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>21:13</p> <p>RATE for change in career perceptions of shock, denial over time</p> <p><input type="checkbox"/> Increased</p> <p><input type="checkbox"/> Present but no change</p> <p><input type="checkbox"/> Decreased</p> <p><input type="checkbox"/> Never present</p>
<p>21:8</p> <p>EARLIER ON, did you ever try to avoid getting emotional when you thought about what was happening to?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>21:13</p> <p>RATE for change in career perceptions of shock, denial over time</p> <p><input type="checkbox"/> Increased</p> <p><input type="checkbox"/> Present but no change</p> <p><input type="checkbox"/> Decreased</p> <p><input type="checkbox"/> Never present</p>

<p>21:14 RATE for carer shock, denial apparent during interview</p> <p>Carer has difficulty talking about sufferer, denies illness, problems from checklist or any difficulty caring. No display of emotion at all</p> <p>Carer admits something wrong, a few problem behaviours, but says no real difficulties and has unrealistic future expectations. Little obvious emotion</p> <p>Carer admits illness, problem behaviours and some difficulties caring. Displays some emotion during interview</p> <p>Carer freely discusses and elaborates on illness, problem behaviours and difficulties. Displays emotion during interview.</p>	<p>I</p> <p>22:1 STAGE II - BARGAINING, HOPE</p> <p>HOWADAYS do you ever find yourself hoping that might get better?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p> <p>22:2 EARLIER ON, did you ever find yourself hoping that might get better?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p> <p>22:3 HOWADAYS do you ever wonder whether the doctors have made a mistake about what's wrong with</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p> <p>22:4 If YES - why?</p>
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<p>22:5 EARLIER ON, did you ever wonder whether the doctors had made a mistake about what was wrong with?</p> <p><input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never</p>	<p>22:6 NOWADAYS do you ever find yourself looking out for news articles or TV or radio programmes which might give hope of a cure for?</p> <p><input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never</p>	<p>22:7 IF YES - what have you seen / read / heard?</p>
<p>22:8 EARLIER ON did you ever find yourself looking out for news articles or TV or radio programmes which might give hope of a cure for?</p> <p><input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never</p>	<p>22:9 Some people in your situation find themselves making bargains - for example, "if only would get better then I would never get angry with anyone again", or "if only someone would find a cure for then I would really believe there was a God etc". NOWADAYS do you ever find yourself making bargains like that?</p> <p><input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never</p>	<p>22:10 IF YES - what do you bargain?</p> <p>22:11 EARLIER ON did you ever find yourself making bargains like that?</p> <p><input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never</p>
<p>22:12 IF we were to think more generally about feeling hopeful, or making bargains about the possibility of getting better - has there been a particular time when you felt this most strongly?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> Career unsure <input type="checkbox"/> No</p>	<p>22:13 IF YES - when?</p>	

		J	
		STAGE III - ANGER, GUILT, QUESTIONING	
<p>22:14</p> <p>RATE for change in career perceptions of bargaining, hope over time</p> <p>Increased <input type="checkbox"/></p> <p>Present but no change <input type="checkbox"/></p> <p>Decreased <input type="checkbox"/></p> <p>Never present <input type="checkbox"/></p>	<p>23:1</p> <p>NOWADAYS do you ever ask yourself, "Why did this have to happen to ...?"</p> <p>All the time <input type="checkbox"/></p> <p>Often <input type="checkbox"/></p> <p>Sometimes <input type="checkbox"/></p> <p>Rarely <input type="checkbox"/></p> <p>Never <input type="checkbox"/></p>		
<p>22:15</p> <p>RATE for career bargaining, hope apparent during interview</p> <p>Career frequently raises possibility of cure / mistake etc. Is actively bargaining / using folk remedies <input type="checkbox"/></p> <p>Career asks about possibility of cure / mistake. Follows media on the subject of dementia in hope of announcement of breakthrough <input type="checkbox"/></p> <p>Career admits occasional hope / bargaining. Asks about current research <input type="checkbox"/></p> <p>Career denies hope / bargaining. Appears totally resigned to reality of downhill progress <input type="checkbox"/></p>	<p>23:2</p> <p>If YES - why do you think it did happen?</p> <p>Earlier on did you ever ask yourself, "Why did this have to happen to ...?"</p> <p>All the time <input type="checkbox"/></p> <p>Often <input type="checkbox"/></p> <p>Sometimes <input type="checkbox"/></p> <p>Rarely <input type="checkbox"/></p> <p>Never <input type="checkbox"/></p>		
<p>23:4</p> <p>NOWADAYS do you ever think that maybe something more could be done to help -?</p> <p>All the time <input type="checkbox"/></p> <p>Often <input type="checkbox"/></p> <p>Sometimes <input type="checkbox"/></p> <p>Rarely <input type="checkbox"/></p> <p>Never <input type="checkbox"/></p>	<p>23:3</p> <p>If YES - what?</p>		
<p>23:5</p>	<p>23:4</p>		

<p>23:6 EARLIER OR did you ever think that maybe something more could be done to help?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>	<p>23:7 NOWADAYS do you ever wonder whether you may have somehow contributed to getting ill?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>	<p>23:8 If YES - how?</p>	<p>23:9 EARLIER OR did you ever wonder whether you may have somehow contributed to getting ill?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>
<p>23:10 NOWADAYS do you ever get guilty feelings at being able to enjoy yourself?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>	<p>23:11 If YES - why?</p>	<p>23:12 EARLIER OR did you ever get guilty feelings at being able to enjoy yourself?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>	<p>23:13 NOWADAYS do you ever get feelings of anger or irritability with other people?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>
<p>23:14 EARLIER OR did you ever get feelings of anger or irritability with other people?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>	<p>23:15 NOWADAYS do you ever feel angry about what's happened to?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>		

<p>23:16 EARLIER OR did you ever feel angry about what had happened to?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>23:17 NOWADAYS do you ever get angry at?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>23:20 EARLIER OR did you ever get angry at God for what happened to?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>23:21 NOWADAYS do you ever get angry with any of the professionals or social services who are involved with?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>
<p>23:18 EARLIER OR did you ever get angry at?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>23:22 EARLIER OR did you ever get angry with any of the professionals or social services who were involved with?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>23:23 If we were to think more generally about some of these more distressing puzzled, or angry, or guilty feelings about - has there been a particular time when you felt this most strongly?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Career unsure</p> <p><input type="checkbox"/> No</p>	<p>23:24 If YES - when?</p>
<p>23:19 NOWADAYS do you ever get angry at God for what happened to?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>			

<p>23:25 RATE for change in carer perceptions of anger, guilt, questioning over time</p> <p>Increased Present but no change Decreased Never present</p>	<p>K</p> <p>24:1 STAGE IV - GRIEF : PREOCCUPATION, MOURNING, DESPAIR</p> <p>NOADAYS, do you ever find yourself preoccupied with thoughts about? (PROMPT - so that it's difficult to think about anything apart from him/her)</p> <p>All the time Often Sometimes Rarely Never</p>
<p>23:26 RATE for carer anger, guilt, questioning apparent during interview</p> <p>Carer frequently raises issues of anger, both generally and directed at sufferer, complaints, discusses own guilt, questions interviewer about illness</p> <p>Carer demonstrates some anger, guilt, questioning throughout interview</p> <p>Carer demonstrates slight anger, guilt, questioning</p> <p>Carer appears entirely without anger or guilt, and does not question the reasons for the sufferer's illness</p>	<p>24:2 IF YES - what about?</p> <p>24:3 EARLIER on did you ever find yourself preoccupied with thoughts about?</p> <p>All the time Often Sometimes Rarely Never</p>
	<p>26:4 HOWADAYS do you spend time looking back and thinking how used to be?</p> <p>All the time Often Sometimes Rarely Never</p>

<p>24:5</p> <p>EARLIER ON did you ever spend time looking back and thinking about how used to be?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>	<p>24:6</p> <p>NOWADAYS do you ever wish or yearn for to be the way he/she used to be?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>	<p>24:10</p> <p>EARLIER ON did you ever wish that could have done certain things that he/she hadn't been able to?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>
<p>24:7</p> <p>EARLIER ON did you ever wish or yearn for to be the way he/she used to be?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>	<p>24:11</p> <p>NOWADAYS do you ever find yourself wishing that you could say things to that you haven't been able to?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>	<p>24:12</p> <p>If YES - what things?</p>
<p>24:8</p> <p>NOWADAYS do you ever wish that could have done certain things that he/she hasn't been able to?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>	<p>24:13</p> <p>EARLIER ON did you ever find yourself wishing that you could say things to that you hadn't been able to?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>	<p>24:14</p> <p>NOWADAYS do you get upset when you think about?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>
<p>24:9</p> <p>If YES - what things?</p>		

<p>24:15 EARLIER OR did you get upset when you thought about?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>24:19 EARLIER OR did you ever feel depressed?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>
<p>24:16 NOWADAYS do you ever cry about what has happened to?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>24:20 NOWADAYS do you ever feel that life has lost its meaning for you?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>
<p>24:17 EARLIER OR did you ever cry about what had happened to?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>24:21 EARLIER OR did you ever feel that life had lost its meaning for you?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>
<p>24:18 NOWADAYS do you ever feel depressed?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>24:22 If we were to think more generally about thinking about the past compared with 's life now, and feeling sad about it all - has there been a particular time when you felt this most strongly?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Career unsure</p> <p><input type="checkbox"/> No</p>
	<p>24:23 If YES - when?</p>

<p>24:24 RATE for change in carer perceptions of grief over time</p> <p> <input type="checkbox"/> Increased <input type="checkbox"/> Present but no change <input type="checkbox"/> Decreased <input type="checkbox"/> Never present </p>	<p>1 STAGE V - ACCEPTANCE</p> <p>25:1 HOW/DAYS can you think calmly about what is wrong with?</p> <p> <input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never </p>
<p>24:25 RATE for carer grief apparent during interview</p> <p> <input type="checkbox"/> Carer visibly extremely upset, weeping and preoccupied such that difficulty completing interview <input type="checkbox"/> Carer visibly upset, intermittent crying and expressions of sadness during interview <input type="checkbox"/> Carer does not demonstrate visible grief, but expresses some sadness when prompted <input type="checkbox"/> Carer does not demonstrate or express grief even when prompted </p>	<p>25:2 Why / why not?</p> <p> <input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never </p>
	<p>25:3 EARLIER ON could you think calmly about what was wrong with?</p> <p> <input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never </p>
	<p>25:4 HOW/DAYS can you think calmly about the future for?</p> <p> <input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never </p>
	<p>25:5 Why / why not?</p>

<p>25:6 EARLIER ON could you think calmly about the future for.....?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>25:7 NOWADAYS do you feel as though you have accepted what has happened to.....?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>25:11 If YES - when?</p> <p>25:12 RATE for change in career perceptions of acceptance over time</p> <p><input type="checkbox"/> Increased</p> <p><input type="checkbox"/> Present but no change</p> <p><input type="checkbox"/> Decreased</p> <p><input type="checkbox"/> Never present</p>
<p>25:10 If we were to think more generally about being able to feel calm and to accept everything about what's wrong with..... - has there been a particular time when you felt this more strongly?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Career unsure</p> <p><input type="checkbox"/> No</p>	<p>25:8 Why / why not?</p> <p>25:9 EARLIER ON did you feel as though you had accepted what had happened to.....?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>25:13 RATE for career acceptance apparent during interview</p> <p><input type="checkbox"/> Career talks freely of illness, problems, and realistically discussed the future. Does not demonstrate grief or distress</p> <p><input type="checkbox"/> Career talks freely about present and future for sufferer but demonstrates slight grief or distress</p> <p><input type="checkbox"/> Career has difficulty talking about present and future for sufferer. Demonstrates grief or distress</p> <p><input type="checkbox"/> Career demonstrates extreme denial or grief / distress throughout interview. Unable to discuss present or future for sufferer</p>

N		SOCIAL DEATH OF SUPERHER	
26:1	Does seem to know and understand everything that's going on? All the time <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Often <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Sometimes <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Rarely <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Never <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	26:6	Is it important to you thatdoes as much for him/herself as possible? All the time <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Often <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Sometimes <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Rarely <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Never <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
26:2	If NO - how does that make you feel? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	26:7	Why is it important /not important? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> All the time <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Often <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Sometimes <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Rarely <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Never <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
26:3	Doesever talk about what's happening? All the time <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Often <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Sometimes <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Rarely <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Never <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	26:8	Is it important to you that always looks their best? All the time <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Often <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Sometimes <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Rarely <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Never <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
26:4	IF YES - what does say about it? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	26:9	Why is it important /not important? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> All the time <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Often <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Sometimes <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Rarely <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Never <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
26:5	How do you feel when talks like that /how do you feel when isn't able to talk? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	26:10	Do you ever find yourself thinking ahead to the time when will die? All the time <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Often <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Sometimes <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Rarely <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> Never <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
		26:11	IF YES - how does that thought make you feel? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

<p>26:12 Some people find themselves rehearsing or going through what might happen and what they might do straight after a death - for example, thinking about the funeral and imagining how it will be. Do you ever find yourself thinking anything like this?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>		<p>26:18 Would you agree that death might come as a blessing to</p> <p>Strongly agree</p> <p>Slightly agree</p> <p>Unsure</p> <p>Slightly disagree</p> <p>Strongly disagree</p>
<p>26:13 If YES - what do you think about?</p>		<p>26:19 Why would you agree / disagree?</p>
<p>26:14 If YES - how does that thought make you feel?</p>		<p>26:20 How does that thought make you feel?</p>
<p>26:15 Do you ever find yourself thinking about what the future would be like without</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>		<p>26:21 Would you agree that in some ways it is as if is already dead?</p> <p>Strongly agree</p> <p>Slightly agree</p> <p>Unsure</p> <p>Slightly disagree</p> <p>Strongly disagree</p>
<p>26:16 If YES - what do you think it would be like?</p>		<p>26:22 Why would you agree / disagree?</p>
<p>26:17 If YES - how does that thought make you feel?</p>		<p>26:23 How does that thought make you feel?</p>

<p>26:24 If we were to think more generally about considering a death and thinking about whether his/her life is worthwhile and about whether you think he/she can take notice of what's going on - has there been a particular time when you felt this most strongly?</p> <p>26:25 If YES - when?</p> <p>26:26 RATE for career perceptions of sufferer as socially dead over time</p> <p>26:27 RATE for social death apparent during interview</p>	<p>H</p> <p>27</p>	<p>CURRENT FEELINGS</p> <p>What is your most important feeling towards just now?</p>
<p>Yes Career unsure No</p> <p>Increased Present but no change Decreased Never present</p> <p>Rate for social death apparent during interview</p> <p>If present sufferer completely ignored / career says no point acknowledging. Career appears to regard sufferer's life as a nuisance. sees no point in sufferer continuing to exist, and looks forward to the death as a positive event</p> <p>Career addresses slight attention to sufferer but appears to regard as hardly worthwhile and thinks ahead to the death</p> <p>Career attends to sufferer but admits some difficulty in seeing the life as continuing to be worthwhile</p> <p>Career wholly positive about sufferer - always attempts to include as if normal, talks to sufferer and acts in accordance with perceived wishes of sufferer. Regards sufferer's continued existence as entirely worthwhile</p>		

<p>0</p> <p>STAGES</p> <p>28 Some people would see the way that a person in your situation feels as changing over time - like passing through a series of stages, starting with the time when they first realize that ... has a problem. Are you able to describe stages in your reactions as a caregiver?</p>	
<p>P</p> <p>CARING - CURRENT SITUATION AND ATTITUDES OF CARE</p> <p>29: CURRENT SITUATION</p> <p>29:1 Roughly how many hours do you spend with each day?</p> <p>29:2 Do you / could you accept help from others in caring for?</p> <p>Yes <input type="checkbox"/> Careg unsure <input type="checkbox"/> No <input type="checkbox"/></p> <p>29:3 If UNSURE / NO - why not?</p> <p>29:4 IF SHARED CARING - who else helps? (Names and status)</p> <p>..... </p> <p>29:5 IF SHARED CARING - what do they do?</p> <p>..... </p> <p>29:6 Overall, how much relief from caring do you get each week?</p>	

<p>29:7 How satisfied are you with the amount of help you get from RELATIVES?</p> <p> <input type="checkbox"/> Completely satisfied <input type="checkbox"/> Fairly satisfied <input type="checkbox"/> Mixed <input type="checkbox"/> Fairly dissatisfied <input type="checkbox"/> Completely dissatisfied </p> <p>29:8 How satisfied are you with the amount of help you get from PROFESSIONALS? (GP, nurse, home help, etc)</p> <p> <input type="checkbox"/> Completely satisfied <input type="checkbox"/> Fairly satisfied <input type="checkbox"/> Mixed <input type="checkbox"/> Fairly dissatisfied <input type="checkbox"/> Completely dissatisfied </p>	<p>30:4 How important is being able to care for when compared with your own needs?</p> <p> <input type="checkbox"/> Great deal more important than self <input type="checkbox"/> Slightly more important than self <input type="checkbox"/> Equally important <input type="checkbox"/> Slightly less important than self <input type="checkbox"/> Great deal less important than self </p> <p>30:5 Why?</p> <p>30:6 Before the onset of the illness did express any particular wishes about how he/she would like to end his/her days?</p> <p> <input type="checkbox"/> Yes <input type="checkbox"/> Career unsure <input type="checkbox"/> No </p>
<p>30: ATTITUDE TO CARING</p> <p>30:1 Have you had to make sacrifices in your own life in order to care for</p> <p> <input type="checkbox"/> Yes <input type="checkbox"/> Career unsure <input type="checkbox"/> No </p> <p>30:2 If YES - what sacrifices?</p> <p>30:3 If YES - how do you feel about that?</p>	<p>30:7 If YES - what were they?</p> <p>30:8 Before the onset of the illness did you discuss the possibility of caring for him/her with</p> <p> <input type="checkbox"/> Yes <input type="checkbox"/> Career unsure <input type="checkbox"/> No </p> <p>30:9 If YES - what did you both decide?</p>

<p>30:10 Would agree that it is right for you to be looking after him/her?</p> <p> <input type="checkbox"/> Yes <input type="checkbox"/> Career unsure <input type="checkbox"/> No </p> <p>30:11 Do you feel under any obligation to look after?</p> <p> <input type="checkbox"/> Yes <input type="checkbox"/> Career unsure <input type="checkbox"/> No </p> <p>30:12 Why / why not?</p> <p>30:13 Why do you care for?</p> <p>30:14 Since you started to care for has he/she been away? (eg. to stay with relative / hospital respite)</p> <p> <input type="checkbox"/> Yes <input type="checkbox"/> Career unsure <input type="checkbox"/> No </p> <p>30:15 If YES - how many times?</p> <p>30:16 If YES - how do you feel when goes?</p>			
		<p>30:17 How likely is it that your relative will enter long term care in a hospital or old people's home within the next year?</p> <p> <input type="checkbox"/> Extremely likely <input type="checkbox"/> Fairly likely <input type="checkbox"/> Maybe <input type="checkbox"/> Fairly unlikely <input type="checkbox"/> Extremely unlikely </p> <p>30:18 Why / why not?</p> <p>30:19 How likely would you be to take a place at (Dykebar) for If it was offered to you tomorrow?</p> <p> <input type="checkbox"/> Extremely likely <input type="checkbox"/> Fairly likely <input type="checkbox"/> Maybe <input type="checkbox"/> Fairly unlikely <input type="checkbox"/> Extremely unlikely </p> <p>30:20 Why / why not?</p> <p>30:21 RATE carer's attitude to caring for sufferer</p> <p> <input type="checkbox"/> Entirely positive about experience - enjoys the role and being with sufferer. Has made no sacrifices. Puts sufferer before self. May speak of caring out of love. Plans to care as long as needed <input type="checkbox"/> Fairly positive about caring - enjoys some aspects of the role and being with sufferer. May regard caring as repayment. Not actively considering institutionalization <input type="checkbox"/> Fairly negative about caring - dislikes most aspects of the role and being with sufferer. May speak of caring out of duty. Has seriously considered institutionalization for future <input type="checkbox"/> Entirely negative about caring - dislikes all aspects of the role and being with sufferer. Has made sacrifices. Puts self before sufferer. Only cares because other options not available </p>	

0		CAREER-SUFFERER RELATIONSHIP
<u>31: CURRENT RELATIONSHIP</u>		
31:1	Nowadays do you and laugh and joke together?	<input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never
31:2	Nowadays do you ever feel cross or angry with?	<input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never
31:3	Nowadays do you ever feel that is possessive of yourself?	<input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never
31:4	Nowadays do you ever feel that interferes too much? (eg. in your life, family affairs, running the house, etc.)	<input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never
31:5	Nowadays do you ever feel any tension or strain in the relationship?	<input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never
31:6	Nowadays do you ever have upsetting disagreements or arguments with?	<input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never
31:7	Nowadays do you ever try to ignore?	<input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never
31:8	Nowadays do you feel there are many positive times in your relationship with?	<input type="checkbox"/> All the time <input type="checkbox"/> Often <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never

<p>31:9 Howdays do you ever wish you could get away from?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	
<p><u>32: PROHIBIT RELATIONSHIP</u></p>	
<p>32:1 Before the onset of the illness did you and laugh and joke together?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>32:5 Before the onset of the illness did you ever feel any tension or strain in the relationship?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>
<p>32:2 Before the onset of the illness did you ever feel cross or angry with?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>32:6 Before the onset of the illness did you ever have any upsetting disagreements or arguments with?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>
<p>32:3 Before the onset of the illness did you ever feel that was possessive of yourself?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>	<p>32:7 Before the onset of the illness did you ever try to ignore?</p> <p><input type="checkbox"/> All the time</p> <p><input type="checkbox"/> Often</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Rarely</p> <p><input type="checkbox"/> Never</p>

<p>32:8 Before the onset of the illness did you feel there were any positive claims in your relationship with?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>	
<p>32:9 Before the onset of the illness did you ever wish you could get away from?</p> <p>All the time</p> <p>Often</p> <p>Sometimes</p> <p>Rarely</p> <p>Never</p>	
R	
CAREER STRAIN	
<p>33:1 Has Looking after affected your PHYSICAL HEALTH?</p> <p>Enormously</p> <p>Quite a lot</p> <p>A bit</p> <p>Hardly at all</p> <p>Not at all</p>	
<p>33:2 If YES - in what way has your physical health been affected?</p> <p>Enormously</p> <p>Quite a lot</p> <p>A bit</p> <p>Hardly at all</p> <p>Not at all</p>	
<p>33:3 Has Looking after affected your MENTAL HEALTH?</p> <p>Enormously</p> <p>Quite a lot</p> <p>A bit</p> <p>Hardly at all</p> <p>Not at all</p>	
<p>33:4 If YES - in what way has your mental health been affected?</p> <p>Enormously</p> <p>Quite a lot</p> <p>A bit</p> <p>Hardly at all</p> <p>Not at all</p>	
<p>33:5 Has Looking after affected your SOCIAL LIFE?</p> <p>Enormously</p> <p>Quite a lot</p> <p>A bit</p> <p>Hardly at all</p> <p>Not at all</p>	

<p>33:6 If YES - in what way has your social life been affected?</p> <p>33:7 Has looking after affected your FINANCES?</p> <p>Enormously <input type="checkbox"/></p> <p>Quite a lot <input type="checkbox"/></p> <p>A bit <input type="checkbox"/></p> <p>Hardly at all <input type="checkbox"/></p> <p>Not at all <input type="checkbox"/></p> <p>33:8 If YES - in what way have your finances been affected?</p>	
<p>36:1 Do you have a religious faith or any other belief which helps you to cope?</p> <p>Faith or belief which is a GREAT help <input type="checkbox"/></p> <p>Faith or belief which is SOME help <input type="checkbox"/></p> <p>Faith or belief but it is NO help <input type="checkbox"/></p> <p>No faith or belief <input type="checkbox"/></p> <p>36:2 If YES - what faith or belief?</p> <p>36:3 If YES - how does it help?</p>	<p>S</p> <p>FAITH</p>

T	U
<p style="text-align: center;">CAREER COPING</p> <p>35:1 Taking everything into account, how well do you think you are coping just now?</p> <p style="text-align: center;"> <input type="checkbox"/> Very well <input type="checkbox"/> Pretty well <input type="checkbox"/> Just about O.K. <input type="checkbox"/> Pretty badly <input type="checkbox"/> Very badly </p> <p>35:2 Has this changed over the time you've been caring?</p> <p style="text-align: center;"> <input type="checkbox"/> Improved a great deal <input type="checkbox"/> Improved a little <input type="checkbox"/> Coping about the same <input type="checkbox"/> Got a little worse <input type="checkbox"/> Got a great deal worse </p>	<p style="text-align: center;">CAREER LIFE SATISFACTION</p> <p>36:1 How do you feel about your life as a whole right now?</p> <p style="text-align: center;"> <input type="checkbox"/> Delighted <input type="checkbox"/> Pleased <input type="checkbox"/> Mostly satisfied <input type="checkbox"/> Mixed <input type="checkbox"/> Mostly dissatisfied <input type="checkbox"/> Unhappy <input type="checkbox"/> Terrible </p> <p>36:2 Has this changed over the time you've been caring?</p> <p style="text-align: center;"> <input type="checkbox"/> Improved a great deal <input type="checkbox"/> Improved a little <input type="checkbox"/> Feeling about the same <input type="checkbox"/> Got a little worse <input type="checkbox"/> Got a lot worse </p>

V		OPINION OF INTERVIEW
37:1	Please rate how you felt about the interview overall	<input type="checkbox"/> Delighted <input type="checkbox"/> Pleased <input type="checkbox"/> Mostly satisfied <input type="checkbox"/> Mixed <input type="checkbox"/> Mostly dissatisfied <input type="checkbox"/> Unhappy <input type="checkbox"/> Terrible
37:2	Here there any questions which you felt I should not have asked?	
37:3	Here there any subjects which were particularly hard for you to talk about?	
37:4	Here there any questions which you felt very pleased that I asked about?	

THE GENERAL HEALTH QUESTIONNAIRE

David Goldberg

Please read this carefully. We should like to know if you have had any medical complaints and how your health has been in general, over the past few weeks. Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past. It is important that you try to answer ALL the questions. Thank you very much for your co-operation.

