CARERS OF THE DEMENTING ELDERLY: COPING TECHNIQUES AND EXPRESSED EMOTION

JANICE ELIZABETH WHITTICK

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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 baice E. Whithick

Date 18 October 1993

Some of the results of this thesis have already been published in the following article and book chapter.

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SUMMARY

The focus of this thesis was the disease senile dementia and in particular the impact that this condition has on the family carers of elderly people with dementia who live in the community.

The study had two main aims. Primarily it set out to identify the stressful situations which carers were facing on a daily basis and to establish how they were coping with them. It also took this issue of coping further and attempted to quantify and measure the specific techniques used in the course of their general caring duties.

Secondly, the study explored the concept of expressed emotion (EE) in this group of carers and linked this to coping. It was thought that those carers who were less able to cope with the situation may also have had a high level of EE. The EE concept has been shown to be a useful indicator of relapse in schizophrenia and it was thought that it may also have had predictive value in the outcome of care for the dementing elderly and their carers.

The data was collected from 100 semi-structured interviews with carers of elderly people with dementia. The longitudinal aspect of this study allowed outcome data to be looked at one year after the initial interview.

The results showed that carers identified stressful situations which were characterised by, inappropriate behaviour as a consequence of disorientation; refusal to co-operate with caregiving activities; incorrect interpretation of people or events; and provocative or hurtful comments. The carers dealt with these

situations by, verbal action; practical action or withdrawal, which could be either physical or psychological. Running parallel to this was very often a lot of anger and frustration although this seemed to change over time.

Carers tended to favour more passive, emotion-focused types of coping and rarely used practical or behavioural techniques. It was not possible to analyse the data in such a way as to come up with a prescription for good coping techniques and reasons for this were discussed. The Ways of Coping checklist did not support a 'coping reduces stress' model. Results suggested that the measure was reflective of stress rather than an independent mediator.

There was evidence that the concept of expressed emotion had relevance for this group of carers and that it seemed to be linked to carer well-being, the carer/dependant relationship and some measures of coping. It did not however prove to have predictive validity in terms of outcome at one year follow-up. Questions about the exact nature of the concept of expressed emotion and whether it merits the status of 'concept' in its own right, or whether it is just a measure of angry feelings on behalf of the carer, towards her dependant were raised.

Few of the variables studied had predictive validity in terms of dependant outcome at one year and the question remains as to the basis on which decisions to institutionalise are made.

Finally, criticisms of the present study and recommendations for future research were made.

PART ONE

INTRODUCTION AND LITERATURE REVIEW

CHAPTER ONE

SENILE DEMENTIA - THE DISEASE

"Dementia is a global impairment of cognitive function that usually is progressive and that interferes with normal social and occupational activities."

Council on Scientific Affairs (1986)

I. INTRODUCTION

The background to this thesis is the disease senile dementia and this chapter lays the foundations for what is to follow. The clinical syndrome is described and there are brief sections on possible causes, theories, risk factors and epidemiology.

II. SYMPTOMS

The American Diagnostic and Statistical Manual-111 (1980) defines dementia:

- A. A loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning.
- B. Memory impairment.
- C. At least one of the following:
 - 1) impairment of abstract thinking, as manifested by concrete interpretation of proverbs, inability to find similarities and differences between related words, difficulty in defining words and concepts and other similar tasks.
 - 2) impaired judgement.
 - 3) other disturbances of higher cortical function, such as aphasia, apraxia, agnosia, constructional difficulty.
 - 4) personality change.
- D. State of consciousness not clouded.

E. Either 1) or 2)

- 1) Evidence from the history, physical examination or laboratory tests, of a specific organic factor that is judged to be etiologically related to the disturbance.
- 2) In the absence of such evidence, an organic factor necessary for the development of the syndrome can be presumed if conditions other than Organic Mental Disorders have been reasonably excluded and if the behavioural change represents cognitive impairment in a variety of areas.

Gilleard (1984) concisely summarized the clinical picture of dementia in his statement that dementia represents a 'progressive deterioration in all areas of brain function which maintain the individual's links with his present and past personal, social and physical environment'. The rate of the degeneration in dementia varies considerably between individuals as cognitive impairment interacts with individual's reaction to this loss. Generally it is recognised that in the early stages there is mild cognitive decline, with difficulty learning material. Memory problems initially may be no more than occasional absentmindedness but deterioration across all memory functions is inevitable. disease progresses, there may be a decreased knowledge of topical information, a breakdown in the ability to perform complex tasks and the loss of insight with emotional blunting and withdrawal. Well established complex tasks, eg. dressing, may then become difficult and the individual's orientation may be markedly Latterly there may be incontinence, no impaired. awareness of present surroundings or experiences and personality. Finally help may be required for all and there is frequently gross self-care tasks

impairment of language and comprehension. These more evident cognitive changes are often accompanied by emotional changes such as anxiety, depression or motivational deficits such as apathy, withdrawal and a loss of interest. The behavioural changes associated with dementia are varied and commonly include wandering and restlessness, incontinence, aggression and hostility.

The impact that this multi-faceted disease can have on the sufferer's family and friends can be devastating as communication becomes difficult and the 'self' or 'person' deteriorates while they may remain physically well and intact. It is the impact that all of this has on the carer that is of concern in this thesis.

III. BRAIN CHANGES IN SENILE DEMENTIA

At post-mortem, the most important features of changes in the brain for establishing the diagnosis are senile plaques and neurofibrillary tangles. Senile plaques consist of a core of protein called amyloid and they affect the axons which transmit information from one neuron to another. Amyloid is not a naturally occurring substance in the brain.

Neurofibrillary tangles occur in the cell body of brain neurons. They are bunches of long thread-like structures. The threads consist of pairs of filaments twined around one another forming a helix. It is thought perhaps that these threads derive from normal structures called neurofilaments which run parallel to the neuron's axis and transport chemicals around the nerve cell.

While plaques and tangles occur in the normal elderly

they are more prevalent in those with senile dementia. They commonly occur in two main sites in the brain, namely, the hippocampus and the cerebral cortex. hippocampus has a vital role in immediate and shortability to memory and in the learn information. The cerebral cortex is the centre for various complex mental processes important in facets intelligence such as language, orientation, perception and initiating voluntary actions. When one considers the basic symptoms of dementia it becomes clear that it is those aforementioned processes that are primarily affected. From the 1950's onwards scientists began to realize that the clinical picture was closely and significantly related to a clinical phenomena.

By the late 1970's there appeared to be an exciting breakthrough when independent groups of researchers identified a cortical cholinergic deficit that was thought to be responsible for the cognitive impairment which is the major feature of the disease. already known at that time that anti-cholinergic drugs could alter cognitive function and in particular short term memory in normal subjects and so the link for possible treatment of the disease was made. Unfortunately, as with most of the new breakthroughs date, this was not the whole story. cholinergic deficit has subsequently been found to be only one of the many neurotransmitter abnormalities underlying the disease. For example, somatostatin which is used by certain neurons in the cerebral cortex has also been found to be deficient in the brains of Alzheimer's disease patients (Beale et al., Similarly, another neurotransmitter. corticotrophin-releasing factor, has been found to be reduced in the cortex of these patients (De Souza et al., 1986).

IV. BRAIN IMAGING TECHNIQUES

Over the past two decades there have been considerable advances in technology which have allowed scientists to advance knowledge of the pathological brain changes associated with the disease.

The earliest brain imaging technique was computerised axial tomography (CT) which, by taking x-rays of the brain, can produce an image which is then interpreted numerically either visually or by examining quantitative differences in density numbers. The scan shows differences in tissue density between various areas of the brain. In general, there is a reduction in the density of brain tissue in Alzheimer's disease although this is subject to regional variation. main changes seen in the brains of Alzheimer's disease patients are atrophy or shrinkage of the brain and enlargement of the ventricles, that is the cavities of the brain containing cerebro-spinal fluid. important to note that these changes are not specific Alzheimer's disease although they are prevalent in those patients than in normal elderly subjects (McGeer, 1986).

Magnetic resonance imaging (MRI) is a more recently developed technique which has the advantage of not subjecting the patient to radiation. It also produces a clearer image and it may be helpful in distinguishing Alzheimer's disease from multi-infarct dementia (Besson et al., 1983).

Another fairly new technique is Positron Emission Tomography (PET) which involves injecting patients with a chemical which emits positrons. This then enables various types of biochemical activity to be traced in the brain. One example of this has been the finding that glucose, the source of the brain's energy, appears to be substantially reduced in Alzheimer's disease (Benson et al., 1983). The possibilities that this technique offer in studying the disease process are endless and exciting new findings are likely in the future.

V. CAUSES OF DEMENTIA

Technically speaking, dementia is a constellation of symptoms and not a disease in its own right. There are many disorders which can produce the syndrome of dementia including Huntington's Chorea, Pick's disease, Korsakov's disease, depression and AIDS but the three major disorders which result in the syndrome of dementia are Alzheimer's disease, multi-infarct dementia and mixed dementia which results from a combination of the two.

i) Alzheimer's disease is the most common dementia and accounts for more than half of all dementias (Katzman, It is characterized by brain changes of 1976). neuronal loss, senile plaques and neurofibrillary tangles and is named after Alois Alzheimer who discovered these brain changes in a 51 year old woman It was later discovered that these changes (1907).were present in the brains of older people who presented with similar clinical symptoms. The term is now commonly used to describe all those suffering from the disease regardless of age and it is debatable whether a separate pre-senile category of the disease should be recognised. As already stated the aetiology of these pathological brain changes is unknown. these brain changes that lead to a reduced ability to

process information which in turn produces the symptoms of poor memory, poor judgement and change in temperament and personality.

- ii) The second major category of dementia is multiinfarct dementia, also known as vascular dementia or arteriosclerotic dementia. This is thought to be caused by a brain infarct or stroke which cuts off the blood supply to a part of the brain. After a succession of these infarcts the symptoms of dementia may become apparent.
- iii) Thirdly, it is not uncommon for both Alzheimer's disease and multi-infarct dementia to co-exist as both are diseases of old age and this is often referred to as a 'mixed dementia'.

It is perhaps no surprise that diagnosis of dementia can be difficult and one cannot be certain of the type of dementia until post-mortem. The issue is further clouded by the possibility of the symptoms being caused by delirium which is acute brain failure and is reversible temporary and condition. depression in the elderly may present with symptoms also common to dementia eq. withdrawal, apathy and muddled thinking. It is therefore important that everv effort is made to determine an accurate diagnosis.

VI. THEORIES OF ALZHEIMERS DISEASE

While the causes of the disease are unknown, there have been many theories proposed to try and explain the origins of Alzheimer's disease. It is not the purpose of this thesis to examine these theories in detail but three of the most prominent theories will be outlined in brief.

i) Genetic Predisposition

One theory suggests that there are genes which predispose an individual to the disease. Given the relatively weak hereditary component of the disease it would seem unlikely that only one gene could be responsible and more likely that there are many genes involved (Wright and Whalley, 1984). The genetic theories seem attractive if one accepts that ageing is a genetically programmed process and that there is individual variation within this. For some of us the process of shutting down the brain in old age, which is predetermined by an individual genetic programme, may come earlier than for others. Further support for the genetic theory derives from our knowledge that most people with Down's syndrome develop Alzheimer's disease in middle age. We know that Down's syndrome is the result of an extra 21st chromosome. This extra chromosome may mean that there is an overproduction of certain essential chemicals which are significant in the development of Alzheimer's disease (Heston, 1984). However, the genetic theories do not explain why in twin studies it has been shown that one twin may dement while his or her identical sibling may not (Hunter et al., 1972).

ii) Toxic Exposure Theory

Toxic-exposure theories propose that the plaques and tangles are caused by environmental, toxic substances which effect distinct parts of the brain. For some time the most likely toxin has been thought to be aluminium which was believed to be responsible for the neurofibrillary tangles. Some studies have shown that excessive levels have been found in the brains of Alzheimer's disease patients, particularly in nerve cells affected by neurofibrillary tangles (Crapper, et al., 1976). Other studies have however, failed to

show this (Wisniewski et al., 1986). Early animal studies found that the brains of some animals when injected with aluminium developed neurofibrillary tangles but these differed from the tangles found in the brains of demented humans. Certainly all of us are exposed to aluminium from the earth's crust and additional sources may be found in our cookware and drinking water but not all of us dement even if exposed to high levels of aluminium. Perhaps then some of us are just more vulnerable to the effects of a toxic substance in the environment. However, recent work by Whalley and Holloway (1985) reported that cases of Alzheimer's disease tend to cluster opposed to be randomly distributed over a given area which might suggest that there is an unknown toxic substance in certain areas.

iii) Infectious Virus

Other theories have suggested that the disease is due to an infectious agent or virus invading the brain. The evidence supporting this comes from two known diseases, kuru and Creutzfeld-Jakob disease both of which produce symptoms of dementia and are known to have long incubation periods of many years. It may be that Alzheimer's disease is also viral in origin. Studies to date have been unsuccessful in infecting animals with the disease and it seems unlikely that it is transmitted between humans through conventional contact. It may be that there is a particularly long incubation period for the virus to take effect but studies have been unable to pick up on this as yet.

As already mentioned, an abnormal protein called amyloid is found in the senile plaques and Prusiner (1984) has proposed that this protein is in fact an accumulation of the virus. Alternately, Ulrich (1985) suggested that it was the neurofibrillary tangles that

are produced by the virus, spreading though the nasal passages to the brain.

In summary then, it may be of course that no single theory will account for the disease but rather there may be some truth in all of them and it combination culmination of some or of the aforementioned elements that is responsible. Deary and Whalley (1988) suggest that Alzheimer's disease may represent the end point of a variety of different and distinct pathways, each of which eventually results in neuronal death.

VII. RISK FACTORS

As with the casual theories, many risk factors have been proposed for Alzheimer's disease but few have been borne out in repeated studies. Some of the more likely risk factors are outlined below.

i) Old Age

Old age in itself is a risk factor and studies have shown that the risk of developing the disease increases with age (Hagnell et al., 1983).

ii) Family History

Where there is a family history of Alzheimer's disease, the risk seems to be greater (Heston, 1981; Whalley et al., 1982). However, there are obvious methodological difficulties in studying this risk factor. For instance, it would be helpful to know if a patient's parents had suffered from the disease but they are likely to have died in an era when little was known about the disease. Also, the patient's own children will likely be too young to be showing any signs of the disease. Heston (1984) in the USA

overcame these difficulties and by using only cases diagnosed by autopsy, found that the risk from parents was 15-23% and from siblings it was 10-14%. The risk varies depending on the age of onset with a decrease in risk for a later age of onset.

iii) Head Injury

Some studies have shown that a significant risk factor is previous head injury. Mortimer et al., (1985) found 26% of Alzheimer's patients had a previous head injury compared with only 5% non-demented, age-matched controls. However, it should be noted that while head trauma likely increases the risk, it does not make the disease inevitable.

iv) Genetic Abnormality

As already mentioned, where an individual has Down's syndrome, or where there is a family history of the abnormality, then the risk of an early onset dementia is greater. Furthermore, people with Down's syndrome have different finger and hand prints from normal people and it has recently been shown that Alzheimer's patients have similar prints (Weinreb, 1985). Seltzer and Sherwin (1986) also found this difference but only in early onset cases. This of course provides evidence for the genetic theories as fingerprints are formed at the foetal stage of development and are genetically controlled.

v) Risk and Multi-infarct Dementia

Finally, as with Alzheimer's disease, the incidence of multi-infarct dementia rises in old age and a family history of the disease also appears to be significant. It is important to note that not all stroke victims dement but where there is evidence of high blood pressure, then the risk of dementia is greater (Ladurner et al., 1982).

VIII. EPIDEMIOLOGY OF THE DISEASE

Further knowledge about risk factors and the natural history of Alzheimer's disease can be gained from epidemiological studies. Such studies may also prove to be of value in planning services for a disease which has been described as a major challenge to public health (Henderson, 1986). Unfortunately, there are some major difficulties with epidemiological studies and interpretation of them can be difficult. To begin with, until recently there has been no universally agreed definition of dementia and few studies have differentiated Alzheimer's dementia from Also, over the years there multi-infarct dementia. have been significant demographic changes which can make projection less reliable. Surveys have also varied in their methodologies with some including the institutionalized elderly while others have confined the survey to community residents only. Owing to the expensive and time consuming nature of such surveys, sample size tends to have been small.

a result of these inherent difficulties As the prevalence of the disease is not known exactly. most quoted rates in the UK are from the survey conducted in Newcastle, by Kay et al (1970). sample size of 758, they reviewed a large number of prevalence studies world wide. They found rates varied dramatically from 2.5% in one UK study (Gurland et al., 1983) to 24.6% in the USSR (Sternberg and Gawrilove, 1978). Even outwith UK studies the rates could vary dramatically from 1.6% (Clarke et al., 1984) to 9.3% (Gilmore, 1977). From a further scrutiny of all of these surveys, Ineichen (1987) concluded that realistic prevalence figures were 1%

for the 65 - 74 age group and 10% for the over 75 year age group. While this prevalence is generally lower than previously quoted, the predicted increase over the period 1983 -2001 is 17.2% for the UK. This increase will be the result of an expanding elderly population due to increased longevity and the post-war 'baby-boom'. Other countries with a predominantly young population will see an even greater increase eg. 52% in Australia and 41% in the USA (Henderson and Jorm, 1986).

Incidence figures are harder to come by as they require a sufficiently large sample to be followed up at regular intervals over many years in order to determine how many of the sample have developed the disease. Bergmann et al. (1973) in a study over 4 years found an annual incidence rate of 0.8% for Alzheimer's dementia and 0.7% for multi-infarct dementia. Mortimer et al. (1981) in a study in the USA found similar rates of 1% for the over 65 years.

Such rates are further complicated by recent findings by Hagnell et al (1981) which reported a possible drop in incidence over a 25 year period, perhaps associated with environmental, nutritional and general life-style changes.

While exact rates may be hard to come by, one thing is certain that dementia is a considerable problem and likely to become an increasing burden on health and social resources in developed countries over the coming decade and beyond. The value of epidemiological work will be considerable and such studies should be seen as complementary to the more medically oriented research.

IX. SUMMARY

This chapter defined senile dementia, described the clinical picture and broadly reviewed the corresponding pathological changes in the brain which are associated with the disease. Commonly used brain imaging techniques were described which may prove invaluable in forthcoming research. Possible causes of the disease and risk factors were identified and finally, epidemiological studies were reviewed. In conclusion, dementia is a multi-faceted syndrome of unknown aetiology.

It seems likely that dementia is going to become an increasing problem over the next few decades and place a considerable burden on public health resources, the community and the families involved in the care of the dementing elderly. Furthermore, if there is no cure for it then it is important that due consideration is given to those people affected by it. They are the sufferers themselves and their carers who struggle to manage the considerable burden that this disease brings to bare upon them.

CHAPTER TWO

THE CARERS

I. INTRODUCTION

As senile dementia becomes an increasing health problem in the latter part of this century, the impact of this devastating condition on the community must be addressed. In spite of the disabling nature of the process, the vast majority of dementia sufferers continue to live in the community. In many cases this is made possible only by the substantial amount of time, effort and support offered by the informal carers. This chapter looks at who those carers are against a background of 'community care'.

II. PROBLEMS OF DEFINITION

There is a considerable problem in defining and identifying exactly who these informal carers are. Gordon et al. (1990) stated that caring about and for one another is a normal part of everyday life and it can be arbitrary to define the point at which the normal caring relationship becomes one of providing 'informal care'. Bonny (1984) suggested that the point is where "the labour outstrips the normal requirements of love". However, objective measurement of this is likely to be hard to come by and especially in large scale surveys. It is perhaps something that becomes more meaningful when the impact of caring is Lewis and Meredith (1988) in taken into account. their study of daughters caring for mothers at home made the salient point that the key to understanding informal care is to appreciate that it is based on relationships which vary in closeness, intensity, stability and fulfilment.

However, many carers provide a considerable amount of care but may not see themselves as performing a caregiving role and would certainly not perceive it as a burden. Others doing relatively little may see their role as substantial. Thus, what constitutes informal care is fairly subjective and most surveys of carers have not taken account of these subjective differences. Most large scale studies have adopted a rather broad definition in order to estimate how many individuals are providers of care in the UK.

III. THE GEOGRAPHY OF CARERS

Temporarily setting these difficulties of definition aside, how many people are estimated to be providers of care in the UK? Rossiter and Wicks estimated that there are 1.25 million full-time carers in the UK and many more who provided care on a parttime basis. Likewise Parker, Baldwin and Glendinning (1984) reported that over 1.3 million people were giving a significant support to disabled dependants in the community. Jones et al (1983) in a random sample of patients over 70 years from a General Practitioners list, found that 85% had been receiving family help of some kind for over a year. The General Household 14% (1985)reported that of the population defined themselves as carers, where the question asked was "... is there anyone living with you who is sick, handicapped or elderly whom you look after or give special help to (for example a sick or handicapped or elderly relative ... ?) And how about people not living with you, do you provide some regular service or help for any sick, handicapped or elderly relative, friend or neighbour...?)". Arber (1990) using the GHS data separated out the dependants over 65 years and found that 10.2% of the adult population were providing informal care to an elderly person.

There is however a danger in considering all dependant groups as similar and there is a growing case for separating out the elderly from other groups (Whittick, 1988, West, Illsley and Kelman, 1984). While there is a societal obligation for parents to care for their children who may be handicapped, it is not necessarily assumed that adult children will care for their elderly parent.

IV. SEX OF THE CARER

What is well established in the carer literature is that for all dependant groups, the primary carer is usually female. The early work of Sheldon (1948) and Townsend (1957) both found that daughters were the usual carers within the family. This has been confirmed more recently by Hunt (1978) in her study of old people at home. Likewise, Nissel and Bonnerjea (1982) in their study of carers of the elderly in the community and Gilhooly (1984) in her study of carers the dementing elderly found that wives daughters were far more likely to become involved in a caring role than were husbands and sons. reasons have been suggested for this, Horowitz (1981) from her American study of carers of the elderly suggested that it was because women are assumed to adopt the caring role more naturally and have traditionally had more time available at home. Women are also thought to feel stronger kinship ties and there is evidence that daughters feel emotionally closer to their parents than do sons (Horowitz, 1981; Johnson and Bursk, 1977). Furthermore, for a woman to give up work to care for a dependant relative probably incurs less financial loss to the family than if her husband were to stop work for the purpose of caring. This was borne out in a recent General Houshold Survey where taking a cut-off of more than 10 hours of care per week, 67% of the carers were female and 49% of them were daughters caring for a parent. The survey also showed that where the carer was male, he tended to provide fewer hours of care compared with female This was also noted by Hunt (1978) in a study of old people at home. She found that it was only with regard to social visits to the elderly dependant that male carers provided hours similar to those provided by female carers.

V. SHARING THE CARE - MYTH OR REALITY?

Once a carer has been identified and adopted her caregiving role, it is sad fact that she tends to care alone (Parker et al, 1984) and 'shared care' between family members is uncommon (Parker, 1985; Gilhooly, 1984) In some cases, this may be because the caring spouse hides many of the difficulties from other family members. Alternatively, perhaps the other family members fail to realize the amount and type of care the dependant requires. However, in a great many cases, it is possible that the other family members just do not want to become involved in giving the care necessary for the elderly person to remain in the community.

VI. THE CHANGING POPULATION OF CARERS

As the proportion of elderly people in our society

increases, and in particular those who develop dementia, there is a corresponding decrease in the available pool of carers and there are several reasons for this as outlined below.

i) Reduction in Family Size

The average family size has reduced over recent decades and there are now, therefore, fewer children available to provide the care. In 1990, there were 1.6 middle-aged children per family available to care for elderly dependants, compared with 2.5 in 1948 (Evans, 1981). The situation is likely to become more extreme as more women choose to remain childless. Of women born in the 1950's 15% are predicted to remain childless (Martin and Roberts, 1984). In addition, fewer women are remaining single and divorce rates are higher. It is unclear at this stage what the implications of these changes will be on the dependent elderly population. Will the adult children of broken marriages and second marriages feel the same loyalty or desire to care for elderly people or step-parents?

ii) Increasing Family Mobility

Another factor which is having major impact on the caring population is the increase in family mobility. However, while children may move further afield in their adult lives to pursue career opportunities, this may be counterbalanced to an extent by ease of travel throughout the world. Improved communications systems can also allow for care to be sustained at a distance.

These changes reflect an improvement in our material standard of living and a further significant change of this kind is a significant decrease in the number of shared households and this of course will have had a major impact on the care provided to ageing parents. Similarly, informal care by neighbours will have

altered as a result of better housing and greater privacy.

iii) Women Entering the Labour Market

Finally, more women than ever before are entering the labour market. In 1981, 57% of married women of employable age in Scotland were in paid employment, a considerable increase over the 16% in 1951. However, this may have had less impact on the caring situation than it might first appear as the increase has been largely confined to part-time employment which allows the women to combine her work with her domestic and caring responsibilities (Joshi, 1989). It is also not unusual for women to give up work or change hours of employment to look after a disabled relative in the community (Gilleard, 1984).

Thus, what appear on the surface to be changes which are likely to have a major impact on the pool of carers may in fact be having little effect on the ability of women to keep on caring. It may of course be that social and political pressure offers the carers no choice.

VII. GOVERNMENT POLICY AND COMMUNITY CARE

"Families, friends, neighbours and other local people provide the majority of care in response to needs which they are uniquely well placed to identify and respond to. This will continue to be the primary means by which people are enabled to live normal lives in community settings."

Griffiths (1988).

The concept of community care is nothing new and in fact originated in the context of care for the mentally handicapped and the 1904-1908 Commission on the Care of the Feeble Minded which advocated

quardianship and supervision in the community. goal has been gradually strengthened by successive policy documents and legislation over the decades. The concept of community care has developed over the years based primarily on the assumption that community based care is better for both the dependant and his or her family. The aim became even more desirable following publications in the 1960's which exposed the negative side of institutional care via the degeneration of the human spirit and the dumping ground after social death but before physical death (Goffman, 1961; Townsend, 1962, Miller & Gwynne, 1972). Following this it was not just the patients' needs that were being called into question but rather the recognition of patients' rights to a life in the community regardless of their disability.

More recently, economic policy has argued that the state cannot bear the vast expense of institutional care and the Government has advocated care by the family in the community with the support of community This is being further emphasized by based services. the closure of large institutions and the discharge of long-stay patients back in to the community, either to the family or to smaller, supported accommodation. it has turned out, the state cannot or will not bear the cost of community care and even further onus has been placed on the families to care. The Government budget for care in the community has now been placed firmly in the hands of local authorities who will assess needs and buy in appropriate services to keep clients at home if at all possible (HMSO, 1989). is most likely that resources will be scarce and priority will be given to the most needy ie. situations where there is no identifiable family carer. Griffiths (1988) also looked to the increasing privatisation of care in the community, with the attractive theoretical benefits of consumer choice.

As conservative policies have dominated the last decade and look set to do so for a significant portion of this decade, it is easy to forget that the community care policy has always received multi-party Malin (1987) begged the question community care "Is it a means of the government evading it's responsibility to ensure that the vulnerable members of society are properly cared for, or is it a liberation of people from dependency on monolithic welfare bureaucracies?" Left-wing policies support the concept for its potential to improve the quality of life of individuals based in a community context and see its execution lying within the realms of the welfare state. Clearly, the concept is all things to all men and therefore leads to further difficulties with definition. Furthermore the meaning has changed over time to mean more than just life outside of institutions, it now refers to support and services, formal or informal within the community. One cannot assume that it is necessarily a good thing even if one agrees with the basic philosophy. theory of community care may be a world apart from the practice, which in effect may be a failure of community services to materialize (Baldwin et al, Recent studies on carers of the dementing elderly in Scotland (Gilleard et al, 1984a & 1984b; Gilhooly, 1984; Whittick, 1989), have demonstrated that where there is an identifiable carer, formal community services are rarely provided.

VII. SUMMARY

This chapter looked at the problem of identifying informal carers, how many there are, who they are, why

this population is changing and the political view on the situation. As there is no cure for dementia and as the formal services have failed to provide adequate support it means that the informal carers are often left to face insurmountable problems alone. The effect that this has on them therefore needs to be addressed.

CHAPTER THREE

STRESS AND CARING

I. INTRODUCTION

Having established that senile dementia is devastating and degenerative condition and secondly, that the majority of sufferers live in the community and receive substantial care from informal family carers, this chapter continues to examine the impact that the caring duties has on this aspect of It will look at the degree of 'community care'. 'burden', 'emotional distress', and depression that the carers are under and how this has been measured in various studies.

As early as 1948, Sheldon recognised that caring for a dementing relative could be stressful. Some years later, Grad and Sainsbury (1965) looked at the concept of burden in different areas of the carer's life and found that 80% reported at least 'some burden' especially with regard to social life and mental This general finding has been repeated in many subsequent studies of carers of the dementing elderly. However, cautious one must be generalising across studies as a multitude of scales and terms have been used in an attempt to measure the emotional impact of the caring role.

II. THE MEASUPEMENT OF BURDEN

Much of the foundation work on stress and caring was pioneered in the late 1970's and early 1980's by the Zarits in the USA. In 1980, they developed the Burden

Interview, a 29 item self-report inventory covering areas most frequently mentioned by carers as problems, namely, health, psychological well-being, social life and finances. The rating scale ranged from responses of 'not at all' to 'extremely' indicating the extent of the burden. The scale was developed from clinical experience and later modified to a shorter 20 item scale. Zarit et al (1980) on a sample of carers obtained a mean score of 31 out of a possible 84. The scale has been used, primarily in the USA, to help determine the correlates of burden.

Various specific questionnaires and scales have been developed and used over the past decade specifically to measure aspects of burden. The concept has certainly been used to advance our knowledge about the caregiving situation and its pertinent difficulties, but what is it these scales are actually measuring?

Zarit et al (1986) defined burden as 'the extent to which caregivers perceive their emotional or physical health, social life and financial status as suffering as a result of caring for their relative'. Other studies have defined burden in slightly different ways including embarrassment and overload, changes in daily routine and role strain. Others have differentiated 'subjective' from 'objective' burden but still within each of these terms a great variety of definitions and meanings may be subsumed.

Poulshock and Diemling (1984) noted the breadth of issues subsumed under the definition of burden and questioned the concept's use. They proposed a model in which burden was defined as the mediating force between the dependants' impairments and the impact on the caregiver. They went on to use their newly defined concept in a sample of 614 carers of frail

elderly. Their indicators of burden corresponded directly to 4 main areas of dependent impairment as measured by the Activities of Daily Living (Lawton, 1963). The carers were asked to what extent the specific impairments upset them or caused a problem for them. Unfortunately, at the end of the study one is left with the feeling that Poulshock and Diemling indeed identified a problem with the use of the concept of burden but were in fact unable to improve upon it in any significant way.

Today, the definition of burden is as nebulous as ever and is generally used to refer to the physical, psychological or emotional, social and financial difficulties that can be experienced by family members caring for impaired elderly dependants. George and Gwyther (1986) suggested that relying on measures of burden posed certain problems. Firstly, because of their carer-specific nature. they cannot administered to noncarers and one cannot assess the relative burden that caring imposes. Secondly, unlike Poulshock and Diemling (1984), George and Gwyther believed that the stressor and its impact become confounded to the extent that one cannot separate caregiving from its impact. Finally, they agreed that burden was multi-dimensional but by relying on total burden scores, specific dimensions are overlooked. Rather, they proposed that the opposite side of the coin from burden be examined, namely well-being and they urged the use of standard scales designed for use on general samples. They suggested that the key areas physical health, mental health, participation, and financial resources could still be looked at.

They went on to research their ideas in a large study of 510 carers of dependants with Alzheimer's disease,

drawn from the mailing lists of a Family Support Programme in the USA. They found no difference between their carers and the general population in terms of physical health but in terms of mental health, carers reported nearly three times as many stress symptoms. Similarly, carers' scores on affect balance and life satisfaction scales were considerably lower than the general population and they were more likely to use psychotropic medication.

In summary, it seems that the concept of burden is of limited use as our endeavour to understand the caring role develops. Researchers should no longer use ambiguous or ill-defined terms and there is a need for specific measures to be used which can then be related to other populations. The more general measures of strain and burden are of some value if one is searching for correlates of distress but otherwise their use is limited. What then of other measures of emotional distress?

III. MEASURES OF PSYCHIATRIC MORBIDITY

An instrument that has been widely used in many research studies is the General Health Questionnaire (Goldberg, 1978). This is a self-administered screening device aimed at detecting psychiatric morbidity in community samples. There are several forms of this instrument ranging from 12 items to 60 items. The items ask about the respondent's emotional state and are not situationally specific, thus it is a valuable tool for comparing across groups and also for comparing the subject group with the general population. For the 28 and 30 item GHQ's, which are most commonly used, Goldberg also the recommended a cut-off score of 5, above which

indicates psychiatric 'caseness'. However, at this level, it has been suggested that the instrument does not distinguish subjects who are merely in a state of distress from those with a diagnosable psychiatric disorder. To overcome this, a higher threshold of 9 may be adopted to identify caseness (Finlay-Jones and Murphy, 1979).

Using the original cut-off point of 5, 'caseness' in various studies on community samples of the general population range from prevalence rates of (Goldberg, 1978) to 23% (Benjamin et al, Regarding mean scores for the general population on the GHQ-30, Finlay-Jones and Murphy (1979), estimated similarly, Goodchild and Duncan-Jones 3 (s.d. 4); (1985) estimated 3.13 (s.d. 4.47). However, despite the GHQ's extensive usage and advantages of easy administration, scoring and wide applicability, it has been criticised and its accuracy questioned. Benjamin et al (1982) suggested that it underestimates the prevalence of psychiatric morbidity, with particular bias against the identification of chronic conditions. One response to the items is 'No more that usual' and it may therefore be difficult to use meaningfully in longitudinal studies.