Have you recently

- A1 - been feeling perfectly well and in good health? Better than usual Same as usual Worse than usual Much worse than usual
- A2 - been feeling in need of a good tonic? Not at all No more than usual Rather more than usual Much more than usual
- A3 - been feeling run down and out of sorts? Not at all No more than usual Rather more than usual Much more than usual
- A4 - felt that you are ill? Not at all No more than usual Rather more than usual Much more than usual
- A5 - been getting any pains in your head? Not at all No more than usual Rather more than usual Much more than usual
- A6 - been getting a feeling of tightness or pressure in your head? Not at all No more than usual Rather more than usual Much more than usual
- A7 - been having hot or cold spells? Not at all No more than usual Rather more than usual Much more than usual
- B1 - lost much sleep over worry? Not at all No more than usual Rather more than usual Much more than usual
- B2 - had difficulty in staying asleep once you are off? Not at all No more than usual Rather more than usual Much more than usual
- B3 - felt constantly under strain? Not at all No more than usual Rather more than usual Much more than usual
- B4 - been getting edgy and bad-tempered? Not at all No more than usual Rather more than usual Much more than usual
- B5 - been getting scared or panicky for no good reason? Not at all No more than usual Rather more than usual Much more than usual
- B6 - found everything getting on top of you? Not at all No more than usual Rather more than usual Much more than usual
- B7 - been feeling nervous and strung-up all the time? Not at all No more than usual Rather more than usual Much more than usual

Have you recently

- C1 - been managing to keep yourself busy and occupied? More so than usual Same as usual Rather less than usual Much less than usual
- C2 - been taking longer over the things you do? Quicker than usual Same as usual Longer than usual Much longer than usual
- C3 - felt on the whole you were doing things well? Better than usual About the same Less well than usual Much less well
- C4 - been satisfied with the way you've carried out your task? More satisfied About same Less satisfied Much less satisfied
- C5 - felt that you are playing a useful part in things? More so than usual Same as usual Less useful than usual Much less useful
- C6 - felt capable of making decisions about things? More so than usual Same as usual Less so than usual Much less capable
- C7 - been able to enjoy your normal day-to-day activities? More so than usual Same as usual Less so than usual Much less than usual
- D1 - been thinking of yourself as a worthless person? Not at all No more than usual Rather more than usual Much more than usual
- D2 - felt that life is entirely hopeless? Not at all No more than usual Rather more than usual Much more than usual
- D3 - felt that life isn't worth living? Not at all No more than usual Rather more than usual Much more than usual
- D4 - thought of the possibility that you might make away with yourself? Definitely not I don't think so Has crossed my mind Definitely has
- D5 - found at times you couldn't do anything because your nerves were too bad? Not at all No more than usual Rather more than usual Much more than usual
- D6 - found yourself wishing you were dead and away from it all? Not at all No more than usual Rather more than usual Much more than usual
- D7 - found that the idea of taking your own life kept coming into your mind? Definitely not I don't think so Has crossed my mind Definitely has

A B C D TOTAL

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HOW HAVE YOU BEEN FEELING RECENTLY?

Please think about how you have been feeling recently.

Below are a number of statements about different feelings. For each one please put a tick in the box which best describes how you have been feeling over the past few months.

1. Particularly excited or interested in something:

Never
 Sometimes
 Often

2. So restless you couldn't sit long in a chair:

Never
 Sometimes
 Often

3. Proud because someone complimented you on something you had done:

Never
 Sometimes
 Often

4. Very lonely or remote from other people:

Never
 Sometimes
 Often

5. Pleased about having accomplished something:

Never
 Sometimes
 Often

6. Bored:

Never
 Sometimes
 Often

7. On top of the world:

Never
 Sometimes
 Often

8. Depressed or very unhappy:

Never
 Sometimes
 Often

9. That things were going your way:

Never
 Sometimes
 Often

10. Upset because someone criticised you:

Never
 Sometimes
 Often

THANK YOU

COPING WITH THE EFFECTS OF GIVING CARE

Please think about how you have tried to deal with the problems which you have experienced because you care for someone who is confused. Please decide whether you have used each strategy, and if so, how often, and then put a tick in the box which best describes how often you have chosen to cope in that way during the past few months.

1. Tried to keep my feelings to myself:

- Never
- Rarely
- Sometimes
- Often
- All the time

2. Criticised or blamed myself:

- Never
- Rarely
- Sometimes
- Often
- All the time

3. Turned my attention to other activities that I could do on my own, such as reading, hobbies, watching TV:

- Never
- Rarely
- Sometimes
- Often
- All the time

4. Thought about practical things to do which might help but put off doing anything about it:

- Never
- Rarely
- Sometimes
- Often
- All the time

5. Tried to find other people who had experienced the same problems:

- Never
- Rarely
- Sometimes
- Often
- All the time

6. Tried to step back from the situation, tried to feel more detached and objective:

- Never
- Rarely
- Sometimes
- Often
- All the time

7. Tried to work out problems calmly with family or friends:

- Never
- Rarely
- Sometimes
- Often
- All the time

8. Tried not to think about what was happening:

- Never
- Rarely
- Sometimes
- Often
- All the time

9. Took my feelings out on someone or something: for instance, shouted, nagged or crumbled; threw things about, broke things:

- Never
- Rarely
- Sometimes
- Often
- All the time

10. Tried to take my mind off things by smoking, drinking, eating, or taking pills to relax:

- Never
- Rarely
- Sometimes
- Often
- All the time

11. Prepared for the worst:

- Never
- Rarely
- Sometimes
- Often
- All the time

12. Asked professionals, friends, or relatives for practical advice and information:

- Never
- Rarely
- Sometimes
- Often
- All the time

13. Tried to work out just what the problems were and what makes things better or worse, so that I could work out a plan for the future:

- Never
- Rarely
- Sometimes
- Often
- All the time

14. Carried out one or more practical things which I hoped would help:

- Never
- Rarely
- Sometimes
- Often
- All the time

15. Told myself that what was happening wasn't really all that upsetting or difficult - things could be far worse:

- Never
- Rarely
- Sometimes
- Often
- All the time

Now that you have gone through the list, please go back over it and put a cross by those items which you have found to be most helpful when you were trying to deal with the problems you have experienced.
THANK YOU

LIVING ARRANGEMENTS QUESTIONNAIRE

YOUR HOME

1. How would you describe your home?

- Detached
- Semi-detached
- Terrace
- Maisonette (4 flats to a block)
- Tenement
- High rise, less than 5 floors
- High rise, more than 5 floors
- Other, please specify

2. If you are RENTING your home, is it

- Rented privately
- Rented from the local authority
- Rented from a housing association
- Other, please specify

3. If you OWN your home, is it

- Owned outright
- Being bought on a mortgage
- Other, please specify

YOUR INCOME

4. If you would prefer not to answer the next question, which concerns your income, please put a tick in this box

5. Which of the following best describes your FAMILY INCOME per week?

- Less than £50
- £50 - £100
- £100 - £150
- £150 - £200
- £250 - £300
- More than £300

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE

III. CARERS' QUESTIONNAIRE - CODING FRAME

QUESTION	VARIABLE	CODE	QUESTION	VARIABLE	CODE
<div style="border: 1px solid black; padding: 5px; display: inline-block;"> CARER'S QUESTIONNAIRE CODING FRAME </div>					
N.B. Code : Data not available/not applicable = 99					
A					
1:1	CAREX DETAILS	V 002	1:1:1	CAREX DETAILS	V 010
2:1	CAREX SEX : Male = 1, Female = 2	V 003	6:1	SUFFERER SEX : Male = 1, Female = 2	V 011
3:1	CAREX AGE : (code directly)	V 004	7:1	SUFFERER AGE (code directly)	V 012
4:1	CAREX MARITAL STATUS : Married - Sp working = 1 Married - Sp unemp = 2 Single = 4 Widowed = 5 Separated = 6 Divorced = 7 Co-habiting = 8	V 006	8:1	SUFFERER MARITAL STATUS : Mar - Sp working = 1 Mar - Sp unemp = 2 Single = 4 Widowed = 5 Separated = 6 Divorced = 7 Co-habiting = 8	V 013
B					
4:1	CAREX WORK :	V 005	C		
4:1:1	Are you working? Yes - full time = 1 Yes - part time = 2 No - unemployed = 3 No - retired = 4 No - housewife = 5	V 005	10:1	GENERAL CARING SITUATION	V 013
4:1:2	Changes full time -> part time to care : Yes = 1 No = 2	V 006	11:1	SUFFERER'S RELATIONSHIP TO CARER : Spouse = 1 Sibling = 2 Mother = 3 Father = 4 In-law = 5 Pa-in-law = 6 Aunt = 7 Uncle = 8 Other rel = 9 Friend = 10	V 014
4:1:3	Gave up work to care : Yes = 1 No = 2	V 007	11:2	HOUSEHOLD	V 015
D					
5:1	QUALIFICATION :	V 009	11:2	Others in household : Yes = 1 No = 2	V 016
5:1:1	Age finished s/r education (code directly)	V 009	11:2	Number APART from carer & sufferer	V 017
5:1:2	Exams : No qualifications = 1 GCE / O grades = 2 Holders / A Levels = 3 College certificate = 4 Degree = 5 Higher degree = 6	V 009	11:2	Number of carer's dependents (18yrs / chronic illness / frail) apart from sufferer	V 016
			11:2	Sufferer resides : With carer = 1 In own home = 2 In institution = 3 Other = 4	V 017

D		SUPERIOR CHARACTERISTICS	
12:		PROBLEM CHECKLIST - FREQUENCY :	
		NOT PRESENT = 0	
		Occasionally/usually = 1	
		Frequently/usually = 2	
12:1	Unable to dress without help	V 018
12:2	Demands attention	V 019
12:3	Unable to get in & out chair without help	V 020
12:4	Uses bad language	V 021
12:5	Unable to get in & out bed without help	V 022
12:6	Disrupts personal and social life	V 023
12:7	Unable to wash without help	V 024
12:8	Physically aggressive	V 025
12:9	Needs help at mealtimes	V 026
12:10	Vulgar habits	V 027
12:11	Incontinent - soiling	V 028
12:12	Creates personality clashes	V 029
12:13	Forgets things that have happened	V 030
12:14	Temper outbursts	V 031
12:15	Falling	V 032
12:16	Rude to visitors	V 033
12:17	Unable to manage stairs	V 034
12:19	Not safe if outside home alone	V 035
12:19	Cannot be left alone for even one hour	V 035
12:19	Handers about house at night	V 037
12:21	Careless about own appearance	V 038
12:22	Unable to walk outside house	V 039
12:23	Unable to hold sensible conversation	V 040
12:24	Noisy, shouting	V 041
12:25	Incontinent - wetting	V 042
12:26	Shows no concern for personal hygiene	V 043
12:27	Unsteady on feet	V 044
12:29	Always asking questions	V 045
12:29	Unable to take part in family conversations	V 046
12:30	Unable to read newspapers, magazines, etc	V 047
12:31	Sits around doing nothing	V 048
12:32	No interest in news about family & friends	V 049
12:33	Unable to watch & follow TV / radio	V 050
12:34	Unable to occupy self doing useful things	V 051
		PROBLEM CHECKLIST - SEVERITY :	
		No problem = 0	
		Small problem = 1	
		Great problem = 2	
12:1	Unable to dress without help	V 052
12:2	Demands attention	V 053
12:3	Unable to get in & out chair without help	V 054
12:4	Uses bad language	V 055
12:5	Unable to get in & out bed without help	V 056
12:6	Disrupts personal and social life	V 057
12:7	Unable to wash without help	V 058
12:9	Physically aggressive	V 059
12:10	Needs help at mealtimes	V 060
12:11	Vulgar habits	V 061
12:11	Incontinent - soiling	V 062
12:12	Creates personality clashes	V 063
12:13	Forgets things that have happened	V 064
12:14	Temper outbursts	V 065

12:15	Falling	V 065			
12:16	Rude to visitors	V 067			
12:17	Unable to manage stairs	V 068			
12:18	Not safe if outside home alone	V 069			
12:19	Cannot be left alone for even one hour	V 070			
12:20	Wanders about house at night	V 071			
12:21	Careless about own appearance	V 072			
12:22	Unable to walk outside house	V 073			
12:23	Unable to hold sensible conversation	V 074			
12:24	Noisy, shouting	V 075			
12:25	Incontinent - wetting	V 076			
12:26	Shows no concern for personal hygiene	V 077			
12:27	Unsteady on feet	V 078			
12:28	Always asking questions	V 079			
12:29	Unable to take part in family conversations ...	V 080			
12:30	Unable to read newspapers, magazines, etc	V 081			
12:31	Sits round doing nothing	V 082			
12:32	No interest in news about family & friends	V 083			
12:33	Unable to watch & follow TV / radio	V 084			
12:34	Unable to occupy self doing useful things	V 085			
13:	SUFFERER PHYSICAL CHANGES (as perceived by carer)					
13:1	Can't fly para as used to : Exactly same = 1 Almost same = 2 Somewhat same = 3 Slightly same = 4 Not at all same = 5	V 086			
13:2	If change : Physical disability (eg weak) = 1 Physical appearance (eg pale) = 2 Social appearance (eg untidy) = 3 Other = 4 Other = 5	V 087			
13:3	Looks physically well : Very well = 1 Fairly well = 2 All right = 3 Rather unwell = 4 Extremely unwell = 5	V 088			
13:4	IF unwell : Physical disability (eg weak) = 1 Physical appearance (eg pale) = 2 Social appearance (eg untidy) = 3 Other = 4	V 089			
14:	SUFFERER OVERALL CHANGES					
14:1	Overall change : No change = 1 Slight change = 2 Moderate change = 3 Great change = 4 Complete change = 5	V 090			
14:2	Most important change : Appearance = 1 Cognition = 2 Personal hygiene = 3 Disruptive behaviour = 4 Apathetic behaviour = 5 No communication = 6 Emotional = 8 Other = 9 No single change = 10	V 091			
14D	Does sufferer recognise carer? Yes = 1 Carer unsure = 2 No = 3	V 092			
14:3	Speed of change : Extremely fast / sudden = 1 Fairly fast = 2 Moderately fast = 3 Fairly gradual = 4 Extremely gradual = 5	V 093			
E	REACTIONS FROM OTHERS					
15:	OTHER'S AWARENESS					
15:1	Change noticed by others : Very big = 1 Fairly big = 2 Moderate = 3 Slight = 4 None = 5 Carer unsure = 5	V 094			

15:2	Compared to carer : Others notice more = 1 Others notice about same = 2 Others notice less = 3 Carer unsure = 4	V 095	18:4	If not been told, can give diagnosis : Full & correct = 1 Partially correct = 2 Incorrect / Don't know = 3	V 111
15:1	OTHER'S BEHAVIOUR Others to sufferer : Over-attentive = 1 Sometimes include = 2 Always ignore = 3 Carer unsure = 4	V 096	18:6	Problems due to : Physical illness = 1 Mental illness = 2 Physical & mental = 3 Neither = 4 Carer unsure = 5	V 112
16:2	Is this behaviour clear? Yes = 1 Carer unsure = 2 No = 3	V 097	18:7	Will sufferer get better : Yes = 1 Unsure = 2 No = 3	V 113
17:1	DISCUSSION WITH LAY OTHERS Discuss with friends / rels? Yes = 1, No = 2	V 098	19:1	KNOWLEDGE - GLOBAL Know another sufferer : Yes = 1 Carer unsure = 2 No = 3	V 114
17:2	Who : Family = 1 Friends = 2 Both = 3	V 099	19:4	DATE carer's knowledge & perception of disorder 1 = Acknowledges illness, names dementia, aware brain change -> behaviour change, progressive, rough time scale. 2 = Correct name, some awareness affects brain, prognosis downhill. 3 = May name, little knowledge of illness, or of prognosis. 4 = Can't name, no obvious knowledge of reasons for condition or prognosis.	V 115
F	CAREER AWARENESS - KNOWLEDGE & PERCEPTIONS			G	CAREER'S PERCEPTION OF ONSET		
18:1	KNOWLEDGE - PERSONAL Discussed with professional? Yes = 1, No = 2	V 100	20:1	Time since noticed SUFFERING (code in years)	V 116
18:2	With G.P.? Yes = 1, No = 2 With Psychiatrist? Yes = 1, No = 2 With Physician / Geriatrician? Yes = 1, No = 2 With day hospital nurse? Yes = 1, No = 2 With ward nurse? Yes = 1, No = 2 With G.P.S.? Yes = 1, No = 2 With family visitor? Yes = 1, No = 2 With other? Yes = 1, No = 2	V 101 V 102 V 103 V 104 V 105 V 106 V 107 V 108	20:3	Time since first found what ACTUALLY wrong (code in years / parts of years)	V 117
18:3	With professional diagnosis (as Dem./Alz) Full & correct = 1 Partially correct = 2 Incorrect/can't recall/ays not told = 3	V 109 V 110	20:4	Learned by : Told by other person = 1 Caught from media / reading = 2 Already knew all about it = 3 Other = 4	V 118
				20:5	Diagnosis & prognosis : Learned suddenly = 1 Learned gradually = 2	V 119
				20:6	Understood at time : Yes - completely = 1 Was unsure = 2 Didn't understand = 3	V 120
					Believed at time : Yes - completely = 1 Was unsure = 2 Didn't believe = 3	V 121

I	STAGE II - BARGAINING, HOPE	J	STAGE III - ANGER, GUILT, QUESTIONING
N.D.	Code 22:1-22:11 : All the time = 5 Often = 4 Sometimes = 3 Rarely = 2 Never = 1	N.D.	Code 23:1-23:22 : All the time = 5 Often = 4 Sometimes = 3 Rarely = 2 Never = 1
22:1	NONADAYS hope might get better :	23:1	NONADAYS ask self "Why?" :
22:2	EARLIER hope might get better :	23:3	EARLIER ask self "Why?" :
22:3	NONADAYS wonder if doctors mistaken :	23:4	NONADAYS think "Maybe something more to help" :
22:5	EARLIER wonder if doctors mistaken :	23:6	EARLIER think "Maybe something more to help" :
22:6	NONADAYS consult media for hope of cure - N.D. not just for general information :	23:7	NONADAYS wonder whether contributed to illness :
22:8	EARLIER consult media for hope of cure :	23:9	EARLIER wonder whether contributed to illness :
22:9	NONADAYS make bargains :	23:10	NONADAYS guilty feelings if able to enjoy self :
22:11	EARLIER make bargains :	23:12	EARLIER guilty feelings if able to enjoy self :
22:14	RATE change in career perceptions of hope, bargaining : Increased = 1 Present but no change = 2 Decreased = 3 Never present = 4	23:13	NONADAYS anger / irritability with others :
22:15	RATE for hope, bargaining during interview : 4 = Frequently raises curse/misdeed etc. actively bargaining/using folk remedies. 3 = Asks curses/misdeeds etc, follow media for breakthrough announcements. 2 = Asks occasional news/breakthrough, asks about success. 1 = Asks news/bargaining, requests resigned to downhill progress.	23:14	EARLIER anger / irritability with others :
		23:15	NONADAYS angry at illness :
		23:16	EARLIER angry at illness :
		23:17	NONADAYS angry with sufferer :
		23:18	EARLIER angry with sufferer :
		23:19	NONADAYS angry at God :
		23:20	EARLIER angry at God :
		23:21	NONADAYS angry at professionals/social services :
		23:22	EARLIER angry at professionals/social services :
		23:25	RATE for change in career perceived questioning, pulle, anger : Increased = 1 Present but no change = 2 Decreased = 3 Never present = 4

23:26	RATE for anger, guilt, questioning during interview 4 = frequent anger, general & directed, complaints, own guilt, questions 3 = Some anger, guilt, questioning. 2 = Slight anger, guilt, questioning. 1 = No anger, guilt, questioning.	V 158			
K	STAGE IV - REOCCUPATION, MORNING, DESPAIR					
N.D.	Code 24:1-24:21 : All the time = 5 Often = 4 Sometimes = 3 Rarely = 2 Never = 1					
24:1	NONADAYS ever preoccupied with thoughts :	V 169			
24:3	EARLIER ever preoccupied with thoughts :	V 170			
24:4	NONADAYS look back :	V 171			
24:5	EARLIER look back :	V 172			
24:6	NONADAYS wish/yearn could be as used to be :	V 173			
24:7	EARLIER wish/yearn could be as used to be :	V 174			
24:8	NONADAYS wish could have done certain things :	V 175			
24:10	EARLIER wish could have done certain things :	V 176			
24:11	NONADAYS wish could saw certain things :	V 177			
24:13	EARLIER wish could say certain things :	V 178			
24:14	NONADAYS get upset when think about it :	V 179			
24:15	EARLIER get upset when thought about it :	V 180			
24:16	NONADAYS cry about it :	V 181			
24:17	EARLIER cried about it :	V 182			
24:18	NONADAYS feel depressed :	V 183			
24:19	EARLIER felt depressed :	V 184			
24:20	NONADAYS feel life lost & its meaning :	V 185			
24:21	EARLIER felt life lost & its meaning :	V 186			
24:24	RATE for change in career perceptions of relief over time : Increased = 1 Present but no change = 2 Decreased = 3 Never present = 4	V 187			
24:25	RATE for relief apparent during interview : 4 = Very upset, weeping etc such that difficulty completing interview. 3 = Upset, intermittent crying & expressions of sadness throughout. 2 = No visible grief, but expresses sadness. 1 = No grief / sadness, even when prompted.	V 188			
L	STAGE V - ACCEPTANCE					
N.D.	Code 25:1-25:9 : All the time = 5. Often = 4 Sometimes = 3 Rarely = 2 Never = 1					
25:1	NONADAYS think calmly about what's wrong :	V 189			
25:3	EARLIER think calmly about what's wrong :	V 190			
25:4	NONADAYS think calmly about the future :	V 191			
25:6	EARLIER think calmly about future :	V 192			
25:7	NONADAYS feel have accepted it :	V 193			
25:9	EARLIER feel had accepted it :	V 194			
ADD	RATE for change in career perceptions of EMOTIONAL acceptance over time : Increased = 1 Present but no change = 2 Decreased = 3 Never present = 4	V 195			
ADD	RATE for change in career perceptions of INTELLECTUAL acceptance over time : Increased = 1 Present but no change = 2 Decreased = 3 Never present = 4	V 196			

25:13	RATE for EMOTIONAL acceptance apparent during interview : 4 = No emotions demonstrated 3 = Slightly emotional 2 = Fairly emotional 1 = Extremes of emotion demonstrated	V 198	26:15	Think of future without sufferer : All the time = 3 Often = 4 Sometimes = 3 Rarely = 2 Never = 1	V 205
26:11	RATE for INTELLECTUAL acceptance apparent during interview : 1 = talks freely of all aspects. 2 = talks freely of most aspects. 3 = difficultly talking about sufferer. 4 = unable to discuss sufferer / extreme fatal.	V 197	26:12	Rehearsing what might do after death : All the time = 3 Often = 4 Sometimes = 3 Rarely = 2 Never = 1	V 204
26:1	SOCIAL RELIEF OF SUFFERER Seems to know & understand everything going on : All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5	V 199	26:18	Death might come as a blessing to sufferer : Strongly agree = 5 Slightly agree = 4 Slightly disagree = 2 Strongly disagree = 1	V 206
26:3	talks about what's happening : All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5	V 200	26:21	As if already dead in some ways : Strongly agree = 5 Slightly agree = 4 Slightly disagree = 2 Strongly disagree = 1	V 207
26:6	Important as much for self as possible : All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5	V 201	ADD	Have your feelings been like grief ? Yes = 1 Unsure = 2 No = 3	V 208
26:9	Important looks their best : All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5	V 202	26:26	RATE change in caret perceptions as socially dead over time : Increased = 1 Present but no change = 2 Decreased = 3 Never present = 4	V 209
26:10	Think has to time still die : All the time = 5 Often = 4 Sometimes = 3 Rarely = 2 Never = 1	V 203	ADD	RATE for RELIEF as socially dead apparent during interview : 4 = Sufferer lifts a nuisance, looks forward to death. 3 = Life hardly worthwhile, thinks dead to death. 2 = Some difficulty seeing life as worthwhile, but never/casualy thinks ahead to death. 1 = Life entirely worthwhile at present.	V 210

30:4	Sufferer needs compared to carer's : Great deal more important than self = 5 Slightly more important than self = 4 Equally important = 3 Slightly less important than self = 2 Great deal less important than self = 1	V 229	30:21	RATE attitude to caring : 4 = Entirely positive, enjoys role, made no sacrifices, sufferer put first, cares for love, will continue as needed. 3 = Fairly positive, enjoys some aspects, may be repayment, not actively considering institutionalisation. 2 = Fairly negative, dislikes most aspects, may be duty, seriously considered institutionalisation for future. 1 = Entirely negative, dislikes all aspects, made sacrifices, self put first, caring as no other option.	V 239
30:6	Previously expressed wishes about end of days : Yes = 1, Carer unsure = 2, No = 3	V 230	0	CAREGIVER-SUFFERER RELATIONSHIP		
30:8	Previously discussed possibility of caring : Yes = 1, Carer unsure = 2, No = 3	V 231	31:	CURRENT RELATIONSHIP		
30:10	Sufferer aware right to be looking after them : Yes = 1, Carer unsure = 2, No = 3	V 232	31:1	Nowadays laugh and joke together : All the time = 5 Often = 4 Sometimes = 3 Rarely = 2 Never = 1	V 240
30:11	Feel obliged to care : Yes = 1, Carer unsure = 2, No = 3	V 233	31:2	Nowadays cross & angry with sufferer : All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5	V 241
30:13	Reasons for caring : Love = 5 Repayment = 4 Duty = 3 No choice = 2 Can't care any longer = 1	V 234	31:3	Nowadays feel sufferer possessive of self : All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5	V 242
30:14	Sufferer ever been away : Yes = 1, Carer unsure = 2, No = 3	V 235	31:4	Nowadays feel sufferer intrudes : All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5	V 243
30:15	If yes, how many times? (code directly)	V 236	31:5	Nowadays tension & strain in relationship : All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5	V 244
30:17	Long term care within one year : Extremely likely = 1 Fairly likely = 2 Maybe = 3 Fairly unlikely = 4 Extremely unlikely = 5	V 237				
30:19	Long term care tomorrow : Extremely likely = 1 Fairly likely = 2 Maybe = 3 Fairly unlikely = 4 Extremely unlikely = 5	V 238				

31:6	<p>Weekdays upsetting disagreements or arguments :</p> <p>All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5</p>	V 245	32:3	<p>Before onset feel sufferer possessive of self :</p> <p>All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5</p>	V 252
31:7	<p>Weekdays try to ignore sufferer :</p> <p>All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5</p>	V 246	32:4	<p>Before onset feel sufferer interfered :</p> <p>All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5</p>	V 253
31:8	<p>Weekdays feel positive times in relationship :</p> <p>All the time = 5 Often = 4 Sometimes = 3 Rarely = 2 Never = 1</p>	V 247	32:5	<p>Before onset tension & strain in relationship :</p> <p>All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5</p>	V 254
31:9	<p>Weekdays wish could get away from sufferer :</p> <p>All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5</p>	V 248	32:6	<p>Before onset upsetting disagreements/arguments :</p> <p>All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5</p>	V 255
ADD	<p>RATE current carer - sufferer relationship :</p> <p>5 = Excellent 4 = Good 3 = Reasonable 2 = Fairly poor 1 = Extremely poor</p>	V 249	32:7	<p>Before onset try to ignore sufferer :</p> <p>All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5</p>	V 256
32:	<p>PERSONAL RELATIONSHIP</p>			32:8	<p>Before onset positive times in relationship :</p> <p>All the time = 5 Often = 4 Sometimes = 3 Rarely = 2 Never = 1</p>	V 257
32:1	<p>Before onset laugh and joke together :</p> <p>All the time = 5 Often = 4 Sometimes = 3 Rarely = 2 Never = 1</p>	V 250	32:9	<p>Before onset wish could get away from sufferer :</p> <p>All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5</p>	V 258
32:2	<p>Before onset cross & angry with sufferer :</p> <p>All the time = 1 Often = 2 Sometimes = 3 Rarely = 4 Never = 5</p>	V 251				

ADD	DATE premeroid career - sufferer relationship : 5 = Excellent 4 = Good 3 = Reasonable 2 = Fairly poor 1 = Extremely poor	V 259
9	CAREER STRAIN		
33:1	Caring affected physical health : Enormously = 5 Quite a lot = 4 A bit = 3 Hardly at all = 2 Not at all = 1	V 260
33:3	Caring affected mental health : Enormously = 5 Quite a lot = 4 A bit = 3 Hardly at all = 2 Not at all = 1	V 261
33:5	Caring affected social life : Enormously = 5 Quite a lot = 4 A bit = 3 Hardly at all = 2 Not at all = 1	V 262
33:7	Caring affected finances : Enormously = 5 Quite a lot = 4 A bit = 3 Hardly at all = 2 Not at all = 1	V 263
5	FATE		
34:1	Religious faith or belief which helps career come : Faith / belief is great help = 4 Faith / belief is some help = 3 Faith / belief is no help = 2 No faith / belief = 1	V 254
34:2	If yes, what? Christian = 1, Other = 2	V 265
34:3	If yes, how does it help : Spiritual = 1 Practical = 2 Both = 3	V 256
T	CAREER COPING		
35:1	Coping just now : Very well = 1 Pretty well = 2 Just about O.K. = 3 Pretty badly = 4 Very badly = 5	V 267
35:2	Change in coping over time of caring : Improved a great deal = 1 Improved a little = 2 Coping about the same = 3 Got a little worse = 4 Got a great deal worse = 5	V 268
U	CAREER LIFE SATISFACTION		
36:1	How do you feel about your life as a whole right now : Delighted = 1 Pleased = 2 Mostly satisfied = 3 Mixed = 4 Mostly dissatisfied = 5 Unhappy = 6 Terrible = 7	V 269
36:2	Change in life satisfaction over time of caring : Improved a great deal = 1 Improved a little = 2 Coping about the same = 3 Got a little worse = 4 Got a great deal worse = 5	V 270
V	OPINION OF INTERVIEW		
37	TATC comments on interview : Positive = 1 Neutral = 2 Negative = 3	V 271

GENERAL HEALTH QUESTIONNAIRE		GHQ SCORING = 0-0-1-1	
A1	Feeling perfectly well	V 272
A2	In need of tonic	V 273
A3	Run down	V 274
A4	Feeling ill	V 275
A5	Pains in head	V 276
A6	Pressure in head	V 277
A7	Hot and cold spells	V 278
B1	Lost sleep over worry	V 279
B2	Difficulty staying asleep	V 280
B3	Constantly under strain	V 281
B4	Edgy and bad tempered	V 282
B5	Scared and panicky	V 283
B6	Everything on top of you	V 284
B7	Nervous and strung up	V 285
C1	Busy and occupied	V 286
C2	Taking longer	V 287
C3	Doing things well	V 288
C4	Satisfied with task	V 289
C5	Playing useful part	V 290
C6	Making decisions	V 291
C7	Enjoy social activities	V 292
D1	Thinking yourself worthless	V 293
D2	Life intrinsically meaningless	V 294
D3	Life not worth living	V 295
D4	Take care with yourself	V 296
D5	Nerves too bad	V 297
D6	Dead and away from it	V 298
D7	Idea of taking your life	V 299
ADD	GHQ-28 section A = somatic symptoms (code directly 0-0-1-1 scoring system) GHQ-28 section B = anxiety and insomnia (code directly 0-0-1-1 scoring system) GHQ-28 section C = social dysfunction (code directly 0-0-1-1 scoring system) GHQ-28 section D = severe depression (code directly 0-0-1-1 scoring system) GHQ-28 TOTAL SCORE (code directly 0-0-1-1 system) CODE for GHQ "caseness" (cut off = 4/5) 1 = case 2 = not a case	V 300 V 301 V 302 V 303 V 304 V 305
SUBSCALE SCORING = 0-1-2-3			
A1	Feeling perfectly well	V 306
A2	In need of tonic	V 307
A3	Run down	V 308
A4	Feeling ill	V 309
A5	Pains in head	V 310
A6	Pressure in head	V 311
A7	Hot and cold spells	V 312
B1	Lost sleep over worry	V 313
B2	Difficulty staying asleep	V 314
B3	Constantly under strain	V 315
B4	Edgy and bad tempered	V 316
B5	Scared and panicky	V 317
B6	Everything on top of you	V 318
B7	Nervous and strung up	V 319

			AFFECT BALANCE SCALE			
			X	N.B.		
C1	Busy and occupied	V 320	1. Particularly excited or interested in something:	V 339
C2	Taking longer	V 321	2. So restless you couldn't sit long in a chair:	V 340
C3	Doing things well	V 322	3. Proud because someone complimented you on some-thing you had done:	V 341
C4	Satisfied with task	V 323	4. Very lonely or remote from other people:	V 342
C5	Playing useful part	V 324	5. Pleased about having accomplished something:	V 343
C6	Making decisions	V 325	6. Bored:	V 344
C7	Enjoy normal activities	V 326	7. On top of the world:	V 345
D1	Thinking yourself worthless	V 327	8. Depressed or very unhappy:	V 346
D2	Life entirely hopeless	V 328	9. That things were going your way:	V 347
D3	Life not worth living	V 329	10. Unset because someone criticised you:	V 348
D4	Make away with yourself	V 330			
D5	Nerves too bad	V 331			
D6	Dead and away from it	V 332			
D7	Idea of taking your life	V 333			
	GHO-28 section A = somatic symptoms (code directly 0-1-2-3 scoring system)	V 334			
	GHO-28 section B = anxiety and insomnia (code directly 0-1-2-3 scoring system)	V 335			
	GHO-28 section C = social dysfunction (code directly 0-1-2-3 scoring system)	V 336			
	GHO-28 section D = severe depression (code directly 0-1-2-3 scoring system)	V 337			
	GHO-19 TOTAL SCORE: (code directly 0-1-2-3 system)	V 339			

Y	COPING CHECKLIST		Z	HOUSE AND INCOME		
	<p>N.B. Code all coping items : Never = 0 Rarely = 1 Sometimes = 2 Often = 3 All the time = 4</p>					
1.	Tried to keep my feelings to myself :	V 349	1. How would you describe your home : Detached = 1 Semi-detached = 2 Terrace = 3 Maisonette = 4 Tenement = 5 High rise under 5 floors = 6 High rise over 5 floors = 7 Other = 8	V 364
2.	Criticised or blamed myself :	V 350	2. IF renting, is it : Privately = 1 From local authority = 2 From housing association = 3 Other = 4	V 365
3.	Turned attention to activities could do alone :	V 351	3. IF owned, is it : Owned outright = 1 On mortgage = 2 Other = 3	V 366
4.	Thought of practical things BUT put off doing :	V 352	5. Weekly family income : Under £50 = 1 £50 - £100 = 2 £100 - £150 = 3 £150 - £200 = 4 £200 - £250 = 5 £250 - £300 = 6 Over £300 = 7	V 367
5.	Tried to find others who'd experienced same :	V 353	ADD RATE CAREER social class : 1 = Professional 2 = Managerial 3 = Skilled manual 4 = Unskilled manual 5 = Unemployed	V 368
6.	Tried to step back, be detached & objective :	V 354	ADD RATE SUFFERER social class : 1 = Professional 2 = Managerial 3 = Skilled manual 4 = Unskilled manual 5 = Unemployed	V 369
7.	Tried to work out problems calmly with others :	V 355			
8.	Tried not to think what's happening :	V 356			
9.	Took feelings out on someone/something :	V 357			
10.	Tried taking mind off things by smoking, drinking, eating, or pills to relax :	V 358			
11.	Prepared for worse :	V 359			
12.	Asked for practical advice & information :	V 360			
13.	Tried working out what problems, & what affects them to make future plan :	V 361			
14.	Carried out practical things which you'd would help :	V 362			
15.	Told self things could be worse :	V 363			

APPENDIX FIVE
CORRESPONDENCE

I. PRELIMINARY INTERVIEWS: APPLICATION FOR PERMISSION
TO CONDUCT STUDY



Stobhill General Hospital
Glasgow G21 3UW

Telephone 041 - 558 0111

DEPARTMENT OF CLINICAL PSYCHOLOGY

DR. M. DOW
MISS I. SINNAK-ARUPPAN
MISS H. SWEETING

HS/JB

13th August, 1986.

Chairman,
Division of Psychiatry,
Stobhill and Woodilee Hospitals.

Dear Dr. Booth,

You will recall that we recently discussed the possibility of my conducting exploratory interviews with the carers of approximately 20 dementia sufferers as a preliminary to a more structured investigation of the concept "Anticipatory Grief." I also mentioned that in addition, since my knowledge of the stresses upon caregivers is as yet only theoretical I would be grateful, if it were feasible, to accompany you or one of the other psychogeriatricians on two or three domicilliary visits in order to gain some first hand impressions of the difficulties faced in caring for elderly dementing persons.

I enclose a little background information, plus my proposal and aims for your perusal. I would, of course, be grateful for suggestions and guidance from yourself or your colleagues, and am happy to attend a divisional meeting to discuss this with you.

Yours sincerely,

Helen Sweeting

Helen Sweeting
Clinical Psychologist.

II. PILOT STUDY: ETHICAL PERMISSION FROM DYKEBAR HOSPITAL



ARGYLL AND CLYDE HEALTH BOARD

PHYSICIAN SUPERINTENDENT
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CONSULTANT PSYCHIATRISTS
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Dr. W.W. Baird
Dr. J. Gallagher

Dykebar Hospital

Grahamston Road,
Paisley PA2 7DE.
Tel.: 041-884 5122

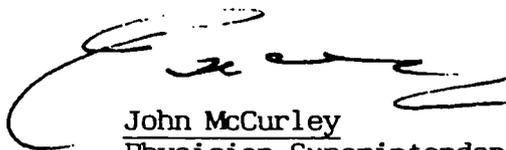
TO WHOM IT MAY CONCERN

Anticipatory Grief in Caregiving Relatives

Research Project

Ms Helen Sweeting

The above Project has been fully discussed by members of the Ethical Committee at Dykebar Hospital and approval given on 19 87.



John McCurley
Physician Superintendent

27 January 1989

III. MAIN STUDY: ETHICAL PERMISSION FROM INVERCLYDE
ROYAL HOSPITAL



ARGYLL AND CLYDE HEALTH BOARD INVERCLYDE GENERAL AND COMMUNITY UNIT

Inverclyde Royal Hospital

Department of Community Medicine

Dr. A. C. Marr

LARKFIELD ROAD,
GREENOCK PA16 0XN
Tel: (0475) 33777 Ext.

Your Ref:

Our Ref:
ACM/RB M5.05
If 'phoning please ask for:

Dr A C Marr

6th February 1990

Miss H Sweeting
Behavioural Sciences Group
University of Glasgow
4 Lilybank Gardens
GLASGOW

Dear Miss Sweeting

ANTICIPATORY GRIEF IN CARERS OF THE DEMENTING ELDERLY

I am writing to confirm that your proposed research project has received approval from the Inverclyde Ethical Committee.

The only minor recommendation to be made concerned the consent form where it was suggested that the wording might be "I am prepared to be involved in the research project concerning the caregivers of elderly persons".

The Committee are anxious to know of the progress and outcome of any studies which they approve, and I will be pleased if you are able to keep us informed.

Yours sincerely

A C Marr
Consultant in Public Health Medicine

IV. PILOT STUDY: LETTER TO POTENTIAL SUBJECTS



ARGYLL & CLYDE HEALTH BOARD

Your Ref:

Our Ref:

Date:

Dykebar Hospital

Grahamston Road
Paisley PA2 7DE
Tel: 041-884 5122

If telephoning, please ask for:
Extension 229

Dear

I work at Dykebar Hospital as a Clinical Psychologist. I am conducting a research project with people who either currently care, or have cared in the past for an elderly confused person. It is to investigate how they feel about their situation, and how they cope with the problems.

I understand that you are one of these carers. I therefore wonder if you might be willing to participate in my research? It would involve a discussion concerning both the problems which crop up, and the ways you have been feeling as you give care. I should add that the doctors from Dykebar who work with the elderly patients know about this project, and are happy for it to go ahead.

If you would like to participate, then so as to cause as little inconvenience as possible, I would be able to see you at your own home. I would be able to visit you on

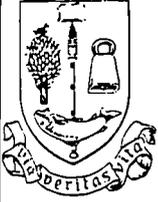
I hope that this will be convenient, but if you do not wish to be involved, or if the appointment is unsuitable, please could you let me know by completing the enclosed form. If I do not hear from you then I will assume that you would like me to visit you.

If you have any queries, or would like further information, please do not hesitate to get in touch. (My daytime phone number is 041-884 5122 Extension 229).

Yours sincerely,

Helen Sweeting.
Senior Clinical Psychologist.

V. MAIN STUDY: VERSION "A" LETTER TO POTENTIAL SUBJECTS



UNIVERSITY OF GLASGOW

BEHAVIOURAL SCIENCES GROUP

PROFESSOR KEITH MILLAR, PhD. C.Psychol. FBPSS
JACQUELINE M. ATKINSON, PhD. C.Psychol. AFBPS
MARY L. M. GILHOOLY, M.Ed. PhD. C.Psychol. AFBPS
RICHARD H. HAMMERSLEY, PhD. C.Psychol. AFBPS

4 Lilybank Gardens
Glasgow
G12 8QQ.

Tel: 041-339 8855 Ext. 6068
Direct Dialling: 041-330 5016
Telex: 777070 UNIGLA
Fax: 041-330 4808

Dear XXXXXXX,

I am a Clinical Psychologist and I am conducting a research project with people who either currently care, or have cared in the past for an elderly confused person. It is to investigate how they feel about their situation, and how they cope with the problems. The aim is improve help to carers in the future by understanding the problems that they have to deal with.

I understand that you are one of these carers. I therefore wonder if you might be willing to participate in my research? It would involve a discussion concerning both the problems which crop up, and the ways you have been feeling as you give care. I should add that the staff at XXXXXX Hospital who work with the elderly patients know about this project, and are happy for it to go ahead.

If you would like to participate, then so as to cause as little inconvenience as possible, I would be able to see you at your own home. I would be able to visit you on

MONDAY 30th OCTOBER at 2.00pm

I hope that this will be convenient, but if you do not wish to be involved, or if the appointment is unsuitable, please could you let me know by completing the enclosed form. If I DO NOT hear from you then I will assume that you WOULD LIKE me to visit you.

If you have any queries, or would like further information, please do not hesitate to get in touch.

Yours sincerely,

Helen Sweeting

VI. MAIN STUDY: REPLY FORM FOR NON-PARTICIPATING
SUBJECTS ENCLOSED WITH LETTER VERSION "A"

To: Helen Sweeting
University of Glasgow Behavioural Sciences Group
4 Lilybank Gardens
GLASGOW
G12 8QQ

Phone: 041-339 8855, Extension 6068 (Secretary)

PLEASE MARK WHICHEVER STATEMENT IS TRUE:

..... I DO NOT wish to participate in the research project
concerning the caregivers of elderly persons.
(If this is the case then you will not be contacted
further.)

..... I DO wish to participate in the project, but would like
to arrange an alternative appointment.
(Any preferences? I would be happy to visit in the
evening if that was easier for you.)

Signed Date

Address

.....

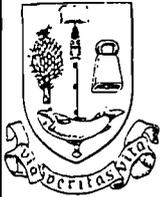
.....

Phone:

PLEASE RETURN IN STAMPED ADDRESSED ENVELOPE.

THANK YOU.

VII. MAIN STUDY: VERSION "B" LETTER TO POTENTIAL SUBJECTS



UNIVERSITY OF GLASGOW

BEHAVIOURAL SCIENCES GROUP

PROFESSOR KEITH MILLAR, PhD, C.Psychol, FBPSS
JACQUELINE M. ATKINSON, PhD, C.Psychol, AFBPS
MARY L. M. GILHOOLY, M.Ed, PhD, C.Psychol, AFBPS
RICHARD H. HAMMERSLEY, PhD, C.Psychol, AFBPS

4 Lilybank Gardens
Glasgow
G12 8QQ
Tel: 041-339 8855 Ext. 6068
Direct Dialling: 041-330 5016
Telex: 777070 UNIGLA
Fax: 041-330 4808

Dear Relative,

I am a Clinical Psychologist and I am conducting a research project with people who either currently care, or have cared in the past for an elderly confused person. It is to investigate how they feel about their situation, and how they cope with the problems. The aim is to improve help to carers in the future by understanding the problems that they have to deal with.

I understand that you are one of these carers. I therefore wonder if you might be willing to participate in my research? It would involve a discussion concerning both the problems which crop up, and the ways you have been feeling as you give care. I should add that the staff at the XXXXX Day Hospital who work with the elderly patients know about this project, and are happy for it to go ahead.

If you would like to participate, then so as to cause as little inconvenience as possible, I would be able to see you at your own home.

If you would like to be involved, please could you let me know by using the stamped addressed envelope to return the form at the end of this letter. I will then contact you to arrange a convenient time to visit.

If you have any queries, or would like further information, please do not hesitate to get in touch.

Yours sincerely,

Helen Sweeting

To : Helen Sweeting, Glasgow University Behavioural Sciences Group, 4 Lilybank Gardens, Glasgow.
041 - 339 8855 (extension 6068)

I would like to participate in the research project concerning the caregivers of elderly persons.

Signed Date

Address

.....

.....

Phone:

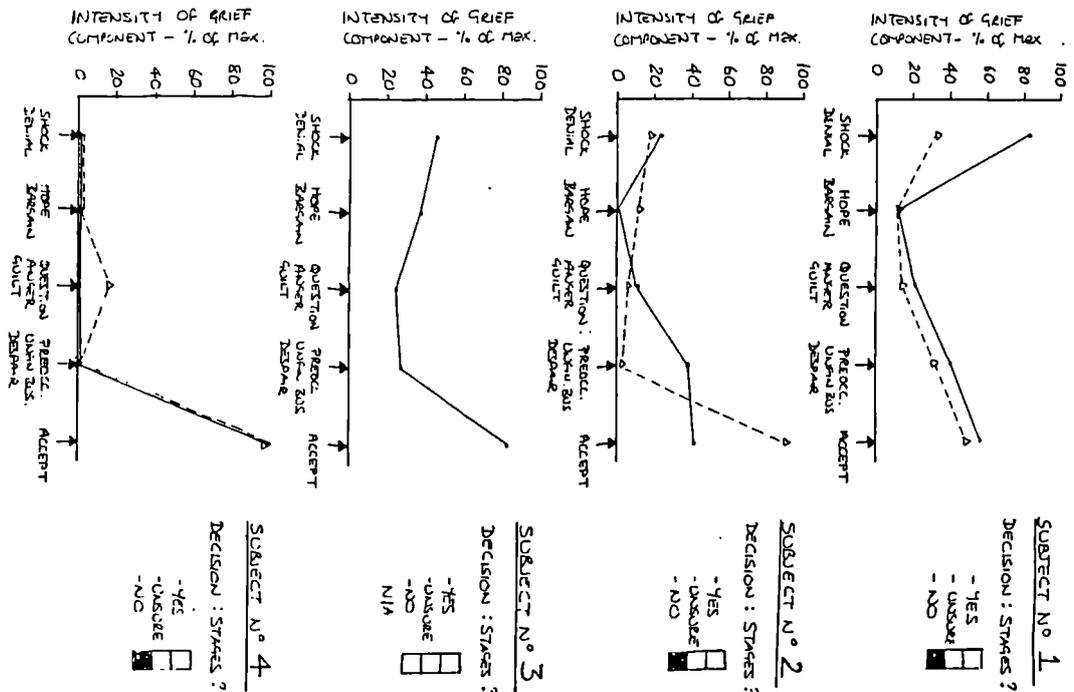
APPENDIX SIX

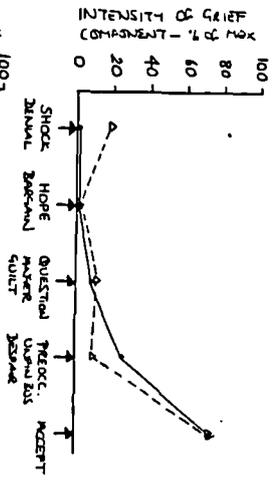
SUBJECT-BY-SUBJECT GRAPHS SHOWING "PATTERN" OF REACTIONS AT TIME OF INTERVIEW AND EARLIER ON IN THE COURSE OF DEMENTIA IN THEIR RELATIVE

These graphs show the "pattern" of each subject's reactions both at the time of the interview, and earlier on in the course of their relative's dementia. They were used as the basis for the classification of subjects' emotional and behavioural reactions as "stages", "unsure stages", or "no stages".

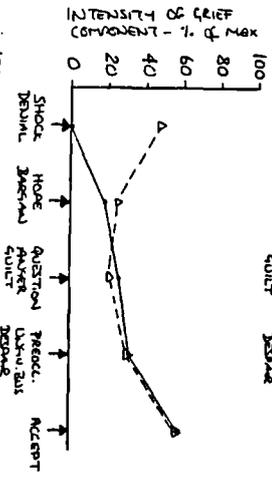
—●— = pattern of carer reactions "nowadays"

—△— = pattern of carer reactions "earlier on"

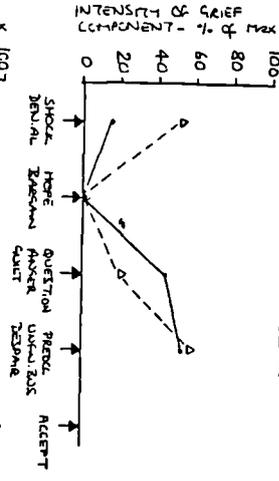




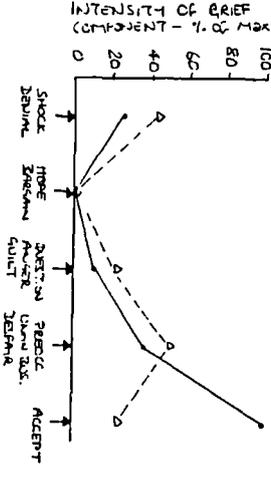
SUBJECT No 5
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



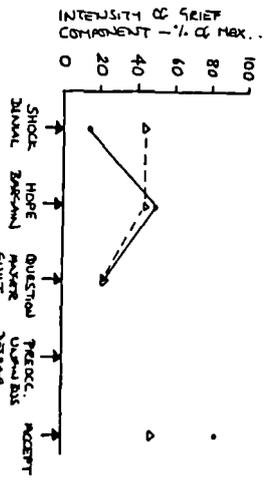
SUBJECT No 6
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



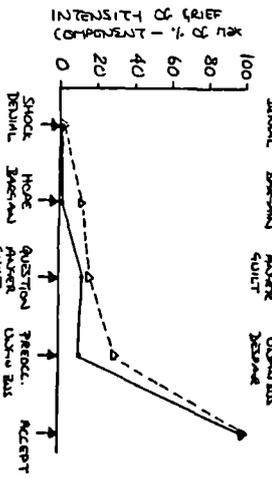
SUBJECT No 7
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



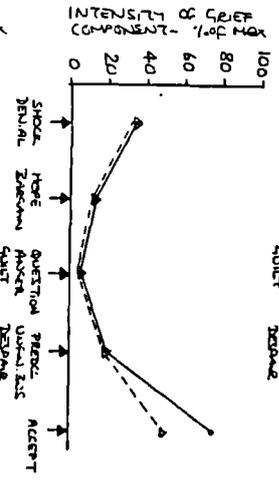
SUBJECT No 8
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



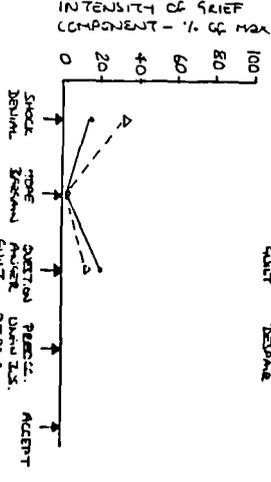
SUBJECT No 9
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



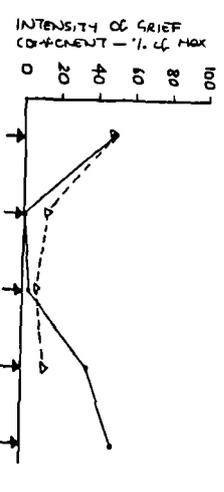
SUBJECT No 10
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



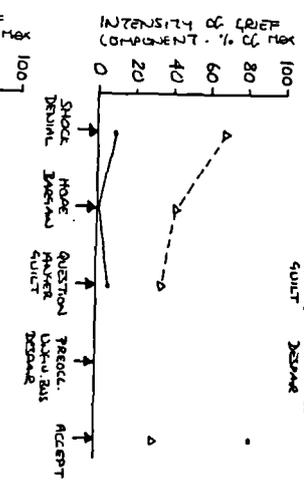
SUBJECT No 11
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



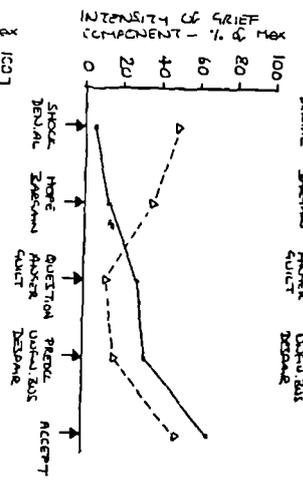
SUBJECT No 12
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



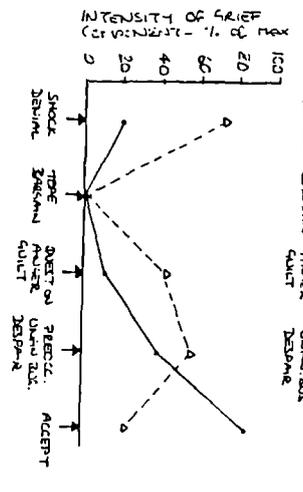
SUBJECT No 13
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



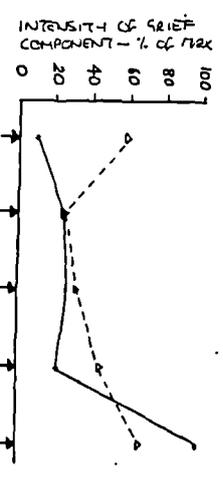
SUBJECT No 14
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



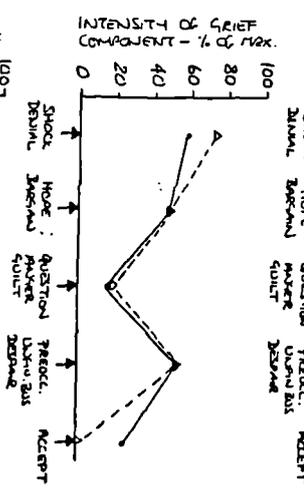
SUBJECT No 15
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



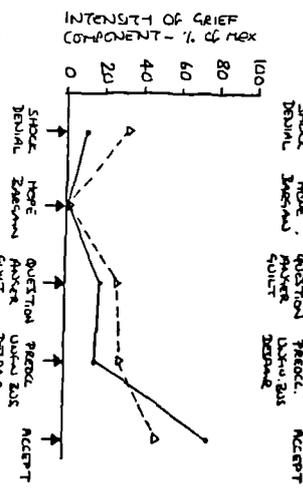
SUBJECT No 16
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



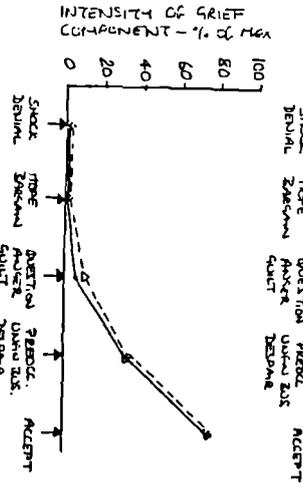
SUBJECT No 17
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



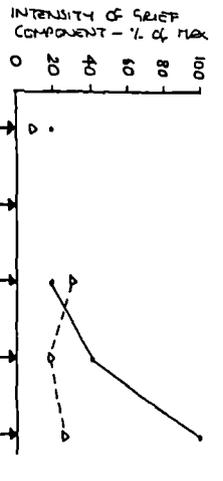
SUBJECT No 18
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



SUBJECT No 19
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



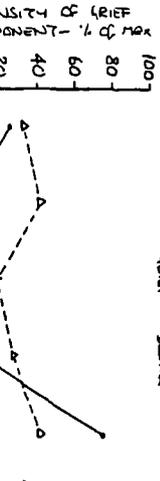
SUBJECT No 20
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



SUBJECT No 21

DECISION : STAGES ?