1. The GHO and Carer Studies

The work of Gilleard and his colleagues (1984a and 1984b, 1985, 1987) made extensive use of the GHQ-30. This research was conducted in Edinburgh in the early 1980's and gathered a sample of carers of elderly patients, 80% of whom had a diagnosis of dementia, from 4 Psychogeriatric Day Hospitals in the Lothian Region. The carers (n=129) were interviewed in their own homes just prior to their dependant commencing attendance at a Day Hospital. These semi-structured

interviews examined carers attitudes to day hospital, looked at psychological well-being using a variety of instruments including the GHQ-30, problems exhibited by the dependant, level of impairment, help received from professional and social networks and the amount of face to face contact between the carer and dependant. A particular asset of this work lay in its prospective methodology. The carers were all interviewed again at 3 months and again at 6 months; thus the breakdown or continuation of care could be examined in relation to various factors.

i. Evidence for emotional distress among carers using the GHO

At this point, let us look at the evidence for emotional distress as measured by the GHQ-30. Using a cut-off point of 5, Gilleard obtained an initial prevalence rate for emotional distress of 73.5%. The mean scores for the sample were 5.8±5.8 for male carers and 12.2±7.8 for female carers.

In order to test the validity of the high GHQ scores, a psychiatrist examined a sub-sample (n=45) of carers after their relatives had been attending the Day Hospital for a short while or while they were on the waiting list. She interviewed the carers using the Clinical Interview Schedule (CIS) (Goldberg et al, An International Classification Diagnosis (ICD-9) was also made in addition to severity ratings. According to the CIS, 19.5% of the sample had been misclassified by the GHQ. Using the ICD-8, 26.8% were misclassified of which 32% were false positives and 17.6% were false negatives. Gilleard et al (1984a) concluded that there was unlikely to be any gross over-classification of psychiatric disturbance using the GHQ with this population.

Another significant and large-scale study conducted around the same time in the South of England by Levin and her colleagues (1986). They obtained a sample of 150 carers of confused elderly dependants from a survey of health and social services. the aims were similar to other work in the field and the project was prospective over a one year period. The GHQ-28 was used and only just over a third of the carers scored above the threshold level. While this represented an elevated level compared with the general population, it was lower than had been found in many other studies. One reason for this may have been that Levin et al's sample, while receiving services, had not necessarily reached the stage of Day Hospital attendance and carers may therefore have been a slightly less stressed group to start with.

Toner (1987) also used the GHQ in his Scottish study and like Gilleard's sample, most of the dependants were attending a Psychogeriatric Day Hospital. intervention study examined the effectiveness information written about dementia in reducing emotional distress as measured by the GHQ-28. The sample size was small (n=18) but an initial mean GHQ score of 10.1 was obtained. This was significantly reduced for those in the intervention group.

High GHQ scores were also found by Whittick (1988) who conducted a postal survey in which she compared three groups of carers, 1) daughters caring for a dementing parent, 2) mothers caring for a mentally handicapped child and 3) mothers caring for a mentally handicapped adult. The daughters were contacted via psychogeriatric day hospitals in Lothian and Tayside regions and asked about their attitudes to caregiving; the GHQ-30 was used as a measure of emotional

distress. Using the traditional cut-off point of 5, a prevalence rate of distress of 66.75% was obtained. This was significantly higher than either of the groups of mothers who showed prevalence rates of 29.6% and 31.1% respectively. Similarly, for the mean scores, the daughters scored 10.4 (s.d. 8.7) which was significantly higher than the mothers who scored 6 7) and 5 (s.d. 7.1) respectively. The comparative nature of this study makes it interesting and innovative but it leaves the sample of daughters caring for a parent with dementia small (n=36). Furthermore, it only tells us about caregiving daughters and they may represent quite a different group of carers from wives, husbands or However, it does provide further evidence that caring for a dementing relative can at least in some circumstances, be stressful.

Brodaty and Hadzi-Pavlovic (1988) also conducted a postal survey of members of a community support group in Australia, namely, the Alzheimer's Disease and Related Disorder Society. This formed a large sample but included carers whose relative institutionalized and those whose relatives had died as well as carers with dependants in the community. The carers were contacted approximately two years after initial membership of the support group and among the many questions asked about caregiving, the GHO-30 was used. An overall prevalence rate for caseness of 48% was obtained with a mean score of 7.3 (s.d. 8.1). For the sub-group of carers who were caring for their dementing relative in the community (n=43) the prevalence rate was 65% with a mean score of 9.7 (s.d. 8.9). These scores are similar to those obtained by the Gilleard projects and in Whittick's and Toner's work. It is interesting that despite the significantly elevated GHQ scores, Brodaty and Hadzi-

Pavlovic (1988) found that the carers' mean score on a specific scale for depression namely, the Zung Depression Scale (1967), was not significantly higher than that found in the general population. authors suggest that this is because the Zung scale has a heavy bias towards biological symptoms of depression, furthermore, a carer can obtain a high GHQ score on items of anxiety alone. Thus the carers may be anxious but not necessarily be suffering from an endogenous depression. It is also interesting that the carers in this study did not take medication in excess of the normal rate for a group of similarly aged subjects in the general population. There was however, a tendency for them to consult medical practitioners more than the average. Again this perhaps reflects their distress as opposed to any illness requiring treatment.

A further recent study which used the GHQ was conducted by Harrington (1989). In this Irish study, Harrington drew her sample from a 'Carers Association' and interviewed 24 female carers primarily about their social supports. Using the GHQ-60, she found a prevalence rate of emotional distress of 79%. The mean score was also significantly higher than that found in the general population for the 60 item version.

In another recent Scottish study of carers of the dementing elderly in the community, Sweeting (1991) obtained a prevalence rate of 49% with the GHQ and a cut-off point of 5. In this study, the mean score was 6.3 (s.d. 6.4).

ii. Contradictory Evidence

After a decade or more of studies using the GHQ

showing an increased prevalence of emotional distress in carers of the dementing elderly, a major Scottish study published results that were somewhat unexpected. Eagles et al (1987), obtained a community sample of 79 carers of elderly people from the register of a GP practice in Inverurie, a small town on the outskirts of Aberdeen. Forty of the sample of dependants were suffering from senile dementia as diagnosed by a psychiatrist, 39 were not dementing. In this way, Eagles and his colleagues were able to compare the effects of living with dementia with living with an elderly, non-dementing relative. The GHQ-60 was used and surprisingly no differences were found between the two main groups. The mean score for the carers of the non-dementing group was 3.62 (s.d. 5.74) and for the dementing group it ranged from 2.95(s.d. 4.38) for those with a mildly demented dependant to 5.13(s.d. 6.29) for those carers with a severely demented dependant.

Several reasons were suggested to explain Firstly, unlike many previous studies finding. including Gilleard (1985), Toner (1987) and Whittick (1988), the carers' dependant had not been referred to the psychiatric services. One is often led to believe that when a dementing dependant is referred to the psychiatric services it is because of their failing condition. Perhaps it is a more accurate reflection of their carers' increasing inability to cope with the demands of caring. We certainly know that it is not those with the most severe impairment who occupy the long-stay beds in the institutions (Gilleard, 1984). However, the study by Brodaty and Hadzi-Pavlovic (1988) also obtained a community based sample and their results did support the original finding. Similarly, Harrington (1989) drew her sample from a community group and found particularly high levels of

emotional distress. Unfortunately, neither of these latter studies tell us what proportion of their respondents were also in touch with the psychiatric services and unlike Eagle's work may not be true community samples. It may even have been the psychiatric services who referred them to the support groups.

Another possible reason for the results in the Eagles study may be explained by the geographical location of Aberdeen is a traditional, northern the sample. Scottish city with a high level of community town in which the study cohesiveness. The undertaken. Inverurie, is а small rural town surrounded by farmland. Eagles remarked that the relatives were particularly stoical and uncomplaining about their caring duties. Finally, Eagles suggested that the GHQ is not an appropriate instrument for detecting psychiatric morbidity in an elderly sample majority of carers, while they may as the distressed, do not suffer from a psychiatric illness.

In summary, as a general measure of psychiatric morbidity, the GHQ has probably been used more than any other standard scale with this group of carers. This has the benefit of allowing studies to be compared and also allowing samples to be compared with the general population. However, one is still left wondering about the exact nature of this morbidity or emotional distress. Are these carers suffering from clinical anxiety or depression? If Eagles and his colleagues are correct and the carers are merely stressed but not suffering from a psychiatric illness, have particularly studies which evaluated depressive symptoms should confirm this.

2. Measures of depression

In the study previously described, Brodaty and Hadzi-Pavlovic (1988) also used the Zung Depression Scale (1967), and found that the mean score for carers was not significantly higher than that found in the general population. They suggested that this was because the Zung scale has a heavy bias towards biological symptoms of depression. A carer could score highly on the GHQ by symptoms of anxiety alone. Thus the carers may have been anxious but not necessarily suffering from a depressive illness.

The Beck Depression Inventory (BDI) (Beck et al, 1961) is a well used screening device and comes in 21 and 13 It was used by Morris et al (1988) in a item forms. study of spouse carers. Twenty carers were contacted via a Day Hospital, a Day Centre and a local branch of the Alzheimer's Society. The main aim of the project was to look at marital intimacy before and after a The mean BDI score was 7.5 (s.d. dementing illness. 6.9) which is higher than normal for an elderly However, only 3 of the sample scored population. beyond the cut-off point of 14, thus indicating clinical depression. Results from a Strain Scale that was also used suggested that they were under a moderate degree of strain.

Another study which investigated depression amongst carers was conducted by Haley et al (1987). They gathered a sample of 44 primary caregivers of the dementing elderly from the local Alzheimer's society, physicians and public announcements in the USA. They also had a group of 44 matched controls who were caring for an elderly relative who was not disabled. They used the BDI, and found raised levels of scores for the carers, the mean was 9.39 (s.d. 5.45) and 43%

had scores within the clinically significant range. The carers also scored lower of the Life Satisfaction Index-Z (Wood et al, 1965) and showed more negative affect toward their relative.

Studies which only use questionnaires are limited in much they can tell us about the carers' psychiatric condition; those which have also used standard clinical interviews may be more helpful. One such study by Pagel et al (1985) studied 68 spouse referred from clinical services and Alzheimers Society in the USA. Twenty-one of the total sample had dependants who institutionalized. Participation in the study was voluntary and the carers were financially compensated time and effort. The carers were interviewed on a total of 4 occasions and interviewers rated them on the Research and Diagnostic Criteria (RDC) (Endicott et al (1981) following a clinical interview using the 'Schedule for Affective Disorders and Schizophrenia Change' (SADS-C) (Endicott et al, The RDC distinguishes those who are currently depressed from those who have been depressed in the past and those who have never been depressed. found that 28 of 68 carers were currently depressed (ie. minor or intermittent depression), 27 others had been depressed at an earlier stage in dependant's illness and the remaining 13 had never been depressed. Interestingly, the BDI was also used and a mean score of 10.3 (s.d. 5.5) was obtained. This is very similar to those levels found in some previously reported studies which used the BDI only. There were no significant differences between the carers of the institutionalized and the community group in terms of their levels of depression. rather surprising as it is not a finding borne out in subsequent studies which have looked at the effect of institutionalization on the carer's mental health.

Gallager et al (1989) also used the RDC and BDI in their study of depression in carers. They had two sub-samples, one (n=158) were carers who had sought help to increase their coping skills, the other (n=58) had volunteered for a longitudinal study of Alzheimers They found that 46% of the help-seeking Disease. group were depressed according to RDC criteria and 18% of the non-help seeking group met the criteria. Ten percent met the criteria for a major depressive Even this is considerably higher than the prevalence of 2.4% of the over 60's with a major depressive disorder in the general population (Kay et al 1964). On the BDI when the traditional cut-off point of 17 was used, 36 of the 155 subjects scored in excess of this thus indicating a clinical depression. When the cut-off was lowered to 10, 68 of the 155 scored higher. On both measures of depression, helpseekers had higher levels and were more likely to be depressed than the non-help seeking group. What conclusions can be drawn from this research? In general terms, the carers were indeed suffering from a greater prevalence of depression than the general Gallagher and his colleagues suggested population. that specific probing questions need to be used to help distinguish between symptoms that are part of the caring situation from those that are truly indicative of a depressive illness, hence the added value of a clinical interview. In doing this they found that the BDI has its uses as a screening tool but using the traditional cut-off point of 17, results in relatively sensitivity and a high false negative rate. Furthermore, they suggested that carers tend to underreport symptoms on self-report measures but give more accurate and full answers during a clinical interview. They also suggested that if using the full BDI, the

lower threshold of 10 should be used. This study is significant in advancing our knowledge of psychiatric disorder among the carers of the dementing elderly. However, the sample, although of good size, was biased in that the majority were help-seekers and may already have been distressed and suffering from symptoms of depression. Unlike the carers in Eagles' study, they may not accurately reflect the majority of the caring population in the community.

Drinka et al (1987) also used a standard screening instrument, backed up by a clinical interview by a psychiatrist. In this study, 127 wives of elderly patients at a Veterans' Hospital in the USA were interviewed. The sample was particularly selective as the patients were seen at this particular clinic because their problems were so complex that other more general hospitals were unable to deal with them. patients themselves were assessed and 73% received a diagnosis of dementia. There was also a high incidence of depression among this group of patients, 69% were thought to be depressed. The wives completed the Carroll Depression Rating Scale and were assessed using the DSM III criterion for depression. alarming 83% met the criteria for a major depressive disorder and this was correlated with the presence of depression in the dependant. It is not easy to assess depression in dementing persons and where possible it is most easy to diagnose in the earlier stages of the dementing illness. Perhaps then, many of dependants were in the early stages of dementia, a time when the carer may be struggling to understand the disease process and, therefore, under particular In addition, we know that these men were presenting with particularly difficult problems which may also have been especially distressing for the carers.

Pursuing the question of whether or not carers are depressed, Fitting et al (1986) gathered a sample of caring spouses from two medical centres in the USA. The fifty-four carers participated in a structured interview primarily looking at the differences in attitudes and mental health between wives who cared and husbands who cared. The authors concluded that the carers who reported depressive symptomatology were, in fact, experiencing a 'transient dysphoric mood', reflecting a demoralized state, as opposed to a major depression. They go on to say that this state is more like the hopelessness experienced in situations of extreme distress rather than a psychiatric illness.

Thus, there seems to be evidence that some carers suffer from depression as a result of their caring duties. The most appropriate way to identify this is by psychiatric interview as standardized questionnaires may lead to under-reporting of symptoms.

3. The use of other measures

There have been a number of carer studies conducted over the years which have used other measures of psychological well-being. Gilhooly (1984) conducted intensive semi-structured interviews (n=48) with carers of the dementing elderly most of whom attended Psychogeriatric Day Hospitals in the Aberdeen area of Scotland. She used the Kutner Morale Scale (Kutner et al, 1956) an eight point scale which correlates highly with other measures of life satisfaction. In the original study by Kutner of 500 elderly subjects, a third were categorized as having high morale (score 5-6), a third as having medium morale (score 3-4) and a third as having low morale (score 0-2). In Gilhooly's

study of carers, morale tended towards the 'low' end of the scale and the mean was 2.95 (s.d. 1.96). way of contrast on her standard measure of mental health, namely, the OARS Multidimensional Functional Assessment Questionnaire (Duke University Centre for the Study of Aging and Human Development, 1978) which was rated by the author established that the carers were in good mental health. This lends further support to the hypothesis that while the carers are distressed and under considerable burden or strain as a result of their caring duties, this does not constitute a psychiatric illness. It is of interest that this study was conducted in the same geographical area as Eagle's project and perhaps the stoical nature the Aberdonians does indeed have significant bearing on all of this. The findings of Eagles and Gilhooly seem to be in the minority but they are both methodologically sound studies and we must pay heed to them.

A recent study by Pruchno and Potashnik (1989) examined the physical and mental health of caregiving spouses of dependants with Alzheimer's They also used measures that had normative bases from the general population and perhaps offers us the most current and informative data to date. They gathered a good sample from public service announcements, community churches, wardens, various hospitals. organisations and They measured psychological symptoms using the 58-item Hopkins Symptom Checklist (Deragotis et al, 1974), they asked use of about the psychotropic medication, they measured depression using the 20-item Center for Epidemiologic Studies Depressions Index (Radloff, 1977) and the Affect Balance Scale (Bradburn, 1969). They also asked basic questions about the carer's physical health as previous studies have shown that self-rated health correlates strongly with more objective measures. The results of this comprehensive study showed that across all indicators of mental health, spouse carers were more depressed, had higher levels of negative affect, were more likely to use psychotropic drugs and reported more symptoms of psychological distress than the general population. In addition, they had poorer physical health than elderly people in the general population.

The Edinburgh studies by Gilleard and his colleagues also endeavoured to measure psychological distress using an adaptation of a 'Strain Scale' developed by Machin, (1980). Gilleard's version was a 13 item scale specifically about the strain associated with caring and covered such areas as fear of accidents, worry, sleep disturbance, depression, frustration, health. disruption to household routine. embarrassment, demand for attention, and lack of pleasure in caring. Also, a 'Burden Scale', developed by Gilleard for this project was also used as a direct measure of the specific burden the carers felt that they were under as caregivers. The five items of burden were self-rated by the carer along a five point scale and covered areas of emotional, physical, social, financial and general burden. These scales demonstrated that the carers did suffer from considerable degrees of strain and burden.

Likewise, Eagles also used the 'Relatives Stress Scale' (Greene et al. 1982) an instrument previously described as used in the Edinburgh studies and is a specific measure of the carers' self-reported strain. With this measure significant differences were found between carers in the dementing group and those in the non-dementing group. Furthermore, the level of stress increased as the dependants level of dementia became

more severe.

IV. SUMMARY

In summary, it seems that carers of people with dementia suffer increased levels of psychological distress compared with the general population. measure which has been extensively used research literature is the GHO. While this has indicated a high level of emotional distress in the carers, the extent to which this reaches a level that deemed to be of psychiatric and clinical significance is less clear. Results vary depending on the measures used and the geographical studied. As our knowledge progresses, it is becoming increasingly clear that researchers should tightly define what they are measuring, and where possible back up screening instruments with clinical interviews. Furthermore, they should use measures which have good normative data so that the results may be compared with the general population. It is also important to take into account how the sample was formed.

CHAPTER FOUR

FACTORS INFLUENCING EMOTIONAL DISTRESS

I. INTRODUCTION

Given that research indicates that the informal carers of the dementing elderly are suffering from some sort of emotional distress, it would seem appropriate to look in some detail at the possible factors which influence this distress. This chapter aims identify some of those factors, namely, the quality of kinship, the carer/dependant relationship, behavioural problems, cognitive impairment, the impact of the services and informal family support.

II. GENDER

As already discussed in a previous chapter the vast majority of carers are female and one of the early variables to be examined in terms of impact on stress was indeed the gender of the carer. In general female carers report higher levels of distress than do male carers (Zarit and Zarit, 1982; Gilleard et al 1984b; Gilhooly, 1984, Levin et al 1984 Pruschno and Resch, 1989).

Interestingly, Eagles et al (1987) found the reverse to be true such that there was a significant relationship between depression in husbands and cognitive impairment in the dependant wives but the reverse was not true. Given major differences in the sampling, the authors suggest that the samples cannot be accurately compared and what we may be seeing in

the other studies is more the effect of age, or sex differences in help seeking behaviour.

Gallagher et al (1989) found that women who cared were generally more depressed than caregiving However, this difference failed to hold true when the dependant's level of impairment was great. be due to the fact that male carers seem to be less emotionally involved with the dependent relative than Also, male carers seem to benefit more do females. from the involvement of the statutory services while this too is associated with increased guilt for women who care (Zarit and Zarit, 1982). It should also be noted that most epidemiological studies on general populations have found higher rates of depression females than males. Other studies on differences have also shown that women are more likely than men to report problems.

III. KINSHIP

The actual blood relationship between the carer and dependant may be a key factor in determining the emotional distress in the caring relationship. The meaning the caring role holds for a carer may well be determined by the relationship between them.

Cantor (1983) in a study of frail elderly and their carers (n=111) concluded that stress and strain were not felt uniformly by all caregivers. She found that spouses were most concerned with finances and their dependant's morale, while children were more concerned about obtaining sufficient help. Spouses also reported greatest physical strain but with regard to emotional strain, children and other relatives were

all equally negatively affected. As one would expect, friends and neighbours were least affected.

In the study described previously by George and Gwyther (1986), the results were analyzed for three different groups, namely, spouse carers, adult child carers and other relative carers. Spouses reported significantly more visits to the doctor and poorer self-rated health than either of the other groups. also reported more stress spouses although this did not reach significance between the spouses and the children who cared. Finally the spouses were more likely to use psychotropic medication, levels of and reported lower affect balance and poorer life satisfaction.

Kinship was also a variable studied by Brodaty and Hadzi-Pavlovic (1988). They found that spouses were particularly prone to suffer from general psychological distress. They suggested that this was the result of isolation and a deteriorating marriage.

Diemling et al (1989) surveyed 180 family members relative who was frail caring for a but necessarily demented. Conversely, they found that at least for co-residency, care-related stress could not be explained by the relationship within the dyad. The spouses and adult children shared similar levels of health and strain. When non-resident children were brought in to the equation, they were found to report the greatest levels of strain. This may be because this group have chosen not to live with their parent of a previously strained relationship. because Alternatively, the worry that not knowing what the elderly dependant is doing or how they are managing in the carer's absence may increase the level of strain.

Gilhooly (1984) split her sample of carers into three kinship groups for part of her analysis. The groups were 'spouses', 'children' and 'other relative'. The blood/role relationship had no bearing on the morale of the carer but where the tie was closer, then the carer had poorer mental health. Gilhooly suggested that this reflected the emotional involvement of the carer with the dependant and his or her illness. If this is so then perhaps it is the quality of the carer/dependant relationship that is more significant as opposed to the actual blood relationship.

IV. QUALITY OF THE RELATIONSHIP

Several studies have addressed the issue of the quality of the relationship. Cantor (1983) found that the quality of the interpersonal relationship between the carer and dependant was a noteworthy contributor to strain.

Gilleard et al (1984a) found that a more negative view of the pre-morbid relationship was associated with higher levels of reported distress. Similarly, Morris et al (1988) in a study of spouse caregivers found that a low 'past' level of intimacy was associated with increased levels of strain and depression. Furthermore, the loss of this intimacy was related to increased levels of strain and depression. This finding makes sense when seen in the light of the bereavement and loss work of Parkes (1970) and Bowlby (1980) where loss frequently results in depression. In the case of dementia it is the loss of the 'person' that may be being mourned and indeed the concept of anticipatory grief is a valid one in the caregiving relationship (Sweeting, 1991).

There is also evidence that if a carer can maintain positive feelings towards his or her dependant then they are less likely to suffer strain (Horowitz and Shindleman, 1981). Similarly, Whittick (1989) in her sample of carers who were either caring for a parent with dementia or for a mentally handicapped child found that carers who held the most positive attitudes towards their dependants and their care were also the carers who were the least emotionally distressed. Conversely, Gilhooly (1984) found no association between the quality of the pre-morbid relationship and the reported level of morale. However, where the pre-morbid relationship was good, then the carer was more likely to want to continue giving care.

Regarding the current relationship, the closer the emotional bond, the lower the reported level of strain (Horowitz and Shindleman, 1981). Similarly, Brodaty and Hadzi-Pavlovic (1988) found an association between psychological morbidity and a deteriorated marital Klusman et al (1981) in a study of relationship. carers of the elderly mentally infirm, developed the concept of closeness and intimacy as important variables within the caregiving relationship. found that the bond was less strong if the dependant was more disabled. Hirschfeld (1981) found that the most important variable determining a family's ability to continue caring for a relative with dementia was 'mutuality', that is, the carer's ability to glean gratification and meaning from the caring situation. Mutuality was strengthened by the extent to which the dependant was seen as reciprocating the relationship by means of his or her existence. The higher the mutuality, the less likely the carer was to consider institutional care.

Levin et al (1984) also found that the feeling of

being close was associated with willingness to care at home and as already stated, Gilhooly (1984) also found that a closer pre-morbid relationship was associated with the desire to continue with care at home.

V. BEHAVIOURAL PROBLEMS

What then of the dependants' characteristics? What is it about caring for a dementing person that is so stressful? Several studies have attempted to identify particular features of the dementing illness that cause the carer the greatest distress.

Wilder et al (1983) conducted a study on family burden and dementia in 162 carers of community resident elderly in a cross-national study between New York and London. They concluded after complex analysis that it was not necessarily the disease per se that was the important factor in explaining family "inconvenience" but rather the noxious behaviour that frequently accompanies dementia that create feelings of "inconvenience".

In an earlier study, Sanford (1975) obtained a sample of 50 supporters, 31 of whom were caring for a dementing dependant. He was looking specifically at problems that were poorly tolerated and found that sleep disturbance, faecal incontinence, poor mobility and dangerous behaviour were most difficult for the carer to tolerate. Hirschfield (1981) also found nocturnal wandering, incontinence and refusal to wash to be the greatest problems.

Gilleard et al (1982) identified 5 problem dimensions, namely, 'dependency', 'disturbance', 'disability',

'demanding behaviour' and 'wandering'. It was the demanding behaviour that had the greatest influence on the carer's level of strain. Demanding behaviour included such problems as demanding attention, always asking questions or needing constant supervision. Brodaty and Hadzi-Pavlovic (1988) also found this association. Further work by Gilleard (1985) with a large sample (n=214) further clarified the major as the need for constant supervision, falls, proneness to incontinence, night-time wandering, and an inability to initiate and engage in meaningful activities.

Machin (1980) in her group of carers found that incontinence, night wandering, refusal to wash, bizarre behaviours, demands for attention and difficult personality were all highly correlated with the carers' level of strain. Conversely, Greene et al (1982) in a similar study found that it was the apathy and withdrawal of the dependant that the carer found most stressful.

There seems to be certain discrepancy of results between studies as to which features of dementia are the greatest stressors. Incontinence is frequently cited as being particularly stressful and this is understandable. In addition to perhaps inconvenience and mess resulting in the inability to control bladder or bowels, there is also the added disadvantage to the carer that his or her dementing dependant is unable to deal with the independently. There may also be voiding inappropriate or embarrassing places or the handling of faeces.

Nocturnal wandering is also a stressful problem, not only because of the possible effects of sleep

deprivation to the carer, but because there is the potential worry that the dependant will 'escape' in insufficient clothing and perhaps get lost outside.

Demanding behaviour is thought by some researchers to cause considerable distress to the carer. Any such behaviour of course means that the carer is 'on duty' or constantly reminded of their relative's deficits, whether this means being unable to leave their charge alone in the house, being constantly followed around the house or being asked repetitive questions. The carer has little chance to distance his or herself from the dependant either physically or psychologically.

Greene's (1982) finding that it was apathy and withdrawal that were particularly stressful can also be explained in that such behaviour may reflect a change in the relationship perhaps similar to loss which of course might lead to low mood in the carer. The reader will recall that as previously reported, Drinka et al (1987) found that depression in caring wives was related to the levels of depression in their dependants and this may be an example of the same phenomenon.

It remains interesting that several studies have failed to establish any link between the behaviour of the dependant and the carer's distress. Zarit et al (1980) found no correlation between either behavioural problems or memory and reported 'burden'. Similarly, Pagell et al (1985) found no significant association between the carers' level of depression and the reported behavioural problems. George and Gwyther (1986) found only a weak link between various aspects of the dependants illness and carer well-being. However, studies which fail to demonstrate a link

between behavioural problems and carers' distress tend to be the exception rather than the rule.

VI. LEVEL OF COGNITIVE IMPAIRMENT

As the degree of cognitive impairment increases, one might expect that the caring situation would become even more stressful as the relationship would further deteriorate and the behavioural problems would increase. However, this is not generally what is found and there may be several reasons for this.

Deimling and Bass (1986) in a large study of families caring for an impaired elderly person found that cognitive incapacity had less effect on carer stress than did disruptive behaviour and impaired social functioning. Likewise, Gilhooly (1984) obtained no correlation between the carers' mental well being and the dependants' level of cognitive impairment or behavioural problems.

Brodaty and Hadzi-Pavlovic (1988) found that carer stress decreased with the duration of the dependants' dementing illness. This was not due to any reduction in problem behaviours as they were correlated with severity and duration. Likewise, Levin et al (1984) found that the degree of dementia was not associated with strain.

What we are perhaps finding here is that carers become less distressed with time and as they become used to and understand more about the illness. It may be in the early stages when the carer is unsure what is going on that she is more inclined to blame the dependant for changes in behaviours and feel greater stress. This finding has important implications for

professionals working in the area and perhaps it should not be assumed that help or support at any predetermined stage in the dementing process is required.

VII. THE IMPACT OF THE SERVICES

Within the community care movement there is the implicit assumption that community services are helpful. A closer review of the literature suggests that this is not in fact always the case and again the research evidence is equivocal.

Levin et al (1984) found that the accumulation of strain was less over a 2 year period when carers received more formal support from community services. However, more detailed questioning showed that many of the carers did not feel that the services they received were relevant or sufficient.

Similarly, Gilhooly (1984) found significant correlations between the carer's morale and the services of the home-help and the Community Psychiatric Nurse. However, she found no link between morale and the day hospital service or meals on wheels.

Horowitz (1981) also found an association between satisfaction with support from the services and the level of the carer's distress, such that the least distressed carers were more satisfied.

In an innovative study which attempted to match needs to services in a tailor-made fashion using a network of professional and voluntary services, Challis and Davies (1986) managed to maintain 50% of the demented elderly at home compared with only 23% of the control group. It could be argued from the evidence shown so far in this thesis that keeping the dementing person at home is not necessarily the best option in terms of the carer's mental well-being. Greene and Timbury (1979) found that the main reason for referral to a day hospital was the degree of strain on the carers. Likewise, Isaacs (1971), found that up to a third of admissions among dementia sufferers to a particular hospital unit were due to exhaustion in the carer.

Unfortunately, there are many studies which suggest that formal services are failing to relieve strain among the carers. Gilleard (1985)relationship between the level of professional support and emotional well-being. Furthermore, Morris (1986) actually found a positive relationship between the amount of formal support and carer strain. Whittick (1988) found no association between the services She also noted that with the received and stress. exception of Day Hospital, the level of service provision was very low.

It could of course be the case that those carers who use the services are already under greater stress than carers who are not referred, and this is the point that Eagles made in relation to his work. For whatever reason, the growing number of studies which fail to show any relationship between the introduction of services and carer well-being should be of concern to the providers of health and social services.

When one looks at the problems of dementia, the demanding behaviour, the disintegration of personality and the loss of a relationship and matches them to the nature of services provided, it becomes apparent that none of the traditional services can possibly

alleviate such difficulties to any great extent. Even two days away at a Day Hospital is only a fraction of the carers week and may not cover the most stressful and difficult times, eg. evenings and sleepless nights.

VIII. INFORMAL FAMILY SUPPORT

Informal support offered by family and friends also tends to be minimal in quantity and some studies have suggested that it has no significant impact on the carer's psychological well-being (Gilhooly, 1984; Gilleard et al, 1984a). It is also important to differentiate the amount of help given from the satisfaction with the help received. It is the latter that is more crucial in terms of carer well-being (Gilhooly, 1984).

Zarit et al (1982), however, found that lower levels of social support resulted in greater burden and Similarly, Morris (1986) found that those carers with most informal support were least depressed and also more satisfied with any formal services that they did receive. Brodaty and Hadzi-Pavlovic (1988) found significant correlation psychological morbidity and dissatisfaction social supports. Likewise, Morycz (1985) interviewed 80 families caring for a relative with senile dementia who attended a Geriatric Psychiatry Out-Patient Clinic in the USA. Using scales created for the study to measure strain, he found that less social support was associated with a greater level of reported strain.

Informal family support does seem to have a greater likelihood of reducing the carers' stress and maybe this is because it is through this sort of relationship that the deficits of the dementing relationship can be met. If a wife has lost the conversation and companionship of her husband, a supporting friend or relative may step in and provide this need. Even a visit from a non-family member may take the pressure off the carer and allow her to attend to someone or something other than her charge. Furthermore, it is anecdotally cited that even those with severe dementia often behave more appropriately when the social situation demands it.

IX. SUMMARY

Research reviewed in this chapter indicated that community services have a limited role to play in reducing the levels of stress experienced by carers and it may be that it is the informal, social support network that has the greatest impact. Clearly, the stress-caring equation is complex and is influenced by gender, kinship, relationship and the behavioural correlates of the dementing process. It may also be that it is the carers own ability to cope with the various demands that mediate between the situation and the outcome. Outcome could be considered both in terms of the carers psychological well-being ability or willingness to continue caring.

CHAPTER FIVE

THE CONCEPT OF COPING

I. INTRODUCTION

In the previous chapter it was noted that some carers are more stressed than others. This does not seem to be entirely accounted for by mediating factors such as sex, kinship or behavioural problems. Furthermore, we know that it is not always the most disabled and impaired dependants who become institutionalised. Thus there are likely to be differences between carers in terms of how they cope with their caring role. This chapter gives a brief historical view of the coping literature and continues to describe some of the main contemporary theories and models of coping and in particular the model used in this thesis (Folkman and Lazarus, 1980).

II. HISTORICAL VIEW OF STRESS AND COPING

Cannon (1932) in his studies of responses in animals to stress, identified physiological changes as a response to an emergency. The notion that stress was a response to emergency situations was then used in the study of humans in extreme situations, instance, war (Janis, 1951), and later the laboratory where the effects of unpleasant stimuli were studied (Lazarus et al 1962). Researchers in these early studies attempted to determine how stress, a deviation from the normal state, affected 'normal' functioning. In 1956, Seyle proposed the original homeostatic model for stress that all demand for change was stressful.

However, it soon became apparent that x amount of stress did not lead to x amount of response and, therefore, it was concluded that there were intervening variables such as coping factors which mediated between the stress and the response.

III. DEFINITIONS OF STRESS

The literature is complicated by a controversy regarding how 'stress' is defined and in particular how it differs from 'strain'. Some researchers have regarded 'strain' as the 'stressor', and 'stress' the resultant effect of it. Others have used the terms interchangeably and indeed the dictionary definition would suggest that 'stress' and 'strain' are in fact the same thing. For the purposes of this literature review, I have used those terms used by the authors in their original publication.