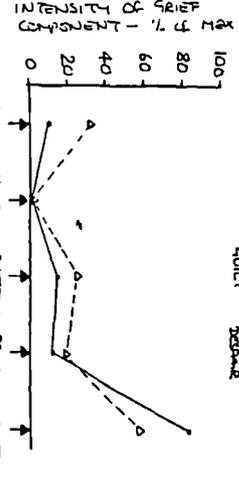
- YES
- UNSURE
- NO



SUBJECT No 22

DECISION : STAGES ?

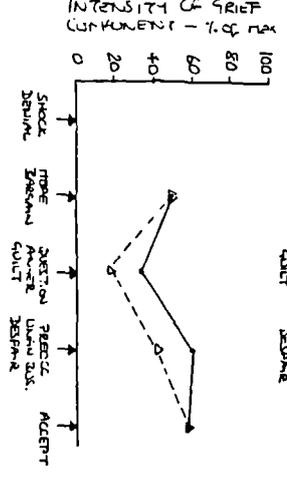
- YES
- UNSURE
- NO



SUBJECT No 23

DECISION : STAGES ?

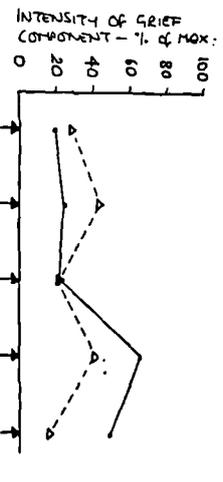
- YES
- UNSURE
- NO



SUBJECT No 24

DECISION : STAGES ?

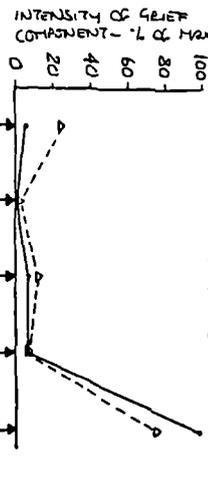
- YES
- UNSURE
- NO



SUBJECT No 25

DECISION : STAGES ?

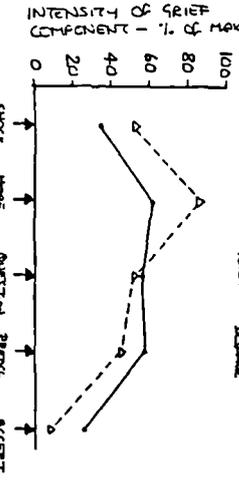
- YES
- UNSURE
- NO



SUBJECT No 26

DECISION : STAGES ?

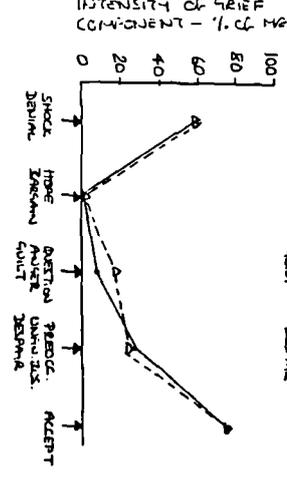
- YES
- UNSURE
- NO



SUBJECT No 27

DECISION : STAGES ?

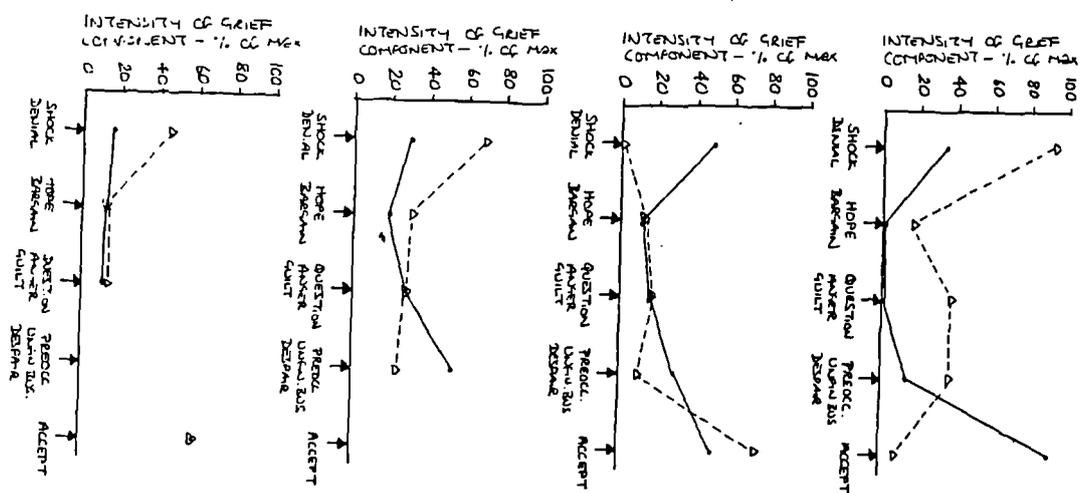
- YES
- UNSURE
- NO



SUBJECT No 28

DECISION : STAGES ?

- YES
- UNSURE
- NO

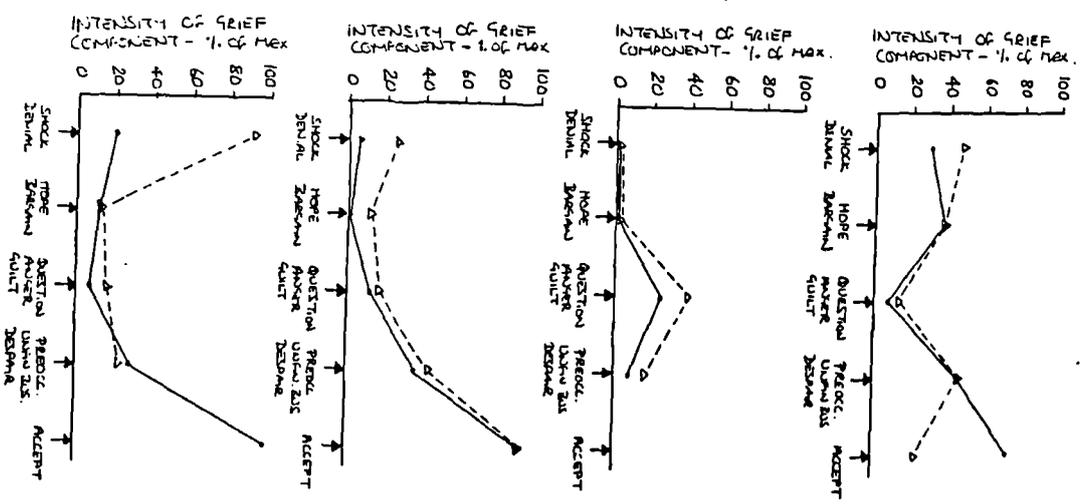


SUBJECT N° 29
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

SUBJECT N° 30
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

SUBJECT N° 31
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

SUBJECT N° 32
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

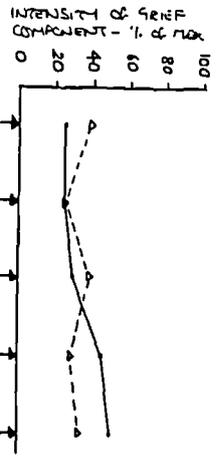


SUBJECT N° 33
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

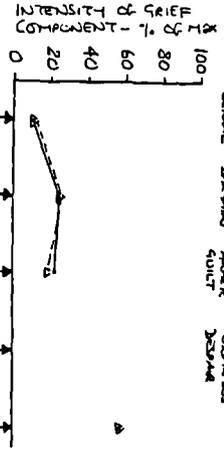
SUBJECT N° 34
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

SUBJECT N° 35
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

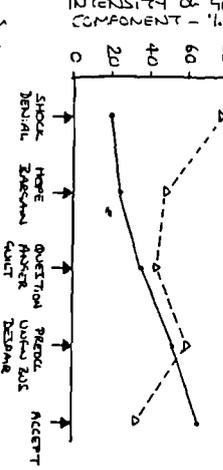
SUBJECT N° 36
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



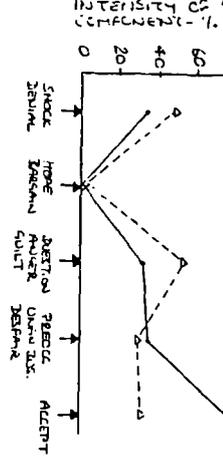
SUBJECT No 37
 Decision: Stages?
 - YES
 - UNSURE
 - NO



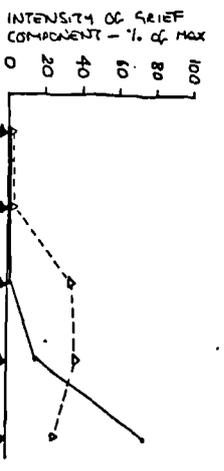
SUBJECT No 38
 Decision: Stages?
 - YES
 - UNSURE
 - NO



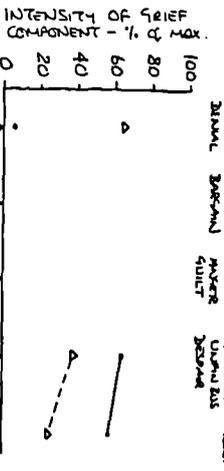
SUBJECT No 39
 Decision: Stages?
 - YES
 - UNSURE
 - NO



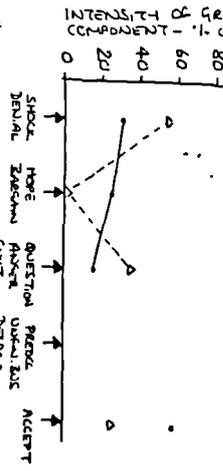
SUBJECT No 40
 Decision: Stages?
 - YES
 - UNSURE
 - NO



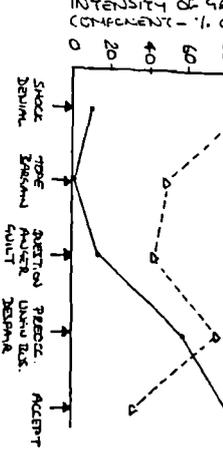
SUBJECT No 41
 Decision: Stages?
 - YES
 - UNSURE
 - NO



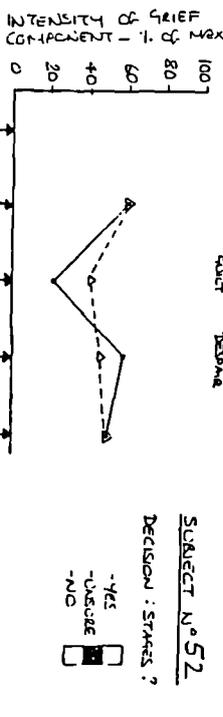
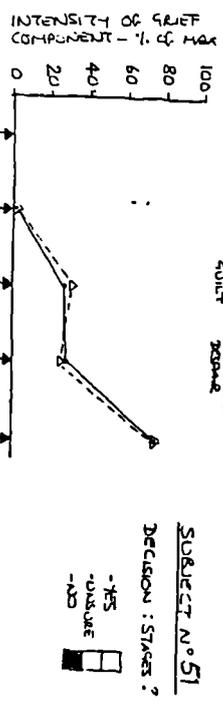
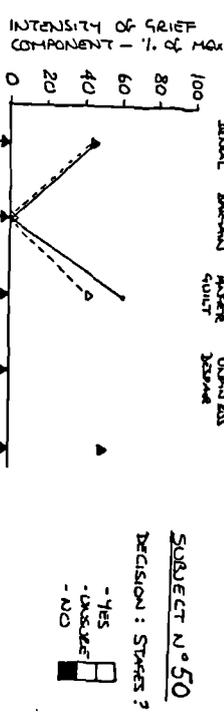
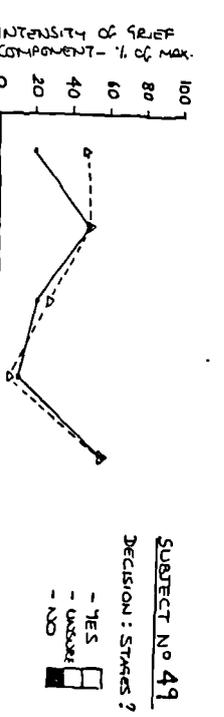
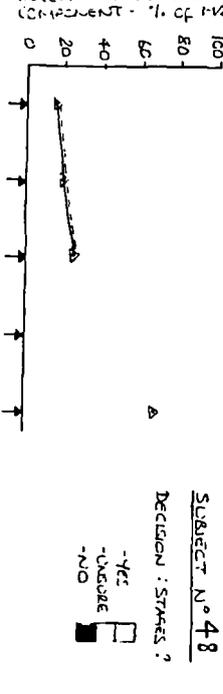
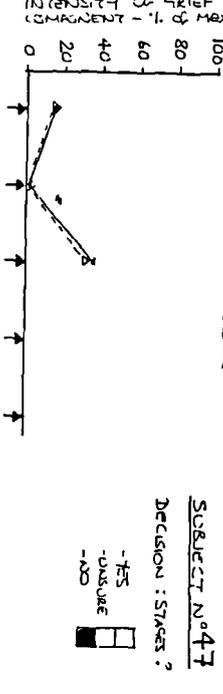
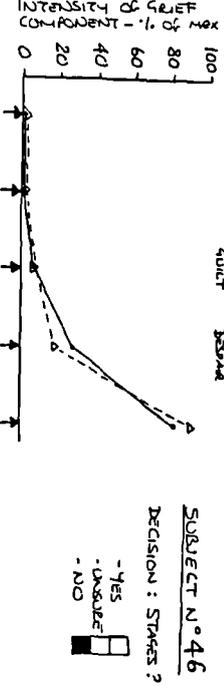
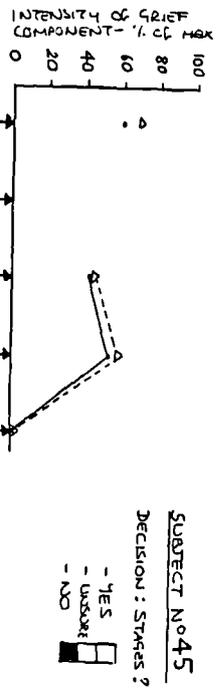
SUBJECT No 42
 Decision: Stages?
 - YES
 - UNSURE
 - NO

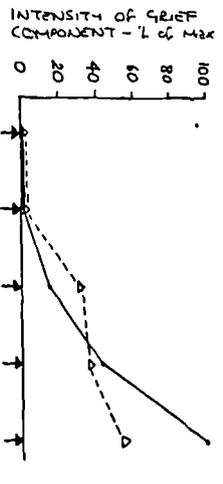


SUBJECT No 43
 Decision: Stages?
 - YES
 - UNSURE
 - NO

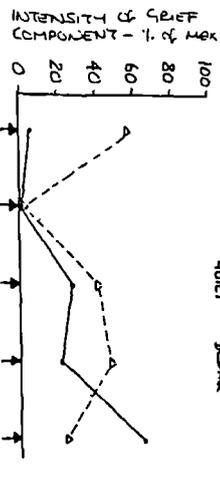


SUBJECT No 44
 Decision: Stages?
 - YES
 - UNSURE
 - NO

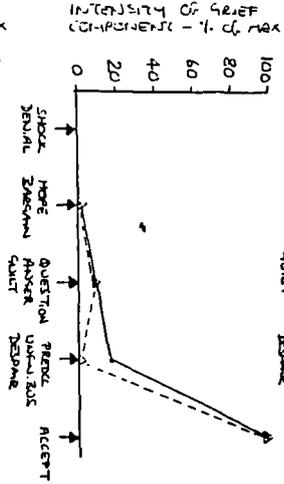




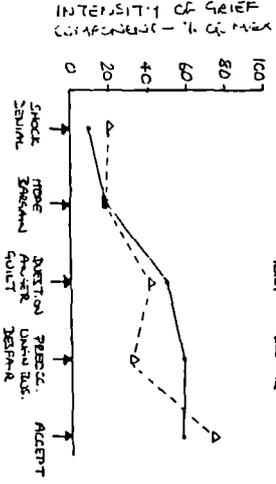
SUBJECT N^o 53
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



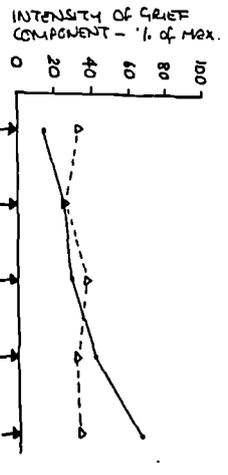
SUBJECT N^o 54
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



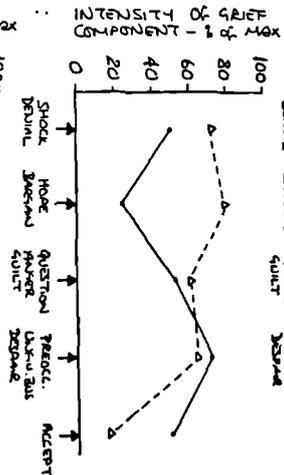
SUBJECT N^o 55
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



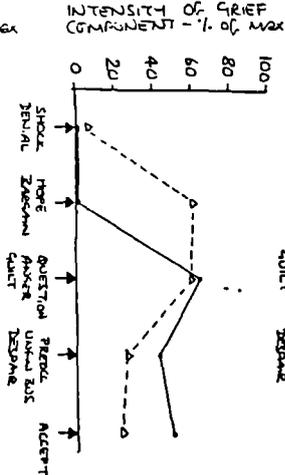
SUBJECT N^o 56
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



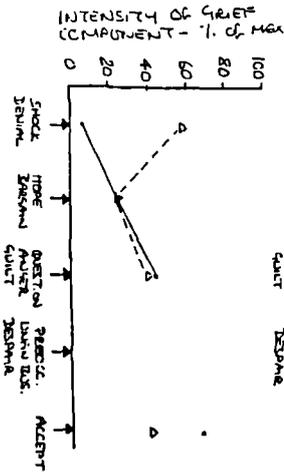
SUBJECT N^o 57
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



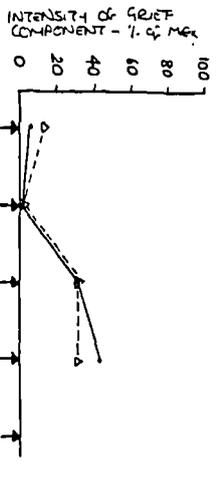
SUBJECT N^o 58
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



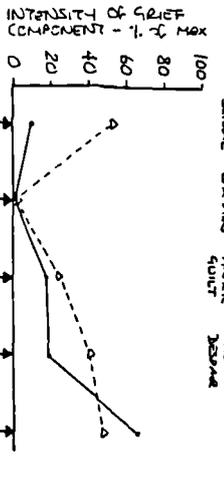
SUBJECT N^o 59
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



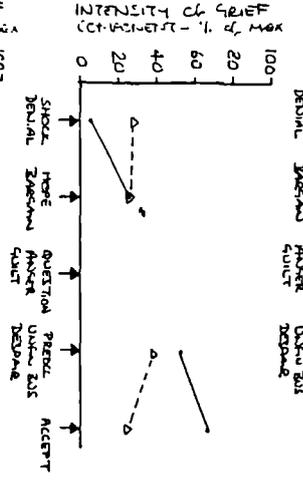
SUBJECT N^o 60
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



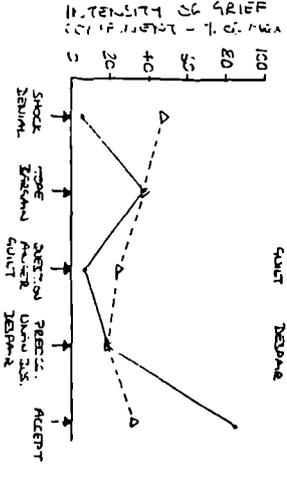
SUBJECT No 61
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



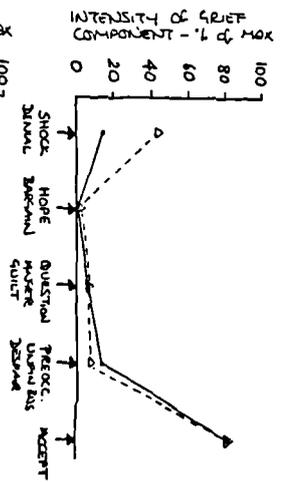
SUBJECT No 62
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



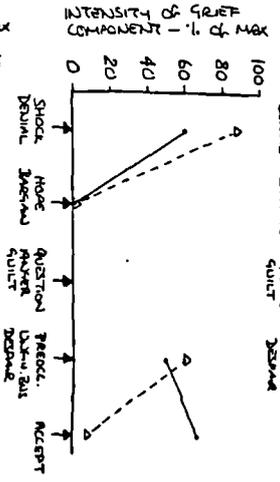
SUBJECT No 63
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



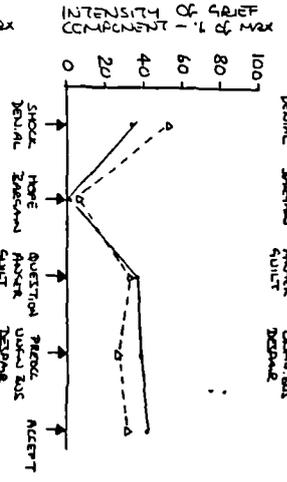
SUBJECT No 64
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



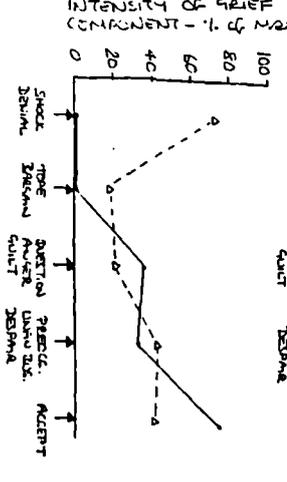
SUBJECT No 65
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



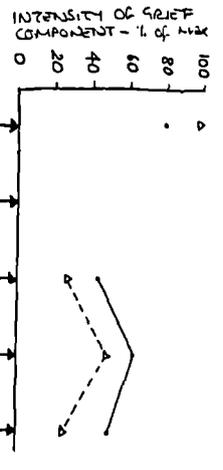
SUBJECT No 66
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



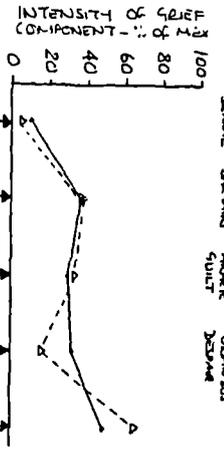
SUBJECT No 67
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



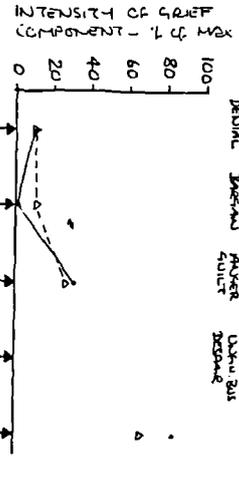
SUBJECT No 68
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



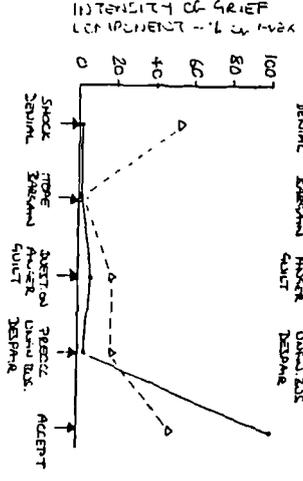
SUBJECT No 69
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



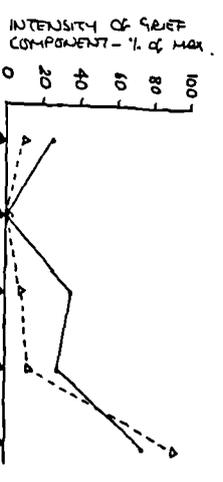
SUBJECT No 70
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



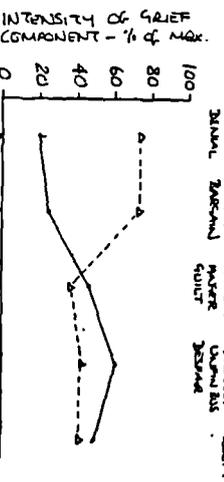
SUBJECT No 71
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



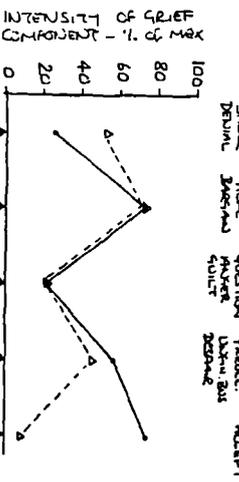
SUBJECT No 72
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



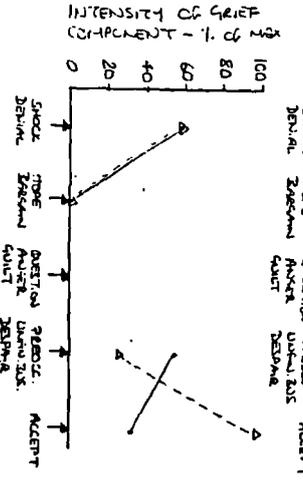
SUBJECT No 73
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



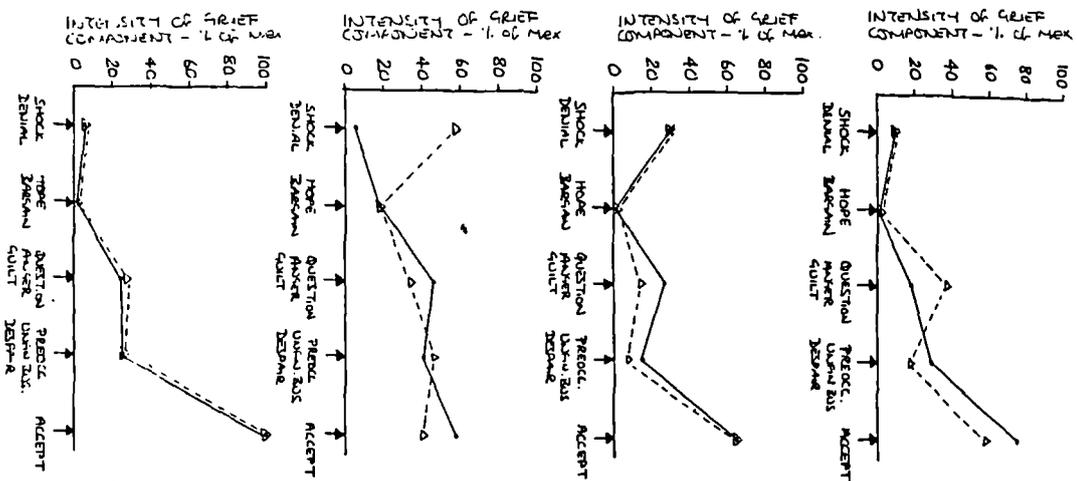
SUBJECT No 74
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



SUBJECT No 75
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



SUBJECT No 76
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

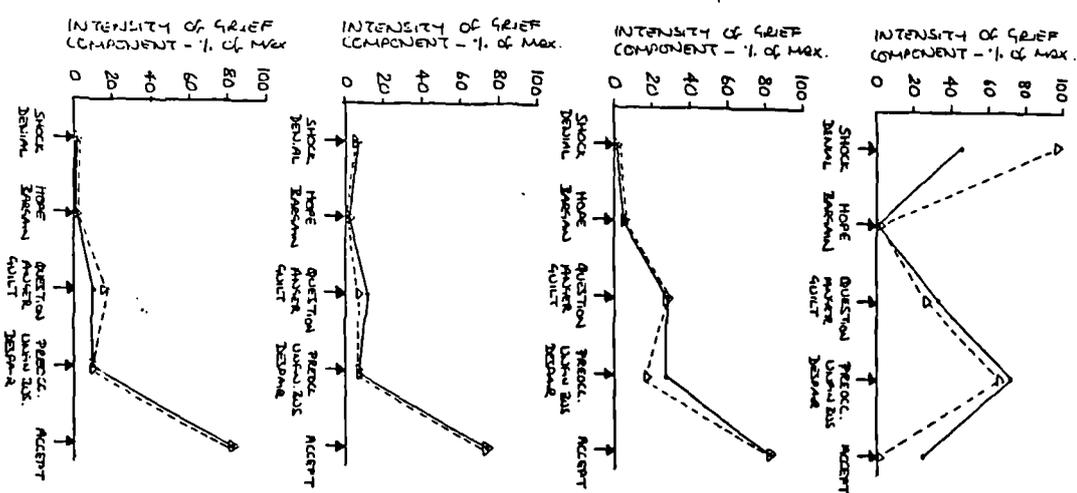


SUBJECT N° 77
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

SUBJECT N° 78
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

SUBJECT N° 79
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

SUBJECT N° 80
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

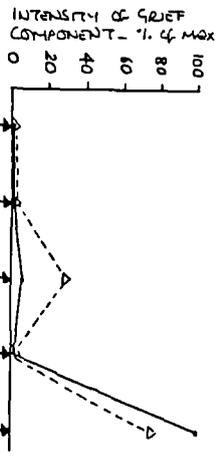


SUBJECT N° 81
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

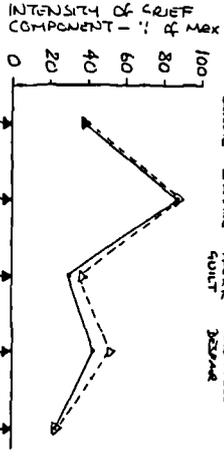
SUBJECT N° 82
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

SUBJECT N° 83
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

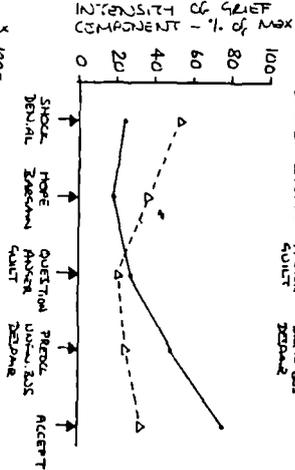
SUBJECT N° 84
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



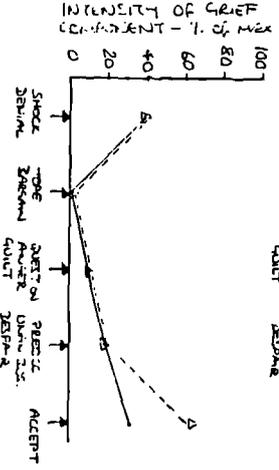
SUBJECT N° 85
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



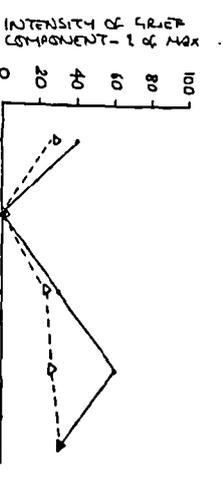
SUBJECT N° 86
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



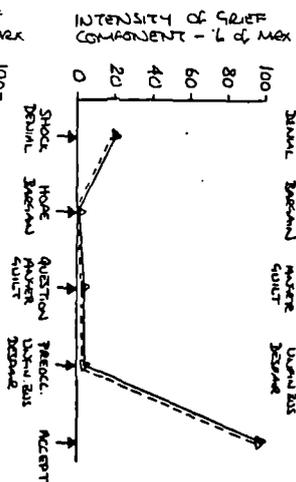
SUBJECT N° 87
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



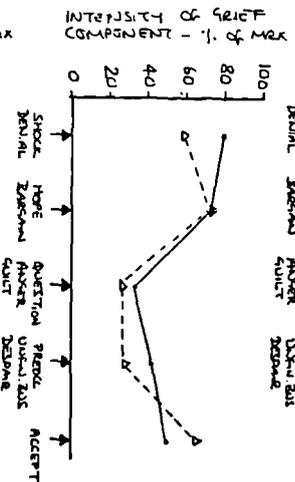
SUBJECT N° 88
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



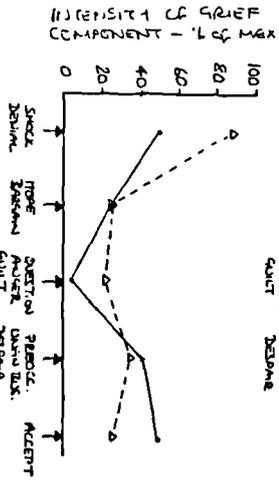
SUBJECT N° 89
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



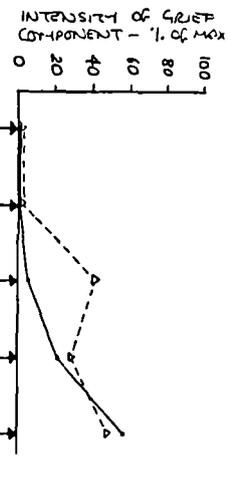
SUBJECT N° 90
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



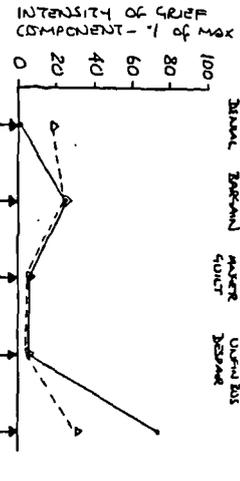
SUBJECT N° 91
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



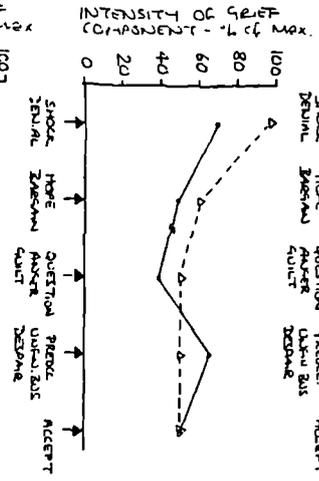
SUBJECT N° 92
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



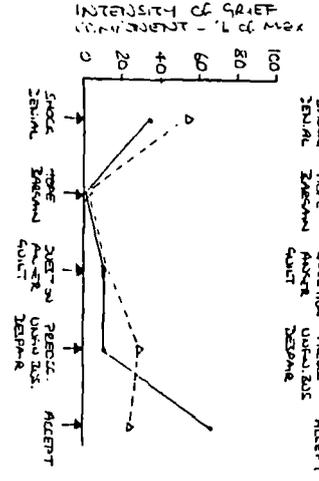
SUBJECT No 93
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



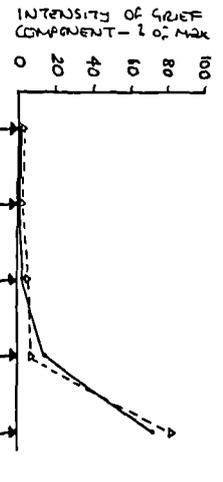
SUBJECT No 94
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



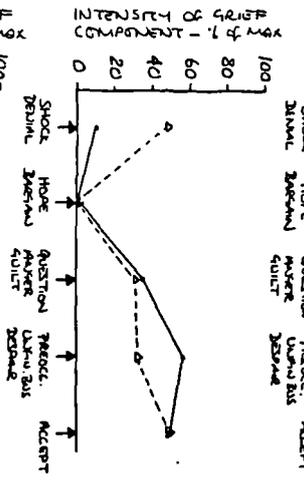
SUBJECT No 95
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



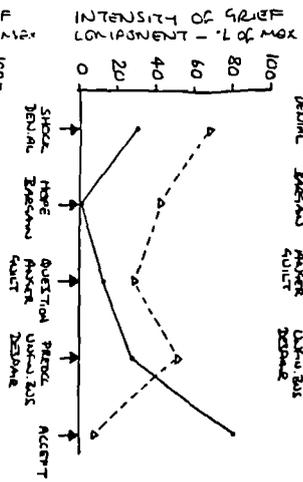
SUBJECT No 96
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



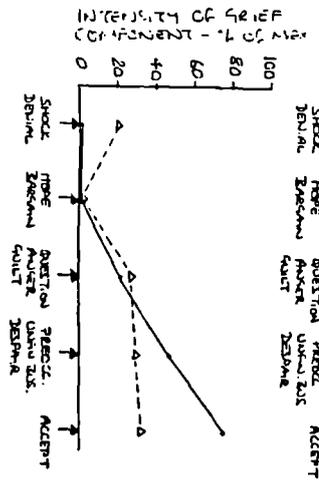
SUBJECT No 97
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



SUBJECT No 98
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



SUBJECT No 99
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO



SUBJECT No 100
 DECISION : STAGES ?
 - YES
 - UNSURE
 - NO

APPENDIX SEVEN

"STAGES", "UNSURE STAGES" AND "NO STAGES":
GRIEF COMPONENT CORRELATION MATRICES PLUS COMPARISONS
AND CORRELATIONS OF REACTIONS OVER TIME

Table A7.1

Correlation matrices (Pearson's r.) - I.S. components of grief: comparison of subjects whose reactions were categorised as "Stages", "Unsure-Stages" or "No Stages"

	Shock/ Denial	Hope/ Barg.	Quest/ Anger/ Guilt	Preocc/ Un.Bus/ Despair	Accept
<u>"STAGES"</u>					
Shock/		*			*
Denial.....	1.000	0.394	0.091	0.296	-0.377
Hope/			*	*	**
Bargaining.....	1.000	0.364	0.429	-0.545	
Questioning/				***	***
Anger/Guilt.....	1.000	0.614	-0.646		
Preocc./Unfin.					***
Bus./Despair.....	1.000	-0.576			
Acceptance.....					1.000
<u>"UNSURE STAGES"</u>					
Shock/				**	**
Denial.....	1.000	0.195	0.078	0.516	-0.565
Hope/				**	
Bargaining.....	1.000	0.176	0.505	-0.129	
Questioning/				***	*
Anger/Guilt.....	1.000	0.662	-0.451		
Preocc./Unfin.					***
Bus./Despair.....	1.000	-0.704			
Acceptance.....					1.000
<u>"NO STAGES"</u>					
Shock/		*	*	***	***
Denial.....	1.000	0.329	0.373	0.557	-0.592
Hope/			*		**
Bargaining.....	1.000	0.267	0.281	-0.467	
Questioning/				***	**
Anger/Guilt.....	1.000	0.606	-0.517		
Preocc./Unfin.					***
Bus./Despair.....	1.000	-0.676			
Acceptance.....					1.000

* = p<.05 ** = p<.01 *** = p<.001

Table A7.2

Correlation matrices (Pearson's r.) - F.A. components of grief: comparison of subjects whose reactions were categorised as "Stages", "Unsure-Stages" or "No Stages"

	Deny	Disb./ Hope	Protest	Yearn	Mourn
<u>"STAGES"</u>					
Deny.....	1.000	0.208	0.115	0.055	0.374
			**		**
Disbelief/Hope.....	1.000	1.000	0.528	0.202	0.466
				*	*
Protest.....			1.000	0.360	0.369
					*
Yearn.....				1.000	0.312
Mourn.....					1.000
<u>"UNSURE STAGES"</u>					
Deny.....	1.000	0.098	-0.042	0.392	0.311
				*	*
Disbelief/Hope.....	1.000	1.000	0.260	0.453	0.378
					**
Protest.....			1.000	0.279	0.499
					**
Yearn.....				1.000	0.504
Mourn.....					1.000
<u>"NO STAGES"</u>					
Deny.....	1.000	0.157	0.246	0.311	0.371
				*	**
Disbelief/Hope.....	1.000	1.000	-0.033	0.281	0.271
					**
Protest.....			1.000	-0.032	0.489
					**
Yearn.....				1.000	0.322
Mourn.....					1.000

* = p<.05 ** = p<.01

Table A7.3

Significant differences (Wilcoxon's matched-pairs signed-ranks test: z) between scores on each of the "nowadays" individual grief items when compared with "earlier on": comparison of subjects whose reactions were categorised as "Stages", "Unsure-Stages", or "No Stages"

GRIEF SCALE ITEM	"STAGES" Proportion (%) carers reporting that over time item is:				"UNSURE STAGES" Proportion (%) carers reporting that over time item is:				"NO STAGES" Proportion (%) carers reporting that over time item is:			
	INC.	DEC.	SAME	z	INC.	DEC.	SAME	z	INC.	DEC.	SAME	z
Feel shocked/ dazed.....	0	80	20	-4.29	4	50	46	-3.21	7	22	71	-1.45
Think "It can't be".....	3	67	30	-3.94	0	33	67	-2.67	7	12	81	-0.63
Minimise problems.....	0	47	53	-3.30	0	28	72	-2.52	5	7	88	-0.67
Try to avoid emotion.....	14	43	43	-2.63	15	30	55	-1.73	15	8	77	-1.24
Difficult to talk.....	0	43	57	-3.18	7	28	65	-2.29	2	5	93	-0.27
Hope might get better....	0	50	50	-3.41	7	11	82	-0.40	0	7	93	-1.60
Maybe doctors mistaken.....	0	27	73	-2.52	0	4	96	-1.00	0	2	98	-1.00
Consult media for cure.....	0	13	87	-1.83	0	0	100	0.00	0	2	98	-1.00
Make bargains.....	3	13	84	-1.62	0	0	100	0.00	2	0	98	-1.00
Ask "Why?".....	0	33	67	-2.80	4	11	85	-0.91	10	5	85	-0.73
Maybe more to help.....	7	23	70	-1.24	11	14	75	-0.51	5	15	80	-1.33
Think maybe contributed...0	0	3	97	-1.00	0	4	96	-1.00	2	0	98	-1.00
Guilty if enjoy self...10	0	37	53	-2.45	11	11	78	-0.42	10	10	80	-0.42
Irritable with others..20	0	23	57	-0.66	11	18	71	-0.70	15	15	70	-0.71
Angry at dementia.....	10	23	67	-1.27	14	7	79	-0.31	15	5	80	-0.98
Angry with sufferer.....	20	53	27	-2.55	29	39	32	-1.69	20	32	48	-1.30
Angry with God.....	0	3	97	-1.00	0	0	100	0.00	5	5	90	-0.73
Angry with formal help..13	0	30	57	-1.64	7	18	75	-1.52	5	10	85	-0.63
Preoccupied...27	0	27	46	-0.23	14	18	68	-0.06	7	2	91	-0.86
Look back....20	0	27	53	-0.28	21	4	75	-1.52	13	0	87	-2.02
Wish for past.....	30	33	37	-0.02	14	4	82	-0.94	5	0	95	-1.34
Wish sufferer could done....3	0	3	94	-0.45	11	0	89	-1.60	5	3	92	0.00
Wish could say.....	17	3	80	-0.94	24	0	76	-2.20	11	0	89	-1.82
Upset if think of sufferer..37	0	47	16	-1.40	56	7	37	-2.65	51	10	39	-3.07
Cry if think of sufferer..33	0	43	24	-1.22	44	12	44	-2.21	37	7	56	-2.35
Depressed....33	0	43	24	-0.88	52	7	41	-2.38	37	5	58	-2.91
Own life meaningless..27	0	17	56	-0.03	35	8	57	-2.04	17	2	81	-2.03
Calm about dementia.....	82	0	18	-4.20	50	15	35	-2.70	16	24	60	-0.28
Calm about future.....	43	10	47	-2.44	24	16	60	-0.87	5	24	71	-2.04
Accept what's happened....86	0	14	4	-4.29	65	0	35	-3.62	11	8	81	-0.59

* = p<.05 ** = p<.01 *** = p<.001 INC = Increased, DEC. = Decreased.

Table A7.4

Correlation coefficients (Spearman's rho) between scores on each individual grief item for "nowadays" and "earlier on": comparison of subjects whose reactions were categorised as "Stages", "Unsure-Stages", or "No Stages"

GRIEF SCALE ITEM	"STAGES"	"UNSURE STAGES"	"NO STAGES"
Feel shocked/dazed.....	0.273.....	0.453**.....	0.453**
Think "It can't be".....	0.227.....	0.595**.....	0.563***
Minimise problems.....	0.336*.....	0.597***.....	0.671***
Try to avoid emotion.....	0.389*.....	0.488**.....	0.687***
Difficult talking to others...	0.552**.....	0.664***.....	0.818***
Hope might get better.....	0.553**.....	0.798***.....	0.916***
Maybe doctors mistaken.....	N/A.....	0.721***.....	0.716***
Consult media for cures.....	0.577***.....	1.000***.....	0.910***
Make bargains.....	0.846***.....	1.000***.....	0.961***
Ask "Why?".....	0.540**.....	0.699***.....	0.785***
Think maybe something more....	0.386*.....	0.800***.....	0.748***
Think maybe contributed.....	0.802***.....	0.801***.....	0.999***
Guilty if enjoy self.....	0.534**.....	0.749***.....	0.777***
Irritable with others.....	0.524**.....	0.820***.....	0.704***
Angry with dementia.....	0.553**.....	0.823***.....	0.825***
Angry with sufferer.....	-0.041.....	-0.258.....	0.216
Angry with God.....	0.997***.....	1.000***.....	0.631***
Angry with formal help.....	0.562**.....	0.731***.....	0.824***
Preoccupied.....	0.387*.....	0.647***.....	0.925***
Look back to past.....	0.455**.....	0.621***.....	0.819***
Wish for past.....	0.286.....	0.908***.....	0.919***
Wish suff. could have done....	0.935***.....	0.968***.....	0.798***
Wish could say.....	0.842***.....	0.977***.....	0.914***
Upset if think of sufferer...	-0.213.....	0.652***.....	0.250
Cry if think of sufferer.....	-0.101.....	0.430*.....	0.662***
Depressed.....	0.210.....	0.666***.....	0.773
Own life meaningless.....	0.463**.....	0.787***.....	0.791***
Think calmly - what's wrong...	0.294.....	0.139.....	0.467**
Think calmly - future.....	0.108.....	0.479**.....	0.737***
Accept what's happened.....	0.315.....	0.482**.....	0.765***

* = p<.05 ** = p<.01 *** = p<.001

APPENDIX EIGHT

INCLUSION AND CODING OF VARIABLES ENTERED INTO STEPWISE
MULTIPLE REGRESSION ANALYSES

I. VARIABLES ENTERED INTO "FIRST ROUND" REGRESSION ANALYSES

Stepwise multiple regression analyses:

- 1 = Current components of grief (I.S. and F.A.).
- 2 = Social death (factors "Anticipate Death", "Life Pointless" and "Sufferer Unaware", and total Rated Social Death).
- 3 = Interview wellbeing/burden measures ("Strain Scale", single-item "Carer Coping" and "Carer Life Satisfaction" measures).
- 4 = Self-complete wellbeing/burden measures (GHQ-28 and ABS).
- 5 = Preference for institutional care ("Carer Willingness to Institutionalise" and rated Attitude to Continued Care).
- 6 = Quality of current carer-sufferer relationship

<u>VARIABLES ENTERED INTO EACH EQUATION</u>	<u>REGRESSION ANALYSIS</u>					
	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>
<u>CARER CHARACTERISTICS EQUATION</u>						
<u>Carer gender</u>	*	*	*	*	*	*
<u>Carer age</u>	*	*	*	*	*	*
<u>Carer religiosity</u>	*	*	*	*		
<u>Carer learning of diagnosis and prognosis</u>	*					
<u>Carer general knowledge of dementia</u>	*	*	*	*	*	*
<u>Carer overall perception of dementia</u>	*	*	*	*	*	*
<u>Carer perception of having experienced grief</u>		*	*	*	*	*
<u>Carer work outside the home</u>			*	*	*	*
<u>Carer given up work to care</u>			*	*		
<u>Number of professional groups with whom carer had spoken</u>			*	*	*	*
<u>Carer use of "negative coping techniques"</u>				*		
<u>Carer use of "positive coping techniques"</u>				*		
<u>Single-item "Carer Coping" score</u>					*	
<u>Single-item "Carer Life Satisfaction" score</u>					*	
<u>SUFFERER CHARACTERISTICS EQUATION</u>						
<u>Sufferer gender</u>	*	*	*	*	*	*
<u>Sufferer age</u>	*	*	*	*	*	*
<u>Sufferer living arrangements</u>	*	*	*	*	*	*
<u>Time since onset of impairments</u>	*	*	*	*	*	*
<u>Time since diagnosis of dementia</u>	*	*	*	*	*	*
<u>Overall change in sufferer perceived by carer</u>	*	*	*	*	*	*
<u>Most important sufferer change perceived by carer</u>	*	*	*	*	*	*
<u>Sufferer ability to recognise carer</u>	*	*	*	*	*	*
<u>Sufferer physical changes perceived by carer</u>	*	*	*	*	*	*
<u>Speed of changes perceived by carer</u>			*	*		
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>						
<u>Total frequency problems from domain "Depend"</u>	*	*	*	*	*	*
<u>From behavioural domain "Can't Do"</u>	*	*	*	*	*	*
<u>From behavioural domain "Incontinence/Hygiene"</u>	*	*	*	*	*	*
<u>From behavioural domain "Apathy"</u>	*	*	*	*	*	*
<u>From behavioural domain "Disturb"</u>	*	*	*	*	*	*
<u>From behavioural domain "Demand"</u>	*	*	*	*	*	*

Variables entered into "first round" regression analyses, continued ...

VARIABLES ENTERED INTO EACH EQUATION	REGRESSION ANALYSIS					
	1	2	3	4	5	6
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>						
Blood/role relationship	*	*	*	*	*	*
Quality of premorbid relationship	*	*	*	*	*	*
Quality of current relationship	*	*	*	*	*	*
Change in quality of relationship	*	*	*	*	*	*
<u>CARER I.S. COMPONENTS OF GRIEF EQUATION</u>						
Current intensity "Shock/Denial"	*	*	*	*	*	*
Current intensity "Hope/Bargaining"	*	*	*	*	*	*
Current intensity "Questioning/Anger/Guilt"	*	*	*	*	*	*
Current intensity "Preoccupation/Unfin.Bus./Despair"	*	*	*	*	*	*
Current intensity "Acceptance"	*	*	*	*	*	*
<u>CARER F.A. COMPONENTS OF GRIEF EQUATION</u>						
Current intensity "Disbelief/Hope"	*					
Current intensity "Deny"	*					
Current intensity "Protest"	*					
Current intensity "Yearn"	*					
Current intensity "Mourn"	*					
<u>SUFFERER SOCIAL DEATH EQUATION</u>						
Social death factor "Anticipate Death" score	*	*	*			
Social death factor "Life Pointless" score	*	*	*			
Social death factor "Sufferer Unaware" score	*	*	*			
<u>CAREGIVING SITUATION EQUATION</u>						
Hours per week relief from caring	*					
Satisfaction with help from relatives	*					
Satisfaction with help from professionals	*					

* = variable entered into regression analysis

II. CODING OF VARIABLES AS ENTERED INTO REGRESSION EQUATIONS

1. Carer Characteristics Equation

Carer Gender

Entered as a dummy variable: 0 = male;
1 = female.