In recent years, there has been a change of view such that stress is no longer viewed as a necessary sequelae to change nor is the model of stress viewed as one-way and inflexible. For example, Pearlin and Lieberman (1979) suggested that stress occurs to the extent that there is some mismatch between the person and the environment. It is important to note that this imbalance may be actual or perceived and there may be a considerable variation in individual reaction to it.

Lazarus et al (1981) limited their definition of psychological stress to the demands that exceed resources as cognitively appraised by the individual. In a similar way, Pearlin and Schooler (1978), recognising the problems of defining stress,

restricted their concept to the reported experience of the emotional upset, that is, the unpleasant feelings of distress of which the individual is aware.

Further complicating the issue is, of course, the varying conceptions of stress, which may emphasize discrete life events or the more ongoing chronic hassles that most of the adult population are faced with to varying degrees throughout their lives.

IV. THE ASSOCIATION BETWEEN LIFE EVENTS, STRESS AND ILLNESS

For many years, researchers and clinicians have noted a link between the events in a person's life and illness or maladjustment. Leif (1948) found that biographical information was significant and related to a patient's medical problems. Antonovsky (1974) reported that similar life events do not lead to the same symptoms in all people and concluded that there must be other factors which influence the effect that these events have on people.

Holmes and Rahe (1967) developed a Schedule of Recent They listed 43 commonly experienced Life Events. events and asked a panel of judges to rate the relative amount of readjustment each event would They took marriage as a middle point and require. assigned it an arbitrary value of 50, other events were then rated in relation to this. While this approach may be criticized on grounds that it does not cover a sufficient range of life events, or that the readjustment weights are not scientifically calculated and that both desirable and undesirable life events are included, this scale has nevertheless proved to influence within the stress be an important

literature.

Subsequent studies have given further evidence to support the link between life events and illness. Rahe (1974) in his study of Navy staff found that the number of life events experienced by staff in the 6 months prior to setting sail was predictive of illness during the voyage. Rabkin and Strueing (1976) their review of the literature concluded that there statistically were modest but significant relationships to be found between increasing numbers of life events and various health problems such as myocardial infarction.

Miller et al (1976) undertook a pilot study to look at the nature of the life events themselves. compared a population of subjects who had attended their GP in the past week with a group of subjects who had not consulted. The subjects were asked to rate themselves on 9 dimensions including 5 common physical symptoms and 4 common psychological symptoms. number of threatening and non-threatening life events during the previous 3 months were assessed. found that the consulters had experienced threatening life events than the non-consulters. Furthermore, the number of threatening events was related to the severity of the psychological problems but not significantly linked to the physical symptoms. Interesting though these results are, it must be kept in mind that this was a pilot study and there were only 34 subjects in each group.

Some years later, Ingham and Miller (1985) explored further the extent to which the characteristics of life events were associated with the severity of symptoms. A sample of 1060 adults were studied over a 3 month period. They found that life events which

included some choice of action and loss were with depression, while life associated associated with threat were linked with anxiety. Those who did not have confidants were most likely to be depressed and a lack of superficial support was associated with both anxiety and depression. However, this study did not look at the exact date of onset of the symptoms although they had occurred during the month before the interview, so it is possible that some of the life events may have occurred after the onset of the symptoms. Relating this to the situation of a carer looking after a dementing relative, if this is perceived as 'loss', then it would follow that the carers would be more likely to be depressed.

In 1987, Miller and his colleagues addressed the question of which factors are implicated in the onset and remission of psychiatric symptoms in women in the community. They found that the stressors with uncertain outcomes led to longer illness and poor social support was associated with continuing illness. The authors admitted that this was an exploratory study and that the results needed to be cross-validated.

In summary, it appears that life events lead to an risk both physical increased of illness and psychological. but more importantly, characteristics of the life events themselves appear to affect the response to the event. However, while life events have been found to be associated with stress and illness, there has been much criticism of the life events methodology.

V. HASSLES AND UPLIFTS

Lazarus and his colleagues suggested that the more

minor stresses and pleasures of life might be more important in adjustment and well-being than the major life events. Kanner et al (1981) devised the Hassles and Uplifts Scale which examined daily hassles over a month period. Hassles were defined irritating, frustrating, distressing demands that to some degree characterize everyday transactions with the environment" for instance, losing things, traffic jams and disappointments. By contrast, uplifts are the positive experiences, such as hearing good news or a good night's sleep. Kanner and his colleagues found that the frequency of hassles was significantly related to psychological symptomatology.

DeLongis et al (1982) assessed the relationship between the life events scores and the hassles scores and found that in a regression analysis, the frequency and intensity of hassles scores accounted for a significant proportion of the variance scores in health, with life events failing to add to this.

Although more recently measures of life events and daily hassles and uplifts have been improved upon, especially by the use of a semi-structured interview technique, there does not appear to be a simple relationship between an event and the degree of stress experienced. The degree of threat an event imposes and the amount of social support available to the individual appear to be influential in the degree of stress experienced. In a previous chapter, studies were cited which indicated the powerful influence of social support on alleviating carer distress (Zarit et al, 1982; Morris (1986).

VI. THE MEASURE OF COPING

As the relationship between stress, life events and

hassles and uplifts has not turned out to be a simple one, research which examines the characteristics of the individual or the situation which might influence the response to stressful events has been carried out. To a large extent, what is considered 'coping' depends a great deal on the outcome criteria. This may be the measure perceived helpfulness, of reduction emotional distress or reduction in the level of the problem. There are, of course, problems inherent in each of these outcome measures. For instance, focusing on helpfulness as perceived by the respondent is very subjective and may not correlate with other Focusing on an outcome of a reduction in measures. emotional distress is slightly less subjective but still fails to capture the implied expectation that coping might actually reduce problems or give rise to an optimal solution.

defined Τf stress is as а mismatch between environmental demands and individual needs or goals, then coping, in order to reduce stress, must change one of the two variables. In other words, coping needs to either reduce demands or increase capacities or else alter one's interpretation of either the demands or the capacities. The two approaches of direct action and interpretive appraisal can occur simultaneously. Furthermore, the effort is probably accompanied by attempts at stress reduction. (1977) draws this all together and argues that for individuals to deal with stress, they must at least move through the following three stages; 1) regulate affect or manage tension, 2) focus attention and simplify the problem by interpretation, and 3) engage in cognitive-processing or problem-solving efforts.

In addition to the more immediate, short term view of stress reduction, several theorists (Moos, 1977;

Benner et al., 1980; Folkman et al., 1979) have placed an emphasis on the longer-term goal of preserving or enhancing the individual's overall capacities and resources for future use. Typically, this involves a sense of the self as competent and valuable, a sense of life as meaningful and coherent, and a sense of social integration.

VII. COPING TRAITS

A 'trait' is a characteristic and the view that coping is a trait suggests that a person will respond in a particular way under certain circumstances. The more general the trait the less it will be limited to any particular situation. Thus it is assumed that a particular coping trait will predict how a person will cope in most or all circumstances.

illustrate this, Roskies and Lazarus To (1980)reviewed the literature on longitudinal studies of parents whose children suffered from illness, deformity, or were soon to die. The results showed that the parents' responses tended to follow a pattern, or series of stages, which were influenced by the external circumstances and the meaning that the parents attributed to the events. One parent who tended to use denial, behaved differently when first told that the child might have to be hospitalized for polio compared with two years later when the child had to use a wheelchair. In the first situation the parent minimized the illness and hoped that it was only a fever or sore throat. In the second instance the parent hoped that if given physiotherapy the child would make significant progress. A year later the parent hoped that a cure for polio would be found. There appears to be a dynamic interaction between the more enduring patterns of behaviour in the individual and their perception of the environment.

The view that coping is a trait suggests that an individual will respond in a particular way under certain circumstances. The more general the trait the less it will be limited to any particular situation and so it is assumed that a particular coping trait will predict how a person will cope in most or all circumstances. Coping "style" refers to the same idea but is usually thought of as a complex set of strategies which we use to relate to the world.

VIII. COPING STYLE

The concept of coping style originated from psychoanalytic sources and was concerned with intrapsychic processes and defence mechanisms. Early studies on coping put considerable emphasis on the intra-psychic processes involved in coping and in particular the 'defense' mechanisms used by the individual.

Vaillant (1977) introduced the concept of 'suppression' which is a conscious effort to block both action and thought related to a certain stressor. It is important to distinguish this from 'denial' which is a refusal to admit to threat. It is thought that denial may have a temporary adjustive value in blocking out disturbances so that the individual can plan how to cope. However, if denial is so complete as to lead the individual to believe that no threat exists, then no coping will be planned.

More recently the view has broadened considerably. For instance, Lazarus and Folkman (1984) proposed

that these intra-psychic concepts form only a part of a wider concept of coping which includes factors such as opportunities, constraints and environmental demands.

Lazarus et al (1970) incorporated cognitive appraisal into their view of stress and coping in which stress was no longer seen as a static relationship between particular properties of the situation and particular properties of the person, but rather as an ongoing transaction made up of a series of events. model, the person appraises the situation constantly; understanding what is happening affects what happens An event is perceived as stressful when it is perceived as threatening or taxing an individual's abilities. The individual's response depends on his or her evaluation of what is the best way to proceed and what response is judged to have the best outcome. Stress and coping are interrelated and coping becomes a factor which is not simply a response to what happened but is a factor that will affect what happens next.

IX. THE PEARLIN AND SCHOOLER MODEL

A great deal of research in the area has focused on specific, sometimes unusual situations, such as exam behaviour or illness behaviour. Pearlin and Schooler (1978) by way of contrast, focused on the ordinary stresses of life. Their starting premise was that coping refers to any response to external life strains that serves to prevent, avoid or control emotional They argue that a fundamental distinction between needs to be made social resources, psychological resources and specific coping responses. Furthermore, resources refer not to what people do but

to what is available to them in developing their coping repertoires. Social resources are represented in our interpersonal networks with friends and family; psychological resources refer to the personality characteristics residing within the individual; and specific coping responses refer to the behaviours, cognitions and perceptions in which we engage when dealing with life problems.

On a sample of 2,300 Chicago adults they identified common life stresses in the roles as marriage partners, economic managers, parents and employees. From interviews, patterns were gradually developed for each role area and a total of 17 coping responses were identified, representing 3 major types of coping which could be distinguished from one another by the nature of their functions. The 3 types were as follows:-

- i) responses that change the situation out of which the strainful experience arises eg. 'negotiation' in marriage or 'punitive discipline' in parenting;
- ii) responses that control the meaning of the strainful experience after it occurs but before the emergence of stress eg. positive comparisons 'count your blessings' or selective ignoring; and
- iii) responses that function more for the control of stress itself after it has emerged eg. 'try not to worry because time itself solves problems' or 'just relax and difficulties become less important'.

It is interesting that in their study, while the responses that change the situation would seem to be the most direct way of coping with life strains, they were less often used. Pearlin and Schooler suggest that this is because people need to recognize the situation as the source of their problem before they can take action and do something about modifying it; such recognition, they say is not always easy.

Furthermore, even if the source is recognised, the individual may lack the knowledge or experience necessary to deal with it. Also, actions directed at the modification of one situation may create another unwanted situation. Finally, some of life's most persistent strains originate in conditions which are impervious to coping interventions. Perhaps the task of caring for a dementing relative is one such persistent strain.

The way an experience is recognized and the meaning that is attached to it determine to a large extent the threat posed by the experience. The same event may be perceived as highly threatening by one individual but quite harmless by another. Pearlin and Schooler maintain that by cognitively neutralizing the threats, it is possible to avoid stress. They found this to be the most frequently reported type of individual coping. Responses that function more for the control of stress itself help individuals to accommodate to existing stress without becoming overwhelmed by it.

In their model of coping, Pearlin and Schooler identified coping functioning at a number of levels which are attained by a plethora of behaviours, cognitions and perceptions. They emphasized the importance of looking beyond personality characteristics in order to identify the coping repertoires. Their analysis showed that it is the psychological characteristics that are more helpful in sustaining individuals facing strains arising out of conditions over which they have little direct control. However, when one is dealing with problems residing in close interpersonal relationships it was the things that one did that makes most difference. Caring for a dementing relative would seem to fall into both categories in that it is very often a situation over which the carer has little direct control but it is also a problem which resides within an interpersonal relationship.

Clearly, there is no one coping response which offers the greatest protection against stress but rather it is more effective to have a varied repertoire of coping. Perhaps this will hold especially true for the carers of the dementing elderly.

1. Some Findings from the Pearlin and Schooler Study

In the drawing up of their model, some interesting results emerged which have relevance to this thesis.

Firstly, they found a significant sex difference whereby males more often showed psychological attributes or used responses that inhibited stressful outcomes of problems. Females, on the other hand, were more likely to employ a response which resulted in more rather than less stress. Relating this to dementia, previous carer studies have shown that female carers are more likely than male carers to report suffering from elevated levels of emotional distress (Gilleard et al, 1984a).

Secondly, there were age differences between young and old subjects but neither were disadvantaged and both were equally well-equipped to deal with stresses; however, the upper age limit in the study was 65 years.

Thirdly, less educated and the poorer subjects were both more likely to be exposed to hardships and, furthermore, less likely to have the means to fend off stresses resulting from these hardships. Certain coping behaviours occurred in all four role areas while others occurred in one area only which suggests that there is both consistency and variability in coping behaviours across situations.

However, their study may be criticised because it asked questions about how the subject usually behaved, and asked about general sources of stress. Thus, the responses were more of a general nature and elicited information about а more general personality disposition rather than providing information about actual coping behaviours in specific situations. There is often a poor relationship between people say they do and what they actually do. further drawback with the study is that it focused unresolved and enduring problems upon and SO successful coping responses were largely ignored.

X. THE DEVELOPMENT OF OTHER COPING MODELS

Feifel et al (1987) looked at coping styles in medical patients faced with a life threatening illness compared with the responses of patients suffering from non-threatening illnesses. The group with the life-threatening illness used confrontation significantly more than the non-threatened group. Acceptance-resignation was used least by both groups.

These results support the view that coping behaviour is determined more by the situation than by the style of coping behaviour. However, this study assessed patients at only one point in time and thus did not allow for any assessment of the dynamic processes involved. Duration of illness was controlled for but it may be that with a chronic illness the coping behaviour changes depending at what stage it is assessed.

Miller et al (1985) conducted a study of women in the community and found that those who responded to life stress by getting angry with themselves or others, ruminating, or using tobacco or alcohol, were more likely to become psychiatrically ill within a year. This finding held true even when the life stress was taken into account. Thus it may be concluded that maladaptive coping is associated with illness even when the amount of life stress experienced is minimal. There was no coping reaction or style which was shown to have a protective function. Unfortunately, this study was not designed as a prospective study and the maladaptive coping reactions were measured only once. Coping style of the respondents before or after the illness was not known.

Thus it would appear that the situation is an important factor in determining coping response and is perhaps more important than any stable coping style within an individual. While it is not possible to identify good coping behaviour, it seems as though we can start to identify patterns of poor or maladaptive coping behaviour.

Trait measures of coping are based upon the assumption that people will behave consistently situations, both at a cognitive and behavioural level. However, little evidence has been found to support this view. It seems as though coping is not a unidimensional concept but is made up of a variety of thoughts and behaviours. For example, people with a physical illness have to handle a multitude of sources of stress, including pain, loss of income, the demands Similarly, caring for a relative of treatment etc. with dementia incorporates numerous sources of stress. Coping also appears to be a shifting process in the course of which the individual may rely on different coping mechanisms at different times. In the early part of an illness, he or she may rely more on defensive strategies, while later on they may use more problem solving strategies. Thus coping is a process and cannot be accurately measured in a static manner.

XI. COPING AS A PROCESS - THE FOLKMAN AND LAZARUS MODEL

Lazarus and his colleagues developed a process model of coping. In this model, coping refers to i) what an individual actually does in a particular situation, and ii) how changes in the situation influences what an individual does.

Folkman and Lazarus (1980) studied a community population over a one year period. The study sought to determine the extent to which people behave in a consistent manner across a variety of stressful events as opposed to being more influenced by the nature of the event, who was involved, age and sex. model, the person and the environment are seen in an ongoing relationship of reciprocal action, whereby each affects and in turn is affected by the other. This process is done through appraisal and coping. Appraisal is the cognitive process via which an event is evaluated in terms of what is at stake (primary appraisal) and what coping resources and options are available (secondary appraisal). Coping is cognitive and behavioural efforts made to master, tolerate, or reduce external and internal demands and the conflicts between them. This behaviour both alters the source of stress and regulates stressful emotions. The former refers to 'problem-focused' coping and the latter to 'emotion-focused' coping. These coping efforts are usually made in response to stress appraisals, and coping and appraisal continue to influence each other during a stressful episode. Coping processes are viewed as what the person thinks and does in a particular situation and the changes in effort that he makes during the course of the episode. While coping is made in response to the appraisal of the stress, coping and appraisal continue to influence each other throughout an encounter.

Folkman and Lazarus used a 'ways of coping' model for their study on a community sample of 100 adults in the They looked at how they coped with the stressful events of daily living over a one year period. information about recently experienced elicited stressful events through monthly interviews, selfreport questionnaires which were completed between the interviews, and a 68-item "Ways of Coping Checklist". questionnaire described a broad range of behavioural and cognitive coping strategies that an individual might use in a specific stressful The respondent endorsed 'yes' or 'no' to situation. each item. The items could be categorised as problemfocused or emotion-focused and this distinction was well supported by good internal consistency. coping episode was classified regarding context eg. health, work, family matters and other. The episode was also classified according to who else was involved in the episode and also according to the respondents' 'appraisal' of the situation.

Three main types of stressful appraisals were identified, namely, i) harm-loss, which referred to damage which had already occurred, ii) threat, this referred to anticipated harm or loss, and iii) challenge, which referred to anticipated opportunity for mastery or gain. The degree of stress experienced

depends upon the relationship between the person and the environment in each situation and is determined by what the individual believes to be at risk and what his options for coping are.

From their study, Folkman and Lazarus (1980) showed that both problem-focused and emotion-focused coping used in most of the stressful episodes encountered. In addition, they found that the individuals were more variable than consistent in The context of the event their patterns of coping. and how it was appraised appeared to be the most influential factors affecting coping behaviour. also found that situations in which the individual thinks that something constructive can be done or situations which require more information both favour problem-focused coping. Conversely, situations where it appears that nothing can be done, favour emotionfocused coping. In a work situation, men were found to use more problem-focused coping than women.

The study also looked at intra-individual coping and the effects of cognitive appraisal, coping and outcome. Primary appraisal was assessed using 13 items describing various stakes with a 5-point Likert scale for the subject to indicate how much each stake was involved in the stressful encounter. A factor analysis was undertaken and two main factors emerged. The first involved threats to self-esteem, and the second involved threats to a loved one's well-being.

Secondary appraisal was assessed using 4 items describing coping options and the subjects recorded on a 5-point Likert scale the extent to which the situation was one "you could change or do something about", "you had to accept or get used to", "you needed to know more about before you could act" or one

"in which you had to hold yourself back from doing what you wanted to do".

1. Results of the Folkman and Lazarus Study

The results showed that coping was strongly related to cognitive appraisal, and the forms of coping that the individual employed depended upon what was at stake and what the available options for coping were. Situations in which the individual felt they could change, involved more confrontative coping, planful problem solving, positive reappraisal, and acceptance of greater responsibility. In situations which were regarded as having to be accepted, they used more distancing and escape-avoidance. If individuals felt that they needed more information before they could act, they tended to seek more social support and used self-control planful and problem Confrontative coping, self-control and techniques. escape-avoidance were used most when the subject felt that they should hold back from what they wanted to do.

In the studies by Coyne et al, (1981), subjects tended to use more problem focused coping in situations they appraised as changeable, and they used emotion focused strategies when they thought there was little they could do about the outcome. This study and others (Aldwin et al, 1980; Folkman et al, 1986) have found problem focused coping and positive reappraisal to be highly correlated. This would suggest that positive reappraisal may facilitate problem focused forms of Alternately, it may be that individuals use problem focused coping when they see a potential for positive change, and this leads to positive appraisal. may be that people develop a positive reappraisal in situations where problem focused coping has produced a good outcome.

2. Criticisms of the Study

As with the majority of other studies, the Folkman and Lazarus work can be criticised on the grounds that it is retrospective. Looking at one's behaviour retrospectively may affect how an individual appraises the situation and their coping behaviours, and it is therefore not possible to establish cause and effect. However, as Folkman and Lazarus suggest, it seems likely that appraisal influences coping, and coping influences the appraisal of what is at stake and what coping options are available to the person.

3. Revisions of the Scale and Recent Developments In 1985, the Ways of Coping Checklist was revised; a few items were adjusted slightly and it became a 66 item questionnaire with a 4 point Likert response. It is the revised version that is used in this research and can be found in Appendix 4.

Developing the original model further, Folkman (1984) looked at the role of personal control in stress and In the early research it was assumed that by believing that one had control over a potentially aversive outcome, reduced stress. In time, theorists came to believe that this was not in fact the case, (Pearlin and Lieberman, 1979; Lazarus. Believing that an event is controllable does not always lead to a reduction in stress or a positive outcome. Similarly, believing that an event uncontrollable does not always lead to an increase in stress or a negative outcome. Furthermore, the effectiveness of problem-focused efforts depends largely on the success of the emotion-focused efforts. If this does not happen, heightened emotions will interfere with the cognitive activity necessary for problem-focused coping. This explains why problemfocused coping and emotion-focused coping occur together in most stressful encounters.

Folkman also emphasized the importance of accurate appraisal for adaptive coping. The individual may risk maladaptive outcomes when the appraisal of control does not match reality. For example, if an event is appraised as uncontrollable when in fact it is controllable, the individual is unlikely to engage in the necessary problem-focused coping. Effective coping seems to be about knowing when to appraise a situation as uncontrollable and abandon efforts directed at altering that situation and turn instead to emotion-focused processes in order to tolerate or accept the situation.

Using the same sample in a later study, Folkman et al (1986) looked at personality factors such as mastery interpersonal trust, self-esteem, values, commitments and religious beliefs, and primary and They found that mastery and secondary appraisal. interpersonal trust, primary appraisal and coping variables were related to psychological symptoms but not to somatic illnesses. The more the subjects felt that they had at stake the more likely they were to experience psychological symptoms. Once planful problem solving was negatively correlated with psychological symptoms.

In a third paper based on the same sample, Folkman and Lazarus (1986) found that the subjects who had the greatest number of symptoms of depression felt that they had more at stake in stressful situations, tended to use more confrontative coping, self-control, escape-avoidance, and accepted more responsibility than those who were less depressed. They also tended to respond with more anger and worry than the subjects

who were less depressed. There was no difference in terms of whether or not they appraised the situation as changeable, whether or not they felt the outcomes were satisfactory or not, and whether or not they felt positive emotions at the start of the stressful situation. Thus they were not entirely negative in either their appraisals or their coping processes.

Abramson et al's (1978) learned helplessness model of depression would predict that the more depressed subjects would be more likely to appraise situations as being unchangeable but this prediction was not supported in this study. The depressed subjects also tended to be more hostile and this supports the work of Billings and Moos (1984) who found that depressed subjects tended to express feelings of anger towards others and this in turn affected the social supports available to them. If this holds true for the carers of the dementing elderly, then it has important implications for the providers of community care.

XII. FURTHER DEVELOPMENTS IN MODELS OF COPING

Ilfeld(1980) using the original Pearlin and Schooler (1978) sample of 2,299 Chicago adults also looked at coping styles in the social roles of marriage, parenting, finances and job. In Ilfeld's view, coping can be approached from a variety of perspectives and there is no single correct approach but whatever view is taken should be clearly specified.

Pearlin and Schooler (1978) see coping as a mediating factor between life stressors and emotional distress. In contrast, Ilfeld sees coping from a broader perspective in that it may precede external life stressors as well as follow on from them. In other

words, coping efforts serve to resolve either the life stressors and/or the personal distress and do not only mediate between them. For his purposes, Ilfeld saw coping as "attempts made by an individual to life resolve stressors and emotional pain"; furthermore coping may occur with or without conscious intent. Using a factor analysis he identified 3 major patterns of coping, namely, i) 'taking direct action' ie. when concrete active steps are made towards what is perceived as the issue in question;

- ii) 'rationalization and avoidance of the stressor' ie. efforts at minimizing, excusing, ignoring and avoiding; and
- iii) 'acceptance of the situation without attempting alteration' ie. when problems are recognised and not minimized but the respondent seems resigned to accept the circumstances rather than change them.

Ilfeld found that respondents did not consistently utilize one coping style across all role areas but employed a repertoire of responses. Ilfeld also identified an independent factor apparent only in the roles of parenting and marriage, namely, 'seeking outside help'. Also within the role of marriage there was a factor of 'withdrawal/conflict' ie. an ongoing cycle of appeasement followed by fighting, followed by temporary withdrawal.

From his analysis, Ilfeld concluded that individuals vary strategies according to the environmental context and that coping styles are tied more to the situation than to the manifestation of a particular personality type. Demographic details had little impact on the type of coping used.

Billings and Moos's (1981) US postal survey looked at a broad array of personal, social and health related

information. They devised a 19 item questionnaire on which the respondents indicated a recent personal crisis or stressful life event and answered how they dealt with the event according to yes/no responses on the 19 items. The 19 items were drawn from a variety of sources but they primarily used the scales of Pearlin and Schooler (1978) and Folkman and Lazarus (1980). They found that all categories of coping responses were used fairly often, although 'avoidance' responses were used least often, and there tended to be more 'problem' than 'emotion' focused coping. Stressful situations involving illness elicited more active-behavioural and problemfocused responses than did most other categories; death related events elicited the least of such Again, it is interesting to speculate categories. where dementia fits in to this. On the one hand it is an illness but it is also about loss. Which coping responses will be most appropriate in terms of alleviating the carers distress? It was also noted that individuals who used 'avoidance' coping had fewer social resources than others. Furthermore, women were more likely than men to use 'avoidance' coping and this ties up with the finding from the Pearlin and Schooler work that women tend to use coping responses which fail to ameliorate the stressor as well as other techniques might. Billings and Moos state that it is probably not possible to identify positive or negative types of coping because of factors that precede the stressful event in the individual's life. However, their study found that active attempts to deal with a stressful event, coupled with fewer attempts avoiding dealing with it, were associated with less stress in the individual.

XIII. SUMMARY

This chapter briefly examined some of the main coping theories and studies. In general, it would seem that environmental and social events can cause stress. However, as a particular event does not always result in a specific amount of stress there appear to be factors within the individual that affect the degree of stress experienced. Individuals tend to have characteristic ways of coping but these are not independent of the environment. Coping is probably best described as a process which changes over time, and the way the individual appraises a situation influences how he or she will react to it.

It does not seem to be an easy task to identify a prescription for good coping although it is perhaps easier to identify coping which may be termed maladaptive.

Empirical studies of coping are in their infancy. In the following chapter, some empirical studies relating to health issues will be reviewed to give a flavour of the variety of research undertaken to date and to set the scene for the study in this thesis.

CHAPTER SIX

EMPIRICAL STUDIES ON COPING AND DISABILITY

I. INTRODUCTION

As was demonstrated in the previous chapter, coping can be viewed as a mediating variable between a stressful situation and outcome. In the case of caring for a dementing relative, coping may intervene between the caring situation and the outcome. The outcome may be about the carer's level of emotional distress or it may be about the decision to relinquish care. In order to explore this further, this chapter will look at some of the empirical studies on coping with disability. The few studies which have examined carers of people with dementia and their methods of coping will also be reviewed.

II. STUDIES OF COPING AND PHYSICAL ILLNESS

Physical illness has been the focus of many studies In a review paper, Bracken and Shepard on coping. (1980) examined the psychosocial processes which either hinder or foster rehabilitation from acute spinal cord injury. Spinal cord injury, because of its sudden onset and severity, could be considered one of the most extreme psychological insults which an individual could be expected to cope with. and Shepard differentiated 'coping' and 'adaptation' such that coping is the psychological defense reaction adaptation represents the longer-term and psychological and social changes demanded by permanent disability. Each serves a different psychological need but both may contain two discrete components -'defense mechanisms' or 'other coping reactions'. Bracken and Shepard note that defense mechanisms are

vital to protect the ego from being overwhelmed by the extent of the injury in the early stages, until the full impact of the trauma can be taken on board. These defense mechanisms, as traditionally defined by Freud, include, repression, denial, reaction formation, regression and projection. However, if these mechanisms are prolonged, then rehabilitation may be hindered and severe depression may follow (Roberts, 1972; Vincent, 1975). Defense mechanisms are normally followed by strong affective reactions protesting the trauma, including anger, hostility and Again, this is thought to be adaptive unless this stage is prolonged into the rehabilitation phase.

Following the initial ego defense and affective reactions there comes a period of cognitive acceptance. This includes not only acceptance of the injury but also a new creative stage of coping whereby the individual learns to master his new environment. It is interesting that the process of coping and adaptation described in this review paper closely resemble the Kubler-Ross stages of grieving. However, the order and time-span of each of the stages remain unclear.

III. PRE-MORBID PERSONALITY, INTELLIGENCE AND COPING

Pre-morbid personality is thought to play an important part in the ability of an injured patient to cope with disability. As expected, people with more 'stable' personalities have been found to cope better (Thorn et al., 1946; Mueller, 1962; Kerr et al., 1972). Furthermore, individuals with higher ego-strength and the ability to delay gratification have also been found to cope better (Roberts, 1972). However,

Wittkower (1954) and Siller (1969) found that dependent and passive personalities coped better.

Early studies examined the effects of intelligence on coping ability and found varying results. Thorn et al (1946) found that patients with a low IQ showed superior coping patterns. Contrary to this, Roberts (1972) noted that individuals with superior intelligence had more opportunities to engage in alternative activities following injury; whether or not they take up these other activities was not made clear.

Thus, as with many other areas, there do seem to be some contradictory findings with regard to the influence of pre-morbid personality and intelligence and coping post-injury. One of the big problems of looking at personality variables is of course that generally no pre-morbid measures are available.

IV. SOCIAL AND FAMILIAL NETWORKS AND COPING

A supportive network of family, friends and medical staff have been found to be helpful in enabling the injured individual to cope (Bracken and Shepard, However, if the patient then fails to enter into the rehabilitation phase, these significant others may become resentful. Significant others are only willing to 'forgive' the patient his normal social duties if he shows a desire to leave the sick This has role as soon as possible. important implications in the coping of the carers of the dementing elderly because the sufferer is of course unable to leave the 'sick role' and this may engender feelings of hostility in the carer and withdrawal of her support at an emotional level. Critics of the

'sick role' theory would argue that it does not apply to chronic conditions.

V. COPING WITH CHRONIC ILLNESS

There have also been numerous studies of coping with chronic illness. One particularly innovative project which looked at coping with chronic illnesses (Felton and Revenson, 1984) was a longitudinal study of 151 middle to older aged adults who suffered from either one of four chronic illnesses, namely rheumatoid arthritis, cancer, hypertension or diabetes. former two were considered 'uncontrollable' whereas the latter two were considered 'controllable' in that they were more responsive to individual and medical efforts at control. The authors were particularly interested in the role of coping to explain psychological adjustment in the sufferer. defined coping as "efforts, both action-oriented and intra-psychic, to manage environmental stresses and or regulate the emotions aroused by the stress". They evaluated the emotional consequences of two coping strategies, namely, 'information seeking', ie. instrumental strategy which in previous research has been found to have beneficial effects on well-being; and 'wish fulfilling fantasy' ie. a palliative technique which has been found to have harmful consequences to well-being. The hypothesis was that 'information-seeking' would be psychologically adaptive with controllable illnesses, while 'wish fulfilling fantasy' would be better for those with uncontrollable illnesses.

Felton and Revenson (1984) devised scales to measure each of the two coping strategies using items from the Folkman and Lazarus (1980) 'Ways of Coping Checklist'. Five items were selected to represent the

'information-seeking' and 8 represented the 'wishfulfilling fantasy'. They also used subscales from the Bradburn Affect Balance Scale (Bradburn, 1969). They found that 'information-seeking' was linked to decreased negative affect, whereas 'wish fulfilling fantasy' was linked to indicators of poor adjustment. Furthermore, those with uncontrollable illnesses were just as advantaged by 'information seeking' as those with controllable illnesses which would suggest that the value of this technique extends beyond the value of the information obtained. The authors suggested that information-seeking may reflect an optimistic mental framework that reinforces the notion that the information obtained will be useful. By contrast, wish-fulfilling fantasy entails ruminating over what might have been and provides no escape from the Finally, this study was stresses of the illness. unable to explain the nature of causation with regard adjustment and coping although the authors suggested that chronic illness often brings about a vicious circle in which unhappiness and difficulties in adjustment lead to wishful ruminations which in turn reinforces feelings of unhappiness.

MacCarthy and Brown (1989) in their study of psychosocial factors in Parkinson's disease, examined coping as one of several intervening variables in the relationship between the disease and psychological adjustment. Parkinson's disease is progressive and stress is known to have marked immediate effects on Also, there is a recognised link the symptoms. between Parkinson's disease and depression but only part of this can be explained by biochemical changes (Gotham et al., 1986). This cross-sectional study used self-report questionnaires to identify the intervening variables in 136 Parkinson's disease They measured clinical severity of patients.

symptoms, functional disability, depression using the Beck Depression Inventory (Beck and Beamesderfer, 1974), the Bradburn Positive Affect Scale (Bradburn, 1969) and acceptance of illness (Felton and Revenson, 1984), self-esteem (Rosenberg, 1967), social support, cognitions relating to the illness and coping. To measure coping they adapted the Folkman and Lazarus (1985) Ways of Coping Checklist and amalgamated it with an adaptation of the Billings and Moos checklist to yield a 28 item scale covering both cognitive and behavioural items. The subjects responded to each item on a 5 point Likert scale with regard to use of each in the previous 6 months.