Carer Age

Entered directly.

Carer Religiosity

Entered as a dummy variable: 0 = faith/belief some or
a great help;
1 = faith/belief no help
or no faith/belief.

Carer Learning of Diagnosis and Prognosis

Entered as a dummy variable: 0 = diagnosis and
prognosis learnt
suddenly;
1 = diagnosis and
prognosis learnt
gradually.

Carer General Knowledge of Dementia

Entered via. post-interview rating. (1 = highest know-
ledge rating; 4 = lowest knowledge rating.)

Carer Overall Perception of Dementia

Entered as a dummy variable from post-interview rating:
0 = "A very horrible/worst possible illness";
1 = "Just what happens when you get old", "An illness
just like any other illness", or "Other".

Carer Perception of Having Experienced Grief

Entered as a dummy variable: 0 = carer unsure/no;
1 = believes definitely
experienced grief.

Carer Work Outside the Home

Entered as a dummy variable: 0 = unemployed/retired/
housewife;
1 = in full/part time
employment.

Carer Given Up Work to Care

Entered as a dummy variable: 0 = no;
1 = gave up work to care.

Number of Professional Groups With Whom Carer Has Had Contact re. Sufferer
Entered directly.

Carer Use of "Negative Coping Techniques"
Entered directly from "Coping with the Effects of Giving Care" scale.

Carer Use of "Positive Coping Techniques"
Entered directly from "Coping with the Effects of Giving Care" scale.

Single-item "Carer Coping" Score
Entered directly.

Single-item "Carer Life Satisfaction" Score
Entered directly.

2. Sufferer Characteristics Equation

Sufferer Gender
Entered as a dummy variable: 0 = male;
1 = female.

Sufferer Age
Entered directly.

Sufferer Living Arrangements
Entered as a dummy variable: 0 = living with carer or
in own home;
1 = living in institution.

Time Since Onset of Impairments
Entered directly.

Time Since Diagnosis of Dementia
Entered directly.

Overall Change in Sufferer Perceived by Carer
Entered directly. (1 = "no change"; 5 = "complete change".)

Most Important Sufferer Change Perceived by Carer
Entered as a dummy variable: 0 = apathetic behaviour,
no communication, or
no recognition;
1 = appearance, cognitive,
personal hygiene,
disruptive, emotional,
other, or no single
change.

Sufferer Ability to Recognise Carer

Entered as a dummy variable: 0 = sufferer definitely recognises;
1 = sometimes/never recognises.

Sufferer Physical Changes Perceived by Carer

Entered directly. (1 = "exactly as used to look"; 5 = "not art all the same".)

Speed of Changes Perceived by Carer

Entered directly. (1 = "extremely fast/sudden"; 5 = "extremely gradual".)

3. Sufferer Impairments Behaviours Equation

Total frequencies from problem behaviour domains "Depend", "Can't Do", "Incontinence/Hygiene", "Apathy", "Disturb" and "Demand" entered directly via 34-item Behaviour Checklist scores.

4. Carer-Sufferer Relationship Equation

Blood/Role Relationship

Entered as a dummy variable: 0 = sufferer is spouse or sibling of carer;
1 = sufferer is parent or in-law of carer.

Quality of Premorbid Relationship

Entered directly as total score on premorbid relationship (interaction) scale. (Higher scores represented better quality of premorbid relationship.)

Quality of Current Relationship

Entered directly as total score on current relationship (interaction) scale. (Higher scores represented better quality of current carer-sufferer relationship.)

Change in Quality of Relationship

Entered directly as total score on premorbid relationship scale minus total score on premorbid relationship scale.

5. Carer I.S. Components of Grief Equation

Current intensities of I.S. components entered directly via scale scores. (Higher scores represented greater experience of component at time of interview.)

6. Carer F.A. Components of Grief Equation

Current intensities of F.A. components entered directly via scale scores. (Higher scores represented greater experience of component at time of interview.)

7. Sufferer Social Death Equation

Total scores on social death factor scales "Anticipate Death", "Life Pointless" and "Sufferer Unaware" entered directly.

8. Caring Situation Equation

Hours Per Week Relief From Caring
Entered directly.

Satisfaction with Help from Relatives
Entered directly. (1 = "completely dissatisfied"; 5 = "completely satisfied".)

Satisfaction with Help from Professionals
Entered directly. (1 = "completely dissatisfied"; 5 = "completely satisfied".)

APPENDIX NINE

RESULTS OF "FIRST ROUND" MULTIPLE REGRESSION ANALYSES

Variables associated with the following factors:

- carer I.S. components of grief;
- carer F.A. components of grief;
- sufferer social death;
- carer well-being/burden;
- carer preference for institutional care;
- quality of current carer-sufferer relationship.

Table A.9.1 Stepwise multiple regression analyses - "predictors" of current I.S. grief component "Shock/Denial"

	Adjusted R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Carer gender (female).....	0.06	0.28	7.58
Carer perception: Dementia =			**
worst/horrible illness.....	0.10	-0.22	6.60
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with I.S. component "Shock/Denial"			
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
Behaviour problem domain			*
"Demand".....	0.05	0.24	6.12
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
Blood/role relationship:			**
sufferer = spouse/sibling.....	0.06	-0.27	7.88

* = p<.05 ** = p<.01

Table A.9.2 Stepwise multiple regression analyses - "predictors" of current I.S. grief component "Hope/Bargaining"

	Adjusted R ²	Beta	F-value
<u>CAREER CHARACTERISTICS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with I.S. component "Hope/Bargaining"			
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with I.S. component "Hope/Bargaining"			
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with I.S. component "Hope/Bargaining"			
<u>CAREER-SUFFERER RELATIONSHIP EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with I.S. component "Hope/Bargaining"			

Table A.9.3 Stepwise multiple regression analyses - "predictors" of current I.S. grief component "Questioning/Anger/Guilt"

	Adjusted R ²	Beta	F-value
<u>CAREER CHARACTERISTICS EQUATION</u>			
Career perception: Dementia = horrible/worst illness.....0.30....-0.55.....42.67			***
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with I.S. component "Questioning/Anger/Guilt"			
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with I.S. component "Questioning/Anger/Guilt"			
<u>CAREER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of current relationship.....0.15....-0.39.....17.99			***

*** = p<.001

Table A.9.4 Stepwise multiple regression analyses - "predictors" of current I.S. grief component "Preoccupation/Unfinished Business/Despair"

	Adjusted		
	R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Carer perception: Dementia =			***
horrible/worst illness.....	0.13...	-0.35.....	15.60
Carer religiosity: Faith/belief			***
no help or no faith/belief.....	0.16....	0.21.....	10.72
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with I.S. component "Preoccupation/Unfinished Business/Despair"			
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with I.S. component "Preoccupation/Unfinished Business/Despair"			
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of current relationship.....			**
	0.08....	-0.29.....	9.05

** = p<.01 *** = p<.001

Table A.9.5 Stepwise multiple regression analyses - "predictors" of current I.S. grief component "Acceptance"

	Adjusted		
	R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Carer perception: Dementia =			**
getting old or just an illness...	0.08....	0.32.....	9.90
Carer general knowledge of dementia (greater).....	0.11....	-0.19.....	7.22
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with I.S. component "Acceptance"			
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with I.S. component "Acceptance"			
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of current relationship.....			*
	0.05....	0.25.....	6.03
Blood/role relationship:			**
sufferer = parent or in-law.....	0.08....	0.19.....	5.22

* = p<.05 ** = p<.01

Table A.9.6 Stepwise multiple regression analyses - "predictors" of current F.A. grief component "Disbelief/Hope"

	Adjusted		
	R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with F.A. component "Disbelief/Hope"			
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
Time since onset			*
of impairments.....	0.04	-0.20	4.80 *
Sufferer age.....	0.07	-0.20	4.55 *
<u>SUFFERER IMPAIRMENT/BEHAVIOURS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with F.A. component "Disbelief/Hope"			
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with F.A. component "Disbelief/Hope"			

* = p < .05

Table A.9.7 Stepwise multiple regression analyses - "predictors" of current F.A. grief component "Deny"

	Adjusted		
	R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Carer age.....	0.09	0.32	11.05 **
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with F.A. component "Deny"			
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
Problem behaviour domain			*
"Demand".....	0.05	0.25	6.56 *
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
Blood/role relationship:			**
sufferer = spouse or sibling.....	0.08	-0.30	9.92 **

* = p < .05 ** = p < .01

Table A.9.8 Stepwise multiple regression analyses - "predictors" of current F.A. grief component "Protest"

	Adjusted R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Carer perception: Dementia =			***
worst/horrible illness.....	0.33.....	0.57.....	50.54

Carer age.....	0.35.....	-0.16.....	28.08
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with F.A. component "Protest"			
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with F.A. component "Protest"			
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of current relationship.....			***
	0.10.....	-0.33.....	11.68

*** = p < .001

Table A.9.9 Stepwise multiple regression analyses - "predictors" of current F.A. grief component "Yearn"

	Adjusted R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Carer religiosity: Faith/belief			*
no help or no faith/belief.....	0.04.....	0.21.....	5.28
Carer perception: Dementia =			*
horrible/worst illness.....	0.07.....	-0.19.....	4.70
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with F.A. component "Yearn"			
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with F.A. component "Yearn"			
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with F.A. component "Yearn"			

* = p < .05

Table A.9.10 Stepwise multiple regression analyses - "predictors" of current F.A. grief component "Mourn"

	Adjusted		
	R ²	Beta	F-value
<u>CAREER CHARACTERISTICS EQUATION</u>			
Carer perception: Dementia =			***
horrible/worst illness.....	0.13	-0.37	15.60
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with F.A. component "Mourn"			
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
Problem behaviour domain			*
"Demand".....	0.05	0.25	6.71
<u>CAREER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of current relationship.....	0.12	-0.36	14.43

* = p<.05 *** = p<.001

Table A.9.11 Stepwise multiple regression analyses - "predictors" of social death factor "Anticipate Death"

	Adjusted		
	R ²	Beta	F-value
<u>CAREER CHARACTERISTICS EQUATION</u>			
Carer perception: Has definitely grieved.....	0.03	0.20	4.19
<u>CAREER I.S. COMPONENTS OF GRIEF EQUATION</u>			
I.S. grief component			**
"Questioning/Anger/Guilt".....	0.10	0.32	11.39
<u>CAREER F.A. COMPONENTS OF GRIEF EQUATION</u>			
F.A. grief component			***
"Mourn".....	0.15	0.40	18.85
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
Time since onset			*
of impairments.....	0.05	0.25	6.48
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
Problem behaviour domain			**
"Demand".....	0.06	0.26	7.29
<u>CAREER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of current relationship.....	0.06	-0.27	7.83

* = p<.05 ** = p<.01 *** = p<.001

Table A.9.12 Stepwise multiple regression analyses - "predictors" of social death factor "Life Pointless"

	Adjusted		
	R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Carer perception: Has			***
definitely grieved.....	0.20	0.40	25.12
Carer perception: Dementia =			***
horrible/worst illness.....	0.23	-0.21	15.65
<u>CARER I.S. COMPONENTS OF GRIEF EQUATION</u>			
I.S. component "Preoccupation/"			**
Unfinished Business/Despatr.....	0.09	0.42	10.57
I.S. component "Hope/"			***
Bargaining".....	0.16	-0.30	10.10
<u>CARER F.A. COMPONENTS OF GRIEF EQUATION</u>			
F.A. component			**
"Mourn".....	0.09	0.31	10.41
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with social death factor "Life Pointless"			
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
Problem behaviour domain			**
"Depend".....	0.08	0.30	9.79
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of current			***
relationship.....	0.14	-0.28	16.77
Quality of premorbid			***
relationship.....	0.20	-2.84	13.03

** = p<.01 *** = p<.001

Table A.9.13 Stepwise multiple regression analyses - "predictors" of social death factor "Sufferer Unaware"

	Adjusted		
	R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Carer general knowledge			*
of dementia (greater).....	0.06	-0.23	6.80
Carer gender (male).....	0.10	-0.23	6.34
<u>CARER I.S. COMPONENTS OF GRIEF EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with social death factor "Sufferer Unaware"			
<u>CARER F.A. COMPONENTS OF GRIEF EQUATION</u>			
F.A. component			*
"Protest".....	0.04	0.22	5.09
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
Time since onset			
of impairments.....	0.08	0.30	9.50
Sufferer physical change			***
perceived by carer.....	0.11	0.21	7.40
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
Problem behaviour domain			***
"Can't Do".....	0.25	0.38	34.72
Problem behaviour domain			***
"Depend".....	0.29	0.24	21.09
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with social death factor "Sufferer Unaware"			

* = p<.05 ** = p<.01 *** = p<.001

Table A.9.14 Stepwise multiple regression analyses - "predictors" of Total Rated Social Death

	Adjusted		
	R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Carer perception: Has			**
definitely grieved.....	0.07	0.28	8.27
<u>CARER I.S.COMPONENTS OF GRIEF EQUATION</u>			
I.S. component			*
"Questioning/Anger/Guilt".....	0.03	0.27	4.46
I.S. component			**
"Hope/Bargaining".....	0.08	-0.23	5.05
<u>CARER F.A. COMPONENTS OF GRIEF EQUATION</u>			
F.A. component			**
"Mourn".....	0.08	0.37	9.36
F.A. component			***
"Disbelief/Hope".....	0.12	-0.24	7.87
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
Sufferer (unable to)			**
recognise carer.....	0.07	0.28	8.51
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
Problem behaviour domain			
"Depend".....	0.08	0.30	9.85
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of current			***
relationship.....	0.18	-0.32	22.16
Quality of premorbid			***
relationship.....	0.24	-0.29	16.68

* = p<.05 ** = p<.01 *** = p<.001

Table A.9.15 Stepwise multiple regression analyses - "predictors" of carer "Strain Scale" score

	Adjusted		
	R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Carer (not) working outside			***
the home.....	0.11	-0.31	13.39
Carer perception: Has			***
definitely grieved.....	0.18	0.28	11.93
<u>CARER I.S. COMPONENTS OF GRIEF EQUATION</u>			
I.S. component "Preoccupation/			***
Unfinished Business/Despair".....	0.29	0.54	40.49
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
None of the variables entered into			
this analysis were found to be			
significantly associated with carer			
"Strain Scale" score			
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
Problem behaviour domain			
"Incontinence/Hygiene".....	0.09	0.32	11.30
<u>SUFFERER SOCIAL DEATH EQUATION</u>			
None of the variables entered into			
this analysis were found to be			
significantly associated with carer			
"Strain Scale" score			
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of current			**
relationship.....	0.07	-0.28	8.74

** = p<.01 *** = p<.001

Table A.9.16 Stepwise multiple regression analyses - "predictors" of single-item "Carer Coping" score (higher scores = coping less well)

	Adjusted R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Carer perception: Has			***
definitely grieved.....	0.10	0.30	12.09
Carer (not) working			***
outside the home.....	0.13	-0.20	8.47
<u>CARER I.S. COMPONENTS OF GRIEF EQUATION</u>			
I.S. component "Preoccupation/Unfinished Business/Despair"...	0.09	0.31	10.43
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with single-item "Carer Coping" score			
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with single-item "Carer Coping" score			
<u>SUFFERER SOCIAL DEATH EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with single-item "Carer Coping" score			
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of current relationship.....	0.15	-0.40	18.64

** = p<.01 *** = p<.001

Table A.9.17 Stepwise multiple regression analyses - "predictors of single-item "Carer Life Satisfaction" score (higher scores = lower life satisfaction)

	Adjusted R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Carer (not) working			***
outside the home.....	0.13	-0.36	16.36
Carer perception: Dementia =			***
horrible/worst illness.....	0.17	-0.22	11.31
<u>CARER I.S. COMPONENTS OF GRIEF EQUATION</u>			
I.S. component "Questioning/Anger/Guilt".....	0.24	0.45	31.98
I.S. component "Shock/Denial".....	0.29	0.24	20.87
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with single-item "Carer Life Satisfaction" score			
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with single-item "Carer Life Satisfaction" score			
<u>SUFFERER SOCIAL DEATH EQUATION</u>			
Social death factor			*
"Life Pointless".....	0.05	0.24	6.11
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of current relationship.....	0.21	-0.47	27.48

* = p<.05 *** = p<.001

Table A.9.18 Stepwise multiple regression analyses - "predictors" of Carer GHQ-28 score

	Adjusted		
	R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Carer use of "negative coping techniques".....	0.25	0.37	22.21 ***
Carer perception: Has definitely grieved.....	0.32	0.26	16.14 ***
Number of professional groups with whom carer has had contact..	0.37	-0.25	13.64 ***
<u>CARER I.S. COMPONENTS OF GRIEF EQUATION</u>			
I.S. component "Preoccupation/Unfinished Business/Despair.....	0.20	0.46	17.09 ***
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
Time since onset of impatments.....	0.10	-0.34	8.55 **
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
Problem behaviour domain "Depend".....	0.08	0.30	6.47 *
<u>SUFFERER SOCIAL DEATH EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with carer GHQ-28 score			
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of current relationship.....	0.24	-0.49	21.16 ***

* = p<.05 ** = p<.01 *** = p<.001

Table A.9.19 Stepwise multiple regression analyses - "predictors" of carer Affect Balance Scale score (higher scores = Greater life satisfaction)

	Adjusted		
	R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Carer use of "negative coping techniques".....	0.19	-0.46	16.73 ***
Carer working outside the home.....	0.24	0.23	11.05 ***
<u>CARER I.S. COMPONENTS OF GRIEF EQUATION</u>			
I.S. component "Questioning/Anger/Guilt".....	0.20	-0.46	17.15 ***
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
Time since onset of impatments.....	0.05	0.25	4.31 *
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
Problem behaviour domain "Disturb".....	0.09	-0.32	7.30 **
<u>SUFFERER SOCIAL DEATH EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with carer Affect Balance Scale score			
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of current relationship.....	0.30	0.55	28.47 ***

* = p<.05 ** = p<.01 *** = p<.001

Table A.9.20 Stepwise multiple regression analyses - "predictors" of Carer Willingness to Institutionalise score (higher scores = less willing)

	Adjusted R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Single-item "Carer Coping"			**
score.....	0.06	-0.27	7.79
<u>CARING SITUATION EQUATION</u>			
Hours per week relief			**
from caring.....	0.07	-0.29	8.69
<u>CARER I.S. COMPONENTS OF GRIEF EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with carer willingness to institutionalise score			
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
Overall amount of change in sufferer as perceived by carer...0.04...-0.22.....			3.99 *
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with carer willingness to institutionalise score			
<u>SUFFERER SOCIAL DEATH EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with carer willingness to institutionalise score			
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of current relationship.....	0.06	0.27	7.54 **

* = p<.05 ** = p<.01

Table A.9.21 Stepwise multiple regression analyses - "predictors" of Rated Attitude to Continued Care (higher score = more positive attitude)

	Adjusted R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Single-item "Carer Life Satisfaction" score.....	0.17	-0.24	20.86 ***
Single-item "Carer Coping" score.....	0.20	-0.24	13.02 ***
Carer perception: Dementia = horrible/worst illness.....	0.22	0.19	10.39 ***
<u>CARING SITUATION EQUATION</u>			
Satisfaction with help from relatives.....	0.06	0.26	6.98 **
<u>CARER I.S. COMPONENTS OF GRIEF EQUATION</u>			
I.S. component "Questioning/Anger/Guilt".....	0.06	-0.26	7.13 **
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with Rated Carer Attitude to Continued Care			
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with Rated Carer Attitude to Continued Care			
<u>SUFFERER SOCIAL DEATH EQUATION</u>			
Social death factor "Life Pointless".....	0.14	-0.39	17.07 ***
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of current relationship.....	0.21	0.38	26.71 ***
Quality of premorbid relationship.....	0.24	0.23	17.01 ***

** = p<.01 *** = p<.001

Table A.9.22 Stepwise multiple regression analyses - "predictors" of quality of current carer-sufferer relationship as reported by carer

	Adjusted R ²	Beta	F-value
<u>CARER CHARACTERISTICS EQUATION</u>			
Carer perception: Dementia =			*
horrible/worst illness.....	0.05.....	0.20.....	6.40
Carer work outside			**
the home.....	0.08.....	0.23.....	5.46
			**
Carer gender (male).....	0.12.....	-0.22.....	5.58
<u>SUFFERER CHARACTERISTICS EQUATION</u>			
Sufferer living arrangements:			***
In institution.....	0.22.....	0.48.....	29.73
<u>SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION</u>			
None of the variables entered into this analysis were found to be significantly associated with quality of current carer-sufferer relationship			
<u>CARER-SUFFERER RELATIONSHIP EQUATION</u>			
Quality of premorbid relationship.....	0.13.....	0.37.....	15.17

* = p<.05 ** = p<.01 *** = p<.001

APPENDIX TEN

CAREGIVER SUBJECTIVE BURDEN: DESCRIPTIVE RESULTS
AND DISCUSSION

Subjective burden was assessed in a variety of different ways, both during the interview and via written questionnaires (completed by those of the carers who were willing) after the interview.

The differing subjective burden measures comprised the following:

ASSESSED DURING THE INTERVIEW (All subjects)

- "Strain scale" (4 items)
- Carer's overall rating of how well they were coping.
- Carer's overall rating of current life satisfaction.

ASSESSED FOLLOWING INTERVIEW

- General Health Questionnaire (GHQ-28).
- Affect Balance Scale (ABS).

I. DESCRIPTIVE RESULTS - CAREGIVER SUBJECTIVE BURDEN

1. Strain Scale

QUESTION : Has looking after ... affected your physical health?

% of carers (N = 97)

Enormously.....	2%
Quite a lot.....	18%
A bit.....	13%
Hardly at all....	9%
Not at all.....	58%

QUESTION : Has looking after ... affected your mental health?

% of carers (N = 97)

Enormously.....	12%
Quite a lot.....	37%
A bit.....	23%
Hardly at all....	8%
Not at all.....	20%

QUESTION : Has looking after ... affected your social life?

% of carers (N = 96)

Enormously.....	23%
Quite a lot.....	30%
A bit.....	21%
Hardly at all....	17%
Not at all.....	9%

QUESTION : Has looking after ... affected your finances?

% of carers (N = 96)

Enormously.....6%
Quite a lot.....17%
A bit.....13%
Hardly at all....8%
Not at all.....56%

Caring was a strain in a variety of ways. In particular, the carers reported that it had affected their mental health and their social lives to a fairly severe extent. Physical health was affected less severely (often strains due to lifting the sufferer), as were the carers' finances: over half the sample reported no strain in either area.

2. Carer Coping Rating

QUESTION : Taking everything into account, how well do you think you are coping just now?

% of carers (N = 97)

Very well.....30%
Pretty well.....37%
Just about OK...30%
Pretty badly.....2%
Very badly.....1%

QUESTION : Has this changed over the time you've been caring?

% of carers (N = 97)

Improved a great deal.....28%
Improved a little.....13%
Coping about the same.....38%
Got a little worse.....8%
Got a lot worse.....12%

By far the majority of carers reported themselves to be coping either pretty well or very well with a difficult situation. Indeed, several appeared to be rather proud of the way in which they had coped. While a fifth of the sample believed they were coping less well than they had done earlier on, twice as many believed they were now coping better. This was generally attributed either to increasing apathy and reduced actively difficult behaviours in the sufferer as their dementia became more severe, or else to the carer "getting used" to the situation or developing increasingly effective coping skills. The improvement in carer coping over time could also be attributed to institutionalisation of some sufferers: of those caring for non-institutionalised sufferers 26 (35%) believed they were

coping better than earlier on, 31 (41%) that they were coping about the same, and 18 (24%) that they were coping worse. In comparison, among those caring for institutionalised sufferers 14 (64%) believed they were coping better than earlier on, 6 (27%) that they were coping about the same, and 2 (9%) that they were coping worse. This distribution differs significantly from the expected (Chi-square = 6.62, $p < .05$). Carers were more likely to report an improvement in the way they were coping following institutionalisation of the dementia sufferer. Despite this, the difference in overall "coping" scores for the carers of non-institutionalised vs. institutionalised dementia sufferers was not significant: respective mean scores = 2.07 and 2.09 ($t = -0.11$, $p = 0.91$).

Mrs. Nisbett, for example, was pleased with the way she had coped with her co-resident mother:

H.S: How do you think you're coping right now?

Mrs. N: I think not bad - pretty well - and it's quite a nice feeling to know that you're coping.

H.S: How are you coping now compared with earlier on?

Mrs. N: I would say better - I think the longer she's stayed with us, we're getting more adapted to it.

Mr. Neil also thought he was coping fairly well, although he expected that it would be harder to cope as his wife's impairments became more severe. (In fact, she was moderately-severely impaired at the time of the interview.):

I think I'm doing not bad - well, I would say so - as I say, at this stage - it'll probably get worse as the years go on like, you know, if we're spared like. She'll even practically lose her mind altogether like, you know, as far as having to do everything for her, you know - take her here, take her there, but as the now I would say I think I'm coping quite well ... I never thought I could cook, I'd never go into a shop for a message or anything like that, and now I've just got to do it.

Mrs. Quail, however, was only "just about" coping with her husband, because she believed there was no alternative:

H.S: How do you think you are coping just now?

Mrs. Q: I don't know - within myself? I know I have to and that's it - willpower, is that what you call it? I try not to show too much to my two daughters because they would get worried, I try to keep it to myself.

Mr. Campbell was one of the two carers who believed they were coping worse following institutionalisation of the dementia sufferer. He believed that since his father had been admitted to long term hospital care he had lost his role as carer, and had become increasingly isolated and depressed:

A year ago I felt I was coping quite well - I've felt worse since my dad went in ... If I'd got a job, say, as soon as my dad went into the hospital ... I think it would have done me a lot of good if I'd got a job straight away ... since my dad went into hospital I see much less of all my family. I've got all the time to go and see them now, but I don't ... I feel as if I'm just wasting a good life and I keep making excuses for myself - I know that I should just give myself a shake and try something, anything ... I don't know what it is, I'm just on a downer.

3. Carer Life Satisfaction Rating

QUESTION : How do you feel about your life as a whole right now?

% of carers (N = 95)

Delighted.....	1%
Pleased.....	18%
Mostly satisfied.....	22%
Mixed.....	28%
Mostly dissatisfied.....	16%
Unhappy.....	14%
Terrible.....	1%

QUESTION : Has this changed over the time you've been caring?

% of carers (N = 93)

Improved a great deal.....	20%
Improved a little.....	16%
Feeling about the same....	28%
Got a little worse.....	18%
Got a lot worse.....	18%

Forty percent of the sample felt at least "mostly satisfied" with their current lives. They tended to think carefully and consider not only their situation with the sufferer when answering this question. As a result, even a difficult situation with the sufferer may have been balanced out by more positive aspects of their lives, such as pleasure at the visits of grandchildren. Thirty percent of the sample, however, felt at least "mostly dissatisfied" with their lives.

In contrast to the estimations of more improvements than reductions in ability to cope over time, the number of carers whose life satisfaction had improved was the same as that whose life satisfaction had reduced. Several commented on this: while their ability to cope with the situation had increased, this did not necessarily mean they felt any better. In addition, there were no significant differences in the distribution of estimated changes in life satisfaction following institutionalisation of the dementia sufferer. Among the carers of non-institutionalised sufferers 22 (31%) reported increased life satisfaction, 21 (29%) reported that their life satisfaction was about the same, and 28 (40%) reported that their life satisfaction had decreased. In comparison, among the carers of institutionalised dementia sufferers 12 (57%) reported increased life satisfaction, 4 (18%) reported unchanged life satisfaction, and 6 (28%) reported decreased life satisfaction. This distribution did not differ significantly from the expected (chi-square = 4.14). Institutionalisation may therefore significantly improve the way carers believe they are coping without significantly improving their life satisfaction.

Mrs. Steadman, for instance, caring for her non-resident father had become increasingly dissatisfied with her life as time went by:

I wasn't so dissatisfied a few years ago,
because you felt so sorry for him - but now I'm
just fed up with it all.

Mrs. Cameron, whose husband was in long term hospital care also described herself as dissatisfied with life:

You haven't got any life right now ...
sometimes I'm down.

However, her life satisfaction had improved from an even lower level since his institutionalisation, because, " I can go out and in, I'm not having to rush back - I've got peace of mind".

Mrs. Marsh felt mixed about her life at the time of the interview:

You've got to take it day by day - if it gets
worse then it gets worse ... I think things
gets a wee bit worse ... it's getting worse and
you know it's getting worse, gradually.

In contrast, Mr. Lees felt mostly satisfied with his life, and he believed that this had increased over the time his wife had been ill:

Obviously you're not pleased with the way
things are - but satisfied, taking everything
into account ... (it's improved) as I've got

used to it - I would imagine there would be a wee bit more resentment five years ago than there is today.

Finally, Mr. Inglis, aged 80 and caring for his moderate-severely impaired wife, Joan, described himself as pleased with his life as it was:

Mr. I: I think it's my age that makes me more contented now ... because I don't go to the dogs, I don't go to the pub, and all my friends are dead, the ones I used to know ... I couldna' say I've any real problems - I'm quite comfortable now, you know.

H.S: What about earlier on?

Mr. I: No, I wasn't as happy then ... I was a bit cross, narky, so was Joan - now she's more resigned to it and I'm resigned to it, that the situation's alright.

4. General Health Questionnaire: GHQ 28

Of the 68 subjects who completed the GHQ-28, 33 (49%) scored above the cut-off of 5, and thus qualified as "a case".

The mean GHQ-28 score was 6.3 (S.D. = 6.4). The range of scores was 0-25 (possible range 0-28, with higher scores representing greater [non-psychotic] psychiatric disturbance).

5. Affect Balance Scale

The mean ABS score was 10.6 (S.D. = 3.9). The range of scores was 3-20 (possible range 0-20, with higher scores representing greater life satisfaction).

II. WHAT DISTINGUISHED THE CARERS WHO COMPLETED THE GHQ-28 AND ABS FROM THOSE WHO DID NOT?

Thirty of the 100 carers in the total sample declined the self-completion questionnaires, two of which (GHQ-28 and ABS) measured carer wellbeing. Of the 70 who received the GHQ-28, four failed to complete it fully. Thus the total number of carers who fully completed the GHQ-28 was 66.

In order to assess whether the carers who declined the self completion questionnaires differed from those who agreed to complete them, the two groups were compared in terms of the following variables: (over page)

- carer gender.....	Via chi-squared analysis
- sufferer gender.....	
- carer-sufferer blood/role relationship.....	
- sufferer living arrangements.....	
- carer age.....	Via t-tests
- sufferer age.....	
- total frequency of problem behaviours.....	
- overall sufferer change estimated by carer.....	
- time since onset.....	
- time since diagnosis.....	
- strain scale score.....	
- single item coping score.....	
- single item life-satisfaction score.....	

The results of these analyses are presented in Table A10.1 (below) and Table A10.2 (over page)

Table A10.1
Proportion (%) of self-completion questionnaire completers and non-completers in terms of carer and sufferer gender, carer-sufferer relationship, and sufferer living arrangements

	Completers	Non-Completers	χ^2
<u>CARER GENDER</u>			
Male (N=26).....	73.....	27.....	0.78
Female (N=74).....	64.....	36.....	
<u>SUFFERER GENDER</u>			
Male (N=42).....	71.....	29.....	0.95
Female (N=58).....	62.....	38.....	
<u>SUFFERER RELATIONSHIP TO CARER</u>			
Spouse/Sibling (N=53).....	66.....	44.....	0
Parent/In-law (N=47).....	66.....	44.....	
<u>SUFFERER LIVING ARRANGEMENTS</u>			
Own/Carers home (N=77).....	64.....	36.....	1.00
Institution (N=23).....	74.....	26.....	

These results demonstrate that those carers who fully completed the GHQ-28 and ABS received a significantly lower score on the single item Life Satisfaction scale. This represents higher Life Satisfaction among this group. The completers did not differ from the non-completers in terms of basic demographic details, sufferer living arrangements, time since onset or diagnosis of dementia in the sufferer, degree of impairment or perceived overall changes which had

Table A10.2

T-test analyses of significant differences between self-completion questionnaire completers and non-completers on carer and sufferer age, total problem behaviour frequency, estimated overall sufferer change, time since onset and diagnosis of dementia, and strain scale, coping and life-satisfaction scores

	Completers	Non-Completers	t-value
Carer age (yrs).....	58.8.....	61.6.....	-1.04
Sufferer age (yrs)...	74.8.....	76.9.....	-1.23
Total frequency			
prob. behaviours....	33.9.....	37.3.....	-1.42
Overall estimated			
sufferer change.....	4.2.....	4.0.....	0.92
Time since			
onset (yrs).....	6.1.....	6.2.....	-0.26
Time since			
diagnosis (yrs).....	3.5.....	3.8.....	-0.63
Strain scale score...	10.2.....	11.4.....	-1.60
Coping item score.....	2.0.....	2.2.....	-1.40
Life-satisfaction			
item score.....	3.6.....	4.4.....	-2.78**

** = $p < .01$

occurred in the sufferer, nor on the Strain scale and Coping item scores.

III. RELATIONSHIP BETWEEN THE DIFFERENT MEASURES OF SUBJECTIVE BURDEN

Clearly, the five different measures of subjective burden differed greatly both in their sophistication, their administration, and in whether they aimed to assess reported "strain", coping ability, life satisfaction, or psychiatric "caseness".

The relationship between the five different measures of subjective burden was analysed via a correlation matrix. Table A10.3 (over page) presents the intercorrelations (Pearson's r) between the five measures.

Table A10.3 demonstrates that the inter-correlations among the measures (despite their disparity in complexity, administration, and exact content) were both high, and highly significant. The "strain" scale was correlated least strongly with all the other measures. It assessed four very different areas, not

Table A10.3
Correlation matrix (Pearson's r): five measures of carer subjective burden.

	Interview ratings			Post-interview questionnaires	
	Strain scale	Coping now	Life satisf. now	GHQ-28	ABS
Strain scale	1.000	0.357***	0.434***	0.418***	-0.415***
Coping now		1.000	0.588***	0.534***	-0.498***
Life satisf.			1.000	0.567***	-0.630***
GHQ-28				1.000	-0.715***
ABS					1.000

*** = $p < .000$

all of which were necessarily "subjective burden". The two post-interview questionnaires - the most sophisticated and previously validated measures of subjective burden - correlated most strongly with each other.

It thus appears that all five of these different measures represented an underlying factor which may be regarded as "carer subjective burden".

IV. PERCEIVED PROBLEM SEVERITY - ANOTHER MEASURE OF "SUBJECTIVE BURDEN"

During the administration of the 34-item Behaviour Problem Checklist, carers were asked not only the frequency at which certain behaviours were exhibited by the dementia sufferer, but also for those behaviours which did occur, how much of a problem the carer found them to be. It soon became apparent that certain behaviours (for example "Demands attention") were consistently rated as causing more of a problem than others (for example "Unable to wash without help") - see Chapter Eight. However, what was also apparent was that some carers consistently rated almost all sufferer behaviours as a problem, while other carers rated almost all sufferer behaviours as not a problem. Thus, it was possible for a carer looking after a sufferer

with only relatively few problem behaviours to give those behaviours a greater total severity score than those whose sufferer exhibited a much greater number of problem behaviours. In other words, the perceived total severity of problem behaviours was not necessarily related to the total frequency of problem behaviours.

Was the carer's perceived severity of problems, regardless of the total number of problems exhibited by the dementia sufferer, related to caregiver subjective burden? In other words, did those carers who reported a higher degree of subjective burden also tend to perceive any problems which they had to deal with as more severe?

In order to answer the above question, an index of the carer's perceived severity of problems regardless of total frequency of problems ("Pure severity") was computed thus:

$$\text{Pure severity} = \frac{\text{Total problem severity score}}{\text{Total problem frequency score}}$$

The possible range of "Pure severity" scores was 0-2. (0 = any carer who declared that none of the reported sufferer behaviours represented a problem, even if they occurred frequently or all the time; 2 = any carer who declared that every sufferer behaviour which they reported represented a severe problem despite only occurring occasionally.)

The relationship between the carers' perceived "Pure severity" of the dementia sufferer's problem behaviours and the five more formal measures of subjective burden was examined. Table A10.4 presents the resulting correlations (Pearson's r).

Table A10.4

Correlation coefficients (Pearson's r) between "Pure severity" scores and five more formal measures of carer subjective burden.

<u>Carer subjective burden measure</u>	<u>Correlation with "Pure severity": Pearson's r</u>
Strain scale.....	0.349***
Coping now.....	0.472***
Life satisfaction now.....	0.329**
GHQ-28 score.....	0.510***
ABS score.....	-0.559***

** = p<.001 *** = p<.000

"Pure severity" was significantly related to all five of the more formal measures of carer subjective burden.

Clearly, those carers who were experiencing greater levels of subjective burden tended to report that they found the behaviours exhibited by the sufferer to be a greater problem. This was regardless of the number or frequency of those behaviours.

V. DISCUSSION

In line with the majority of previous studies, being the caregiving relative of a dementia sufferer was found to be a source of subjective burden.

When "Strain" was divided into four components (effect of looking after the dementia sufferer on caregiver physical health, mental health, social life, and finances) the findings were of much greater impact on carer mental health and social life than on their physical health or their finances. As Gilleard [1984, p.77] notes, this finding that "the primary expression of strain is in psychosocial impairment rather than in physical or financial well being" has been endorsed by many researchers following Grad and Sainsbury [1965 - see Gilleard, 1984] who first introduced this four part rating of family burden.

Despite the psychosocial strain, the majority of carers reported that they were coping either pretty well or very well with the situation. Overall coping ability had improved somewhat over time: while a fifth of the carers believed they were now coping less well than they had done earlier, two fifths believed they were now coping better. However, this could be attributed to some extent to institutionalisation. Carers were significantly more likely to report that they had experienced improved coping following admission of the dementia sufferer. It was thus interesting to find that there was no significant difference in overall "coping" scores for the carers of community vs. institutionalised sufferers. This suggests that the coping scores for the relatives of institutionalised sufferers may have been much worse prior to admission. Possibly the difficulty which these carers were having in coping contributed to the decision to institutionalise their dementing relatives. This could be explained as the "survival effect" first proposed by Gilhooly [1984]. She suggested that one reason for her finding of a positive correlation between duration of care and high carer morale plus good carer mental health was the operation of a "survival effect" in her sample of community caregivers. It was only those who had a good psychological well being who survived the situation of being a community carer over a long period of time. Similarly, in the present study, it may have

only been those who were coping adequately who survived the situation of being a community carer. This result also corresponds somewhat with another study which actually found that when carers were followed up there was evidence of increased use of psychotropic drugs after institutionalisation [Colerick and George, 1986]. These authors found the fact that relinquishing care to professionals may not necessarily relieve the burden of caregiving was difficult to explain, and they suggested it should be investigated further.

The responses to the single item measure of life satisfaction were more normally distributed around the mean than those of the coping item: 40% of the sample felt at least mostly satisfied with their current lives, while 31% felt at least mostly dissatisfied. Possibly this reflects the slightly different construction of these two scales (5-point coping vs. 7-point "Delighted-Terrible" life satisfaction). Ford [1979] reports that the originators of the "Delighted-Terrible" scale found it to achieve a much more even spread across all the scale values than simply using a set of seven numbered boxes without verbal "prompts". The other possible reason for this result is that it is a true reflection of the fact that while a carer may be coping adequately with the situation, at the same time they may not feel satisfied with their life. This would accord with comments made by the carers regarding the fact that while their ability to cope with the situation may have improved over the time that they had been caring, this did not necessarily mean they felt any better. Given this, it was also interesting to find that while institutionalisation may lead to an improvement in carer coping, it did not lead to a significant change in their life satisfaction. This suggests that a carer's assessment of how they are coping may be more likely to be based on the practicalities of the situation. With practise, coping may improve, and of course, with removal of the dementia sufferer to an institution, coping is likely to improve. In contrast, a carer's life satisfaction may be more likely to be based simply on the fact that they have a relative with dementia. This situation will not improve, regardless of the amount of practise gained at the tasks of caregiving, nor even if the sufferer is institutionalised. In addition, life satisfaction may be reduced for some of the carers of institutionalised dementia sufferers by the burden of visiting.

Forty-nine percent of the 68 subjects who completed the GHQ-28 qualified as "a case". This contrasts with Goldberg's figure of 16.3% of a random community sample who qualified as "cases" when assessed via the GHQ-60.

The mean GHQ score in the present sample was 6.3. These results correspond with others which have found a high prevalence of GHQ "caseness" among caregivers. For example, Gilleard, Belford and Gilleard et. al. [1984] report the following proportions in three separate studies of community supporters of the elderly mentally infirm: 62%, 73.5%, and 57%. Toner [1987] found a mean GHQ-28 score of 10.7 for a group of 18 relatives looking after a dementia sufferer at home. It will be noted that the GHQ results from the present study suggest somewhat lower psychiatric morbidity. It might be suggested that the reason for this is that the present study included carers of both institutionalised and community dementia sufferers. The hypothesis would be that the relatives of institutionalised dementia sufferers may have lower GHQ scores and thus pull down the overall average score of the sample. In fact this was not the case, since as with all the other measures of subjective burden there was no significant difference in GHQ scores among the carers of dementia sufferers living in the community vs. those living in long term care. The reason could be that those carers who declined to complete the GHQ may have a higher subjective burden than the completers. While GHQ completers did not differ from non-completers on the 4-item "Strain" scale nor on the single item measure of Coping, the non-completers did have significantly lower Life Satisfaction as assessed by the single-item life-satisfaction measure. (Indeed, possibly this was the reason why they declined to take the self completion questionnaires: their burden was great enough already without adding to it by the filling in of questionnaires.) This suggests that the GHQ completers may have been a somewhat biased (towards less subjective burden) sub-sample, thus lowering the overall average GHQ score of the sample. The final possibility is that GHQ scores obtained in some previous studies do not represent the "true" level of psychiatric morbidity among the caregiving relatives. This is suggested by the fact that other studies suggest fairly good carer well-being or mental health. (For example, Eagles, Beattie and Blackwood et. al. [1987] and O'Connor, Pollit and Roth et. al. [1989] both report a very low prevalence of GHQ "caseness" among the community caregivers of dementia sufferers - in fact, far lower than the 16.3% quoted by Goldberg [1978] as the level of caseness in a random community survey. Similarly Gilhooly [1984] found fairly good mental health among her sample of community carers.

The mean ABS score of 10.6 is unfortunately fairly meaningless as it stands. This is because there are no norms with which to compare it. As was discussed in Appendix Two, the ABS has been scored in different ways

by different researchers. In fact, Moriwaki [1974] suggests that "while the ABS is applicable to an aged population, differential age norms should be developed to increase further its utility in comparing various age groups and age-related changes" [p.73]. Given that Ford [1979] suggests the ABS ought to be sensitive to changing social experiences, it was interesting to find that there was no significant difference in ABS scores between the carers of community vs. institutionalised dementia sufferers. But again, of course, this may reflect the "survival effect": that only the community carers who achieve higher ABS scores survive, those with lower ABS scores are more likely to end up placing the dementia sufferer into long term care, after which their ABS scores rise to around the same level as the survivors.

Given the range in sophistication of the five different instruments used to assess subjective burden in the present sample of carers, the level of inter-correlations among the measures suggests that they are indeed directed toward a common underlying construct. While all the correlations were highly significant, the lowest (between $r=0.36$ and $r=0.43$) were found between the "Strain scale" and other measures. This could be accounted for by the fact that the strain scale attempts to assess total carer burden rather than simply their subjective burden or well-being. For example, it includes financial strain from caring. Although, as Zarit [1989] points out, distressed or depressed people may often estimate the magnitude of events inaccurately, this is presumably less likely in the case of fairly objective variables such as "finances" than in the case of subjective well-being variables such as "feeling that everything is going your way". The highest correlations were between the two (longer) self-completion instruments, the GHQ-28 and ABS. This corresponds somewhat with Lohmann's [1977] observation that correlation coefficients among a variety of measures of life satisfaction, adjustment, and morale could almost be predicted on the basis of the number of items in each measure. However, the correlations between the two single item questions (coping and life satisfaction) and the other measures of burden or well-being in the present study were higher than those obtained by Lohmann [1977] using a global question ("How satisfied are you with your life?"). She suggests that a global question may not be an appropriate way to measure an area as complex as life satisfaction. In contrast, the results of the present study accord with Bradburn and Caplovitz's [1965] belief that the best first approach to the problem of the measurement of well-being or distress may well be a straightforward single question.

It was interesting to find that on the 34-item (sufferer behaviour) Problem Checklist, the index of the carer's perceived severity of the dementia sufferer's problems regardless of the total frequency of those problems (termed "pure severity") was significantly correlated with each of the five formal assessments of subjective burden. Obviously this result should not really come as a surprise. Again, it corresponds with Zarit's [1989] observation on the possibility of an over-estimation of events by distressed or depressed people. It also accords with Gilleard's [1984] account of the reason for developing the format of the 34-item Problem Checklist to include separate ratings of occurrence of deficit or disturbing behaviours and their "problem" status for the supporter. This was because of "the distinction made by many supporters between noticing their dependent's disabilities and labelling them as problems" [1984, p.67]. However, Gilleard does not go on to suggest that 34-item Problem Checklist responses could actually be used as significant predictors of carer burden (or vice versa). Thus, if inspection of the checklist indicates a high "pure severity" of problems (ie. behaviours all rated as "severe problem" by the carer even if they only occur occasionally), this would suggest that this carer is experiencing a high degree of subjective burden. Similarly, if a carer expresses a high degree of subjective burden (for example, "coping very badly", "unhappy about life as a whole"), this would suggest that this carer will also tend to rate each of the behaviours displayed by their dementing relative as a "severe problem".

VI. SUMMARY

This appendix has presented descriptive results with regard to carer subjective burden or well-being, as measured in the present study.

There was clear evidence of subjective burden amongst caregiving relatives. While institutionalisation of the dementia sufferer was associated with a reported improvement in carer coping ability, it was not associated with a reported increase in their life satisfaction. There was evidence that those carers who had agreed to fill in the self-complete questionnaires may have had a greater life satisfaction than the non-completers. Despite the varied length and sophistication of the five measures of carer burden employed in the present study, they were significantly inter-correlated. This suggests that they were tapping a common underlying construct. There was evidence that a further useful assessment of carer subjective burden

might be the degree to which they rate the behaviours displayed by their dementing relative as "a problem".

The final section of the appendix discussed the significance of these results.

APPENDIX ELEVEN

CARING FOR A DEMENTIA SUFFERER IN THE COMMUNITY:
DESCRIPTIVE RESULTS AND DISCUSSION

The living arrangements of the 100 dementia sufferers at the time of the interviews with their carers were as follows:

- 61 lived in the carer's home
- 16 lived in their own home
- 23 lived in long-term care.

This appendix focuses on the carers of dementia sufferers living in the community: the situation they faced, their beliefs about the role of caregiver, and their willingness to continue in that role in the future.

I. CARING FOR A DEMENTIA SUFFERER IN THE COMMUNITY -
DESCRIPTIVE RESULTS

1. Relief from Caring

Table All.1 shows, in descending order, the areas from which help in caring for the sufferer in the community had been received.

Table All.1

Help received in caring for a dementia sufferer in the
community

<u>Group providing support</u>	<u>Received by % of carers</u>
	(N = 77)
Family.....	62%
Hospital day facility.....	52%
Hospital respite facility.....	39%
Other day facility *	30%
Local authority day facility.....	14%
Friends.....	9%
Local authority respite facility.....	6%

* Other = Alzheimer's Society day centres.

NON-RESIDENT CARERS

Those caring for non-resident sufferers obviously gained relief away from the sufferer whenever they went back to their own homes. However, this was not necessarily the equivalent of relief from caring: several carers described constantly worrying about the sufferer, and some would receive phone calls from the

sufferer at extremely frequent intervals. Sometimes these required the carer to go back over to the sufferer's home to sort out muddles. Mrs. Davis, who lived about three miles away from her non-resident mother described just such a situation:

H.S: How much time do you spend at your mum's?

Mrs. D: It depends - some days I can be there all day, depending on how she's feeling, other days it can be maybe 3 or 4 hours. Then, the likes of last night, she was on the phone mostly all last night, through the night - I've had about 2 hours' sleep ... I couldna' do the half of what I do for her if I didn't have the car, because I've to go out sometimes in the early hours of the morning. Sometimes she's on that phone one o'clock in the morning and I've to run down there to her one o'clock in the morning ... one week it was the pension book, her pension book had disappeared, she couldn't find the pension book ...

The approximate number of hours spent in the sufferer's home by the 16 non-resident carers ranged from 9-160 hours per week. The 160 hour-per-week carer moved in with her mother for lengthy periods. When she was eliminated from the data, the range of time spent in the sufferer's home was 9-44 hours per week (mean = 20.3 hours, S.D. = 9 hours).

RESIDENT CARERS

For the majority of resident carers, relief came if the sufferer attended day hospital or day care, or if they had helpful family members who would take over the surveillance of the sufferer. A few received "professional" sitter services. The average relief from caring each week for the 61 resident carers was 10.7 hours - the equivalent of two days' attendance at day hospital/care by the sufferer. (Range = 0-29 hours, S.D. = 7.1 hours.)

Mrs. Quail, whose husband's dementia had been diagnosed only recently received no relief. She said that she didn't know how he would react if he was cared for by anyone else; nor was she sure that she would be able to accept help from others.

One of those who greatly appreciated day hospital care was Mrs. Timms:

Tuesday and Thursday - I look forward to them two days because I know where my mammy is. She's at the hospital ... I've got from about half ten to about half three or four o'clock.

Although day care had failed in his wife's case, Mr. Nichol had given up his job in order to care for her. This meant that he qualified for Invalid Care Allowance which he used to buy in a sitter service six days a week, "four hours a day - afternoon or evening, it depends what I want to do".

2. Satisfaction with Support

SATISFACTION WITH INFORMAL SUPPORT

QUESTION : How satisfied are you with the amount of help you get from relatives?

	<u>% of carers (N = 70)</u>
Completely satisfied.....	41%
Fairly satisfied.....	11%
Mixed.....	29%
Fairly dissatisfied.....	13%
Completely dissatisfied....	6%

Although half the carers of non-institutionalised dementia sufferers were satisfied with the help they got from relatives, one fifth were dissatisfied.

Mrs. Quail, for instance, was completely satisfied with the help which the rest of her family gave in caring for her husband - including joining the hunt when he wandered away from home:

Sometimes when I'm awful worried and he's out, Jenny will follow in the car and she'll find him. He's usually in Motherwell, walking up to the building where he was born ... I don't know what I'd do without them.

Mrs. Scott was also completely satisfied with the help which she received from the family in caring for her husband. Although her daughter lived in England, one son lived locally, and the other was still living in the parental home:

They're very good ... if I needed them to get out at night there's always one of them available ... they help as much as they can.

By no means all carers were as satisfied with family help, though. For instance, Mrs. Cooper, caring for her mother, said of her family:

They're no' interested - they don't want to know and they just want to tell me what to do and what not to do, and that's it ... I'm very dissatisfied about that.

Mrs. Thom felt that she had been abandoned by her family to her task of caring for her mother:

Her sister called round the day before Christmas Eve - her sister lives in Johnstone -

this is the caring family, you know, and the last time we saw her was in 1982 (seven years previously), and she called in and ... nothing, really nothing, and she said to me, "Dear God, she doesn't know me", and of course I said to her, "Well, my dear, I had a job to recognise you".

SATISFACTION WITH FORMAL SUPPORT

QUESTION : How satisfied are you with the amount of help you get from professionals?

% of carers (N = 73)

Completely satisfied.....	55%
Fairly satisfied.....	19%
Mixed.....	22%
Fairly dissatisfied.....	4%
Completely dissatisfied....	0%

Three quarters of the carers of non-institutionalised dementia sufferers declared themselves to be satisfied with the professional help which they had received, and almost none were dissatisfied. (Of course, this may have been biased by the perception of the interviewer as one of "the professionals", however, comments did seem to indicate genuine satisfaction.)

Mrs. Quinn, for example, spoke of the professional input (G.P., Community Nursing, and Alzheimer's Society) received by her non-resident mother in the following terms:

Everybody's been great ... really and truly, I feel that my doctor's done as much as he could.