Their analysis of this scale was interesting and has particular relevance to the analysis in this thesis. From the results, the number of strategies used and the total amount of coping activity were computed. A principal components analysis was then performed and a varimax rotation which yielded 4 factors with eigenvalues greater than 1. These 4 factors together accounted for 40.8% of the variance. The items with loadings greater than 0.45 formed the subscales. first and third subscales were highly correlated (r=0.54), had some overlap in terms of items and were therefore combined for subsequent analysis. The fourth subscale was thought to be of dubious value, had a low alpha value (0.43) and contained few items This left two subscales which and so was rejected. were renamed, positive coping and maladaptive coping. The positive coping scale contained items such as 'Asked for practical advice or information' and ' Told myself things would be alright in the end'. such 'maladaptive' subscale contained as 'Increased smoking drinking or taking pills' and 'Criticized or blamed myself'.

Multiple regression analyses were then carried out entering coping along with other variables in to the equations. Regarding depression, functional disability proved to be the index of impairment which was the best predictor; this accounted for 16% of the In terms of the intervening variables, variance. self-esteem and maladaptive coping contributed a further 30% to the variance. Interestingly, neither the duration nor the stage of the illness nor it's severity contributed independently to the depression. The measures of physical disability which proved to be the best predictors of acceptance of illness were the Activities of Daily Living and the maximum severity of the illness during the day (30% of the variance). Maladaptive coping contributed a further 4%. For the prediction of positive well-being, no index physical impairment was found to be significantly related. When the intervening variables were entered, self-esteem, positive coping and the instrumental support available to the subject accounted for 30% of the variance.

In their discussion of their findings on coping, MacCarthy and Brown (1989) note that they run contrary to expectations. Patients who used a limited range of apparently helpful strategies were better off than those who used a wider range and included those items associated with poor psychological well-being. also begs the question of how helpful flexibility in coping really is when the individual is faced with such severe and chronic problems. Furthermore, persistent efforts at mastery may be inappropriate or event maladaptive in situations where the potential for control is limited. It was also noted as with most other studies that a combination of emotion and problem focused strategies were used. Where individual frequently used 'positive' strategies, they

were more likely to maintain well-being although this was unrelated to depression. The strategies which were associated with poor adjustment tended to be emotion focused.

This is an interesting and useful study for its attempt to introduce a psychological dimension to a physical illness. It is also ambitious inclusion of such a wide variety of measures. Nevertheless, on closer examination of the coping data the identification and labelling of the sub-scales is The final two sub-scales are not clearly itemised in the article but the 4 initial factors from where they came are. Apparently contradictory items fall within one factor and the initial naming of them is misleading. For instance in the second factor, which was initially named 'Acting out and distraction' 'maladaptive' factor, later became the following item is found; 'Tried to get emotional support'. Such an item is not on the surface easily linked to either of the above labels. Also, it is included in the factor along with such disparate items as 'Avoided other people'. There are numerous other such instances and perhaps one should be wary of the labels attached to these factors. illustrates the very real difficulties there are in trying to analyze and make sense of measures of coping.

Finally, the authors acknowledge a weakness of the study lies in its cross-sectional nature and thus little can be said about the process of coping.

VI. COPING WITH A DEPENDANT'S ILLNESS

In many cases of ill-health it is not just the

sufferer who must evolve through a process of coping but very often the family is also involved in coping with disability. A spouse's adaptation to the stress of living with chronic illness has been shown to relate to his or her own mental and physical health as well as contributing to the patient's general well-being (Shambaugh et al., 1967; Abram et al., 1971).

In an interesting study, Schoenman et al (1983) looked the spouses of male haemodialysis patients. at Chronic renal failure as an illness is incurable, and the treatment of haemodialysis is extremely demanding. It is also an ongoing situation over which one cannot master complete control. This study aimed to identify systematically those spouses who were able to deal more effectively with the situation. They used the Rotter Internal-External Locus of Control (Rotter, 1966) which deals specifically with the issue the extent to the perception of individual feels that he or she has control over one's own reinforcements. They found that those wives with a high external locus of control showed poorer psychological adjustment, as measured Spielberger Stait-Trait Anxiety Inventory (Spielberger et al 1970) and the Beck Depression Inventory (Beck, 1961). This confirms previous findings in a similar study (Strickland, 1978). Interestingly, differences were found between those who underwent home dialysis compared with those who attended a medical centre for this purpose.

VII. COPING WITH A DEPENDANT WITH A DEMENTING ILLNESS

There have been few studies which have systematically examined the coping techniques of the carers of the dementing elderly. Those that have been undertaken have been reported in recent years and this most

likely reflects the natural progression within this area of research. Initially the research was about establishing whether or not the carers were under stress; there was then a series of studies looking for mediating factors of this stress within carer and dependant characteristics. It is therefore a logical move to look at the mediating influence of coping on all of this.

How do carers cope? Gilhooly (1987) looked at coping strategies used by carers (n=17) of the dementing Adapting the work of Pearlin and Schooler (1978) she differentiated between behavioural coping and psychological coping. Behavioural coping referred to finding out about and making use of health and social services and the organisation of help from family and friends. Psychological coping referred to efforts to modify or control the meaning of the stressful experience. Examples of psychological coping included 'Making positive comparisons', for instance, where a hardship is evaluated as being an improvement over the past or the forerunner of an Also, 'Selective ignoring' which easier future. involved searching for some positive attribute or circumstance within the stressful experience. ordering of life priorities' which involved moving or keeping stressful experiences in the least valued areas of life, the result of this was to reduce the significance of the problems. Also, 'Converting hardship to moral virtue' which is best expressed by sentiments such as 'take the bad with the good'. Gilhooly found that those carers who used behavioural strategies had higher morale than those using only psychological ones. Those who were coping least well tended not to use any of the psychological techniques, had the lowest morale, and were coping least well. Furthermore, men were greater users of behavioural

coping than were the female carers.

Levine et al (1983) studied coping behaviour in a small sample of ten carers of the dementing elderly. At the time of the study, five of the dependants were hospitalized and five were living at home with their The level of impairment was described as mild to severe. In an interview, the carers were asked about the daily problems they encountered through their caring role and also the attempted solutions. Coping style was also evaluated through an instrument designed by the authors called the "Inventory or Hypothetical Problem Situations" (IHPS). For this the carer was presented with ten situations typical in caring for a dementing person, namely, insomnia and restlessness at night, wandering, incontinence, difficulty in dressing, aggressive behaviour, falls, embarrassing behaviour, restriction of the carers' freedom of movement, and financial burden. For each situation, the carer was presented with five possible courses of action, or responses, to be rank ordered. The choices were thought to be representative of coping as described in the literature.

These responses were, i) no response, ii) positive internal dialogue, iii) the choice of hospitalisation/giving up iv) original problem solving, and v) consultation with community resources, physicians or friends. The responses were then averaged to give a profile of coping for each individual. Coping choices of 'no response' or 'hospitalisation' were seen as relative helplessness, while the remaining three responses were seen as more active coping. The Locus of Control scale (Rotter, 1960) was also used in this study.

This information was then amalgamated and each

individual was scored on 3 aspects of coping behaviour, namely, the presence of problem solving ability, active coping style as defined on the IHPS and the use of coping self-statements. individual could score anything from 0 to 3, the higher the score, the better the individual thought to be at coping. Analysis showed that the skilful copers tended to have an internal locus of control, were more likely to be spouses and of higher social class (III or IV). By way of contrast, less skilful copers tended to have an external locus of control, be more likely to be a child or sibling and be of lower social class (V). Also, those carers who had been caring for longer tended to be more skilful. These are the most likely logical reasons for these results; spouses probably tend to cope better because of the nature of the carer:dependant relationship, those from higher social classes are probably better at coping because of the likelihood that they are better off and can buy in services, or are able to mobilise external help more skilfully. Those with an internal locus of control may be cope better because they are more likely to believe that the situation is to some extent within their control compared with externals. This confirms the results of the study previously described by Schoenman et al (1983).

However, there was a weakness in this study in that Levine and his colleagues had no measure of carer well-being and made an assumption about what constitutes 'good coping'. They assumed that active coping was better than passive forms of coping although do not back up this assumption in any way. Furthermore, in the light of Meichenbaum's work on 'self-talk' they make the assumption that this too is a good coping strategy for carers of the dementing

elderly. While it is easy to see the logic behind these assumptions, it is a considerable leap to taking as read that these are necessarily good coping techniques for this group. As has been suggested from other studies, caring for a dementing relative is a rather unique situation which may not be best dealt with through logical, active procedures. One could argue that a passive acceptance of the situation would be better for the carers mental well-being.

Coping techniques were also studied by Pratt et al They surveyed 240 carers of Alzheimer's disease patients to examine coping techniques and to relate them to perceived burden. They drew their sample from ongoing support groups and from carers who had attended a one-off educational lecture on the Information was gathered by questionnaire disease. incorporating the Burden Scale (Zarit et al 1981) and the Family Crisis-Oriented Personal Evaluation Scales This latter questionnaire (McCubbin et al 1981). contains 30 items which represent 8 coping strategies that individuals or families may use in response to problems or difficulties. The originators of the scale acknowledged that this only represented a small proportion of the repertoire of coping skills actually used. The coping strategies identified can be divided in to either an internal or external category. three internal strategies were i) reframing, ie. the ability to redefine stressful experiences in a way that makes them more understandable and manageable; ii) confidence in problem solving; and iii) passivity, avoidance responses to problems. The external strategies are described as those strategies that reflected the extent to which families actually used the social support resources that available to them. The five resources were as follows i) spiritual support; ii) extended families; iii)

friends; iv) neighbours; and v) community resources. At a glance it could perhaps be argued that the use of spiritual support could also be described as an internal strategy.

The results of the study showed that the three internal coping strategies were significantly related to the carers' burden score. Confidence in problem solving and reframing were significantly associated with lower levels of burden while passivity was significantly correlated with higher levels of burden. Regarding the external strategies, seeking spiritual support was correlated with lower levels of burden. Support from extended family was also related to lower levels of burden. The authors suggest that spiritual support may be of importance in dealing with chronic problems because of the contribution to selfesteem and the clarifying of expectations. It is also possible that spiritual support helps to clarify the meaning of a situation and allows the individual to neutralize the threat and cognitively reappraise the Similarly, the internal strategies of situation. reframing and confidence in problem solving may alter the meaning given to the stressful situation and allow the carer to view it in a way that it can be overcome or more easily accepted. Passivity is about avoidance of the problem and while this may be an adaptive coping strategy in adult life, the authors suggest that in later life it may be less helpful and a realistic acceptance of the situation may be more valuable. The authors concluded that further research is needed to explore the relationship between burden and coping techniques.

This study's strength lay in the large number of carers surveyed. It perhaps tells us less about coping techniques than it might because of the

restricted scale used. Furthermore, of the total sample, some of the dependants were institutionalised although this was not accounted for in the analysis of the coping information. Given that institutionalisation represents a major change in the care practice and in the emotions of the carer, it was perhaps an error to have ignored this as an important subsample.

In a recent study, Morrissey et al (1990) looked at coping resources and depression in spouse carers of the dementing elderly. With a sample of 47 carers they studied the self-rated impact of caring across different areas of life, namely, marriage, work and recreation. They found that the patient's disability had a more negative impact on the carers' marriage and recreation than did any of the coping resource variables. The carers work was the only area in which the coping resources could alleviate the carers level of depression. They concluded that the area of life in which stress occurs is an important factor in understanding stress the and coping process. Unfortunately, this study said little about the coping per se, beyond a description of some of the techniques used.

VIII. SUMMARY

This chapter looked at some of the major studies in coping with disability from the carers' point of view and in particular, coping with caring for a dementing relative. There seems to be some advantage to the carer in adopting 'behavioural' strategies (Gilhooly, 1987). An internal locus of control and years of experience also seem to be beneficial (Levine et al., 1983). Passivity is not thought to be a helpful coping strategy (Pratt et al., 1985). However, there

has been relatively little work in this area and the basic question regarding what coping means to carers has not yet been fully answered. We still do not know what carers do in their efforts at coping with the demanding situation. Furthermore, it would seem likely that there will be enormous variation in coping as the demands of the illness itself are so varied. It is also likely that coping will be influenced by other factors such as carers' attitudes and feelings towards relatives and understanding of disease The next chapter will look at the processes. emotional relationship, through the concept expressed emotion, between carer and dependant as another, and perhaps the most significant variable in the coping process.

CHAPTER SEVEN

THE CONCEPT OF EXPRESSED EMOTION

"The EE index is best viewed as an indicator of the 'emotional temperature' in the household, a fluctuating marker of the 'intensity' of a relative's emotional response at a given time".

Vaughn (1989).

"High EE relatives display less effective coping responses, and may adversely affect the patient by creating an unpredictable environment".

Kuipers and Bebbington (1988).

I, INTRODUCTION

One factor which may have an important influence on a carer's ability to cope is the 'expressed emotion' in the household. Expressed emotion (EE) is a concept which relates to the emotional atmosphere within a caregiving family and refers in particular to the feelings expressed by the carer about and to his or The concept originally developed her dependant. within the literature on schizophrenia but more recent evidence suggests that it also has relevance in the study of other dependency groups. If it exists with the same influence on the carers of the dementing elderly as it does for other groups then it may well prove to be an important factor in understanding the relationship and in particular the carer's ability to cope and continue or discontinue caring.

This chapter will outline the history of the concept before going on to look at the traditional and alternative ways of measuring expressed emotion. Construct validity will also be reviewed, as will the factors which seem to interact with EE. The focus will then turn to the evidence to support the EE concept within other carer-dependant groups including the dementing elderly.

II. HISTORY OF THE CONCEPT

The concept of expressed emotion dates back to the 1950s and the work of Brown and his colleagues (1958; 1959) in their studies of male schizophrenics who were being discharged from psychiatric hospitals back into the community. They noticed that the rate of relapse of the schizophrenic symptoms was related, in part, to the emotional atmosphere within the family to which they returned. The risk of relapse was greater if the caring family was overtly hostile and critical towards their dependant. This was not so of families that did not hold this critical, blaming attitude. The former became known as 'high' expressed emotion families, the latter as 'low' expressed emotion families. They also noted that prolonged face to face contact with the caring relative made relapse more likely and that the EE phenomenon also existed among non-family carers.

It was also noted in these early studies, (Brown, 1958), that high EE responses were strongly associated with high levels of family burden, thus reducing the carers' ability to cope and leading to a greater negative emotional response towards the patient. Thus it would seem that EE is undoubtedly linked with stress and coping, and yet relatively little research has examined the interaction between emotional responses and the coping skills of family members (Falloon, 1988).

One of the problems of the early studies was that they were entirely retrospective and in order to overcome

this, Brown et al (1962) conducted a prospective study. They interviewed 128 schizophrenic patients and their nearest female relative, just prior to discharge, 2 weeks after and at 1 year follow-up. The caring relatives were rated on the amount of 'emotion expressed', the level of 'hostility' and 'dominance'. The rating of dominance was not found to be of importance while the other two components were once again found to be indicative of relapse.

These early studies used rather crude measurements of affect and this was an area that Brown and Rutter (1966) and Rutter and Brown (1966) developed in later studies and the ratings became part of the Camberwell Family Interview (CFI). By 1972, Brown and his colleagues were using fairly refined ratings another prospective study. Expressed emotion was measured from a rating of marked emotional overinvolvement, 7 or more critical remarks and hostility. Of these 3 components, the number of 'critical comments' was found to be most predictive of relapse. Once again, the results of previous studies were a relapse rate of 58% was obtained for confirmed; patients from high EE families, while a rate of 16% was found for low EE families at 9 month follow-up. This did not relate to prior behavioural disturbance on the part of the patient. Furthermore, if the face to face contact was high and exceeded 35 hours in a week the risk of relapse was again increased.

Whilst the number of critical remarks made in the course of the interview was the most important component, emotional over-involvement also emerged as significant. Where emotional over-involvement was high, there was a tendency for the carer to be overprotective, dramatic about aspects of the illness and generally over-involved and displaying emotional

distress during the interview. It was found to be most common amongst parents who would treat their adult offspring like a child again and less common among spouses who were perhaps more inclined to resist such dependency. Subsequent studies have in fact failed to demonstrate the existence of this component in non-parent carers.

1976, the study by Brown et al (1972)In replicated again by Vaughn and Leff (1976a, 1976b). They shortened the Camberwell Family Interview as the frequency of critical comments was found to independent of the length of the interview. original findings regarding relapse EE and were replicated and in addition, other potential protective factors were identified. It was found that patients returning to a high EE family could reduce their risk of relapse if they complied with regular medication or if the amount of face: face contact was kept low. both factors were adhered to then the risk of relapse was 15% at 9 month follow-up compared with 92% if neither protective factor was in operation. study and in subsequent work the critical comments threshold was reduced to 6 comments per interview. this work the hostility component was not used.

Similar results regarding relapse are continuing to be replicated both in this country and abroad. In Geneva, Barrelet et al (1990) identified 66% of his French speaking sample as high EE households. At 9 month follow up, relapse for this group was 33%, which was significantly higher than that of the low EE group who had a 0% relapse rate. Also, as in other studies, critical comments was the component primarily responsible for the predictive validity.

III. CONTRADICTORY EVIDENCE

There have of course been some studies conducted over the years which have failed to replicate the original findings. In a German study, Kottgen et al (1984) failed to obtain significant associations between EE and outcome. In a British study, MacMillan et al (1986) found that the relationship between EE and outcome was influenced by another variable, the duration of the untreated illness between the onset of symptoms and initial hospitalization. Similar results were found by Parker and Johnston (1987). However, no relationship between EE and duration of illness was found in a study by Nuechterlein et al (1986). Vaughn (1989) explains some of these discrepancies by differences in methodology and interpretation.

IV. THE MEASUREMENT OF EE

The Camberwell Family Interview continues to be widely used in the assessment of EE. However, even the shortened version can take up to 4 hours of interview time and between 125 and 175 training hours are said to be required to become a reliable rater. It has always been the intention that all adult family members are interviewed; in practice many studies have involved only the key caring relative. It is interesting that there are few 'mixed families', that is families with both high and low EE relatives within the one household. Until the mid 1980's there was no widely published, easily accessible and comprehensive information about the measurement of EE.

The CFI measures EE on 5 scales as outlined below:

i) <u>Criticism</u> - this is measured by counting the total number of critical remarks made by the carer in the

course of the interview. The comments can be deemed critical by content and/or voice tone alone but must indicate unambiguous resentment or disapproval of the person, eg, 'He's so lazy, he doesn't even bother to feed himself'. If, however, the comment was then qualified by the carer either blaming herself or by showing an understanding that the behaviour can be accounted for by the illness, eq 'He's so lazy, he doesn't even bother to feed himself, but I really should be more tolerant - it's all part of his illness', then the remark could no longer be counted as critical. This disqualification rule does not apply if the comment is judged critical by voice tone More than 6 critical remarks uttered in the interview is indicative of a high EE family.

- ii) <u>Hostility</u> this refers to a much more general negative feeling about the dependant and is judged by the rater on a 3 point scale. A positive score on this alone is sufficient to make a judgement of high EE.
- iii) Emotional over-involvement this refers to an extreme emotional response, on behalf of the carer, about her dependant or his illness. It is sometimes illustrated by an over-protectiveness towards them, eg, 'I can't leave him for a moment, I have to be with him 24 hours a day'. As previously mentioned, this has been found to be relevant only to caring parents.
- iv) <u>Positive remarks</u> this is the total number of comments made by the carer about her dependant which reflect praise and approval of them. This positive dimension has not been shown to add anything to the overall dimension of EE.
- v) Warmth this is measured by voice tone alone and

rated on a 5 or 6 point scale. Like the number of positive remarks, this component doesn't add a great deal to the total concept of EE. It also tends to be much more stable over time than the 'critical remarks' component. Most studies have found a significant and negative correlation between 'warmth' and 'critical remarks' (Vaughn and Leff, 1976; Leff et al., 1982; Szmuckler et al 1987).

V. ALTERNATIVE METHODS OF MEASURING EE

In response to the complexities involved in measuring EE using the traditional Camberwell Family Interview, researchers have explored alternative measures with promising results. For example, Kreisman et al (1976) developed an 11-item questionnaire for completion by This 'Patient Rejection Scale' measured rejecting feelings towards the dependant and had moderately reliability high and test-retest correlations. Using this scale on a sample of schizophrenics and their carers, Kreisman and her colleagues found that PRS scores were predictive of the risk of re-hospitalization. Freire et al (1982) also used this scale on a schizophrenic sample and found a significant correlation between the PRS score and the amount of face: face contact between the carer and the dependant. Furthermore, they found association between the PRS score and the degree of psychopathology as measured by the Brief Psychiatric Rating Scale. In a cross cultural study, Watzl et al (1986) administered the PRS to a German sample and obtained similar results to those of the original study on a new York City sample. In 1980, the scale was extended to 24 items to include positive as well as negative attitudes and feelings of the carer towards his or her dependant. The carer responded to the items along a 7 point Likert scale. No particular training was required in order to administer or score it and it was uncomplicated and non-threatening for the carer to complete.

McCreadie and Robson (1987) used this version or the PRS with a group of carers of schizophrenics Scotland and compared it with the CFI. They found that the PRS could differentiate between groups of high and low EE relatives. However, as there was a wide range of scores within the high EE category, a individuals could cut-off point for not ascertained. They concluded that the PRS was a useful research tool but questioned its clinical application. et Snyder al (1988)also with а group schizophrenics and their carers. found a strong correspondence between traditionally rated EE levels and PRS scores. They concluded that the degree of convergence between the two measures was sufficiently high for the two measures considered to be interchangeable.

Recently, Cole and Kaazarian (1988) reported a new measure of EE using the 'Level of Expressed Emotion This 60 item scale was well constructed and shown to have fair internal consistency. reliability and construct validity. Another method of measuring EE was used by Gilhooly and Whittick (1989) on a sample of carers of the dementing elderly. measured EE by rating transcripts of lengthy taperecorded interviews. Two independent raters counted the frequency of critical comments made both in the first hour and throughout the entire interview. There was evidence of high EE in the sample and the frequency of critical comments ranged from 0 to 78.

In recent years there has also been the development of the 'Five Minute Speech Sample (Magana et al. 1986) which measures only 5 minutes of the carer talking uninterrupted about his or her dependant and yet is thought to be an accurate measure of the global EE concept. Several studies have also observed interactions between the carer and dependant directly. Sometimes, the family has been asked to discuss a disputed topic or a family meal has been observed (Miklowitz et al 1984; Strachan et al 1986; Szmuckler et al 1987).

VI. THE CONSTRUCT VALIDITY OF EE

Over the past decade there have been various attempts to examine the construct validity of the EE concept at both behavioural and psychophysiological levels. Valone et al (1983), with a sample of disturbed adolescents found that high EE parents made a significantly greater number of critical remarks during face to face interactions than did low EE parents. In this study a parental interview was used as opposed to the Camberwell Family Interview.

Similarly, Kuipers et al (1983)examined interactions of schizophrenics towards their caring relatives and found that high EE relatives spent more time talking and less time looking at their dependants compared with low EE relatives. Berkowitz et al (1981) also found that lower EE relatives were better listeners than high EE relatives. Interestingly, no difference was found regarding the dependants' behaviour. This of course confirms the earlier findings that the EE concept was not influenced by the patients' previous or current levels of behavioural disturbance. Miklowitz et al (1984) in a sample of 42 schizophrenics and their parents found that high EE parents uttered more negative affect statements than did low EE parents.

Hooley (1983) asked a sample of depressed patients and their spouses to discuss a topic upon which they disagreed. This was done in the absence of the interviewer. She found that high EE relatives directed more critical comments at the patient, disagreed with them more and were less accepting of their points of view. In addition, they were found to be less positive, display more negative non-verbal behaviour and they were less likely to self-disclose. Hooley suggested that interacting with a high EE relative was stressful for the patient and the patient would disengage verbally and non-verbally from the stressful situation.

Vaughn (1989) in a summary of the EE work reported that low EE relatives were more likely to believe that the patient was suffering from a genuine illness, be empathic and tolerate greater levels disturbance. They were also more likely to cope in a more flexible and adaptable way with greater problem solving skills, compared with high EE relatives. They were also more likely to be calm in a crisis and behave in less obtrusive and confrontational ways. However, a key assumption is that the relative will present at the EE interview or observation in the same way as he or she habitually does at home, expressing the same attitudes or feelings. Parker and Johnston questioned the construct validity of (1988)hypothesising that it could be influenced by such factors as defensiveness or social desirability. They administered the Eysenk Personality Inventory (Eysenk and Eysenck, 1963) along with the CFI, predicting that high EPI neuroticism scores, which are linked with intense emotional reactions, would be linked with high They were unable to demonstrate such a link. EE. However, there was a significant correlation between mothers (but not fathers) who scored high on the "lie" scale of the EPI and those with low EE. The authors suggested that this had to do with a desire to appear socially desirable and concluded that low EE could indeed be faked.

Perhaps then evidence for the concept may be gathered psychophysiological sources. Attempts psychophysiological validation were initiated Tarrier et al (1979) who found that spontaneous skin fluctuations in skin conductance measurements could discriminate between patients from high and low EE In their experiments, they found that when the key relative entered the room the low EE patients quickly habituated to normal levels whereas patients with a high EE relative maintained high arousal levels and failed to habituate over a 30 minute period. they concluded that low EE relatives appeared to have calming influence on schizophrenic patients. Similar findings were replicated by Sturgeon et al (1981), Tarrier and Barrowclough, (1987), Tarrier et al (1988).

Valone et al (1984) examined psychophysiological activity in parents and disturbed adolescents both before and during emotionally charged confrontations. They found that interactions between the dependant and high EE parents were more emotionally arousing than those between dependant and low EE parents. They also found that the arousal levels of high EE parents were also higher than low EE parents.

In more recent studies, MacCarthy et al (1986) found that highly critical relatives seemed to provide an unpredictable home environment for schizophrenics. Greenley (1986) found that high EE was correlated with the relatives' levels of anxiety and especially when

they failed to attribute their dependants' behaviour to the illness.

VII. FACTORS_INTERACTING WITH EE

As research on the concept has developed over the years, two main factors have emerged as mediating influences on EE. These are the patients' medication and the amount of face: face contact between the carer and his or her dependant.

Brown et al (1972) were the first to discover that maintenance medication could protect patients from relapse within high EE families. This finding was later replicated by Vaughn and Leff (1976a). However, in a later study, Vaughn et al (1984) found there was only an improvement in the clinical course when there was also a low level of contact between patient and carer. However, in a German study, Dulz and Hand (1986) found there were no advantages to patients in terms of outcome, in taking regular neuroleptic medication.

Earlier than this Brown et al (1962) found that schizophrenics were less likely to relapse if they spent less than 35 hours per week in face: face contact with their caring relative, where the caring relative fell into the high EE category. Again, this finding was confirmed by Brown et al (1972) and Vaughn and In contrast, in a later study, Vaughn Leff (1976a). et al (1984) failed to replicate this in study in the Similarly, in more recent studies (Hogarty, USA. 1985; Dulz and Hand, 1986) no interactive effect was found between EE, contact hours and clinical outcome. Perhaps it is the nature and quality of the contact time that is more significant than the quantity and this could be established through enquiring about the quality of the relationship between the carer and dependant, as has been done in this thesis. Hubschmid and Zemp (1989) also addressed this issue. addition to administering the CFI on 17 parents with schizophrenic children, they also questioned them interactions between themselves and their They found that high EE relationships had dependant. a more negative emotional climate, a conflict-prone structure and particularly rigid patterns interaction. Thus it would appear that EE relates to qualities within and aspects of the patient-relative relationship.

In these earlier studies it was also noticed that the effects of the drugs and the face: face contact were additive and there where was compliance with medication and low face: face contact, then this could protect the dependant in a high EE family. It had no impact on low EE families. Vaughn and Leff (1976a) found a relapse rate of 92% in patients who spent more than 35 hours a week in face: face contact with their caring relative and who did not take maintenance medication. Conversely, patients in high EE families who spent less than 35 hours per week in face: face contact and who did take medication had a relapse rate of only 15%, that is a similar relapse rate to patients in low EE families.

More recently, Leff and Vaughn (1980) have found that episodes of schizophrenia can be triggered by an excess of preceding life events. This was found to hold true only for low EE families but not high EE families.

VIII. THE EE CONCEPT AND OTHER DEPENDENT GROUPS

"There is nothing intrinsic to the EE concept that

should limit it to schizophrenic patients **
Koenisberg and Handley (1986).

To date there have been relatively few studies which have examined EE in other dependent groups. Those studies which there have been are outlined below.

1. Functional disorders

Vaughn and Leff (1976a) studied EE with a group of depressives and their primary carers. Similar results were obtained but only when the threshold for critical comments was lowered. Hooley (1985) replicated the findings on another group of depressed patients and suggested that the lower threshold was perhaps necessary, due to the typical self critical nature of depressives. More recently, Miklowitz et al (1986) found that the EE concept has good predictive power for cases of recent onset mania.

2. Eating disorders

Fishman-Havstad and Marston (1984) found that EE was a good predictor of weight loss and maintenance of weight loss in obese women. Similarly, Flanagan and Wagner (1991) looking at compliance with a weight loss programme and the level of EE in the primary relative. They found that those obese patients who were living with high EE relatives were less likely to comply with the diet and were more likely to be anxious compared with those who lived with a low EE relative. In this study the threshold for critical comments was also lowered.

Szmukler et al (1985) found that the EE index was a good predictor of adherence to a treatment programme

for patients with anorexia nervosa but failed to be predictive of outcome.

3. Dementia

As already reported, Gilhooly and Whittick (1989) looked at the carers of the dementing elderly. High EE correlated with the sex of the carer, with females being more critical, the carer's psychological wellbeing, with high EE carers having lower morale, and a poor quality of pre-morbid relationship. Outcome was not examined in this study.

A similar group has also been studied by Bledin et al (1990) who looked at a sample of daughters and their dementing parents. He used the traditional CFI and while he found evidence for the concept in over half of his sample, EE was not related to outcome at 9 month follow-up.

Orford et al (1987) assessed EE in 4 groups of carers with dependants from various dependency groups. groups were adult psychiatric patients, functional disorder. dependants with a elderly dependants with a chronic physical disorder or an elderly dependant with senile dementia. Unlike the results from previous studies, high EE levels were not found in any group and the threshold level was therefore lowered to >2 critical comments. They found that at this level 52% of carers with an adult psychiatric dependant, 42% with elderly functional patients, 17% with a physically disabled patient and 17% with a dementing dependant fell into the high EE category. Regarding the latter group, Orford and his colleagues observed that while the carers found many of the behaviours and characteristics of dementia irritating and frustrating, they usually described them or qualified their comments in a way which expressed compassion or understanding. While this is an interesting and pioneering project, the subsamples were small (n=12) and adopting such a low threshold for 'high' EE seems unusual. It may be that a larger group would have demonstrated the effect of EE. It may also be that the CFI is not the most appropriate instrument for measuring EE with these groups. Orford et al comment that the CFI does not appear to be a particularly sensitive measure for the given sample and indeed the emotional over-involvement component was not thought to be suitable for dementia, giving the caring demands of the illness.

IX. OVERVIEW OF THE EE CONCEPT

The concept of EE has evolved over the years and is still most commonly measured during an interview covering various aspects of the illness, the impact upon the family, the household routine and the amount of daily contact between the carer and dependant. Although there have been some studies which have failed to replicate the original findings they tend to be in the minority.

However, although the concept may well be valid and reliably measured, we still cannot say exactly what the EE concept reflects as it has no external definition. It does seem to be the case that high EE families cope least well with crises and tend to be more worried and distressed than low EE families. However, it cannot be assumed that low EE carers are effective at coping with all sources of stress within the family. Nevertheless, low EE relatives seem to

have a calming influence on patients and it may be more fruitful to study them and their characteristics than concentrate on the high EE families. of the content of the critical comments shows that high EE families tend to blame the person rather than the illness and this may reflect a poor understanding of the illness on behalf of the carer. It has also been found that EE components are generally lower after recovery from an acute episode of schizophrenia and especially the level of critical remarks et al., 1972., Leff et al, 1982, and Hogarty et al. 1986). The measure of warmth seems to be more stable. It may of course be that EE simply reflects the anger and resentment the carer feels towards her dependant and this in turn may be a reflection of the quality of their relationship. Perhaps then the literature has complicated a rather more simple concept of feelings and relationships.

There is however evidence from various studies that the critical comments component is amenable to change either by intervention or even spontaneously, perhaps as the carer comes to terms with his or her caring role (Falloon, 1988). It could therefore be concluded that criticism, and perhaps therefore EE is in fact a No study to state measure and not a stable trait. date has been able to clarify whether high EE precedes the florid schizophrenic episode or not. intervention work undertaken in recent years (Leff et 1982) illustrates how often the carer dependant operate within a mutually interdependent environment which means that one party's behaviour influences the other. Consequently, influencing one part of the system through intervention could have a beneficial effect on the whole family. The relationship between EE and outcome is perhaps more complex than it was initially thought.

X. THE LINK BETWEEN EE AND COPING

There does seem to be growing evidence that EE in fact represents an aspect of ongoing family interactions and there is, therefore, a very clear link between the concept and the carers' ability to cope. In their review article Kuipers and Bebbington (1988) suggest that there are three groups of relatives. There are the low EE relatives who cope with all aspects of the caring situation. At the other end of the spectrum there are the high EE relatives who have many problems and cope badly with all of them, including the patient. In between they propose there is a group who may vacillate between categories, perhaps depending on their abilities to learn new coping skills.

Bledin et al, (1990), linked EE to coping and found that carers with higher levels of EE used more maladaptive coping skills in caring for their dementing relatives and compared with carers with lower levels of EE. These carers also showed higher levels of strain. Thus, there appears to be a link between EE, stress and coping in the carer and the literature points towards further research to clarify this relationship (Kuipers and Bebbington 1988).

This thesis will take this link forward in an exploratory study of coping and expressed emotion in the carers of the dementing elderly.

XI. SUMMARY

This chapter described the concept of EE, it's history and it's measurement. In recent years, the traditional method of measuring EE has been challenged by new, simpler methods. From it's origins in the schizophrenic literature the chapter then went on to look at research supporting the existence of the concept in other dependency groups and in particular among the carers of the dementing elderly. Finally a link between EE and coping was made thus setting the scene for this thesis.

CHAPTER_EIGHT

AIMS OF THE PRESENT STUDY

The aims of the present study were, firstly, to identify and explore the range of coping techniques used by the carers of the dementing elderly. Secondly, to investigate the concept of 'expressed emotion' amongst the carers of the dementing elderly and to relate this to coping.

It was also thought that carers could be rated as good or poor copers and that EE would be an intervening variable. In addition, it was thought that outcome, in terms of breakdown of care could be predicted by coping and EE.

Thus, the relationships between coping, EE and outcome were explored to test the hypotheses that poor coping methods and high EE were more likely to lead to breakdown of care.

In addition, carer well-being as a relevant variable in the above relationships was examined.

While the nature of this study was in part exploratory ie. to define features of carer coping, some specific hypotheses were also tested. These are detailed below under the two main headings of 'coping' and 'expressed emotion'.

I. COPING

There were seven main components to this empirical investigation. The first three sought to define, 1) the stressful situations which required coping, 2)

the coping behaviour and 3) the techniques the carer reported using in the fulfilment of her caring role. The remaining four components (4-7 below) gave rise to hypotheses concerning the adoption and effectiveness of the coping techniques.

1) What are the stressful situations with which carers must cope on a daily basis?

The literature tells us about the caring duties in a fairly general way and research has pointed towards those aspects of the dementing illness which carers find most distressing. However, no study to date has specifically asked carers to describe a recent stressful incident. To do so would offer great insight into the nature of caring on a day to day basis and highlight exactly with what the carer is having to cope.

2) What are the actions of carers in attempting to cope with these stressful situations?

Having identified a stressful situation it is important to establish how carers actually cope with it. Previous studies have tended to describe more general coping strategies but without linking them to specific incidents.

3) What are the coping techniques adopted by carers in fulfilling their caring role?

The literature has gone some way towards identifying general personal coping techniques but no study has presented carers with a comprehensive list from which to detail the full range of techniques they might use in the course of their caring duties.

4) Does a wide range of coping techniques improve the well-being of carers?

At this stage we do not know whether it is more helpful to employ a wide range of coping techniques or whether it is more helpful to have a smaller and perhaps more consistent set of skills. As one might argue that a wide range of techniques might offer greater adaptability, it was hypothesised that there would be a positive relationship between the range of coping techniques used and carer well-being.

5) Which coping techniques contribute most to carer well-being?

Even where a range of techniques is found to be effective, some may contribute more than others to well-being. For instance it could be argued that practical problem-solving techniques, which may bring practical change in about the situation, positively associated with well-being. therefore hypothesised that those techniques which represented practical ways of coping would be associated with higher carer well-being.

6) Is coping affected positively by the carer's professional and social network?

We are living in the era of 'community care', although the impact of services on carer well-being is unclear. However, it is generally acknowledged that professional and social support have beneficial effects and one might therefore expect that there is a relationship between the support received and how well the carer is judged to be coping. It was hypothesised that those in receipt of more support are better able to cope.

7) Do coping techniques predict outcome at one year follow-up?

Over the past decade, researchers have been attempting to identify factors which influence institutionalisation. It may be that the carers' coping efficacy is an important mediating factor in this equation, and one might hypothesise that there is a relationship between carer coping and outcome in terms of breakdown of care. It was predicted that those who cope poorly would be more likely to have institutionalised their dependant within one year, compared with those who coped more ably.

II. EXPRESSED EMOTION

There is good evidence that the concept of expressed emotion in carers is of predictive value of relapse among schizophrenics. There is also growing evidence that the concept has relevance within other care groups. The confirmation that it is a valid concept for the carers of the dementing elderly has yet to be proven and the evidence to date is contradictory. Exploration of the concept in this thesis should go some way towards clarifying its validity amongst this dependency group. In addition to the exploratory nature of this aspect, specific hypotheses were raised with regard to EE and its relationship with other variables in the care-giving equation.

1) Are EE and coping associated?

What part does EE play in the coping process? Recent studies have made the link between EE and coping such that 'high EE' relatives appear to be poor copers compared with 'low EE' relatives. If this holds true then it may be an important variable in coping with caring for a person with dementia. Specifically, one might predict that there is a relationship between coping and EE such that carers who are thought to be coping well will have lower EE.

2) Are EE and carer well-being associated?

Given the nature of EE, one would expect that it would have a great influence on the carers well-being. High EE is about hostility and criticism and may well be related to a higher level of emotional distress. Thus, one might predict that there is an association between EE and carer wellbeing such that high EE carers are more distressed than low EE carers.

3) Is EE affected by the carers' professional and social network?

It could be predicted that carer EE is the result of a build-up of anger and frustration and that this would be exacerbated by isolation. It was therefore hypothesised that a greater input of professional and social support would have a positive effect on lowering EE.

4) Does EE predict outcome at one year follow-up?

In the area of schizophrenia, the value of EE lies in its predictive validity of relapse of symptoms. In

other disorders eg. eating disorders, it is predictive in terms of adherence to treatment programmes. It might therefore be reasonable to hypothesise that there is a relationship between EE and the breakdown of care. It was predicted that high EE carers would be more likely than low EE carers to institutionalise their dependant within one year.

PART TWO

METHOD

CHAPTER NINE

METHOD: STUDY SAMPLE, PROCEDURES, MATERIALS AND MEASURES

I. INTRODUCTION

By its very nature and because of the paucity of previous research in the area, this study was primarily exploratory.

The study involved three main phases as follows.

- i) Phase one was a pilot study which involved the use of a wide range of semi-structured questionnaires and interviews with the carers. The twenty carer/dependant pairs who participated in this phase also formed the first twenty subjects of the main phase of data. The full details of the pilot study can be found in Appendix 1.
- ii) Phase two formed the main data collection part of the project and an additional eighty carers participated in semi-structured interviews. The dependants underwent a brief cognitive-behavioural assessment.
- iii) Phase three involved a postal follow-up study one year after the initial interview. All 100 subjects were approached for follow-up. The outcome data from hospital or similar sources formed an important part of the follow-up.

This chapter describes the method of the present study. First there will be an overview of the sample, including a description of how the sample was gathered and the socio-demographic characteristics of the subjects. This will be followed by a description of the materials and measures of the main study.

II. PROCEDURES

1. The Setting

The data collection was carried out over a 3 year period in Perth, Edinburgh and West Lothian. All carers were interviewed in their own homes usually in the absence of their dependant. The dependants were assessed either in their homes or at the hospital within two weeks of the interview with the carer. Trained nursing staff also assisted with the assessment.

2. The Selection of Carers

were recruited from Psychogeriatric Hospitals, Community Psychiatric Nursing Services and the records of consultant psychogeriatricians. staff within NHS hospitals were asked to identify all patients, living in the community of their catchment area, who had a diagnosis of an organic dementia and who had a caring relative. The inclusion criteria for carers was that they be either resident with the sufferer or if non-resident visiting at least four times a week. As the investigator also worked in two of these hospitals, possible carers were identified at ward meetings and generally in the course of her work. active data collection periods the potential subjects were approached as they made contact with the hospital services.

In an attempt to recruit a sample of carers who were not in contact with the psychiatric services,

individual consultant psychogeriaticians were also asked to identify any carer:dependant pairs whom they saw in the course of their work but who for whatever reason had decided against further contact with the services. In addition, local 'Alzheimer's Disease Society' (as it was then called) support groups were contacted on a regular basis to identify any carers who were not in contact with the local hospital services. Thus a wide variety of sources over several months was required to yield a total sample of 100 carers.

3. Contacting the Carers

All carers who met the aforementioned criteria for inclusion in the study were sent a letter inviting them to participate in the study (Appendix 3). A specific time was suggested for the investigator to call at their home to explain more about the project; where possible, this was at a time when the dependant would be at the Day Hospital. A stamped-addressed card was also included for the carer to reply and either confirm the time, ask for another time to be set, or decline any involvement. Following the carer interview, the dependant was approached and their cooperation sought for a brief assessment.

To reach a sample size of 100, 124 carers were approached. At the end of the interview, the carers was asked if they could be contacted again, by post in a year's time for follow-up. None of the carers who participated in the original study refused to continue in the follow-up study at that time. Of the 20 interviewed for the pilot study, 18 were available one year later for a follow-up interview. Of the postal follow-ups (n=80), 71 (89%) returned completed questionnaires. If there was no response to the

initial follow-up letter, the carer was either contacted by telephone or sent a further letter requesting her participation along with the relevant forms and a stamped-addressed envelope. Letters of thanks were sent to all participating carers after the initial interview and again on receipt of their follow-up information.

III. THE INTERVIEW

The carers were interviewed in their own homes at a mutually convenient time. Permission was sought to tape record the interviews and in only 6 cases was this refused. Participants were assured of confidentiality of all data and in particular the project's independence from the hospital. The carer knew from the introductory letter that the interviewer was a Clinical Psychologist from a nearby Psychiatric Hospital and the research was introduced in standard form:

" I am carrying out research to find out more about how carers, like yourself cope with caring for someone like your relative. I am also interested in finding out how the relationship between you and your relative has been affected. The work is being carried out at Glasgow University and is being sponsored by the Alzheimer's Disease Society. Anything you tell me will be treated confidentially and I will not go back to the hospital with anything you tell me"

The interviews lasted from a minimum of one hour to a maximum of six hours. The longer interviews were split over two sessions. On average, the interview was completed within an hour and a half.

As already mentioned, the author attempted to arrange

carer interviews at a time when the sufferer would be absent from the home. In cases where this was not possible, the sensitive nature of some of the questions was explained and it was suggested that the carer be interviewed in a separate room from the dependant. If the carer refused, the interview proceeded anyway and if necessary, the questions were read by the carer as opposed to being read to him or her by the interviewer.

In some cases, more than one family carer was present on arrival at the house. In such cases, the primary carer was identified and all questions were addressed to him or her.

At the end of the interview, carers were told that their dependants would be seen by the researcher at the hospital for a brief assessment. No carer objected to this and in fact seemed delighted that their relative would be getting further attention from a professional. In some cases it was not possible to assess the dependant at all, for instance, if they lived alone and had no services to the home. In such cases, it was felt that an assessment would represent too much of an intrusion in to their home and the lost data was accepted.

IV. MATERIALS AND MEASURES

The interview schedule represented an amalgamation of questions, scales and adaptations of scales known to the investigator from her previous research in the area, her clinical experience, knowledge of the literature and from the planning of this particular project. Twenty interviews were conducted for the purposes of a pilot study and modifications were made on the basis of this for the main phase of data

collection. The changes were minimal enough to enable the pilot data and the main phase data to be considered and analyzed as one. In addition, t-tests were computed for the pilot data and the main phase data using a random selection of variables, namely, carer's age, dependant's age, GHQ score, Patient Rejection Scale score and the length of time caring. There were no significant differences between the two groups which further supported the amalgamation.

1. The Carer Ouestionnaire

Section I - Demographic Information

Standard demographic information was gathered about the carer and the dependant, including information marital status, kin about age, relationship, occupation, and education. Information was also gathered from the carer about the dementing illness and its onset. These rather open-ended question allowed the researcher to make a judgement about the extent of the carer's knowledge of the dementing process. The number of years the carer deemed herself to have been the main carer was also recorded.

Section II - Professional Services and Social Networks

The carer was asked about other members of her family, whether or not they lived locally, how often they visited and whether their visits were of a practical or purely social nature. The carer was also asked to rate her satisfaction with this help on a 5 point scale. She was also asked the extent to which she would like more help from the family. Finally the researcher made a rating of how satisfied she felt the carer really was with help from the family.

The carer was then asked to identify the frequency of visits from various professional and voluntary services and similarly, to rate satisfaction on a 5 point scale. As before, the investigator made a rating of how satisfied she felt the carer really was. Additional information was gathered about attendance at Day Hospitals, Day Centres and Carers Groups.

Finally in this section, the carer was asked about the extent of help from friends and neighbours, whether more help would be desirable and there was a question about the frequency of the carer's social life.

There followed a few additional questions to obtain basic information about financial help, suitability of present housing for both carer and dependant and a preliminary question about what the carer thought would happen in the future regarding care.

Section III - Pre-morbid and Current Relationship

Two simple questions were asked to determine the quality of the relationship between the carer and her dependant both before the onset of the dementing illness and as it stood at the time of interview. These questions which use a 5 point rating scale were also used in Gilleard's Day hospital study (1985) and were found to correlate well with a multi-item questionnaire on the relationship (Machin, 1980).

Section IV - Carer's Health

At this stage a few questions were asked about the carers own health. She was asked to rate her own general health on a 5 point scale. She was also asked if she had visited her own doctor in the past 6 months

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and if so for what reason. There was a specific question about medication she was taking and she was asked if she had ever suffered from 'nerves' or depression. Finally, she was asked if she felt that her health had suffered as a result of having to care for her relative.

Section V - Perceived Problems of the Dependant

While an independent assessment of the dependants' cognitive and behavioural functioning was regarded as important, the carers' perception of his or her dependant's disability was arquably even The Problem Checklist pertinent to this thesis. (Gilleard et al., 1984) was used for this purpose and provides data on both the frequency of problems and also the severity of these problems from the carer's point of view. The 34 items cover common problems a carer may encounter in caring for her dementing relative. Each item was read aloud to the carer and she was asked whether that particular behaviour occurred, 'much or all of the time', 'occasionally' or 'never'. If it happened at all, the carer was asked whether it was 'a great problem', 'a small problem', or 'no problem'. In this way both the frequency and severity of problem behaviours could be measured.

Section VI - The Measurement of Coping

Three measures of coping were used in this study.

1) The carer was asked to think back over the previous week and recall a) an incident that happened between herself and her dependant which she found particularly stressful or difficult to cope with and describe the incident to the interviewer. She was then asked to b)

describe how she coped with this situation. This was an adaptation of a method first described by Folkman and Lazarus (1980). This section was recorded verbatim and later categorised by the investigator and an independent rater (H.H.). A second independent rater (L.B.) then rated a random sample of the qualitative information. This was followed by,

- 2) The Ways of Coping Checklist (Folkman and Lazarus, 1984) which was the primary measure of the carers' coping techniques used in this study. This was completed, relating to the carers role in caring for her dementing relative. This questionnaire was read aloud to the carer and each item was endorsed on a 4 point scale, indicating the extent to which each item was used or not. Finally,
- 3) The interviewer also made a subjective judgement, at the end of the interview, on a 5 point scale, as to how well she felt the carer was coping.

In addition to these aforementioned measures of coping, the researcher recorded, throughout the interview, any further voluntary mention of how the carer coped with caring for her dementing relative.

Section VII - Measures of Expressed Emotion

The main measure of the carers' level of expressed emotion was by an adaptation of the Patient Rejection Scale (Kreisman, 1979). This questionnaire was chosen in preference to the usual Camberwell Family Interview which (Vaughn Leff, 1976a) requires and interviewer to undertake lengthy and expensive training in London in order to become a reliable It was in response to the difficulties associated with the CFI that Kreisman and her

colleagues developed an 11 item questionnaire for completion by carers. This original scale measured feelings of rejection towards the patient. Using this scale, Kreisman et al(1979) found that scores were predictive of risk of rehospitalization schizophrenic sample. Freire et al(1982) similarly found a significant and positive correlation between the PRS score and the amount of face/face contact between the carer and dependant. Interestingly they found no association between the PRS score and the degree of psychopathology as measured by the Brief Psychiatric Rating Scale. In a cross-cultural study, Watzl et al(1986) administered the PRS to a German sample and obtained similar results to those of the original New York sample.

The original scale was extended by Kreisman et al (1979) to form a 24 item scale which included positive negative attitudes and feelings of the as well as carer towards her dependant. As in the previous form, the respondent answers each question on a 7 point Likert scale. No particular training is required to administer this questionnaire and it has been found to be straightforward and non-threatening for the carer to complete. For example, McCreadie and Robson (1987) this version with a group of schizophrenics and compared it with the CFI. They found that while the PRS could differentiate between groups of high and low EE relatives, owing to the wide range of scores within the high EE category, a specific cut-off point for individuals could not be obtained. They concluded that the PRS was a useful research tool but had a limited use in a clinical setting.

Snyder et al (1986) in a study with a group of carers with schizophrenic dependants also found a strong

correspondence between traditionally rated EE levels and PRS scores. They concluded that the degree of convergence between the two scales was sufficiently high for the two measures to be considered interchangeable. The PRS was identified as a useful screening tool worthy of further investigation.

The PRS was adapted by the investigator for use on this sample and was the primary measure of hostility and criticism. The author also made post interview ratings of warmth, hostility, critical comments and emotional over-involvement on 5 point scales.

Section VIII - Measures of Psychological Wellbeing

Several well recognised measures of psychological well-being were used in this study to measure anxiety, depression and emotional distress. The Zung Self-Rating Anxiety Scale (Zung, 1971) was completed by each carer to measure her level of self-reported anxiety. This scale was chosen in preference to because the investigator others had used it extensively in clinical practice and found it to be in the detection of anxious symptoms. measures anxiety as a clinical entity and makes an attempt to quantify the symptoms of this disorder using the most commonly agreed upon diagnostic criteria. This scale was introduced in the main phase of data collection and marks a change from the State-Trait Anxiety Scales (Spielberger, 1970) which were found to be too cumbersome when administered to the pilot sample.

The Beck Depression Inventory (Beck, 1974) was administered as a measure of depression and was felt to be the most appropriate for this group. This 13 item scale had also been used clinically by the author

over a number of years.

The General Health Questionnaire (Goldberg, 1978) was also used. As we have seen from the literature review, this is a well known screening device used to detect psychiatric morbidity in community settings. It has been extensively used in research and in particular with carers of the dementing elderly; it was therefore thought to be an appropriate choice of instrument for this study. The 28 item version was used in this instance.

The Kutner Morale scale (1956) was also used as a more general measure of well-being as it has been suggested that carer's distress is more a lowering of general morale as opposed to a diagnosable psychiatric state. This simple 7 item scale was developed for use on an elderly sample and comprises a continuum of responses to life and living problems that reflect the presence or absence of satisfaction, optimism and expanding life perspectives. This has also been used in previous studies of carers (Gilhooly, 1984).

Section IX - Face to Face Weekly Contact

One of the key variables in the EE literature is the amount of face to face contact between the carer and dependant. This was measured using a retrospective diary matrix, first used by Gilleard et al (1984a) in their Day Hospital study. This tool enables the interviewer to record a reasonably accurate picture of the extent of contact that the carer and dependant have in a typical week. To avoid inaccuracies elicited by general questions about the time "usually" spent in caring, the time sample is the actual week preceding the interview. The interviewer begins with "today" and works backwards focusing attention on

specific days, periods and behaviours. Each day of the week is divided in to 4 periods; morning, afternoon, evening and night time. The scoring convention is not to record the precise number of hours for each behaviour but to give an estimate of contact time. Each part of each day is scored for half the time or the whole time depending on the duration of the behaviour. The behaviours measured. consequently the questions asked for and completion of the matrix are eg. "Yesterday morning, were you with your (relative) all day? Did either of you go out? Did anyone visit? The final result is a total number of hours face/face contact, the frequency of outings for the carer and the dependant, together and alone, and the total number of visits to the home over the past week. It also tells the interviewer whether the carer's nights were disturbed.

Section X - Locus of Control

"If a high EE relative is one who is more controlling, that implies that Rotter's scale should reveal differences between high and low EE relatives."

(Hooley, 1985)

The locus of control scale (Rotter, 1966) was also used with carers in the main data collection phase. In addition to the possible links with EE, it was possible that it also linked with the carer's coping skills and possibly her psychological well-being.

2. The Dependants' Assessment

Following the interview with the carer, the dependant was assessed using the Clifton Assessment Procedures for the Elderly (CAPE) - survey version (Pattie and Gilleard, 1979). The cognitive assessment was carried out by the investigator or a member of qualified nursing staff who had been trained in the use of this

instrument by the investigator in the course of her clinical work. The Behavioural Rating Scale section was completed by the member of staff who was most familiar with the dependant. In most cases this was the staff at the Day Hospital but on occasions, Community Psychiatric Nurses and Home-Helps were consulted.

Information about the dependant was also gleaned from the patient's case notes and in particular, the diagnosis, medication and the number of dementia related stays in hospital.

3. The Follow-up Information

All carers in the pilot study (n=20) were interviewed one year on to obtain information about how circumstances, feelings and coping had changed over the year. On the basis of these interviews, postal questionnaires were devised for the main phase (n=80) of data collection.

For all subjects, one year after the initial interview, information was obtained from hospital sources as regards the current circumstances of the carer and her dependant. Depending on whether the dependant was still in the community, in care or had died, an appropriate letter (see Appendix 3) was sent out with the corresponding questionnaire and the GHQ-28.

i) Continuing Community Care

If the dependant was still being cared for in the community, the questionnaire (Form A) asked the carer to compare the overall situation with how it had been a year before. She was also asked whether there had

been any changes in the help from other family and professional services. As in the initial interview, the carer asked what she thought would regarding her relative's future care. She was also asked to rate her level of coping and how it compared Similarly, she was asked about her with a year ago. physical, mental and general health. There was a question about whether or not the carer's feelings towards her relative had changed and if so, in what The carer was then presented with a list of 22 words, both positive and negative and asked underline those that described how she felt about her There were also specific questions about relative. the degree of anger the carer felt both towards her relative and about the care that she gave.

ii) Institutional Care

In situations where the dependant had moved into care, either residential, NHS or a private nursing home, an alternative questionnaire was sent (Form B). This asked the carer whether the move had made the situation better or worse and also asked her to state how she felt she was coping now. As in Form A she was asked to rate her physical, mental and general health in terms of change and current status. Similarly, she was asked if and how her feelings towards her relative had changed. The same list of descriptive words were presented, to describe how the carer felt about her relative.

iii) Death

In situations where the dependant had died, a third form (Form C) was sent. Details of the place and time of death were obtained by the researcher. The carer was asked how she was coping now and compared with a year ago. She was also asked to rate her physical, mental and general health. As with all forms, there was additional space for additional information.

V, SAMPLE

1. Demographic details of the total sample

The sample comprised of 100 relatives of patients with a primary diagnosis dementia. At the time of the first interview, 67 were co-resident, the remaining 33 were non-resident pairs.

- 2. <u>Demographic details of the carers</u> (n=100)
- 1. CARER SEX: The sample comprised of 75 female and 25 male carers.
- 2. CARER AGE: The mean age of the carers was 61.2 years (s.d. = 13.8, range = 21-89 years).
- 3. CARER MARITAL STATUS: The majority of the carers were married or cohabiting (n = 80). The rest were single (n = 9), widowed (n = 6) or divorced/separated (n = 5).
- 4. CARER RELATIONSHIP TO DEPENDANT: Just over a third of the sample were daughters (n = 36). Almost a quarter were wives (n = 23). The rest were husbands (n = 18), sisters (n = 6), sons (n = 5), nieces (n = 3), nephew (n = 1) or other (n = 8).
- 5. CARER SOCIAL CLASS BY OCCUPATION: There was a bias towards the lower end of the social scale. Over a third were in social class III (manual) (n = 35). The rest were in social class IV (n = 25), social

class V (n = 12), social class I (n = 3), social class II (n = 19) or social class III (non-manual) (n = 6).

- 6. CARER EDUCATION: The majority of the carers had left school without formal qualifications (n = 63). A proportion had obtained a leaving certificate or equivalent (n = 18). A similar proportion had gone on to college (n = 17) or university (n = 2).
- 7. CARER EMPLOYMENT: At the time of the study, almost half of the carers had retired from employment (n=47). A minority were in full-time employment (n=11), a few were in part-time employment (n=16), or unemployed (n=10). The remainder described themselves as housewives, ie. had not worked since marriage and were not seeking employment (n=16).

3. Carers' Health

A major part of this study concerned the carers' psychological and physical well-being and so a wide range of measures were used to obtain a detailed picture of this.

i) Formal Scales

THE GENERAL HEALTH QUESTIONNAIRE - 28 ITEMS: The mean GHQ score for the total sample was 4.2 (s.d = 5.5, range = 0 - 21. Taking a cut-off point of \geq 5, 31% could be described as suffering from some degree of psychiatric morbidity. Sixty-nine percent scored below 5. It is noteworthy that both the mean score and the relative number of cases is lower than has been found in previous carer samples although is still

higher than is found in the general population. Goodchild and Duncan-Jones (1985) found a mean of 3.13 (s.d = 4.47) in their community sample. Goldberg (1978) in a community study estimated a prevalence of 16.3% caseness, taking the 5 point threshold level.

THE ZUNG SELF-RATING ANXIETY SCALE: The carers' mean score on the Zung Self-Rating Anxiety Scale was 32.6 (s.d = 7.9, range = 20 - 56). This compares with a mean of 33.8 ± 5.9 for a group of normal adult subject (Zung, 1971).

THE BECK DEPRESSION INVENTORY - 13 ITEM: The mean score on this measure was 4.8 (s.d. = 4.3, range = 0 - 25. Taking the recommended cut-off point of 5, 43% of the sample scored ≥ 5 which indicates they were suffering from at least a mild degree of depression.

THE KUTNER MORALE SCALE: On this measure of psychological well-being, 32% of the sample scored between 0 and 2, indicating 'high morale'; 47% scored between 3 and 4 indicating 'medium morale', and the remaining 21% scored between 5 and 6 indicating 'low morale'.

ii) Informal measures of carer well-being

In the course of the interview, the carers were also asked to rate, on a 5 point scale, their own general health as they felt it had been over the past year. Of the 100 carers who answered this question, 7 described their health as 'very poor'; 26 described it as 'poor'; 27 described it as 'average'; 25 described it as 'good'; and 15 described it as 'very good'. Without an appropriate comparison group it is difficult to comment on this as it may be that for their age, social class etc. they compare favourably.

However, this starts to seem less likely when we take into account that 48% felt that their health had suffered 'somewhat' as a result of caring for their dependant, 7% felt that it had suffered 'a great deal'. Fifty-three percent had visited their GP for their own health in the past 6 months and 26% been treated for 'nerves or depression' at some time in the past. At the time of interview, 53% were medication of some kind. 11% taking psychological problem, 47% for a physical problem. Some fell into both categories.

4. Demographic characteristics of the dependants

- 1. DEPENDANT SEX: The dependant sample comprised of 69 females and 31 males.
- 2. DEPENDANT AGE: The mean age of the dependants was 79.2 years (s.d. = 7.2, range = 58 95 years).
- 3. DEPENDANT MARITAL STATUS: Almost half of the dependant sample were married or cohabiting (n=46). Similarly, almost half were widowed (n=44). The rest were single (n=8) or divorced/separated (n=2).
- 4. DEPENDANT SOCIAL CLASS: As with the carers, there was a bias towards the lower end of the social class scale, as determined by occupation. Social Class I (n = 1), Social Class II (n = 15), Social Class III (n = 15), Social Class III (n = 15), Social Class IV (n = 27) and Social Class V (n = 15).
- 5. DEPENDANT EDUCATION: The vast majority of the dependant sample had left school with no formal qualifications (n = 91), a minority had obtained a leaving certificate (n = 3), or continued on to college education (n = 4) or university (n = 1).

5. Other Dependant Characteristics

- 1. DEPENDANT IMPAIRMENT: The Clifton Assessment Procedures for the Elderly (CAPE) - survey version was administered to a proportion of the dependants (n = The grades indicated levels of moderate to 70). severe cognitive and behavioural impairment with maximum dependency in a majority of the dependants. grades were as follows:- Grade Α ie. impairment, independent elderly (n = 1); Grade B ie. mild impairment, low dependency (n = 4); Grade C ie. moderate impairment, medium dependency (n = 9); Grade D ie. marked impairment, high dependency (n = 32); Grade E ie. severe impairment, maximum dependency (n = 24).
- 2. TIME SINCE ONSET OF DEMENTIA: The carers, by their own estimation had been caring for an average of 41.2 months (s.d. = 28 months, range = 4 months to 13 years). This estimation coincided with when they had first noticed something was wrong and the time when they felt that they had taken on the role of caring.
- 3. DEPENDANT DIAGNOSIS: For the majority (n = 95), medical case notes were consulted to obtain a medical diagnosis of the disease. In over half of the cases, they were noted to have 'dementia' although the specific type was not specified (n = 53). Of the remainder, some were given a diagnosis of Alzheimer's Type dementia (n = 28), some were thought to have a multi-infarct dementia (n = 11), or a mixed dementia (n = 1), or a pre-senile dementia (n = 1). For one, there was no diagnosis noted in the medical records although medical staff were of the opinion that she was suffering from a dementing illness.

- 4. DEMENTIA RELATED HOSPITAL ADMISSIONS: Information on the number of hospital admissions related to the dementing process was obtained for most of the sample (n=93). Of them, the majority had no hospital admission (n=67). For the rest, some had only one such admission (n=17), the others had up to five such admissions. These admissions included respite admissions to relieve the carer.
- 5. DEPENDANTS MEDICATION: At the time of the first interview, information on medication was gathered for 77 of the dependants. Thirty-five (45%) were taking medication for a physical illness. Relative to this the symptoms of dementia were relatively untreated, probably indicating the absence of a suitable drug. Anti-psychotic medication was being taken by over a third of the sample (n = 30), others were taking hypnotics (n = 14), anxiolytics (n = 2), anti-depressants (n = 4), anti-parkinsonian medication (n = 2), or anti-hypertensive medication (n = 4). Approximately a quarter of this sample were taking no medication at all (n = 19).

6. <u>Social and Professional Networks for Carer and Dependent</u>

1. SOCIAL VISITS FROM FAMILY: Only 2 of the total sample had no family living locally although in terms of the contact the carer had with family, the picture was somewhat different. This analysis was based on the responses of 99 carers. Almost half of the sample saw one of their relatives for a social visit at least once daily (n = 44). Over a third saw a relative at least weekly (n = 37), of the remainder, fourteen saw a relative every few weeks and not less than monthly, and four never saw any relative.

1

2. PRACTICAL HELP FROM FAMILY: In many cases, although there were frequent social visits, there was very little practical help given to the carer by the family. Of the total sample, 24 received 'no practical help', 23 said they received 'some', 28 received 'quite a bit', and 25 felt they received 'a great deal'. On the amount of help they received, 20(24%) were 'completely satisfied', 21(25%) were 'fairly satisfied', 16(19%) were 'satisfied', 12(14%) 'fairly unsatisfied' and 15(18%) were 'completely unsatisfied'.

However, 61 said they did not want any more help from their families, 18 said they would like 'some more help' and 19 said they would like a 'great deal more help'.

The investigator also rated each carer on a 5 point scale as regard to how satisfied she felt the carer actually was with family help. Thirteen were judged to be 'completely satisfied', 22 were rated 'fairly satisfied', 27 'satisfied', 12 'fairly unsatisfied', and 23 'not at all satisfied'. Thus, the interviewer felt the carers were probably less satisfied with the help they received from their families than the carers themselves rated they were.

3. BENEFITS RECEIVED: Almost half of the sample (n = 43) were in receipt of an Attendance Allowance at the time of the first interview. Eight received some other form of benefit. Sixty-one carers said they did not want any more financial help, 32 said they would like 'some' more and 7 said they would like a 'great deal more'.

- 4. SUITABILITY OF HOUSING: The carers were asked to rate the suitability of housing for themselves and for their dependant. For themselves, 73 felt that their housing was 'suitable', 22 rated it as 'adequate', 5 felt it was 'unsuitable'. For their dependants, 52 felt it was 'suitable', 34 judged it to be 'adequate', 14 rated it 'unsuitable'. The usual reason for unsuitable housing was stairs, with bedroom or toilet being upstairs.
- 5. CARER: DEPENDANT CONTACT: Using the weekly matrix as described in the measures section, the amount of contact between the carer and her dependant over the week prior to interview ranged from 1 hour to 98 hours, with a mean of 58.3 hours (s.d. = 31.8 hours).
- 6. OUTINGS AND VISITS IN THE PREVIOUS WEEK: In this week as defined in the matrix, the number of outings both alone and with the dependant were counted, as were the number of visits to the carer and/or the dependant, where the dependant was living in the same household. The details are shown in Table 9.1 below.

Table 9.1

Outings and visits by and to both carer and dependant during the week prior to interview

during the week prior to interview			
Number of outings together (n=96)	<u>n</u>		
none	61		
one	11		
>two <four< td=""><td>17</td></four<>	17		
>four	7		
Number of outings for dependant alone			
(n=96)			
none	28		
one	15		
>two <four< td=""><td>43</td></four<>	43		
≥ four	10		
Number of outings for carer alone (n=75)			
none	12		
one or two	24		
three or four	12		
five or six	19		
≥seven	8		
Number of visits to carer/dependant(co-resident) (n=96)			
none	22		
one or two	33		
three	10		
≥ four ≤ nine	23		
≥ ten ≤ twenty-one	10		
	-		

Without comparing this to a suitable comparison group of non-carers it is difficult to make much comment. It would appear though that for a significant number there are indeed few opportunities to get away from the house without their dependant and certainly over half of the carer saw at most two people visiting their house in a week. It must also be remembered that these visits included any professional visitor to the house, and the outings included chores such as shopping or a visit to the doctor. For virtually all the dependants, their outings in the absence of their carer meant a visit to the Day Hospital or Day Centre.

7. AMOUNT OF PROFESSIONAL HELP RECEIVED: In terms of the amount of support received from professionals in the community, the carers were asked to state how often each service attended. The results are shown in Table 9.2 below.