Miss McBride described the domino-effect of help which she had had while caring for her sister:

... any help I've asked for, I've had it ... once I found out what was wrong with her then I got in touch with the Social Work department and they sent somebody down, and I had the doctor in anyway to see about the Attendance Allowance, and then I found out about the Alzheimer's and started going to their meetings. It all sort of clicked into place - I found out the more help you get, the more they offer you. The likes of, as soon as she qualified for the Attendance Allowance, that was fine, she got the £23 extra which helps, then I found out about the I.L.F. (Independent Living Fund), but she would never have qualified for the I.L.F. if I hadn't found out about the Attendance Allowance ... and the I.L.F. has now told me she should enquire, she should be entitled to extra money on the

pension, so I've found if you get the break-through to start with, then you get all the help after then.

One of the few carers who was dissatisfied with professional help (despite quite large amounts of it, allowing, together with family help, some relief from caring six days a week) was Mr. Sadler, who looked after his mother:

Sometimes I get fed up with them - the doctor comes once a month and writes out prescriptions, then he goes away - and the nurses, they come every day but the-day and Sunday, but they just come, they wash her, if she's in the bed they bring her in through here, then they go away ... It's me that's got all the responsibility - they go away, that's their duty done. I've got all that day, into the night, the next morning, and then they come, they do their wee stint, and they're away ... It's the carer that's got all the responsibility.

3. Attitudes to Caring

SACRIFICES IN ORDER TO CARE

QUESTION : Have you had to make sacrifices in your life in order to care for ...?

% of carers (N = 76)

Yes.....	37%
Carer unsure....	14%
No.....	49%

Half the carers of non-institutionalised dementia sufferers were sure that giving care had not involved them in any sacrifices. Of those who had made sacrifices, by far the most frequent was having given up their social lives in order to care: 74% of them cited this as their sacrifice.

Mrs. McEwan had sacrificed her social life to care for her husband:

... I've had to give up a lot - I mean, that friend of mine, we were everywhere, we wouldn't think nothing of jumping on a bus and going here, there and everywhere - days round the shops. I couldna' tell you what like Glasgow is, now.

Mrs. Nisbett had sacrificed her part-time sales assistant job to care for her mother:

Oh, I would say it's a sacrifice - I mean, I

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was quite happy in my job, my life was going fine until then.

Although half these carers did not regard themselves as having made sacrifices, this did not necessarily mean that they had not relinquished certain things in order to care for the dementia sufferer. However, because they had done so willingly - because they perceived the sufferer as having deserved it, or because they believed the sufferer would have done the same for them - it was not perceived as a sacrifice. For example, Mr. Yates, caring for his mother, said:

To sacrifice something, it would need to be something that was that important. She's more important - to me, anyway.

Mrs. Kelly believed it was only fair to repay her mother for the care which she had given in the past:

Well, she ran after us for all they years, and she tried to give us a wee bit ... and she washed a lot of stairs and wee jobs for us - likes of for us, she never got it.

The duty of a wife to care for her spouse was regarded by Mrs. Baird as negating any sacrifices which she might have had to make in order to look after her husband:

No, I don't really feel - no, no, it's not a sacrifice, no - as I said already, when you get married and it's for better for worse, for richer for poorer, in sickness and in health - and that's the way, as I say, we were brought up. And he's worked all his days, I mean - goodness gracious, surely I can look after him for this wee while now.

WHOSE NEEDS CAME FIRST?

QUESTION : How important is looking after ... compared with your own needs?

% of carers (N = 75)

Great deal more important than self.....	69%
Slightly more important.....	9%
Equally important.....	19%
Slightly less important.....	1%
Great deal less important...	1%

The overwhelming consensus among community carers was that the dementia sufferer's needs were at least equally important to their own. For some, this was simply the way it should be because of their love for the sufferer; often it had been that way long before the onset of the dementia. For others, the needs of the

sufferer simply had to come first, because they were so helpless or vulnerable if left unaided.

Mrs. Calder put her husband's needs before her own because he couldn't survive by himself:

H.S: Who gets put first in this house?

Mrs. C: Oh, him - definitely.

H.S: Why?

Mrs. C: I don't know - I know he can't do anything for himself - he doesn't really realise what's wrong with him ... I just keep him happy and contented.

Mrs. Scott's husband had been first throughout their married life:

The family say, "You'll have to start thinking about yourself instead of dad all the time" ... I've always put him first.

The reason why Mr. Sadler rated his mother's needs as equal to his own was a practical one: in order to care for her, he had to care for himself as well:

If I've got to look after my mother I've got to look after myself, haven't I - to look after her.

In fact, this was also the reason why Mrs. McAleer, one of the carers who put herself first, did so: in order to care for a dementia sufferer she believed that "practically, you must" look after yourself.

THE WISHES OF THE SUFFERERS THEMSELVES

QUESTION : Before the onset of the illness, did ... express any particular wishes about how he/she would like to end his/her days?

% of carers (N = 75)

Yes.....8%
Carer unsure.....0%
No.....92%

QUESTION : Before the onset of the illness, did you discuss the possibility of caring for him/her with ...?

% of carers (N = 75)

Yes.....11%
Carer unsure.....0%
No.....89%

QUESTION : Would ... agree that it is right for you to be looking after him/her?

% of carers (N = 73)

Yes.....45%
Carer unsure.....32%
No.....23%

Although only about 10% of this group of community carers reported they had ever discussed the possibility of dying or caring for the sufferer prior to the onset of dementia, 70% believed that they knew what the sufferer's wishes would have been. Almost half the sample felt that the sufferer would believe it was "right" that the carer was looking after them at home.

Mrs. Dewar's mother (who had no insight into her condition) had made her expectations quite clear, with the result that Mrs. Dewar felt obliged to continue looking after her:

H.S: Would your mum think it was right for you to be looking after her?

Mrs. D: Oh, aye ... I mean, even now, if I suggest - the time she went to Forsyte House for a fortnight, or if I suggest anywhere, it's "Oh, I'm not going in there, you're no' getting rid of me".

Although he had not said as much, Mrs. Tait believed that her husband would expect to be cared for by his own wife in his own home:

He's the type of person that would expect you to do that - the sort of old fashioned type. Although he's only in his 60s, he's always been a very old fashioned type of person - he was brought up with old grandparents ... and even the family, he would just expect them to do it ...

Mrs. Baird had no idea how her husband would have felt about the way she was caring for him:

I don't know how he would have felt about that - but we never ever discussed that, we never ever thought it would come up to being anything like that.

Those carers who believed that the dementia sufferer would not have wished to be looked after by relatives in the community generally attributed this to the sufferer's previous "independence". Miss McBride, for example, guessed her sister's wishes as follows:

She would probably have said, "Oh, just stick me in a home" ... because she's never been ill in her life - physically, she's never been ill, she's strong as an ox.

Why did such carers continue to look after the sufferer? Mrs. McEwan explained how it might be easy to assent with "stick me in a home" when all was well, but that it was a different thing to consign a severely impaired and dependent dementia sufferer to an institution: (over page)

Well, my husband always said to me, "If ever ..." - when he seen my mother (who had suffered from dementia and died in long-term institutional care), that he says, "Well, I would hope", he says, "If ever I - thingummy, you'd put me into hospital" - which I - it's a different thing when it happens to them ... it's alright saying it when you've all your faculties and you're alright, but it's a different story if you become ... I mean, depending on your family and you canna' do for yourself. You wouldna' want to - when the time comes when you werena' able and didna' know what was going on round about you, you wouldn't want to go.

REASONS FOR CARING FOR THE DEMENTIA SUFFERER

QUESTION : Do you feel under any obligation to care for ...?

	<u>% of carers (N = 77)</u>
Yes.....	35%
Carer unsure....	10%
No.....	55%

Over half the sample stated that they did not regard caring for a dementia sufferer in the community as an obligation. The reasons which they gave for caring were classified into one of four groups, as shown in Table A11.2 below.

Table A11.2
Reasons for caring for the dementia sufferer at home.

	<u>% of carers (N = 74)</u>
Love.....	35%
Duty.....	35%
Repayment.....	22%
No choice.....	8%

There was a significant relationship between carer-sufferer blood/role relationship and the reason for caring for the dementia sufferer within the community. Those who were caring for a spouse or a sibling were significantly more likely to state that they were caring out of love, whilst those caring for a parent or in-law were more likely to be caring out of a sense of duty, repayment or because they had no choice (chi-squared = 7.27, 1d.f., p<.01).

One of those who cared out of love was Mr. Fergus, who described how he felt about looking after his wife:

H.S: Do you feel under any obligation to look after her?

Mr. F: Not for a man and his wife situation - provided that you've always been close, and we've always been close - that's my girl there.

This continuation of a long marital relationship into a caring one was also described by Mr. Salter:

H.S: Is it like an obligation, having to look after her?

Mr. S: Well, put it this way - you've stayed together and you've ate together and you've slept together and you've done everything together, so when it comes to the - the latter years of your life, you just cling together just the same.

However, marriage vows could also bring with them a sense of duty to care for the dementia sufferer. Mrs. McEwan, for instance, believed that caring for her husband was her job:

Well, to me it is my job, because as I say, he is my partner in life and it's up to you to do what you can for them while you're together.

The other main reason given for looking after the dementia sufferer at home was repayment: either for the attention which the sufferer had previously bestowed on the carer, or simply for being a good and thus deserving person. For example, Mrs. McCabe believed it was "our responsibility - it's up to us to help" her mother, because as she said:

Well, my mum was always there when we were kids. She was always there when we needed her for anything, she was always there.

Mr. Yates continued to care for his mother because she in her turn had cared for other elderly relatives and so in his opinion did not deserve to be placed in long-term institutional care:

... when her mother took ill she was working down in Leeds ... and she had a good job, but she didn't think twice about packing it in to come back here and look after her mother - she did that, and when my father became ill she looked after him ... so if she could do it without thinking about it and look upon it as her duty, why should I be any different really? That's the way I look at it, it's something she would do.

A few relatives continued to care because they had no choice. Mrs. Young, who looked after her husband, was one of these:

It's really at the stage where you're just putting in the time until they say he's to go in.

Similarly, Mr. Sadler, who had remained unmarried, lived in the parental home, and had been made redundant, believed there was no choice but to look after his mother:

I wouldna' say I want to do it - I've been left with it and I canna' do nothing else - I wouldna' say I'm daft at doing it, but she's my mother. I care for my mother and that, but it's just circumstances that happened.

4. The Possibility of Giving up Community Care

QUESTION : How likely is it that ... will enter long-term care in a hospital or old people's home within the next year?

	<u>% of carers (N = 76)</u>
Extremely likely.....	20%
Fairly likely.....	4%
Maybe.....	16%
Fairly unlikely.....	9%
Extremely unlikely.....	51%

QUESTION : How likely would you be to take a place at (local hospital) for ... if it was offered to you tomorrow?

	<u>% of carers (N = 75)</u>
Extremely likely.....	9%
Fairly likely.....	0%
Maybe.....	3%
Fairly unlikely.....	1%
Extremely unlikely.....	87%

The relationship between these two scales was examined by dividing them in two at the point between "fairly likely" and "maybe". Table A11.3 (over page) shows the numbers of carers who fell into each of the four categories which resulted from combining institutionalisation within a year "likely" versus "maybe or unlikely" with institutionalisation tomorrow "likely" versus "maybe or unlikely".

Over two thirds of caregiving relatives did not think it was particularly likely that they would give up caring for the dementia sufferer within the next year. Among those who did, there was a clear Guttman type distribution: no carer thought they would be likely to accept an institutional placement for the dementia sufferer tomorrow unless they also thought it was likely that the sufferer would enter long-term care within the next year. (Hardly a surprising result.)

Table A11.3
Numbers of caregiving relatives willing to place dementia sufferers into long-term care.

		<u>INSTITUTIONALISATION</u> <u>WITHIN A YEAR</u>	
		LIKELY	MAYBE/ UNLIKELY
<u>INSTITUTION-</u> <u>ALISATION</u> <u>TOMORROW</u>	LIKELY	7	0
	MAYBE/ UNLIKELY	10	58
Total N = 75			

This result differs significantly from a random distribution of carers among the four categories (chi-square = 23.3, $p < .001$ after Yates' correction).

Several relatives believed that while institutional care was not currently appropriate for the dementia sufferer, it would be within a year. Given the Guttman-type distribution of responses to these two items, they could be summed to form a total "Carer Willingness to Institutionalise" scale. This scale was used in the regression analyses to identify "predictors" of the willingness of community caregivers to institutionalise dementia sufferers. (See Chapter Seventeen.)

Mrs. McAdam was absolutely determined that her husband should not enter long-term care. She had refused to place his name on any waiting lists and believed that in an emergency an institutional bed would be found for him should it become necessary:

I would really need to be forced physically to do anything permanent about residential care - I think I would need to collapse ... which is why I've refused to put his name down on the permanent list. The health visitor's been at me, the doctor's been at me. They'll say to me, "It's alright, you don't have to take the place", but I've heard of one or two occasions when they've been quite cross when you don't ... I'm afraid if I collapsed tomorrow something would be done, I'm quite sure.

One of those who was anticipating the need for long-term care within a year - but not just yet - was Mr. Gibson, caring for his mother at home: (over page)

H.S: Is it likely that your mum will go into long-term care within the next year?

Mr. G: Yeah, it's going to be quicker than that. Now we know it's a weekly deterioration with my mum - and she's getting a lot of care, you know, love and care off my sister and I, but it's now more professional care she's looking for, you know - a nurse, we're actually trying to get a nurse to come in during the day.

H.S: What if Dykebar were to phone and say they had a place for her tomorrow?

Mr. G: Not yet, not yet - I mean, the decision's coming because I'm going to be away in October, and if I'm not here during the day my mother can't be left on her own, and you can't ask anybody to come in. Physically it's a deterioration, that's the thing that is going to put her into a home.

Finally, Mrs. Lennox would have been willing for her husband to enter institutional care immediately:

H.S: Is it likely that if I came back this time next year he would still be at home?

Mrs. L: The doctor's trying to get him hospitalised for me - thinks he's ready for it, and I said, "Yes, I'm just beat with it all" - I really am.

H.S: What if they phoned and said there was a place in Dykebar from tomorrow?

Mrs. L: Oh yes, I've told the doctor - I had an appointment with him yesterday, and he says, "Well, how do you feel?" I says, "I've had enough". He says, "I'm waiting on you saying that". Mention that a year ago, I'd have said, "No, no!", but this past year has really got me down that I feel he's needing - he's been in hospital for a break and when I go to see him he doesn't even recognise me hardly - he knows it's me, but he couldn't care less - if I'm going away it doesn't upset him. That's why I think he's ready for it.

5. Post-interview "Attitude to Continued Caring" Rating

Following the interview, ratings of "Attitude to Continued Caring" were made on the basis of comments and impressions gained during the interview. Table All.4 (over page) presents the results of this rating, together with the criteria upon which it was based.

Table All.4

Post-interview ratings of "Attitude to Continued Caring"

% of carers (N = 76)	Criteria for levels of "Attitude to Caring" (Ordered positive - negative)
28%.....	Entirely positive; enjoys role; made no sacrifices; sufferer put first; cares for love; will continue as needed.
43%.....	Fairly positive; enjoys some aspects; may be repayment; not actively considering institutionalisation.
26%.....	Fairly negative; dislikes most aspects; may be duty; seriously considering institutionalisation for the future.
3%.....	Entirely negative; dislikes all aspects; made sacrifices; self put first; caring as no other option.

The results of this rating clearly mirror the other results and comments in this chapter. The majority (over two thirds) of the sample of community carers were rated as fairly or entirely positive about their role.

The post-interview "Attitude to Continued Caring" were significantly related to the total "Carer Willingness to Institutionalise" score: $r = .669$ ($p < .000$).

II. DISCUSSION

Gilleard [1984] points out that in Britain there is enormous variation in the provision of community services for the elderly mentally infirm. The average amount of relief from caring received by co-resident carers in the present sample was almost 11 hours per week, representing approximately two days at a day hospital or day centre. However, this may well be an over-estimate of the average day care available in Britain, for the following two reasons. The first of these was that in order for the investigator to contact the sample they obviously had to have some dealings with the formal services themselves. Thus, they may represent a biased sample. The second reason is that the geographical area covered in the present study is relatively well catered for by formal services: in addition to the "usual" NHS psychogeriatric day hospitals and local authority day centres, the Alzheimer's Society runs two projects (Paisley and Motherwell) which also arrange day care.

Possibly as a result of this provision of day care (but possibly simply because the interviewer was perceived as "a professional"), the expressed level of satisfaction with the amount of help received from "professionals" by community carers was generally good. The Alzheimer's Society and psychogeriatric day hospital staff generally received praise, while the GPs tended to bear the brunt of any criticisms. General practitioners may not perceive dementia as a medical problem. While carers quite clearly appreciated that the GP could not intervene to "cure" dementia, there was also the belief that the GP should demonstrate concern and continued interest in both the sufferer and the carer by calling regularly - say, once a month. GPs were usually praised for showing concern, and not for actual medical interventions. Satisfaction with family help was generally somewhat lower - possibly the expectations of the family were higher, possibly they were easier targets to blame than the professionals. For some community carers, the scenario was clearly the oft-described one of a single "primary" caregiver surrounded by relatives who offered criticism or advice, but no practical assistance. Having said this, it should also be pointed out that half the current sample of community carers stated that they were at least fairly satisfied with the help they got from their relatives.

Almost half the community carers of dementia sufferers believed that they had not made any sacrifices in order to care. The vast majority believed that caring for the dementia sufferer was more important than their own needs. Over half stated that they did not regard caring for their dementing relative as an obligation. Some carers, then, were clearly positive about looking after their relative in the community. This was also reflected in the fact that half believed it was "extremely unlikely" that their relative would enter institutional care within the next year. To the outside observer, caring may appear an exhausting, frustrating and depressing task. For some community carers this may be the case, but for many the benefits appear to outweigh the costs. Or perhaps it is rather that the costs of relinquishing care are so great that they outweigh the benefits which might accrue. As Whittick [1987] points out, institutional care is generally regarded with suspicion and distaste by family caregivers. It is therefore very much the last resort for most carers, associated with guilt at what may be perceived as their own failure to continue coping. Caring out of love (rather than out of duty, a sense of repayment, or because there was no other choice) was significantly more likely when the sufferer was a spouse or sibling rather than a parent or in-law:

caring was often accepted as one's job, the extension of a long relationship, and to some extent this removed the sense of obligation. This finding agrees with a number of other studies which have found a lengthy close relationship to be associated with a low preference for institutional care [for example, Gilleard, 1984; Gilhooly, 1984]. In particular, Colerick and George [1986] have also described spouses as more likely to accept their role as caregiver and to believe that the dementia sufferer continues to occupy a central role in their lives.

It was interesting to find that while very few of the sample of community carers reported they had ever discussed the possibility of dying, or caring for the sufferer prior to the onset of dementia, the majority believed they knew what the sufferer's wishes would have been. Almost half believed the sufferer would advocate that they should remain in the community. Whether this resulted from a life-long understanding of the sufferer's beliefs in such matters, or whether it fitted in with the beliefs of the carer is impossible to say.

III. SUMMARY

This appendix has described and discussed the position of the 77 subjects in the present study who were caring for a dementing relative within the community.

The amount of relief from caring received by both co-resident and non-resident caregivers was presented, together with their satisfaction with both the formal and informal support received. A survey of the attitudes towards caregiving demonstrated that for many community carers, the benefits of continued caring outweighed the perceived costs of the institutionalisation of their dementing relatives. Caring out of love was found to be associated with looking after a spouse or sibling. For some community carers in this situation, the task of continued care was not perceived as a burden.

APPENDIX TWELVE

FACTORS ASSOCIATED WITH QUALITY OF CURRENT CARER-SUFFERER RELATIONSHIP

I. INTRODUCTION

One of the most consistent variables to emerge from analyses of the factors associated with carer grief components, with sufferer social death, with carer subjective burden, and with preference for institutional care was the quality of the current carer-sufferer relationship. A poor current relationship was associated with what would be regarded as negative aspects of all these other variables. That is, it was associated with a greater current intensity of I.S. grief components "Questioning/Anger/Guilt" and "Preoccupation/Unfinished Business/Despair" (and with F.A. grief components "Protest" and "Mourn"). It was associated with greater endorsement of items from social death factor "Life Pointless". It was associated with increased carer subjective burden. Finally, it was associated with a more negative attitude towards continued community care.

This appendix seeks to define the "predictors" of the quality of the current carer-sufferer relationship.

II. "PREDICTORS" OF A GOOD CURRENT CARER-SUFFERER RELATIONSHIP

Stepwise multiple regression analyses were used in order to identify those factors associated with higher quality of current carer-sufferer relationship as reported by the carer. Analyses were conducted using score on the "Current Relationship" (interaction scale) as the dependent variable.

In the first round, four multiple regression analyses were conducted. The variables within each area which were entered into the regression equations were those which it was hypothesised might impact upon the quality of carer-sufferer relationship. (For details of the coding of the variables as they were entered into the regression equations, please refer to Appendix Eight.) These variables comprised the following:

CARER CHARACTERISTICS EQUATION

(1) Carer age; (2) Carer gender; (3) Carer work outside the home; (4) Number of professionals carer had spoken

to with regard to sufferer and dementia; (5) Carer general knowledge of dementia; (6) Carer overall perception of dementia; (7) Carer perception of having experienced grief.

SUFFERER CHARACTERISTICS EQUATION

(1) Sufferer age; (2) Sufferer gender; (3) Sufferer living arrangements; (4) Time since onset of impairments; (5) Time since diagnosis of dementia; (6) Overall change in sufferer perceived by carer; (7) Most important change in sufferer perceived by carer; (8) Sufferer ability to recognise carer; (9) Sufferer physical changes as perceived by carer.

SUFFERER IMPAIRMENTS/BEHAVIOURS EQUATION

(1) Total frequency of problems from behaviour problem domain "Depend"; (2) domain "Can't do"; (3) domain "Incontinence/Hygiene"; (4) domain "Apathy"; (5) domain "Disturb"; (6) domain "Demand".

CARER-SUFFERER RELATIONSHIP EQUATION

(1) Carer-sufferer blood/role relationship; (2) Quality of premorbid carer-sufferer relationship.

The results of the four "first round" stepwise multiple regression analyses can be found in Appendix Nine.

Table A12.1 presents the results of the "final round" stepwise multiple regression analysis for quality of current carer-sufferer relationship. Where necessary, the direction of the relationship for those variables in the equation is explained.

Table A12.1
"Predictors" of quality of current carer-sufferer relationship as reported by carer

	<u>Adjusted R²</u>	<u>Beta</u>	<u>F-value</u>
Sufferer living situation (institutionalised).....	0.22	0.48	29.73
Quality of premorbid relationship.....	0.35	0.34	27.53
Carer gender (male).....	0.40	-0.26	22.90
Carer work outside the home.....	0.43	0.19	19.69

*** = p<.001

The results presented in Table A12.1 demonstrate that a better relationship (for example, more laughter, less tension, fewer arguments, carer happy to be with sufferer) was more likely when the dementia sufferer was in long-term care, when there had been a good premorbid relationship, when the carer was a male, and when the carer was in paid employment.

III. DISCUSSION - "PREDICTORS" OF CURRENT RELATIONSHIP

The importance of institutionalisation as a "predictor" of a better quality carer-sufferer relationship presumably reflects the fact that living with a dementia sufferer can be tiresome, frustrating, or depressing. If the carer is neither primarily involved in their physical care, and also - perhaps most importantly - in control of the length of time over which interaction will take place, then the quality of the relationship improves. It is much easier to get on well (or at least not badly) with a dementia sufferer when you know you do not have to spend too much time with them and that you can decide when to leave. Several carers made comments to this effect; for example that they felt "more loving" towards a sufferer since they had been admitted to long-term care.

A better relationship was also more likely when the carer was in paid employment. As noted with regard to the impact of outside employment on carer well-being (see Chapter Sixteen), employment diverts a carer from the task of caring and provides a social outlet. In addition it means that the sufferer is still capable enough to be left alone or that there is a "sitter" both frequently and readily available. Perhaps most important with regard to its impact on the quality of their relationship is the fact that employment removes co-resident carers from the presence of the dementia sufferer. Both this result and the impact of institutionalisation on quality of current relationship suggest that the less a caregiving relative is in contact with the dementia sufferer, the better will their relationship be.

A good premorbid relationship increased the chances of a good current carer-sufferer relationship. Clearly, a bank of happy memories of a long-standing, close relationship acts to safeguard that relationship. The "habit" of getting on well tends to persist despite the impairments of the dementia sufferer. The other side of the coin is that if two people did not get on particularly well prior to the onset of dementia, then it is somewhat unreasonable to believe that their relationship might improve once one of the dyad begins

to exhibit dementia. Indeed, tension and trivial arguments are more likely to increase than decrease.

The final variable which emerged as significantly associated with a good current relationship was being a male carer. This is something of a surprise. Why should male carers report a better relationship with the dementia sufferer than female carers? Possibly the key word here is "report". It may be that female carers tend to perceive their relationship with the sufferer as poorer than do male carers. (An objective observational study of carer-sufferer interactions would be the only way of validating the quality of relationship as reported by the carers.) It is interesting that while other studies have not examined the association between carer gender and the quality of their relationship with the sufferer, female carers have generally been reported to be experiencing greater subjective burden than males [for example, Gilhooly, 1984; Gilleard, Belford and Gilleard et. al., 1984; O'Connor, Pollitt and Roth, 1989]. This finding has been attributed to the fact that male carers may be less emotionally involved with the sufferer and their illness, may be less willing to report their distress, may find the physical tasks of caring easier, or may find caring something of a novelty and thus a source of rewards and interest. Thus it is possible that the present result arises from the fact that female carers are more willing to report a poor current relationship with their dementing relative. It is also possible - particularly given the fact that less contact with the dementia sufferer was associated with a better quality relationship - that the poor current relationship reported by female carers results from the suggestion that they are emotionally and physically involved with the sufferer and their illness to a greater extent than are males. In addition, if female carers really do find the physical tasks of caring more difficult, dull, or trying than men, it might be assumed that this would not be conducive to a cheerful or relaxed relationship with the dementia sufferer among female carers.

IV. SUMMARY

This chapter presented the results of stepwise multiple regression analyses designed to identify factors associated with quality of the current carer-sufferer relationship, as reported by caregiving relatives. The reason for this analysis was that (poor) quality of relationship had emerged as significantly related to the presence of distressing carer grief components, sufferer social death, carer subjective burden, and their increased preference for institutional care.

A good current relationship was found to be associated with institutionalisation of the dementia sufferer, good premorbid relationship, male caregivers, and carers who had employment outside the home. The reasons for these findings were discussed.

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