Table 9.2

The frequency of visits from the professional services in the community. Shown for the entire sample (n=100) and also for co-residents (n=67) and non-residents (n=33)

왕 Service/Frequency Resident Non-resident GP Never Less than monthly 20 1 or 2 X monthly Weekly or more <u>Psychiatrist</u> Never Less than monthly 81 1 or 2 X monthly 0 Weekly or more Social Worker Never Less than monthly 1 or 2 X monthly Weekly or more <u>District Nurse/</u> <u>Health Visitor</u> Never Less than monthly 1 or 2 X monthly CPN Never Less than monthly 1 or 2 X monthly Weekly or more Home-Help Never Less than monthly
1 or 2 X monthly
Weekly or more Weekly or more <u>Voluntary Services</u> Never Less than monthly 1 or 2 X monthly Weekly or more

The most noteworthy point from the above table is that regardless of residency, the majority of dependants

and carers do not receive many visits from the community services. The one exception seems to be the Home-Help service which provided a service to more than half of the dependants who were living alone. Furthermore, this service was provided at least on a weekly basis.

Other Services

The other main service received by the dependants in this sample was the Day Hospital service. Sixty-seven percent of the sample attended at least one day per week. There was little difference between the resident and non-resident groups with 69% of the former and 64% of the latter attending. The mean number of days attendance for the sample was 2.4.

As for the Day Centres run by either the Social Services or the Voluntary Sector, only 30% of the sample attended, and on average 1.5 days per week.

For the carers, 25% attended a local 'Carers' Support Group' and there was at least one regularly running in all areas included in the study.

Satisfaction with the professional Services

The carers were asked to rate their satisfaction with the professional help received on a 5 point scale. Twenty-seven percent said they were completely satisfied, 33% were 'somewhat' satisfied, 18% placed themselves at the 'average' mid-point, 5% said they were 'somewhat' dissatisfied and only 1% was completely dissatisfied.

Just over a third of the total sample (36%) said they would like more help. However, this r presented only

25% of the resident group but over half of the non-resident group (58%).

The Professional Care Index

The level of contact with each formal service was combined to produce a 'Professional Care Index' (PCI). This was the sum of the frequency of the visits from the GP, Psychiatrist, Social Worker, District Nurse or Health Visitor, CPN, Home-Help, Voluntary Service visitor or 'other'. Each service was scored as 0,1,2 3 depending on the frequency of visits. In addition, there was an additional score of 0 or 1 for attendance at a Day Hospital or Day Centre. Scores ranged from 1 to 14 with a mean score of 5.9 (s.d. 3.1).

7. Future Care and Quality of Relationship

1. CARERS VIEW OF FUTURE CARE: The carers were asked to state what they felt was going to happen regarding their dependants care in the future and the results are detailed in Table 9.3 below.

Table 9.3

The carers' view of care in the future	(n=100)
Placement Long-term hospital/nursing home care Part IV residential care Carer will continue as long as able Unable to say Other	n 37 16 37 7
other	J

It is interesting that approximately half of the carers foresaw institutional care and therefore at the time of interview must have had an end in sight for their caring role.

2. PRIOR AND CURRENT RELATIONSHIP: Carers were asked to rate the quality of her relationship with her dependant prior to the onset of the dementia and also to rate the quality of it now. The details are shown in Table 9.4 below.

Table 9.4
The perceived quality of the carer:dependant relationship prior to the onset of dementia and currently at time of interview (n=100)

Relationship	<u> Pre-morbid</u>	Current
very poor	2	8
poor	7	26
average	12	26
good	18	17
very good	61	23

We can see a very clear shift down the scale such that more carers rate a poorer current relationship compared with the quality of the relationship prior to the onset of the dementing process.

VI. SUMMARY

This chapter described the method of the current study. Semi-structured interviews with 100 primary carers of dementing dependants, living in the community were conducted. The chapter outlined the measures used in the research. Those used in the main phase were developed in the pilot study and full details of this study are described in Appendix 1. The demographic characteristics of the sample, plus the carers' well-being and dependants' level of impairment were also presented. Information about the professional and social networks was shown.

PART THREE

PRESENTATION AND DISCUSSION OF RESULTS

CHAPTER TEN

RESULTS AND DISCUSSION OF QUALITATIVE ANALYSIS OF COPING INFORMATION

I. INTRODUCTION

This is the first of four chapters which present and discuss the results of the coping and EE data. This chapter presents a qualitative view of carers' coping and addresses the first two questions as set out in the aims. Firstly, what are the stressful situations the carers are having to face on a daily basis in the fulfilment of their caring role? Secondly, in relation to these stressful situations what are carers actually doing in their attempts to cope?

The subsequent three chapters will continue to address the remaining questions and hypotheses set out in the aims. Each chapter will contain a short presentation and discussion of the results before being brought together for a discussion and conclusions section at the end of the thesis.

In an attempt to find out which aspects of the caring situation carers found most stressful and difficult to cope with carers were asked this very question. The thesis also addressed the issue of how the carers coped with these situations, in other words what they actually did. This chapter provides the reader with qualitative information about the caring situation and coping. It is not the purpose of this section to analyze the data statistically but rather to serve as a descriptive introduction to the subsequent chapter on the quantitative analysis of coping.

II. METHOD

In the semi-structured interview, carers were asked to describe a stressful incident which had occurred between themselves and their dependants over the past They were then asked to describe what they did in that situation, in other words, how they coped. This was recorded verbatim and on audio-tape. transcriptions were then reviewed by the investigator and categories of incident 'type' were developed. This had also been done for the data from the pilot study where 7 categories were devised. These categories are described in Appendix One. When the total sample was considered the categories devised on the basis of the 20 pilot cases were found to be less useful than they had been in the pilot study a means of describing the main coping strategies and also somewhat cumbersome. The process was therefore repeated for the total sample by the investigator. The transcripts were also rated by an independent rater (H.H) and on the basis of the two similar systems a final set of categories was established. The same process was undertaken for the responses'. Thereafter, an inter-rater reliability study was undertaken with a further independent rater (L.B) and the results are included in this chapter.

III. RESULTS

- (N.B. All names of carers and dependants in this thesis have been changed to protect confidentiality).
- 1. What were the stressful situations which the carers were facing on a daily basis?

Numerous stressful situations were described by the carers but they broadly fell in to four types:-

1) INAPPROPRIATE BEHAVIOUR AS A CONSEQUENCE OF DISORIENTATION - for example, wandering either in the house or outside, living in the past, and getting up at night and dressing. This category also included situations made particularly difficult by the dependant's memory impairment. It was frequently followed by inappropriate behaviour. This category was well illustrated by the following example where Mrs McColl was caring for her dementing husband.

"Well sometimes he takes an attack. He says 'What time is it?' and he says he needs to go to work. He's determined and nothing will stop him."

Or in the case of Mrs Lewis who also cared for her dementing husband.

"He gets so mixed up in the night; he goes into the cupboard instead of the toilet. He can't use the toilet".

2) REFUSAL TO COOPERATE WITH CAREGIVING ACTIVITIES for example, reluctance to go to day care or
resistance to washing or help from the carer. The
following examples illustrates this category. Mrs Gow
who cared for her mother who attended the local day
hospital.

"She refused to go to the Day Hospital. She started crying and saying I was rotten. I ended up banging my head off the wall."

Similarly, Mrs McCabe who cared for her dementing aunt.

"She was out in the morning with us. In the afternoon she wanted to go out alone and I said no and she threw a temper tantrum, threw her purse on the floor". 3) INCORRECT INTERPRETATION OF PEOPLE OR EVENTS - this category is similar to category 1) but is characterised primarily by mistaken identity of people or places. This often came about through the dependant's hallucinations. Miss Lacey cared for her mother,

"She mistook me for her sister. Mum awoke from sleep and thought I was her sister".

Similarly, for Mrs McLean who cared for her father,

"He thought I was my mother and I should be moving in to his bed".

And for Mrs Dell, who cared for her mother,

"She hides her purse, then accuses me of stealing it. She phoned yesterday and asked if I'd been in the house, I have a key. Something was wrong, she'd no money and got very agitated".

4) PROVOCATIVE OR HURTFUL COMMENTS - this was the category for the kind of situation where the dependant hurt the feelings of the carer either by being aggressive, or being ungrateful or often by failing to recognise the carer. For instance, Mr Murray who described the difficulties in caring for his wife,

"Sometimes she says hurtful things when you've been doing your best".

Or another wife described her husband's behaviour,
"He says I'm a liar giving him too many pills".

Miss Caldwell who cared for her mother,

"Ma's twisted with me. She wants to go to bed at 5pm. I put bottles in, then she gets annoyed if I say the bed's ready. Then she wants coffee. She gets twisted."

Such situations caused carers to be worried and anxious about the whole situation regarding their dependant. They were difficult situations to deal with because they were so pervasive, compared with the relatively quick and practical tasks of, for example, dealing with a wet bed.

The situation types were by no means mutually exclusive and sometimes one incident involved two or more of the above categories.

Table 10.1 below shows the frequency breakdown of stressful situations. In several instances, more than one situation was mentioned. Three carers were unable to mention any.

Table 10.1

Frequency count of stressful situations (multiple codings).

Refusal

	Behaviour	Cooperate	Incorrect Intrprtn.	Remarks	
N	53	12	17	24	_

From the table we can see that the most frequently reported stressful situation was primarily about inappropriate behaviour resulting from disorientation. This was followed by situations which were marked by the hurtful remarks made to the carer by the dependant. Thirdly, there were the situations characterised by the dependant's misinterpretation of people or events. Finally there were the situations in which the dependant would refuse to cooperate with the carer.

2. How did the carers cope with these situations?

The coping responses were initially reviewed by the investigator and also by the independent rater and an amalgamation of the two systems was devised which best described the broad categories of coping responses. Coping fell into 3 main types, 1) Verbal Action, 2) Practical Action, and Withdrawal. Within the 'Verbal' category were subcategories of i) calming/ persuasive talk, ii) instructive talk, and iii) angry the 'Practical' talk. Within category i) supervisory action, subcategories of and Within the 'Withdrawal' category there substitution. i) were sub-categories of physical, and ii) emotional/psychological.

- 1) VERBAL ACTION or talk this could be either instructive, corrective, persuasive and included angry expression of the carer's feelings. This coping response was used to some extent by a majority of the carers. By breaking this category down further we can see that it has many meanings and purposes.
- i) <u>Calming Talk</u> this was the sort of gentle talk used by the carer in an attempt to pacify the distressed dependant. In this example, a wife described how her husband thought she was another woman and her husband became distressed at this and tried to leave the house to get the Police. When asked how she coped, she explained:

"I tried to calm him down, gave him tea, spoke to him and told him I wasn't a stranger. Eventually I got him to lie down and spent two hours talking him round."

This could also be described as persuasive talk and very often is the first strategy the carer will try.

In the situation illustrated below, a daughter describes how her mother awoke one morning (in Perth) and announced that she was ready to go to Orkney. The daughter described,

"I tried to talk her round but she wouldn't have it. My husband dealt with it, I left the situation but came back in and tried to speak to her."

ii) <u>Instructive talk</u> - Sometimes, the talk was much more instructive, as the carer would tell the dependant what to do. For example, in this instance when a wife described her husband, mistaking a bucket for the toilet.

"I told him what to do, I said 'Put that bucket down and use the toilet".

Similarly, the carer may use talk to orient the dependant to reality.

"He keeps going on about his tablets. We give him his tablets with his dinner but seconds later he doesn't think he's had them. I must have gone over that with him twenty times."

iii) Angry talk - The talk could be primarily an expression of anger as in this case of a daughter who was getting 'phone calls from her mother in the middle of the night. When asked how she coped she said;

"I told her to get back to her bed and shouted at her 'Can you not read the time?'".

The reader will note that this could also be described as instructive talk with an emphasis on angry expression. However, the element of anger was deemed to be sufficiently to the fore to create a subcategory.

2) PRACTICAL ACTION - This referred to practical action and although primarily of a non-verbal nature, it was often accompanied by verbal action. In this example, a sister described what she did when her dementing sister started bed-wetting.

"I said 'Your bed's wet'. She said it must have been the rain. I set to and brought sheets over. I don't like it but I have to get on with it".

The nature of many of the stressful situations would account for the fact that many carers undertook practical action for the incident cited and also for other situations mentioned spontaneously in the course of the interview.

i) <u>Supervisory action</u> - this sub-category defined action that was primarily supervisory and therefore strived to maintain the dementing person's independence. An example of a supervisory action might be as in the case of this wife who found it difficult to cope with her husband's repetitive shaving.

"I get very angry, he'll have just shaved an hour ago and he starts again. I tell him he's just had one, I won't do it for him. There's nothing else I can do. I try to encourage him to use an electric shaver, it's less hassle."

ii) <u>Substitution action</u> - this was action which took over a task for the dementing person and could therefore be said to create dependency. As an example of action which creates dependency, this wife described how she coped with her husband who was always 'fiddling about' and wandering through the night.

"I get up, get hold of him and put him back to bed".

In this next example, practical action was the main strategy and again it was substitution rather than supervisory. This daughter's mother continually refused to go to the Day Hospital and when asked how she coped with this, the daughter replied:

"I don't find it difficult to cope at all. I have to force her, dress her, pull her up and get her out".

In this example, another daughter described how the morning of her mother's Day Centre Christmas party, her mother decided she was going to wear a dress which was soiled. Here is how she coped with it:

"I offered to wash if for her but she insisted it was clean. Eventually I took it from her. We had an argument about it, it happens a lot and I can't always persuade her - sometimes I have to be determined"'

- 3) WITHDRAWAL this could be either i) physical or ii) emotional/psychological. Many carers would cope by withdrawing from the stressful situation.
- i) Physical withdrawal Sometimes the carer would physically removing him or herself from the dependant's presence. The following example illustrates this as one carer described her response to her mother's difficult behaviour using physical withdrawal.
- "I said, 'If you're going to act like a child I'll treat you like one'. I walked out and left her. Ten minutes later, she'd forgotten and never mentioned it again. If I hadn't walked out, it'd have got worse."

The reader will note that in addition to the physical distancing, the carer initially took verbal action in

her attempt to cope with and resolve the situation.

ii) Emotional or psychological withdrawal Psychological distancing was much less often used but
is well illustrated by this gentleman talking about
coping with his wife saying hurtful things to him when
he felt that he had been doing his best.

"I try to keep her as relaxed as possible and put it down to frustration. In the early days I thought it was because she was awkward and I used to get frustrated and loose my temper. Over the past year, I've realized that that's negative and it's best to go along with it. I try not to react myself and let things bounce over my head - absorb it rather than reject it.....I just accept the hurtful things".

Table 10.2 below shows a frequency count for each of the categories of coping response. These were multiple codings and one carer could describe several coping responses to the one stressful situation.

Table 10.2
Frequency count for categories of coping responses.

	<u>n</u>
<pre>VERBAL ACTION - calming/persuasive - instructive - angry</pre>	(88) 39 23 26
PRACTICAL ACTION - supervisory - substitution	(40) 18 22
<pre>WITHDRAWAL - physical - psychological/ emotional</pre>	(25) 17 8

The table shows that the most frequently reported coping response was verbal action, usually of a

calming or persuasive nature. Practical action was more commonly used than withdrawal. Physical withdrawal was more commonly used than psychological or emotional withdrawal.

Table 10.3 shows the distribution of coping responses by stressful situation.

<u>Table 10.3</u>

Distribution of 'coping responses' by 'situation type'.

					_
Stressful situation					
Inapprop. Refusal Incorrect Hurtful				Hurtful	
	<u>Behaviour</u>	<u>Cooperate</u>	Interprn.	<u>Remarks</u>	
Coping					
VERBAL					
ACTION	(49)	(9)	(12)	(18)	
-calming	19	3	8	9	
-instructive	= 17	2	2	2	
-anger	13	4	2	7	
PRACTICAL					
ACTION	(26)	(4)	(5)	(5)	
-supervise	11	1	3	3	
-substitute	15	3	2	2	
WITHDRAWAL	(7)	(6)	(4)	(7)	
-physical	6	4	3	4	
-emotional	1	2	1	3	

From this table we can see that for all types of stressful situation, the carer was more likely to use 'Verbal Action' and particularly of the 'calming' or 'persuasive' kind to cope with the situation.

3. Inter-rater reliability for the stressful situations and the coping responses

In order to test for inter-rater reliability of the categories for the stressful situation and the coping responses, a second independent rater (LB) was given

a 50% random sample of the transcripts and information about the classification system. In accordance with this, she classified the information and Kappa coefficients, as described by Fleiss(1975), were carried out to test for inter-rater agreement. The results can be seen in Table 10.4 below. The 'Strength of Agreement' is in accordance with the classifications devised by Landis and Koch (1977).

Table 10.4

Inter-rater agreement between the interviewer (JW) and an independent rater (LB) for the stressful situation and coping responses - Kappa coefficients.

	Kappa	Strength of Agreement
Stressful situation	0.33	fair
<u>Coping response</u> Calming/persuasive talk	0.64	substantial
Instructive talk	0.67	substantial
Anger	0.75	substantial
Practical action -supervisory	0.29	slight
Practical action - substitution	0.50	moderate
Withdrawal-physical	0.70	substantial
Withdrawal-emotional	0.54	moderate

As can be seen from the above table, there is a substantial level of agreement for the following items; calming or persuasive talk, instructive talk, anger and for physical withdrawal. There is agreement for the other items also but to a lesser extent. The lowest level of agreement is for the rating of the stressful situation. Further work would be required if this were to be adopted as a satisfactory system of categorisation.

4. Changing Coping Strategies over Time

In many cases, carers described how their approach to caring and coping with difficult situations had changed over time. A daughter described her way of coping with her mother hiding her purse and then accusing her of stealing it.

"In the past I used to row with her. Yesterday I just ignored it and said the home-help would be down to sort it out - that pacified her".

Another daughter-in-law described how she had learned to cope with her mother-in-law's confusion.

"I just agree with her. Explaining makes it worse and arguing is no use".

5. Individual differences in coping

Clearly, what worked for one carer and dependant did not work for another. While persuasive talk was good for one pair, it could be a failure for another.

"I can tell her something but five minutes later she's forgotten. So, I tell her again, several times and then I get mad. I'm not very tolerant".

"She gets ready for the Day Hospital every morning. I tell her it's Sunday and she doesn't go today and I show her the paper. It takes a long time to convince her and half an hour later she's ready again".

Similarly, the psychological distancing technique of ignoring was useful for some but not others.

"She (mother) will start shouting out the blue that I should get out of the house. I ignore it and she forgets about it".

"She (mother) goes on and on about her clothes. Once you've had it for a wee while you could scream. I try to keep my temper and answer her questions and tell her to keep quiet but it doesn't stop. I can't do anything about it. If you ignore her she keeps on and on".

This should not come as a surprise, as individuals we are all unique and our ways of communicating and interacting with others and our families covers a wide spectrum, there is no reason to believe that in dementia individual differences will lessen or that behaviour will become more alike or will respond to the same treatment.

6. Anger and Frustration

Running in parallel with the three main categories of coping outlined above, were very many instances of the carer getting angry with her dependant; most often realizing that this was a useless emotion. For instance,

"I used to get angry back at him but now I just humour him".

"I shout at him and give him a row. He gets annoyed, it doesn't work".

Sometimes the aggression might become physical, for instance, this daughter described her reaction to her mother whom she felt deliberately annoyed her.

"I sometimes get angry and shout 'I'm no waene'. Sometimes I shake her if I get really angry".

Or in this case of a husband who cared for his dementing wife.

"The other night she wouldn't come to bed with me. I woke up at 4.00am and she was sitting with her fur coat on in the bathroom. I nearly lost my command, she wouldn't come to bed. I pulled her by the coat and she started to scream. I warned her about the

neighbours. I was so upset I nearly clouted her across the jaw."

In any discussion of coping it is vital to understand the emotional aspect which runs parallel to behavioural strategies. It may be that this emotional aspect in fact was the expressed emotion which this and other studies have attempted to measure. event, it is this emotion that described the frustration and also the sadness of the caring situation. It may even be more appropriate to have categorised it as 'not coping'.

IV. DISCUSSION

This chapter presented qualitative data which examined in detail the sorts of stressful situations which the carers were identifying in the course of their caring role. These divided in to four main situation types, namely, 1) Inappropriate behaviour as a consequence of disorientation, 2) Refusal to cooperate caregiving activities, 3) Incorrect interpretation of people or events, and 4) Provocative or hurtful Situations characterised by disorientation remarks. and confusion are the very trade-marks of dementia. which clearly indicate The features SO disintegration of the personality and the links with the past, who they are and who they have been. Unlike physical problems the carer had more difficulty in making sense of the difficult situation. Similarly, refusal to cooperate probably led to frustration on the part of the carer, a reminder that not only were skills being lost but that the situation was becoming increasingly difficult for the carer in her role. Finally, situations which were characterised by the emotional pain which they caused the carer formed their own category and indicated that it was not the physical but the emotional burden of care that the carer found so difficult to cope with. It is the hurt and emotional blows which the carer struggles with most.

Of the four types of situation mentioned, it would be unlikely for them to be prominent features of someone caring for a physically frail dependant. These situations all result from the dementia itself. problems are not about situations such as increasing dependency or falls but about the very symptoms of dementia that make it the devastating disease that it In other words they are about the disintegration of the person, the failure to recognise familiar people, the forgetfulness, and disorientation and the effect the illness has on the and his or her feelings. The stressful situations are about the behaviour that is out of character for the dependant, the aggressiveness, the pettiness and the upsetting remarks and behaviour; the very things which make the disease so 'abnormal'. For a carer who is striving to maintain stability and normality and indeed being encouraged to do so by the professional services, the media and perhaps also other family members, it is understandable why these situation types were identified as particularly stressful.

This chapter also identified three main coping responses used by the carers in response to the above stressful situation types, namely, 1) Verbal action, 2) Practical action and 3) Withdrawal. Verbal action or 'talk' was used by most of the carers at least some of the time and took many forms. It was often used to persuade the dependant to do or not to do something and it sometimes did or didn't work. Nevertheless,

there seemed to be a powerful need for the carers to attempt this strategy often before taking further or other more direct or practical action. There is nothing surprising about talk or verbal emerging as a theme. As normal adults we communicate with one another much of the time by talking and there is no reason why this should change in dementia even although the meaning of the communication for the dementing person may be lost. It also seems unlikely if verbal communication even has completely meaningless and has no impact, that the carer should change the natural habits of a life time and suddenly stop communicating in this way. addition, it is an entirely natural and perhaps automatic human to response instruct another individual what to do if he or she is having difficulties. It may be futile but the individual who is giving the instruction may feel compelled to try. However, it is easy to see how failure to comprehend and follow even simple instructions may lead to even greater frustration especially on the part of the carer which perhaps explains the frequent citing of the second main coping theme of practical action. this coping type, the carer would literally something for the dependant, for example, bring them back from wandering outside or, provide practical help with bathing or dressing. Some carers wanted to resist this at all costs, preferring to maintain their dependant's independence. Maybe some carers also found the task disagreeable if for example, it involved giving intimate care to a parent. Some carers would see it as most important that their dependant was at left the dignity of attempting to themselves rather than the carer taking over the whole task for them. By contrast, others would take over the task completely, maybe finding it quicker, less frustrating or perhaps producing a more acceptable

For many carers if their dependant had previously been a particularly tidy and individual, the deterioration of personal hygiene or dress sense was difficult to tolerate and therefore perhaps easier to cope with by taking over the task and making the end result 'more like it used to be'. For some, to have their dependant well groomed was important for them as this was a sign to others that they were doing their job well. They would no more have tolerated an unkempt dependant than they would have kept a dirty or untidy home. It may also have been the case that for some carers to have their relative badly groomed would have been a constant reminder that things were not right, or otherwise worse than they might be. Many did it for the sake of the dependant, because their relative would always have wanted to look nice, or would never have gone out without her hat on.

However, by taking practical action, the carers were removing adult status and in some cases taking away basic rights, such as choice, freedom to go where one pleases etc., in a way that would not be tolerated in many residential facilities or hospitals. principals of freedom, dignity and choice are upheld by the management of these care facilities and indeed are the philosophies of care within them. question then arises, does this matter anyway? Is it upsetting for the dementing individual struggle to dress and perhaps realise even momentarily that something is far wrong, than to suffer the indignity of having his or her daughter carry out the most basic of human tasks? It would seem sensible on the one hand to advise the carer to do what is least distressing for the dependant but this may not coincide with what is least distressing for the carer. As for professional carers, can we really offer guidelines and advice across the board or is that in itself taking away the individual's right to choose? Thus the whole issue of advising or training carers how to cope is open to debate and will be picked up again in the final section of this thesis.

The third main coping technique was withdrawal by the carer and this could be either physical or psychological.

Physical withdrawal was cited frequently by the carers in this sample and in general seemed to work reasonably well as a coping technique. It often served to allow the carer time-out from a fraught situation and also sometimes did likewise for the dependant in that it allowed him or her to 'forget' about the difficult incident. For many carers however, it would conceivably be difficult to leave a crisis situation, perhaps leaving the dependant in Also, once again, the natural human some danger. desire to normalise and stabilize difficult situations may prevent the carer from physically withdrawing from the event. However, if in general terms, withdrawal is good for both the carer and her dependant, is institutionalisation the ultimate withdrawal perhaps partially explains why emotional distress is lessened by institutionalisation but increased by continued contact through caring in the community? (Gilleard, 1985).

Psychological withdrawal frequently meant ignoring the dementing person and like all the other techniques this sometimes worked and sometimes failed. For most adults, ignoring a close relative's words or actions is considered impolite and therefore not something that is likely to come automatically to the carers. Some parents will use this technique to modify their

young childrens' maladaptive behaviour eq. ignoring a temper tantrum. However, it is not something that we tend to use as adults to modify the behaviour of adult members of our families and may therefore be difficult and unnatural for the carer to do. By using this as a coping strategy the carer herself may feel guilty. Furthermore, it is unlikely to work as a long-term solution owing to the impaired memory and learning capacity of the sufferers. This failure to learn may account for increased frustration and maybe even resentment on the behalf of the carer. On the other hand, psychological distancing may help the carer in the short-term allowing her to switch off from the immediate stress of the situation. Again though, this runs counter to what professionals generally advise care staff to carry out in terms of 24 hour Reality Orientation. This may or may not be good practice for the carer or the sufferer and once again it seems that we are unable to offer a blanket prescription for all carers and their dependants.

Changing Strategies over Time

A theme running through the coping strategies was the variability of coping over time. While the accounts from the carers were subjective and retrospective, their coping talked spontaneously of how strategies had changed over time. This understandable when one considers that as the disease progresses, the problems change and the carer also changes in how he or she adapts to what is happening. Verbal persuasion may be more appropriate in the early stages where the dependant is more capable, but this may give way to more direct action or practical tending as the disease progresses and the dependant becomes more impaired.

Perhaps in the early stages of the disease dependant may appear more insightful and normal, and the carer may find it harder at this stage to take on board and accept that the dependant is ill and cannot always help his or her actions. It became apparent from the interviews how a number of carers, in spite of a good understanding of the dementing process, would still cite an incident in which she felt that the dependant had deliberately annoyed or upset her. This is likely because as humans we are well capable of operating at different level of understanding. Furthermore, we know that dementia manifests itself in different ways as the dementing person goes through this chaotic and variable gamut of emotions, actions and reactions, how else then can we expect the carer to react but with a chaotic and variable gamut of emotions, actions and reactions. The carer cannot always accurately predict what the sufferer will do next, so how can she accurately plan how she will cope and react? So many carers emphasized that they 'just take each day as it comes'.

Anger and Frustration

Also running parallel to all of the three strategies mentioned above was the expression of anger of both a physical and verbal nature. There was also a common feeling that carers knew that this wouldn't work but they seemed unable to stop themselves reacting in this way. Anger frequently led the carer to feeling guilty and especially if there was physical abuse involved. However, it should be noted that actual physical abuse of the dependant by the carer was rare. It could have been that the emotion of anger arose out of striving to interpret the situation as 'normal' and therefore becoming annoyed when the dependant reacts in an 'abnormal' manner. If the carer were able to see the

situation as 'abnormal' in the first instance, her angry reaction may have been less likely or at least the level of anger may have been lessened. However, if as humans we strive to maintain normality and balance in our lives, then continually interpreting our dependants' actions or our circumstances as 'abnormal' may cause us undue stress which may then lead to an inability to cope with the situation. Once again it seems that we are unable to offer a blanket prescription regarding either the anger or a way of construing the possible cognitions which triggered it.

Also, it should be noted that what is a normal form of communication in one family would be considered a major row in another. Perhaps those carer/dependant pairs who always communicated in more aggressive and outspoken ways will continue to do so at a more extreme level in the course of dementia. Thus what may be a good coping strategy to encourage in one diad may be completely unnatural and maladaptive to both parties in another caring pair. For the purpose of this thesis, this element of anger and frustration which runs parallel to the coping strategies may in fact be representative of high EE.

V. SUMMARY

This chapter reviewed and discussed the data from this thesis on the stressful situations experienced by the carers and their strategies for coping. Possible reasons for the findings were discussed and difficulties for professionals working in the field were highlighted.

CHAPTER ELEVEN

RESULTS AND DISCUSSION OF QUANTITATIVE COPING INFORMATION: HOW CARERS COPE

I. INTRODUCTION

The previous chapter addressed the specific question of what is most stressful about caring for a dementing person, and what, specifically, the carers were doing to cope with these situations. This chapter continues to examine the coping techniques which carers reported using in fulfilling their caring role. Hypotheses concerning the range of techniques, and concerning the relationship between the techniques and other relevant variables were tested.

II. METHOD

In this study the main measure of coping was the 'Ways of Coping Checklist' (Folkman and Lazarus, 1985) which was completed by 98 carers in the course of the first interview. A split-half reliability analysis was carried out for the 'Ways of Coping Checklist' and the correlation between the forms (r=.7375, df.96, p<.001) was evidence for a high reliability.

However, as the complete 66 item questionnaire was rather unwieldy and difficult to make sense of, factor analysis was undertaken. It was anticipated this would produce a few, concise interpretable factors which could then be correlated with other variables. A principal components analysis plus a varimax rotation yielded 7 factors with eigen values greater than 1.0. These 7 factors accounted for 38% of the variance. Unfortunately, the factors were not easily interpretable and although further analysis was undertaken, and is detailed in Appendix Two, it did not make psychological sense and was therefore not helpful in furthering our understanding of carer coping.

In the light of this, greater emphasis was then placed on the individual coping items that were used by at least half of the carers and further analysis undertaken with them.

III. RESULTS

1. The most frequently reported coping techniques

In a general sense, which coping techniques did carers identify with in carrying out their role as carer? attempting to answer this question, carers completed 'Ways of Coping Checklist'. item respondent endorsed each item with regard to the degree to which she used that technique. This was either, 'Not used', 'Used somewhat', 'Used quite a lot' or 'Used a great deal'. However, endorsing 'Used somewhat' was not considered to be sufficiently prevalent to constitute a coping technique, and so items were subsequently recoded such that 'Used somewhat' was grouped with 'Not used'. This gave the scale a 'Yes'/'No' or 'Used/Not used' dichotomous coding which is incidentally how the scale was originally formulated.

From a frequency count of the checklist we can see just which techniques carers most frequently reported using in their caring role. Table 11.1 below, shows a rank ordering of the most frequently used items on the 'Ways of Coping Checklist'.

Table 11.1

Rank ordering of the most frequently reported coping techniques from the 'Ways of Coping Checklist'.

Item	<u>% reporti</u> n=98	<u>ng</u>
37.	Maintain my pride and keep a stiff upper lip.	75
53.	Accept it since nothing can be done.	74
65.	I remind myself how much worse things could be.	72
54.	Try to keep my feelings from interfering with	
	other things too much.	68
15.	Look for the silver lining, try to look on the	
	bright side of things.	64
14.	I try to keep my feelings to myself.	63
	I just concentrate on what I have to do next.	63
55.	Wish that I could change what is happening or	
	how I feel.	56
41.	Don't let it get to me, refuse to think too	
	much about it.	50
49.	I know what has to be done, so I'm doubling	
	my efforts to make things work.	50
64.	I try to see things from the other person's	
	point of view.	50

The above represent the items used 'Quite a bit' or 'A great deal' by ≥ 50 % of the sample. The most striking point about these items is that they are very much of a cognitive/emotional type as opposed to behavioural/practical types of coping. This perhaps reflects the nature of the dementing process and the limitations of using practical methods of coping.

2. The least frequently reported coping techniques

Which coping techniques were carers least likely to use? Once again, from the 'Ways of Coping Checklist' the least frequently reported items were rank ordered and are shown in Table 11.2 below. This represents items endorsed by ≤ 25 % of the sample.

Table 11.2

Rank ordering of the least frequently reported coping techniques from the 'Ways of Coping Checklist'

<u>Item</u>		
	n=	98
	Take a big chance or do something risky.	1
16.	Sleep more than usual.	7
52.	Come up with a couple of different solutions.	7
17.	I express anger to the person who caused	
	the problem.	9
29.		10
	Get away from it for a while.	10
	Avoid being with people in general.	10
	Take it out on other people.	12
	Refuse to believe it will happen.	12
	Change something about myself.	12
	Have fantasies or wishes about how things	12
59.	turn out.	12
<i>c</i> 2		12
63.	I think about how a person I admire would	
	handle the situation and use that as a model.	12
	I jog or exercise.	13
39.	Change something so things will turn out	
	alright.	14
	I am inspired to do something creative.	15
	Apologise or do something to make up.	15
05.	Bargain or compromise to get something	
	positive from the situation.	16
	Find new faith.	16
21.	Try to forget the whole thing.	17
33.	Try to make myself feel better by eating,	
	drinking, smoking, drugs or medication etc.	19
51.	Make a promise to myself that things will be	
	different next time.	21
31.	Talk to someone who can do something concrete	
_	about the problem.	22
45.	Talk to someone about how I'm feeling.	22
	Ask a relative or friend I respect for advice	
	I'm changing or growing as a person in a good	• 2 3
23.	way.	24
AΩ	Draw on my past experiences.	24
	Talk to someone to find out more about the	24
08.		2.4
	situation.	24

These items are considerably varied although there were several items which would indicate practical and behavioural methods of coping eg. 63,52,39,56,66,45,42,08,17,31.

3. How do these coping techniques relate to carer well-being?

It was hypothesised that there would be a relationship between some of the coping techniques and carer wellbeing and that perhaps it would be the more practical techniques which would be associated with better well-To test this, individual items were looked at in terms of their association with carer wellbeing as measured by the GHQ, Beck Depression Inventory, Zung and the Morale Anxiety scale Kutner Dichotomous coding for the 'Ways of Coping Checklist' was used such that to be considered a practised technique, the subject had to endorse either 'Used quite a bit' or 'Used a great deal'. Similarly for the GHQ, subjects were classified as either a 'case' or 'not a case' using the conventional cut-off point of 5. For the BDI the cut-off point of 5 was used to indicate 'depressed' or 'not depressed'. Neither the Zung Anxiety scale nor the Kutner Morale scale have recognised cut-off points and so for the Zung the sample were divided at the mean to indicate 'more anxious' or 'less anxious'. For the Kutner Morale scale, those scoring between 1 and 3 were considered to have 'higher morale' while those scoring between 4 and 6 were classed as 'lower morale'.

All items from the 'Ways of Coping Checklist' which were used by at least 50% of the sample were crosstabulated with the measures of well-being. Only one item showed a significant association with well-being. This was item 49. 'I know what has to be done, so I am doubling my efforts to make things work'. Details are shown below.

Table 11.3
Chi-square coefficients for GHQ, BDI, Zung and Kutner for item 49.

	<u>GHO</u>	BDI	Zung	<u>Kutner</u>
Chi- Squared (1 DF)	5.926	11.975**	10.814**	.132
		*p<.01 **	p<.001	

Item 49. 'I know what has to be done, so I am doubling my efforts to make things work' was the only single item which was significantly associated with well-being as measured by the Beck Depression Inventory and the Zung Anxiety scale. It was approaching significance (p<.05) with the GHQ.

It should be emphasised that the direction of causality is not know and it is therefore not known whether coping by doubling one's efforts causes more distress or whether when a carer has become either depressed or anxious she will then use this technique.

Further caution should be exercised in interpreting this solo finding as in carrying out such a large number of crosstabulations there is an increased probability of finding some significant correlations sporadically (Type I error). While there is a method of correcting for this (Bonferroni's correction), if this was done in this thesis, the significance level would be lowered to the extent that no significant findings could be reported.

4. Does the range of coping techniques relate to carer well-being?

Perhaps the sheer number of coping techniques the

carer uses is an important determinant of well-being The hypothesis was tested that there would be a relationship between the range of coping responses and carer well-being. Each carer was assigned a score for the checklist. One point was assigned to every item endorsed as 'Used quite a bit' or 'Used a great deal', and the items were summated. The mean number of items checked was 20, with a minimum of 4 items and a maximum of 38. This new variable correlated at a significant level with the measures of well-being but not in the expected direction and so the hypothesis was rejected. The correlations were as follows: GHQ (r=.311, p<.01); Zung (r=.322, p<.01); BDI (r=.253, p<.01). The greater the range of coping techniques used, the poorer the carer's psychological wellbeing. However, if we were to accept a higher significance level in view of the number of correlations being conducted, then this finding would fail significant. Once again, caution must be exercised in interpreting these findings.

There were no significant correlations between the number of items endorsed and the age of the carer, the prior or current relationship, the interviewer rating of coping, or the level of dementia as determined by the CAPE. Finally, it failed to correlate with the carer's locus of control or the hours of face to face contact in the week.

Is the concept of coping measurable? Or is it something that should not be measured in such an exact and quantifiable way? Perhaps it is something more nebulous but that a clinician can assess in a limited way. If one asks someone if they are coping or not, they understand the meaning of the question and can usually give an answer. Can the clinician make a valid judgement on this then?

5. The Interviewer Rating of Coping

At the end of every interview, the investigator (JW) made her own rating on a 5 point scale as to how well she felt the carer was coping. The distribution of scores over the sample is illustrated in Table 11.4 below.

Table 11.4

Distribution of the interviewer coping ratings.

Rating	<u>n (%)</u> n=98
Very Poor	4 (4.1)
Poor	20 (20.4)
Average	32 (32.7)
Good	32 (32.7)
Very Good	10 (10.2)

These ratings were made on a subjective basis by the investigator. Clear criteria were not established in advance and the judgement was made very much in accordance with general feelings. It is also relevant at this stage to bear in mind that the investigator had at this stage many years of interviewing experience with this client group and therefore, the judgement was made in accordance with the wider population of carers. Furthermore, she was also a qualified clinical psychologist and had several years of experience with the adult and elderly population through her clinical work.

6. How do the interviewer ratings of coping relate to other variables?

To find out if the interviewer's ratings of coping related to other factors, the hypothesis that there would be a relationship between the interviewer rating of coping and other relevant variables was tested. Pearson's correlation coefficients were calculated.

i) Interviewer Rating of Coping with Carer Variables

The relationship between coping and the carer variables are shown in Table 11.5.

Table 11.5
Correlations between the interviewer coping ratings and carer variables.

	Carer's <u>Age</u>	Carer's <u>Sex</u>	Residency	Years <u>Caring</u>
Interviewer <u>Coping</u>	.014	.254*	075	.151
	* p<.0	1		

There was a significant correlation between the sex of the carer and the ability to cope as rated by the interviewer (r=.254, p<.01), thus males were judged to be coping significantly better than females. The carer's age, number of years caring and residency were not related.

ii) <u>Interviewer Rating of Coping with Dependant Variables</u>

The hypothesis was tested that there would be a relationship between the interviewer's rating of coping and other dependant variables. However, there was no significant relationship between the interviewer's rating of coping and the dependant's age, dependant's sex, CAPE score or number of hospital admissions. The hypothesis was rejected.

iii) Interviewer Rating of Coping with Carer Wellbeing Measures

The hypothesis that there would be a relationship

between the interviewer's rating of coping and carer wellbeing was tested. It was predicted that those who were rated as coping better would have better mental The interviewer's rating of coping was health. significantly related to all measures of wellbeing, as follows, GHQ (r=-.430, p<.001), Zung (r=-.363,p<.001), BDI (r=-.396, p<.001), Kutner Morale Scale (r=.317, p<.001), Carer's self-rating of health (r=.284, p<.001), Health suffered through caring (r=-.244, p<.001). Those who were rated as better copers were significantly less likely to be depressed, anxious or score highly on the GHQ. Furthermore, their morale was higher, they rated their general health as better and were less likely to feel that their health had suffered as a result of their caring duties.

iv) <u>Interviewer Rating of Coping with Relationship and</u> <u>EE Measures</u>

The hypothesis that there would be a relationship between the interviewer rating of coping and the quality of the carer dependant relationship was tested, such that those who were deemed to be coping better would report a better relationship with their dependant. There was a significant correlation between the interviewer's rating of coping and the quality of the current relationship (r=.240, p<.001), such that those thought to be coping better also rated their own current relationship with their dependant as better.

The hypothesis that there would be a significant relationship between the interviewer's rating of coping and EE was tested. It was predicted that EE would be higher in carers where the interviewer rating of coping was lower. There was a significant and negative correlation between the interviewer rating of

coping and the Patient Rejection Scale (r=-.258, p<.01) such that those who were rated as coping better, also scored lower on the Patient Rejection Scale. Thus the original hypothesis was accepted.

In addition it was hypothesised that there would be a significant relationship between the interviewer's rating of coping and the interviewer's ratings on the EE dimensions. There was a significant correlation between the interviewer's rating of coping and the interviewer's rating of hostility (r=-.276, p<.01), such that those who were rated as better copers were also rated as displaying less hostility about their relative in the course of the interview. None of the other EE ratings were significantly related.

There was no association between the quality of the prior relationship, the frequency of face to face contact between the carer and her dependant in the previous week nor the carer's score on the Locus of Control scale.

v) <u>Interviewer Rating of Coping and Professional and Social Networks</u>

Finally the interviewer rating of coping failed to correlate significantly with the carer's view of how suitable her housing was, the frequency of her social life, the amount of help she was receiving from her friends or the amount of professional help she was receiving (PCI). Thus the hypothesis that professional and social supports would be associated with better coping was rejected.

The highest correlations were with the measures of well-being and it may be in judging the carers' ability to cope, what was actually being looked at was

a clinical view of her mental state. It is also interesting that it relates to low hostility scores and a low score on the Patient Rejection Scale. This too would make sense in that to conduct an interview in an environment with high EE and hostility would be unlikely to leave the interviewer with the feeling that the carer was coping particularly well.

7. What are the best predictors of the interviewer's rating of coping?

Taking this further in an attempt to identify the best predictors of the Interviewer Coping Variable, a Stepwise Regression was undertaken and the results are shown in Table 11.6.

Table 11.6

Stepwise multiple regression analysis - predictors of the interviewer rating of coping.

	Adjusted <u>R2</u>	<u>Beta</u>	<u>F-value</u>
Variable entered on Step Number 1. GHQ	.18	44	17.60***
Variable entered on Step Number 2. Current Relationship	.25	.27	13.04***
Variable entered on Step Number 3. Kutner Morale Scale	.28	.20	10.40***

*** p<.0001

Variables entered in the equation but not contributing to the equation included, the carer's sex, the carer's health, the extent to which the carer's health has suffered through caring, the Patient Rejection Scale and the interviewer's rating of hostility. Thus the GHQ was the best predictor of the interviewer's rating of coping. The quality of the current carer:dependant relationship was also important as was the carer's level of morale.

This would lend support to the view that what is in fact being measured by the interviewer is primarily the carer's psychological well-being.

8. Who are the 'good' copers?

Finally a Discriminant Analysis was undertaken to try and form a clearer picture of the 'good coper', as rated by the interviewer. The Discriminant Analysis will reject all cases where even one variable is coded missing and so, three separate analyses were done to maximise the number of cases considered in each run. The results are shown in Tables 11.7 - 11.9 below.

Table 11.7

Discriminant analysis of the interviewer rating of coping with carer variables.

	_	_	_
	Wilks'		
<u>Variable</u>	<u>Lambda</u>	<u>F-value</u>	
Carers' age	.99	.14	
Carers' sex	.95	4.93+	
Spouse or other	.99	.21	
Residency	.99	.30	
Social class	.99	.31	
Employment	.99	.98	

+ p < .05

In this analysis, the only variable which discriminated 'good' versus 'poor' copers was the sex of the carer, with males more likely to be rated as 'good' copers. Neither the carer's age, nor whether she or he was a spouse or not discriminated the 'good' copers. Similarly, good coping was not determined by

social class, employment status or whether or not the carer and dependant were co-resident.

Table 11.8

Discriminant analysis of the interviewer rating of coping with dependants' variables.

	Wilks'	
<u>Variable</u>	<u>Lambda</u>	<u>F-value</u>
Dependants' age	.99	.67
Dependants' sex	.99	.78
CAPE	.99	.17
Hospital admissions	.99	.35
Medication	.99	.37

None of the dependants' variables significantly discriminated between 'good' and 'poor' copers.

Table 11.9

Discriminant analysis of the interviewer rating of coping with other relevant variables.

	Wilks'	
<u>Variable</u>	<u>Lambda</u>	<u>F-value</u>
Years caring	.99	.20
View of future care	.99	.16
Prior relationship	.98	1.40
Current relationship	.88	11.65**
Carers' health	.98	1.51
Carers' health suffered	.98	2.20

** p<.001

In this analysis, the quality of the carer's current relationship with the dependant discriminated significantly between the 'good' and the 'poor' copers. The number of years caring, the quality of the prior relationship, the carer's current health rating failed to discriminate between the two groups. Similarly, whether the carer felt she would continue to care in to the future or whether she felt her

health had suffered as a result of her caring duties did not discriminate between the 'good' versus 'poor' copers.

III. DISCUSSION

This chapter presented the results of the quantitative analysis of the 'Ways of Coping Checklist' which was the main instrument of data collection on coping in this thesis.

1. The techniques used

The 'Ways of Coping Checklist' was used in an attempt to find out which coping techniques carers reported using in the fulfilment of their caring role. It was able to answer this by producing a list of the most frequently used items.

At the top of this list and the item used by the vast majority of carers (75%) was 'Maintain my pride and keep a stiff upper lip'. This could be said to typically represent the attitude of the British public and one wonders whether this item would appear so high in other nations. Similarly, the other top items were about the psychological techniques of accepting the situation, repressing feelings and generally holding back emotionally and behaviourally.

The carers also indulged in wishful thinking or often just taking one step at a time and not looking or planning ahead. With the relatively unpredictable course of dementia, it is understandable why such coping strategies were employed. How can one plan ahead when not only the course of the disease but the behaviour and symptoms it involves cannot be predicted with any degree of accuracy?

Thus the most striking fact about how carers cope is that they tend to do so in emotional, psychological ways with little practical or behavioural input. This is confirmed when one examines the list of least used items which contain many more practical solutions. Why might this be so? Why do carers favour the more emotional and passive forms of coping? It may be that this reflects the nature of dementia, and because of the very nature of the illness, there is very little that one can 'do' which would make any appreciable difference. Adjusting one's mental state to one of passive acceptance may be all that can be achieved. It is also interesting that the one practical item in the list is item 49. 'I know what has to be done, so I'm doubling my efforts to make things work' and this is the one item that was significantly associated with poorer psychological well-being.

It is also possible that those who do care in the community into the middle and latter stages of dementia tend to be a more passive group of carers who cope in more passive and emotional ways compared with those carers who institutionalise their dependant early on in the illness.

Another explanation may be that the carers have attempted the more practical solutions in the past but met with little success and they then progress on to more psychological and passive forms of coping. Certainly the qualitative data confirmed that there was some sense that the ways in which carers coped did indeed change over time.

Alternately, it may be that the carers do not use the more practical and behavioural methods because they do not know how, or have not thought to try them.

However, it is important to remember that these carers were not in the main novices but had been caring for some time, on average for between three and four years. It would therefore seem unlikely that they had not tried and tested a great many coping techniques in the course of their dependants' illness.

Or, it could be the case that individuals who get in to the caring situation in the first place are simply not 'doing' people. In a study of carers' support groups (Collins, 1983), it was found that carers were reluctant to learn and use behavioural techniques to manage their dementing relative, preferring to attend the groups for social support alone. It could of course be that this finding bears out the hypotheses Nevertheless, it is a relevant mentioned above. finding for therapists working in the area and maybe inappropriate to expect carers to behavioural strategies that they do not tend to use anyway for whatever reason.

Finally, Folkman and Lazarus (1985) noted that effective coping was about knowing when to appraise a situation as uncontrollable and abandon directed at altering that situation and turn instead to emotion-focused processes in order to tolerate or accept the situation. It could be argued that caring with а dependant dementia is indeed uncontrollable situation and hence emotion-focused coping is more effective.

2. The range of techniques used

There was a significant relationship between the range of techniques used and wellbeing such that the wider or greater the range, the poorer the carers' psychological wellbeing. It could be that using a wide range is not helpful to the carer and perhaps a narrower and more consistent repertoire helps the carer feel better. As the direction of causality is not known, it could of course be that carers who are already highly distressed use more and more coping techniques as they strive to cope with the demands of the situation.

3. The Factor Analysis of the Ways of Coping Checklist

As previously mentioned, it had been hoped that the Factor Analysis would yield easily interpretable and concise factors which would forward our understanding of carer coping. In particular it was hoped that the factors would form sensible groupings which could have been correlated with some of the other variables, especially carer well-being and outcome, and produce prescription for 'good' and 'poor' techniques. Unfortunately, this was not the case. As factors they remained cumbersome and difficult to They did not make sense from a psychological point of view and it was therefore impossible to communicate about them in any meaningful way. factor analyses had limited power to indicate stable inter-individual dimensions of coping style.

The reader will recall that the 'Ways of Coping Checklist' as a measure of coping was selected above all others because it contained a fully comprehensive list of items and had been widely used on other samples. So what were the reasons as to why this measure failed to be particularly useful on this group of subjects?

Firstly, the instrument was originally designed to be used in response to a specific, identified problem situation, described in advance by the respondent. In

this research, that situation was pre-determined for all respondents as the role of caring for a dementing It may be that this situation was too diverse and variable for the purposes of the analysis. Not only between subjects but within subjects, the caring role comprises of many facets which change as the disease progresses and also from day to day or even minute to minute. Thus the caring role cannot be defined specifically and а great many varied techniques are called upon to deal with it. Perhaps then it was a futile search to try and identify specific types of coping.

Also, the questionnaire had not been used with carers previously and perhaps it was inappropriate for use with this population. Having said that, if the other points hold true, it is likely that there would have been the same problems with analysis had other scales been used. In other words, maybe coping with caring is not a quantifiable or measurable entity. It is also noteworthy that on returning to the literature again, it is clear that the factors claimed and labelled by previous researchers in fact contain dubious and sometimes contradictory items, and applied rather liberal interpretations to them.

4. The Interviewer Rating of Coping

At the end of each initial interview, a global rating of coping was made by the interviewer on a 5 point scale, ranging from 'very poor' to 'very good'. These categories were not pre-determined but reflected the interviewer's own subjective feeling about what was going on in the household in terms of the primary carers ability to cope with the caring situation.

This measure correlated significantly with all the

'good' copers were also significantly less likely to feel that their health had suffered as a result of their caring duties. It may of course be that all that had been created was another measure of carer well-being and that the interviewer had in fact, unwittingly made an accurate clinical judgement on the carers' mental state. This may indeed be the case but begs the question of what is coping? Is it not inexorably linked with our mental health?

Thus a good carer was likely to be someone who was not upset, had a rational and balanced view of the situation. This was also most probably reflected in the atmosphere in the house at the time of interview.

There was also a statistical relationship between coping and a good current relationship. Where the relationship had deteriorated or never been good, the carer was probably less accepting or at ease with the situation.

The rating also correlated significantly and negatively with the interviewer's rating of hostility and also the level of expressed emotion. Where the atmosphere was judged to be hostile and the level of EE was high, an interviewer would be less likely to leave with the impression that the situation was stable and that the carer was coping well.

It was interesting that the interviewer's rating of coping was not related to either the dependant's level of impairment or the frequency of the problem behaviours reported by the carer. In other words coping has less to do with the situation and more to do with the person giving the care. It is also of note that the carer's ability of cope is not

necessarily compromised when a certain level of impairment is reached.

5. Gender issues in coping

Another main finding from the interviewer's rating of coping was the finding that males were judged to cope better than females. Why might this be? It could be that men in fact do cope more ably with the demands of the caring situation, or it could be that in an interview situation they are more likely to give the impression of coping better and be less inclined to talk about their problems and emotional issues.

If men do in fact cope better it could be because they take a different approach to the caring situation than do females. A subjective impression the interviewer has gained in many years of talking to carers is that men do seem to be better able to remove the emotion from the caring situation and view it as an objective task. It is more likely that a man will lock his wife in the house while he goes out than a woman will lock in her dementing husband. The literature suggests that women are more natural carers and tend to develop closer kinship ties throughout their lives (Horowitz, Furthermore, biologically women are the 1981). natural carers of children in the embryonic stage and traditionally for most of the child's life. this makes it all much more difficult for a woman to see the caring in terms of a task and to somehow withdraw her emotional involvement. Also, majority of women have experience of caring for children throughout the child's development and during short-term physical illnesses. However, in this sort of caring there are innate rewards in watching the development and maturation of a healthy child, or the recovery from a short illness. Running in parallel to this is usually a relationship which is mutually rewarding to both mother and child. By way of contrast, in dementia there is no progress or recovery and rather than the development of a relationship, there is the disintegration and deterioration of the relationship. This experience runs counter to all the woman's previous experiences throughout her life as a carer.

The men of the older generation, represented in this sample were less exposed to the experiences of caring either in child rearing or in the nursing physically ill relatives. It may be that owing to this lack of experience, finding himself in a caring role for the first time, he does not have expectations to be cast aside and will take the situation at face He may also see it as quite appropriate to take over the running of the house and maintain his position as the dominant partner. All this may happen at a more subconscious level for the woman and she may not be aware that she is in fact viewing the dementing situation in the same way as previous caring roles, with an expectation of innate satisfaction and reward, accompanied by recovery and return to the status quo. If this is the case, then it is understandable why women cope less well and are more emotionally distressed by the whole process.

IV. SUMMARY

After a considerable amount of analysis, it seems as though very little has been achieved in terms of furthering our understanding of what constitutes 'good' versus 'poor' coping. This research has established what carers tend to do in terms of coping but whether or not such techniques are helpful for the carers' own well being is less clear.

The concept of coping appears to have defied quantification and measurement. This may have to do with the sheer diversity of techniques required to cope with a dementing illness.

CHAPTER TWELVE

RESULTS AND DISCUSSION OF THE PATIENT REJECTION SCALE AND OTHER EXPRESSED EMOTION MEASURES

I. INTRODUCTION

The previous chapter explored the concept of coping within the sample of carers. It was suggested that one intervening variable in terms of how well a carer copes could be explained by the concept of expressed emotion. The literature in recent years has pointed towards EE as a relevant variable, suggesting that those families in which there is a high level of EE are also the families where the carers are coping less well (Kuipers and Bebbington, 1988).

This chapter examines the evidence for the relevance of the concept within this group of carers. It also tests hypotheses which examine the relationship between EE and coping, the carers' wellbeing, and the professional and social services.

II. RESULTS

1. <u>Does the concept of expressed emotion have</u> relevance for carers of the dementing elderly?

i) The Patient Rejection Scale

The Patient Rejection Scale was the main measure of Expressed Emotion in this study. The Patient Rejection Scale scores ranged from 32 to 113 with a mean of 67.4 (sd 18.20). Thus if we accept the

evidence from previous studies that the PRS is a valid alternative to measure the concept, then we can conclude that there is sufficient range in scores.

ii) Inter-rater reliability of the EE ratings

In addition to the formal questionnaire, there were also interviewer ratings made after the interview, along the dimensions of the CFI. In addition to the investigator's own ratings of EE, an independent rater (G.M) was given a brief training by the investigator about the nature of EE and in particular the critical comments dimension. This particular component was focused on as it has been demonstrated in the literature to be the most salient component of EE (Brown et al. 1972).

Forty-eight tape recorded interviews were then selected randomly to be rated on the critical comments dimension by the independent rater. Of the 48, 14 were not sufficiently clear recordings to allow accurate ratings to be made. Of the remaining 34, there was a significant correlation (r=.50, p<.01) between the two raters on the critical comments rating, thus indicating a moderate relationship between the two raters on this dimension.

iii) Relationships between the EE dimensions

The interviewer's rating of critical comments correltated significantly with the other important dimensions of EE and the interviewer rating of coping as shown in Table 12.1.

Table 12.1

Correlation coefficients (Pearson's r) between the interviewer's rating of critical comments and other EE measures.

Emotional

Over

Involvment Warmth Hostility PRS Coping

Critical

<u>Comments</u> -.250 -.446** .758** .582** -.164

** p<.001

As the PRS was the main measure of EE in this study, this measure was then correlated with the interviewer's ratings as shown in Table 12.2 below.

Table 12.2

Correlation coefficients (Pearson's r) between the Patient Rejection Scale and the Interviewer ratings of EE.

Emotional

Critical Over

Comments Involvment Warmth Hostility Coping

PRS .582** -.319* -.568** .704** -.297*

*p<.01 **p<.001

The Patient Rejection Scale correlated well with all the measures of EE as rated by the interviewer. Bearing in mind that these ratings were made in accordance with the instructions from The Camberwell Family Interview, albeit without the formal training, it was heartening to find the substantial correlations.

The one slightly surprising finding was the negative correlation with Emotional Over-involvement.

Traditionally, this is considered an important component of EE and should correlate in a positive direction. This anomalous result may reflect a problem with the Patient Rejection Scale in picking this up. Alternately, it could be a problem in the EE concept in incorporating this element in to what is essentially a negative concept. Orford (1987) has argued that this is an inappropriate part of the concept given the nature of the caring duties in dementia, the increasing demands made upon the carer and the inevitable taking over of self-care.

So far, there would appear to be good evidence that the concept has some relevance among carers of the dementing elderly. However, it may be that EE is in fact not a complex phenomenon in its own right but just a measure of anger or frustration which is a consequence of poor coping and which is associated with poor relationships. The following sections will address these questions, primarily by looking at the correlations between the PRS score and other variables.

2. How does EE relate to coping?

The hypothesis that high EE was associated with poor coping skills was tested. There was a significant and negative correlation between the PRS score and the interviewer's rating of coping (r=-.258, p<.01) and this would confirm the hypothesis that there is a relationship between high EE and poor coping.

3. How does EE relate to carer well-being?

The hypothesis that high EE would be associated with poorer carer well-being was tested. The PRS score

was correlated with various measures of carer wellbeing and the results are shown in Table 12.2 below.

<u>Table 12.3</u>

Correlation coefficients (Pearson's r) between the Patient Rejection Scale and carer well-being.

	Carers'				Locus	Carers'	
	<u>yde</u>	<u>GHO</u>	Zung	<u>BDI</u>	Control		
PRS	380**	.270**	.232*	.278**	.097	080	

* p<.01 ** p<.001

The age of the carer was significantly related to the Patient Rejection Scale, in a negative direction, such that the younger the carer, the higher her score on Patient Rejection Scale. There were also the significant relationships between the Patient Rejection Scale score and her psychological well-being as measured by the GHQ, the Zung Anxiety Scale and the Beck Depression Inventory, such that higher scores on these measures were associated with a high score on the Patient Rejection Scale. There was no significant association between this measure and the carer's Locus of Control or her own rating of her general health. There was also no relationship between the Kutner Morale Scale and the PRS score.

4. What other variables does EE relate to?

In order to explore the concept further, the PRS score was correlated with other relevant variables. In particular, was it related to anything about the dependant? Neither the age of the dependant, nor his or her level of impairment, nor the number of dementia related hospital admissions, nor the number of problem behaviours described by the carer, related to the carer's score on the Patient Rejection Scale. The

number of years spent caring was also unrelated but the hours of face to face contact between the pair was related to EE in a negative direction (r=-.314, p<.01). In other words, the fewer the hours of contact in the week, the higher the score on the Patient Rejection Scale.

When other variables were correlated with the PRS neither the carers' social class nor the number of outings either together or alone were related to the PRS score. However, the number of visits made to the carer's home was significantly related (r=-.318, p<.001) such that the fewer the visits, both professional and social to the carer's home, the higher the score on PRS scale.

The other main relationship with EE was with the quality of the carer/dependant relationship both current (r=-.607, p<.001) and pre-morbid (r=-.481, p<.001). In other words, the poorer the quality of the carer/dependant relationship, the higher the level of EE.

5. Further analysis of EE

In order to clarify the nature of the EE concept, a stepwise regression was undertaken to try and determine the best predictors of the Patient Rejection Scale. All the variables correlating at p<.001 were entered in to the equation. The results are shown in the Table 12.3 below.

Table 12.3 Stepwise multiple regression analysis - predictors of the Patient Rejection Scale.

	Adjusted R2	<u>Beta</u>	F-value	
Variable entered on Step Number 1. Interviewer rating of Hostility	.49	.71	70.69***	
Variable entered on Step Number 2. Current relationship	.58	35	50.89***	
Variable entered on Step Number 3. GHQ	.61	.20	39.32***	
Variable entered on Step Number 4. Visits to carers' home	.63	15	32.00***	
*** p<.0001				

*** p<.0001

The interviewer's rating of Hostility was found to be the best predictor of the Patient Rejection Scale. At step 2, the carer's rating of the quality of the current relationship emerged. The GHQ and the number of visits to the carer's home over the previous week also play an important part in predicting the Patient Rejection Scale score.

Analyses of Variance were then carried out for the Patient Rejection Scale with other dichotomous variables, namely residency and whether or not the carer and dependant were spouses. Results showed that there was a significant relationship between residency and the PRS (r=8.52, p<.01) and also whether or not the pair were spouses (r=14.75, p<.001). Thus those carers who were resident with their dependant had lower levels of EE. Similarly, spouse carers also had lower EE compared with non-spouse carers.

6. What features distinguish 'high' from 'low' EE carers?

In an attempt to discriminate between 'high' and 'low' EE carers, the Patient Rejection Scale scores were split at the median for the sample. Those scoring above the median score of 64 were put in the 'high' category, those scoring below the median were put in the 'low' category. A Discriminant Analysis was then undertaken to identify variables which would differentiate between the two groups. The results are shown in Table 12.4 below.

Table 12.4

Discriminant analysis of the Patient Rejection Scale with carer and dependant variables.

	Wilks'	
<u>Variable</u>	<u>Lambda</u>	<u>F-value</u>
Carers' age	.89	10.67*
Carers' sex	.95	4.46+
Residency	.98	1.96
Dependants'age	.99	.87
Dependants'sex	.99	.18
Years caring	1.00	.36
Prior relationship	.86	14.31**
Current relationship	.77	24.90***
Carers' health	.99	.67

+p<.05 *p<.01 **p<.001 ***p<.0001

Several of the variables discriminated significantly between 'high' and 'low' EE carers. The carer's age was one discriminating factor, in that the 'high' EE carers were significantly younger than the 'low' EE carers (55.7 years as against 64.6 years). The sex of the carer discriminated significantly at the .05 level with females more likely to be 'high' EE carers. The quality of both the pre-morbid and the current relationship also differentiated between the 'high' and 'low' EE carers with those reporting a better

relationship more likely to be in the 'low' category.

Other variables which were entered into the discriminant analysis but failed to show a significant relationship were whether the dependant attended Day Hospital or not, how the carer viewed the future in terms of care and whether or not she believed that her health had suffered through her caring duties.

7. How do the professional and social services relate to EE?

The hyothesis that the amount of professional and social support are associated with EE was tested. could be that professional or social support to the carer or dependant has the beneficial effect of reducing the anger and frustration felt by the carer. Alternately, it could be that those carers who demonstrate an already high level of frustration and are assigned a higher level of anger The level of contact with each formal provision. service was combined to produce a 'Professional Care This was the sum of the frequency of Index' (PCI). visits from the GP, Psychiatrist, Social Worker, District Nurse or Health Visitor, CPN, Home-Help, Voluntary Service visitor or 'other'. Each service was scored as 0, 1, 2, or 3 depending on the frequency of the visits. In addition there was an additional score of 0 or 1 for attendance at a Day Hospital or Day Centre. Scores ranged from 1 to 14 with a mean score of 5.9 (sd. 3.1).

The PCI was then correlated with the PRS score (r=-.220, ns); the relationship was not significant, thus the professional support received could not be described as an intervening variable. However, it

should be noted, that the level of professional support was generally low and thus as an independent variable did not vary very much, making significant findings hard to obtain.

level of social support? What about the To investigate this further, the number of visits to the carer's home was correlated with various measures of It should be noted that the number of visits included professional as well as social visits to the carer and so it is not strictly a social support variable. However, it could be argued that all visits provide some form of social contact. This contact variable correlated with the PRS score (r=-.296, p<.01), emotional over-involvement (r=.360, p<.001) and warmth (r=.335, p<.01). It is interesting that there are non-significant negative correlations with the more negative dimensions of EE, namely hostility and critical comments. Thus where the level of EE is high and the atmosphere is hostile and negative, the carer sees fewer visitors to her home. It could be that visitors are more reluctant to call because of the atmosphere or it could be that because they don't call that the carer's level of EE rises.

III. DISCUSSION

The concept of EE was explored in this study using the Patient Rejection Scale as the main measure. The results from this gave a mean score comparable to that obtained in a study of relatives of schizophrenics which also confirmed the PRS as a reliable research tool (McReadie and Robson, 1987). It was also encouraging that the PRS scores correlated highly with the interviewer ratings of EE which were adapted from the Camberwell Family Interview. The exception, was

the rating of Emotional Over-involvement and the most likely reason for this is that it is not a relevant component part in the carers of the dementing elderly because of the very demanding nature of the dementing illness and the inevitable and increasing dependency of the disease. It is also traditionally more often found in studies of parents with children and therefore would be again irrelevant in this study.

Expressed emotion, as measured by the PRS score correlated highly with the measures of carer well-being but with the exception of the Kutner Morale Scale. Thus, high EE carers have poorer mental health. Similarly, in a study using the PRS, Freire et al (1982) found a significant relationship between the PRS and the carers' psychopathology. Is EE just another measure of carer well-being?

Female carers were also found to have higher levels of EE and if as suggested, EE may be little more than another measure of well-being, then this finding was to be expected. Thus it could be part of the same phenomenon that compared to female carers, male carers seem to be less likely to divulge their difficulties and worries to the interviewer. Alternately, male carers may indeed feel less angry and hostile and therefore be less likely to express this in the interview. Sex differences have not been reported in other EE studies.

As with most of the previous EE studies, the PRS score was not related to the dependant's psychopathology, or in this case the level of impairment or frequency of problem behaviours. Thus the EE concept pertains primarily to the carer and not the dependant.

Unlike other studies, the hours of face to face

contact was correlated to the PRS score but in a negative direction. Given the literature, one would have expected the correlation to be significant but in a positive direction. What may have been happening the effect of confounding variables with here was Non-resident carers showed significantly residency. higher levels of EE than did co-resident carers. the case that if the carer:dependant relationship is poor and EE is high, the carer may see it as intolerable that her dependant might move in with her. Another possibility is that kinship is the confounding variable, in that spouse carers showed significantly lower levels of EE than non-spouse Spouses would also be more likely to spend a greater number of hours in face to face contact in the week compared with other relatives. It is also understandable that the spouses were more accepting and willing carers compared with children, siblings or even more distant nephews and nieces. Few previous studies have examined kin difference in much detail, preferring to concentrate on one group. Furthermore, in dementia, of course, there is not an equivalent situation of a parent caring for an adult child.

EE and the Quality of the Carer: Dependant Relationship

The other main finding from this study was the relationship between EE and the quality of both the current and pre-morbid carer:dependant relationship. If a carer feels and exhibits hostility to her dependant it is likely that it is to some extent an indication that the current relationship between them is poor. Also, perhaps the hostility would be more inclined to be expressed without explanation or reserve if the relationship had always been poor.

EE and Coping

The schizophrenic literature has also shown that high EE families cope less well (Kuipers and Bebbington, 1988) and indeed in this study the PRS score correlated with a poorer level of coping as rated by the interviewer. Expressions of anger, hostility and a poor relationship are going to lead the interviewer to view the carers' coping skills as poor or weak. This of course raises a further question as to whether EE is just another measure of coping.

Is EE an appropriate concept for dementia?

In the schizophrenic studies, high EE is correlated with relapse of symptoms in the dependant. Clearly in dementia, relapse of symptoms is inappropriate. However, if high EE exacerbates the family situation and perhaps distresses the dependant then this may lead to an increase in disturbing behaviour in the dementing dependant which would in turn perhaps lead to the carer herself feeling unable to continue caring. Hence there could conceivably be and increased rate of institutionalisation among high EE carers.

However, it could be argued that this is not an analogous situation since outcome is an external event which may be governed by factors outwith the power or control of the carer or her dependant. We have already seen that outcome is unrelated to carer wellbeing or dependant impairment, and thus it may be inappropriate as an outcome measure for EE. In retrospect, it would have been better to compare dependant symptoms at one year as a more analogous situation to relapse.

What is this concept EE?

What then is this concept called 'Expressed Emotion'? Have we identified anything more than a measure of anger and resentment that is more likely in non-spouse and younger carers who do not live with their dependant? Did any of the previous studies tap on any other dimension than the hostility and anger which for many is an inevitable part of the caring process?

Or is it just another way of measuring the quality of the pre-morbid and current relationship between the carer and her relative? There is a clear and simple link between the quality of the relationship and the expression and feeling of anger and hostility about the caring role.

Alternately, is it another measure of coping? Those who express little anger and therefore could be said to be more accepting of their caring role may in fact also cope more ably. Again the link is clear and easy to make sense of.

Similarly, the correlations with carer well-being are understandable and it could be argued that EE is just tapping in to another measure of the carer's psychological state.

When one returns to the EE literature in the light of this study, it becomes apparent that these questions have not been asked. Perhaps they now should be in order to clarify the exact nature of the EE phenomenon.

IV. SUMMARY

This chapter looked at the evidence for the EE

phenomenon in this group of carers. If one accepts the existence of the concept in its own right then it seems to be linked with coping, carer well-being and the quality of the carer/dependant relationship. However, the chapter also raised some fundamental questions about the exact nature of the concept and whether indeed it is anything more than a measure of anger and hostility in the carer which inevitably relates to other variables. As to whether or not EE has predictive validity in terms of outcome, this will examined in the next chapter.

CHAPTER THIRTEEN

ONE YEAR ON - OUTCOME, PREDICTORS AND ATTITUDES

I. INTRODUCTION

The reader will recall that one year after the initial interview, all carers were followed up; the pilot sample was re-interviewed and the main sample followed-up by postal questionnaire. This allowed the investigator the opportunity to not only examine outcome at a year but also to relate this to possible relevant variables and in particular to coping and EE.

The results are presented in three sections. Section one looks at the association between carer well-being and outcome. Section two looks at the predictors of breakdown of care and specifically tests the hypotheses that coping and EE are predictors of whether or not care breaks down. In section three, information on attitudes to caring and coping at one year follow-up is presented.

II. RESULTS

1. Outcome and the relationship with well-being

i) Placement of dependants at one year

Table 13.1 shows the whereabouts of the dependants one year after the initial interview. This data was gathered from medical records.

	<u>n</u>	
Community	39	
Residential care	6	
Longterm NHS care	25	
Private nursing home	7	
Died	23	

Thirty-nine of the sample were still in the community one year after the initial interview. Thirty-eight had moved into institutional care of some kind and 23 had died. Of those who had died, 14 had died in an institution, 2 had died in the community and for the remaining 7, the place of death was unknown. On average, the dependants had died 7 months after the initial interview.

ii) Follow-up GHO Scores

The mean GHQ score at one year follow up for the 78 carers who completed and returned them was 4.58 (sd 5.07) with a range from 0 to 22. Forty-one percent scored \geq 5 indicating psychiatric morbidity. This compares with a mean of 4.20 (sd 5.51) for the initial measure although there is a 10% increase on the percentage of the sample who scored \geq 5. More detailed analysis of the changes in the GHQ scores, are shown in Table 13.2 below.

Table 13.2

Differences in GHQ scores over the one year period t-tests for various outcome groups.

m- 1 1	n	<u>Initial score</u>	1 yr score	<u>t</u>	
Total		2 01	4 20	0.2	
GHQ	76	3.91	4.38	.82	
Commun	_	2 22	5 10	0 104	
GHQ	33	3.00	5.12	3.13*	
<u>Instit</u>	<u>utional</u>	ized			
GHQ	31	5.16	3.58	1.48	
Died					
GHQ	12	3.17	4.42	1.31	
4					

*p<.01

Looking at the sample as a whole, there is no change in mean GHQ scores over the one year period. However, if the sample is broken down in to outcome groups, differences over time start to emerge. For the carers who are still caring for their dependant in the community, there is a rise in the mean GHQ score which is significant at the .01 level. For those carers whose dependants have been institutionalized, there is a decrease in the mean GHQ level although this fails to reach significance. For those whose dependants have died, there is a slight rise in the mean GHQ level but this is not significant.

iii) Changes in GHO over time

In order to test whether institutionalisation has any real effect on GHQ, the data was re-analyzed for the dependants who were still alive at one year according to whether or not care had broken down using a repeat measures ANOVA. The results are presented in Table 13.3 below.

Table 13.3

Change in GHQ as a result of carer circumstances at one year, where the dependant is still alive - repeat measures ANOVA.

Initial GHO Follow-up GHO

No Breakdown of care

3.0(sd.5.3) 5.1(sd.5.2)

(n=33)

Breakdown of care

5.2(sd.6.1) 3.6(sd.4.3)

(n=31)

1) There was no overall difference in GHQ scores between the two groups :-

$$ss = 3.08$$
, $df = 1$, $F=.07$, ns

2) There was no overall difference in GHQ scores
across time :-

$$ss = 2.34$$
, $df = 1$, $F = 0.19$, ns

3) There was a significant interaction between outcome and time:-

Thus it can be concluded that where care breaks down and the dependant is institutionalised, there is a significant reduction in the carers' emotional distress. Where care does not break down and the carer continues to care in the community, there is a significant increase in the carers' emotional distress.

In the light of this finding, it would be reasonable to proceed and use this outcome criteria to test the effectiveness of coping or as a 'warning' sign of high EE.

2. EE and Coping as Predictors of Outcome

i) Expressed Emotion

As was discussed in previous chapters, one of the most critical factors of EE is its potential to predict outcome. In the schizophrenia literature, high EE predicts outcome. It was thought that if this was a useful concept in the area of the dementing elderly, then it would perhaps have a predictive value in terms of outcome at one year.

For this analysis, the deceased group was recoded depending upon the place of death, namely whether care had broken down prior to death or whether they had died in the community. Where this was not known, they were omitted from the analysis. The results are shown in Table 13.3.

Table 13.3

T-tests for PRS mean scores by outcome, comparing situations where there had been a breakdown of care with situations where there had been no breakdown of care over the one year period.

	No Breakdown of care(n=39)	Breakdown of care(n=51)	t
Patient Rejection Scale	66.13	67.45	34ns

There was no significant difference between the initial PRS scores and outcome; thus, EE failed to have predictive validity and the hypothesis was rejected.

ii) Coping

In order to determine whether an initial measure of coping would be predictive of outcome at one year, the interviewer rating of coping by outcome was examined. The results are shown in Table 13.4.

Table 13.4

T-tests of mean coping score by outcome, where coping was rated by the interviewer on a 5 point scale and 1='very poor' and 5='very good'. Comparing situations where there had been a breakdown of care with situations where there had been no breakdown of care over a one-year period.

	No breakdown care(n=41)	Breakdown of care		 t
Interviewer Coping	3.32	3.20	. 541	ns

There were no significant differences between the groups by outcome in terms of the initial coping measure, thus, coping failed to be predictive of outcome.

iii) Other Initial Measures by Outcome Group

In order to try and determine some of the other early measures that perhaps related to outcome, further t-tests were carried out. All the major carer and dependant variables were analyzed in order to try and determine those variables present at the first interview that were related to outcome. For this analysis the deceased dependants were again reclassified according to whether care had broken down prior to death or not. The variables examined were the Kutner Morale, Zung anxiety, Beck Depression

Inventory, Locus of Control, Hours of Contact, Prior Relationship, Current Relationship, Carers' Health, Years caring, Carers' age, Dependants' age and the CAPE. None of them were significant.

Crosstabulations were then undertaken for various dichotomous variables. The results of this are shown in Table 13.5 below.

Table 13.5

Crosstabulations of outcome with other variables.

Variables by Outcome	Chi-squ.	<u>DF</u>
Residency	3.56+	1
Carers' Sex	.04	1
Carers' Marital Status	1.89	4
Relationship	7.21	7
Dependants' Sex	.02	1
Future Care	4.40	4

+ p = .059

While none of the variables were significant, Residency approached significance. For those still remaining in the community, 78% were co-resident and 22% were non-resident with their carer. For those where care had broken down within the year, 60% were co-resident and 40% were non-resident.

Neither the sex of the carer nor the sex of the dependant made a significant difference to outcome. Similarly, the carer's marital status and her relationship to the dependant were not significant.

3. Further follow-up data

All carers were sent postal questionnaires at one year. Those carers whose dependants were still alive (n=77) were asked to rate the situation, their health, their ability to cope and their feelings towards their

relative and the care situation.

i) How did the carers rate their situation now compared with a year ago?

At one year follow-up, all carers whose relatives were still alive were asked to rate their current situation compared with a year previously. The results are shown below in Table 13.6 and have been differentiated for those still caring for their dependant in the community and those whose relative had moved in to institutional care of some kind.

Table 13.6

Carers' rating of the situation at follow-up compared with a year ago - t-test analysis on group mean scores.

<u>Item</u>	Community	<u>Institution</u>
	n=24	n=26
Much better	0 (0%)	11 (42%)
Better	1 (4%)	12 (46%)
Same	9 (37%)	1 (4%)
Worse	13 (54%)	2 (8%)
Much worse	1 (4%)	0 (0%)

t = 8.32, p<.0001

There was a significant difference between the two groups in that the majority of the carers who were still caring for their relative in the community rated their situation to be either the same or worse than a year ago. By way of contrast, the majority of those carers whose relative was now in institutional care rated their situation to be better or much better.

ii) How were carers coping compared with a year ago?

Related to this, all carers were asked specifically to

rate how they felt they were coping compared with a year ago. For this analysis and some of the others to follow in this section, the sub-group whose dependants had died by one year remained in the sample and analysed as a group in their own right. This was done as it was felt important to recognise the potential effect of bereavement upon the carer's attitudes and feelings compared with other outcomes. The results are shown in Table 13.7 below.

Table 13.7

Carers' rating of coping compared with a year ago one way analysis of variance for between group means.

	Community	<u>Institution</u>	<u>Died</u>
	n=26	n=27	n=12
Much better	0 (0%)	15 (55%)	2 (17%)
Better	3 (12%)	9 (33%)	4 (33%)
Same	18 (69%)	1 (4%)	5 (42%)
Worse	5 (19%)	2 (7%)	1 (8%)
Much worse	0 (0%)	0 (0%)	0 (0%)

F=4.486, p<.01

To find out where the significant difference lay, ttests were then carried out between the groups. Significant differences were found between all groups Between 'Community' and 'Institution' as follows. (t=7.15, p<.001); and between 'Community' and 'Died' groups (t=2.34, p<.05); and between 'Institution' and 'Died' groups (t=-2.53, p<.05). The group of carers whose relative was now institutionalised stated that they were generally coping better or much better than a year ago. Even the group of carers whose relative had died were generally rating an improvement in coping. It was the group who were continuing to care in the community who noted things were the same or worse than the previous year.

The carers were then asked to state specifically how

they were coping. This was asked of all carers at one year and the responses are shown in Table 13.8 below.

Table 13.8

How carers judged themselves to be coping at one year follow-up - one-way analysis of variance for between group means (n=64).

	<u>Community</u>	<u>Institution</u>	<u>Died</u>
	n=24	n=27	n=13
Very badly	0(%)	0(0%)	0(0%)
Badly	1(4%)	1(4%)	1(8%)
Average	16(67%)	9(33%)	6(46%)
Well	6(25%)	9(33%)	6(46%)
Very well	1(4%)	8(30%)	0(0%)

F=.859 ns

In all groups, the carers generally felt that they were coping at least average and in some cases, above average. Only 4.7% of all the carers felt that they were coping badly.

iii) The carers rate their health one year on

Several questions were asked regarding various aspects of the carers health at one year after the initial interview. Again the deceased group were included as a sub-group to look at the potential impact of bereavement. The results are shown in the Tables 13.9 to 13.11 below.

Table 13,9

How did the carers rate their physical health compared with a year ago? - one way analysis of variance for between group means (n=65).

Much better Better Same	Community n=26 0(0%) 2(8%) 16(61%)	Institution n=27 6(22%) 8(30%) 9(33%)	Died n=11 0(0%) 3(27%) 6(55%)
Same Worse	16(61%) 7(27%)	9(33%) 2(7%)	6(55%) 2(18%)
Much worse	1(4%)	2(7%) 2(7%)	0(0%)

F=.8874 ns

There was no significant difference between the groups in how they rated their physical health although more than half of the group (52%) whose relative was institutionalised rated their physical health as better or much better than the previous year. Only 8% of the carers still caring in the community rated similarly.

The carers were then asked to differentiate between their physical and psychological health and were asked to rate the latter independently.

Table 13.10

How did carers rate their psychological health compared with a year ago - one way analysis of variance for between group means (n=62).

	Community	<u>Institution</u>	<u>Died</u>
	n=25	n=26	n=11
Much better	0(0%)	6(23%)	1(9%)
Better	2(8%)	10(38%)	6(54%)
Same	21(84%)	7 (27%)	3(27%)
Worse	2(8%)	3(11%)	1(9%)
Much worse	0(0%)	0(0%)	0(0%)

F=6.739, p<.0001

In order to determine where the significant difference

or differences lay, t-tests were carried out. Significant differences were found between i) the 'Community' and 'Died' groups (t=3.16, p<.01) and ii) the 'Community' and 'Institution' groups (t=3.51, p<.01); but not between the 'Died' and 'Institution' groups (t=-.31, ns). The majority of the institutionalised group (61%) and also the group whose dependants had died (63%) rated their psychological health as better or much better than the group whose dependants were still in the community. The community group primarily rated their general health as the same as the previous year.

Finally they were asked to make a general rating about their general health and the results are shown in Table 13.11 below.

Table 13.11

How did the carers rate their general health compared with a year ago? - one-way analysis of variance for between group means (n=84).

	Community	Institution	Died
	n=35	n=33	n=14
Very poor	0(0%)	0(0%)	0(0%)
Poor	4(11%)	6(18%)	3(21%)
Average	20(57%)	11(33%)	9(64%)
Good	8(23%)	13(39%)	2(14%)
Very good	3(9%)	3(9%)	0(0%)

F=.479 ns

Almost half of the carers rated their general health as average, over a third rated it as good or very good. Again there was a trend, albeit non-significant for the institutional group to rate their general health as better than the carers in either of the other groups.

iv) How did the carers feel about their dependants one year on?

The carers whose relative was still alive were then asked a series of questions about their feelings towards their relative and in particular about their feelings of anger. The results are shown in the Tables below.

Table 13.12

How had the carers feelings towards their relative changed? (n=50).

	Community	<u>Institution</u>
	n=24	n=26
Not at all	22(92%)	20(77%)
Yes, in a +ve way	0(0%)	5(19%)
Yes, in a -ve way	1(4%)	0(0%)
Yes, unspecified	1(4%)	1(4%)

The overwhelming majority of the carers whose relative was still alive did not feel that their feelings towards them had changed over the previous year. There was some evidence that for those carers whose relative had been institutionalised, for their feelings if anything to become more positive.

Table 13.13

How angry did the carers feel towards their relative? - t-tests for between group means (n=46).

	Community	<u>Institution</u>
	n=24	n=22
Much more angry	0(0%)	1(5%)
Slightly more angry	4(17%)	0(0%)
Same	17(71%)	7(32%)
Slightly less angry	1(4%)	1(5%)
Much less angry	2(8%)	13(59%)
Slightly more angry Same Slightly less angry	4(17%) 17(71%) 1(4%)	0(0%) 7(32%) 1(5%)

t = -3.75, p<.001

In spite of stating that their feelings had not changed, when asked specifically about angry feelings

towards their relative, a majority of those who had institutionalised their relative said they felt much less angry with them now compared with a year ago. There was also a significant difference between the two groups with the majority of the community sample feeling the same as the previous year.

In terms of just how angry they felt, the results can be seen in Table 13.14 below.

Table 13.14

How angry did the carers feel towards their relative? (n=48). T-tests between the means for the 'Community' and 'Institutional' groups.

Not at all angry Slightly angry	Community n=23 9(39%) 13(56%)	Institutional n=25 24(96%) 1(4%)
	13(56%) 1(4%)	1(4%) 0(0%)
Angry Very angry	1(4%) 0(0%)	0(0%) 0(0%)

t=5.03, p<.001

Only a third of the sample admitted to any feelings of anger at all towards their relative. However there was a significant difference between the groups with the 'Community' group expressing significantly more anger than the 'Institutionalised' group.

In an attempt to differentiate between feelings of anger towards their relative as opposed to anger about the care they gave, a question was specifically asked about the care aspect. This was asked only of the group of carers who were continuing to care in the community at one year follow-up.

Table 13.15

How angry did the carers feel about the care they were giving compared with a year ago? (n=25)

	<u>n</u>	
Much more angry	0	
Slightly more angry		(16%)
Same	18	(72%)
Slightly less angry	2	(8%)
Much less angry	1	(4%)

Only 4 carers rated that they felt more angry, 3 rated

that they felt less angry; 18 rated their anger about the care they give as the same. What this meant in terms of exactly how angry they were is shown in Table 13.16 below.

Table 13.16

How angry were the carers about the care they were giving? (n=24).

Not at all angry Slightly angry	n 13 (54.2%) 11 (45.8%)
Angry Very angry	0

Regarding the ongoing care they were giving, just over half said they were not angry at all; 45.8% admitted that they were slightly angry.

v) What words described the carers feelings towards their dependant?

For all carers whose dependant was still alive, they were asked to read through a list of adjectives and mark those that best described their feelings towards their relative. This list was devised by the investigator but was not piloted in the initial phase of the study. Fifty-one carers completed this section, and their responses are illustrated in Table

13.17 below.

Table 13.17

Adjectives marked by the carer to describe her feelings towards her dependant - chi-squared tests for differences between the community group and the institutionalised group.

<u>Adjective</u> Loving	Community 13	Institution
Sad	13	14 18
Guilty	5	10
Critical	0	0
Annoyed	3	1
Devoted	5	7
Affectionate	5	12
Irritated	7	0 *
Hostile	0	0
Warm	3	11 +
Provoked	0	0
Caring	17	14
Negative	1	0
Friendly	4	11
Hatred	0	0
Positive	0	1
Angry	1	0
Fond	2	10 +
Infuriated	1	0
Protective	10	10
Exasperated	8	1 *
Resentful	2	0

* p<.01 + p<.05

This adjective checklist was not tested out on a pilot sample and so caution should be exercised when looking at the results. In the main, the carers described their feelings as loving and caring with a strong element of sadness. They also felt protective and affectionate towards their dependant but there was also a tendency towards feeling guilty. In general, they did not endorse the negative adjectives regarding their feelings.

There were however significant differences between the community group and the institutionalised group on four adjectives. The community group checked

significantly more often on the adjectives 'irritated' and 'exasperated'. The institutionalised group checked significantly more often on the adjectives 'warm' and 'fond'.

vii) Changes in the amount of help received

For the group who were still caring for their relative in the community, questions were asked about changes in the help received by family and professional services. The results are shown in the tables below.

Table 13.18

Had there been changes in the amount of help the other family members were providing? (n=31)

 Much more
 1 (3.2%)

 More
 5 (16.1%)

 Same
 23 (74.2%)

 Less
 1 (3.2%)

 Much less
 1 (3.2%)

In general, for those carers who were still caring for their dependant in the community, there was no change in the amount of family help they were receiving after one year.

Table 13.19

Had there been any change in the amount of help received from the professional services? (n=31).

	n
re 4	(12.9%)
15	(48.4%)
11	(35.5%)
1	(3.2%)
ss 0	•
	15 11 1

It is encouraging to note that for this sample of carers who were continuing to look after their dependant at home, that 61.3% stated that they were now getting more help from the professional services compared with a year ago.

viii) Community carers view of the future

The community carers were then asked to make a judgement about the care of their relative in the future. The results are shown in Table 13.20 below.

Table 13.20

What did the carers think would happen regarding the future care of their dependant? (n=35).

	<u>n</u>
LTC (NHS or Private)	12 (34.3%)
Residential Care	4 (11.4%)
Live with other relative	2 (5.7%)
Continue to care	17 (48.6%)

One year on, almost half the carers are stating that

community

indefinitely. Forty-five percent are accepting the notion of institutional care of some description.

will continue caring in the

III. DISCUSSION

they

In terms of outcome at one year, the results in this study very much reflected the 40:40:20 rule referred to in the literature (Knopman et al.1988) which shows that at 18 month follow-up of a community sample, forty will still be in the community, forty will have moved into institutional care and twenty will have died.

Similarly, the changes in the GHQ scores by outcome group also reflect what has previously been found in the literature (Gilleard et al 1984), namely that

institutional care is good for the carers' well-being and continued care in the community is not. This was also backed up by the carers' own views on how they were coping and their feelings towards their relative.

It was disappointing that EE failed to predict outcome at one year. In the design of the study, it had been considered that high levels of EE might be related to institutionalisation at one year.

Similarly, it would have been interesting if some initial measure of coping had been predictive of outcome at one year. One could have hypothesised that the 'good' copers would still be continuing to care in the community while those thought to be 'poor' copers would have institutionalised their dependants. Clearly, the process of institutionalisation is not clear cut.

It was somewhat surprising to find that none of the initial carer variables were related to outcome one year on. Outcome at one year was unrelated to the severity of dementia, the emotional or physical health of the carer, ability to cope or level of expressed emotion. Likewise the level of community service provision did nothing to either hasten or delay institutionalisation.

So how is the decision made? When a key member of staff decides that the time is right? Or when a carer for some other reason decides that enough is enough?

V. SUMMARY

This chapter looked at the results of the follow-up study one year after the initial interview. Results showed that this sample of dependants were much like others in terms of outcome and the carers too were similar in terms of the impact that outcome had on them. None of the variables studied proved to be accurate predictors of outcome and the decision to institutionalise seems to lie outwith the realms of this study.

CHAPTER FOURTEEN

FINAL DISCUSSION - RESULTS, METHODOLOGICAL ISSUES AND RECOMMENDATIONS

I. INTRODUCTION

All the previous chapters in the results section of this thesis contained a discussion of the results. Thus, in this final chapter only a brief overview and final discussion of the results will be given. This chapter will also concern itself with some of the methodological issues arising from this thesis and will conclude with some recommendations for both future research and clinical practice in the area.

II. SUMMARY OF RESULTS

The demographic details of the carers in this study demonstrate that as a sample they were very much like other groups of carers studied in previous research. The majority were female, in late middle-age, and from the lower social classes. Similarly, their dependants were predominantly female with marked impairment and maximally dependent upon their carer. Likewise, when professional and social networks were examined it was found that regardless of residency, the majority were not receiving community services. The home-help service was the exception, approximately half of the non-resident dependants being visited by a home-help at least once per week. These demographic similarities mean that the sample were representative of carers and thus the findings may be generalised to other carers with

confidence.

The primary aim of this study was to identify the coping techniques used by these carers dementing elderly. This was done by first identifying the specific stressful situations which the carers were having to cope with on a day to day basis and then examining the coping techniques used in dealing with them. A simple qualitative analysis identified four types of stressful situation, inappropriate behaviour as a consequence disorientation, refusal to cooperate with caregiving activities, incorrect interpretation of people or events, and provocative or hurtful comments. The most frequently cited stressful situations were those which fell into the category of 'Inappropriate behaviour as a result of disorientation'. It is these situations that so characterise dementia and distinguish it from other diseases.

The carers coped with these situations in three main ways, namely be verbal action, practical action and withdrawal. The most frequently cited coping techniques were those primarily employing 'verbal action', usually of a calming or persuasive nature. This perhaps represents the carer's continuing efforts to make normal the situation and ease the potential frustration.

Running parallel to this was a theme of anger which reflected the high levels of hostility and frustration in many carers, and should perhaps be considered as evidence of high EE. There was also some evidence of changing coping techniques over time. This qualitative information was for the purposes of 'setting the scene' and statistical analysis was not undertaken.

The main measure of coping for the purposes of by The Ways of Coping Checklist. analysis was Analysis of this scale identified that carers more often used passive and emotional types of coping as opposed to more active and practical techniques. Only one item from this list correlated significantly with well-being. Item 49. 'I know what has to be done, so I am doubling my efforts to make things work' a significant and positive association with the score on the Beck Depression Inventory and the Zung Anxiety Scale. Thus, using this technique was associated with psychological distress. Further analysis of checklist became complicated and the Factor Analysis was difficult to interpret. Thus it was not possible identify adaptive versus maladaptive techniques. However, this in itself was interesting and perhaps confirms the diverse nature dementing process. It may be that it is just too complex and constantly changing that it becomes difficult to quantify in a meaningful way.

A third measure of coping was by a simple rating by the investigator, post-interview. Analysis of this found male carers to be judged as better copers than female carers. Good copers also suffered less emotional distress and generally rated themselves to be in better health compared with those judged by the investigator to be poor copers.

The range of coping techniques used was found to be important in determining the carers' psychological well-being. Carers who reported using a wider range of techniques suffered poorer psychological well-being compared with those who reported using a narrower range.

Furthermore, using these measures of coping it was not possible to predict outcome at one year. Perhaps this is because the decision to institutionalise is a particularly complex one and can not be simply determined by how well the carer is thought to be coping.

The second strand of this thesis was to investigate the concept of expressed emotion among the carers and to link it with coping. The Patient Rejection Scale was the main measure of EE used in this study. Using this and the investigator's own ratings of the concept, it did seem to be measurable amongst this group of carers although it did not have predictive value for outcome at one year. It was also found that younger carers and non-spouses had higher levels of EE compared with older carers and spouses.

The study also set out to examine the impact of EE on carer well-being. High EE was related to poor psychological well-being and poorer quality relationships both prior to the onset of dementia and currently as rated by the carer. Females and non-resident carers also reported higher levels than males and resident carers.

However, as EE was unrelated to outcome and therefore cannot be used as a risk indicator in dementia as it may be for other dependency groups. Nevertheless, it raises many more fascinating questions about the exact nature of this concept.

Finally, the outcome data showed that at one year follow-up, the sample remained representative with 39% of the dependants still being cared for in the community, 38% of the dependants had moved into care and 23% had died. Also, where care broke down and the

dependant was institutionalised, there was a significant reduction in the carer's level of emotional distress. Where care did not break down there was a significant increase in the carer's level of emotional distress.

III. DISCUSSION OF METHODOLOGICAL ISSUES

Several methodological issues emerged in this study which warrant further discussion, namely, the representativeness of the sample, the measures of coping and the use of the Patient Rejection Scale as a measure of expressed emotion.

1. How representative was the sample?

In a recent critique of the caregiving literature, Barer and Johnson (1990) noted that most samples select their subjects from self-help groups, community agencies and other formal sources and this brings in to doubt the representativeness of the samples. Thus they claim that little is known about the "myriad of informal caregivers" who do not have contact with the services or even informal institutions.

The investigator was aware from the outset of this difficulty and endeavoured to overcome it. The primary drawback was that the criterion for acceptance in the study was a medical diagnosis of an organic dementia on behalf of the dependant and thus all dependants had been seen at least once by a psychiatrist and were arguably then part of the system. However, it was known that not all carers would subsequently be offered or even take up the

offer of services thereafter. In an attempt to reach these carers who were not in receipt of statutory services, close contact was maintained with the consultant psychiatrists in the North of Edinburgh and West Lothian throughout the study period so they could alert the investigator to this sample. twenty carer:dependant pairs were identified who were in receipt of services and the investigator contacted them in the usual manner. Sixteen of the twenty (80%) of this sub-sample refused to participate study. This compared with an overall acceptance rate of 81% would suggest that if carers do not want involvement from the services then it makes sense that neither do they want to spend time becoming involved in research and chatting to the investigator. It begs the question of whether we can ever obtain a true 'non-service' sample. There is also the issue of whether there is indeed a great untapped pool of carers in the community who are completely unknown to the services. In Scotland where medical provision is relatively good, one suspects that, at least in the area of dementia, the untapped pool may not be as great as some would have us believe.

2. The choice of measures of coping

At the outset of this study, the Ways of Coping Checklist was selected for a quantitative measure of coping and was intended as the main measure in this study. It was selected because of its comprehensive and wide-ranging items and also its frequent use with other community samples. The investigator's rating of coping was very much a simple technique put into practice after each interview.

Thus it came as an initial disappointment and somewhat

of a surprise when the Ways of Coping Checklist was so difficult to interpret after Factor Analysis. As the great unwieldy form could not be reduced to meaningful factors, it was not possible to identify patterns of adaptive or maladaptive coping. It was not possible to write a prescription of good coping.

It may have been that the Ways of Coping Checklist was not an appropriate instrument for use on this sample and certainly when it had been used in previous studies it pertained to a specifically defined event which the respondent would describe. In this study the caring role was predetermined for each respondent and certainly the questionnaire made sense in the light of this. However, it may have been that this was too broad a situation to consider and hence the responses were also wide-ranging. Given the diverse nature of dementia, it is likely that the responses will be similarly wide-ranging in order to match the disease and so cannot be easily interpreted by a process such as factor analysis. If this is the case then other coping questionnaires may not have fared any better. It may be that coping with dementia defies quantification using these measures.

It is interesting that the qualitative information reduced to fairly fundamental coping techniques that probably did not vary from the sorts of techniques that we all use in our everyday life. To talk to try and resolve the situation or lend some practical assistance, or take over and do something ourselves are how we all tend to behave in situations where another human being is not managing. Why should it be any different with dementia? The anger and frustration also came out in the qualitative data and is understandable given the nature of the disease. In retrospect we could have learned a lot more from the

qualitative perspective, if the study had been set up differently. Perhaps this is the direction for future research and that we should stop trying to quantify what is potentially rich and complex material until extensive and thorough qualitative data has been gathered, analyzed and interpreted.

The final measure of coping was the investigator's rating and it was interesting how this was related to other factors and in particular the carer's level of emotional distress. This begged the question of what was really being measured and what exactly coping is. Is it not in fact the absence of emotional distress in response to a given event?

In conclusion then, it would seem that the Ways of Coping Checklist is an inappropriate instrument to measure coping with a dementing dependant. The situation is too diverse, constantly changing and influenced by too many interpersonal factors. In attempting to measure it we risk loosing the richness of the situation and it would seem that the way ahead is a well planned qualitative analysis.

It also seems that we are still a long way from being able to come up with a prescription for good coping because of the uniqueness of each situation, its constantly changing nature, the couple's history and their own individual style of communication and interaction. This means that professionals are not yet in a position to give 'good' advice or 'train' carers how to cope. It is important that they do not try and assume this educational role.

3. The use of the Patient Rejection Scale as a measure of EE

At the inception of this study, EE was a possible influencing factor on carer coping. At this time it was exceptionally difficult to obtain information about the Camberwell Family Interview other than by attending an expensive and infrequent training course. The PRS was therefore chosen and adapted as a viable alternative. The PRS was becoming widely used both in this country and abroad and was further developed for this study following personal communication with Kreisman, the originator of the measure.

The investigator also made her own ratings of EE in line with the CFI categories and was encouraged to find high correlations between them. Furthermore, these correlated reasonably well (r=.50, p<.01) with the ratings by an independent rater. Thus it could be concluded that the PRS is a reliable instrument to measure EE.

IV. RECOMMENDATIONS

In light of the results and discussion, the following recommendations can be made with regard to future research and also with regard to professional practice with carers.

1. Recommendations for future research

Further research into the coping techniques amongst the carers of the dementing elderly should begin with a good qualitative analysis. Further attempts at quantification are only likely to be fruitful after an extensive qualitative analysis. By attempting to quantify too early, the research risks minimising the diverse nature of the disease and the constantly changing process of care. This study may pave the way for future work in the area.

The EE concept does not seem to have predictive validity for this group in terms of outcome. However, this study did throw up some interesting questions about the nature of EE. Further research is required generally to clarify this and in particular to determine whether or not it is any more than a complex way of describing anger on the part of the carer. Either way, there are differences in carers and it may be that the high EE carers would benefit from intervention from the formal services. This has been shown to be beneficial in other dependency groups (Goldstein et al., 1978, Leff et al., 1985, Tarrier et al., 1988) and certainly worth pursuing among carers of the dementing elderly.

Few of the variables studied were related to outcome at one year and the question remains as to what factors determine institutionalisation. We know it has little to do with the level of impairment, or even the carer's health. It may have something to do with residency, social networks and kin relationships and this merits further research. Also within that there will be other factors operating and they deserve further attention.

2. Recommendations for professional carers

It was not possible in the light of this research to identify a prescription for successful coping and this

will be a disappointment to professionals in the area who provide support to the informal carers. What is important is that professionals recognise that every carer/dependant pair is different with different and constantly changing needs. It is important that the professionals recognise this and attempt no more than education about the disease and ongoing support relevant to whatever stage the carer is at.

At this stage it is not possible to know whether intervention for high EE families would be helpful. It certainly has proven so in other groups and it may also be a good use of resources in this group also. Certainly in this study the high EE carers received fewest visitors and hence likely received the least support. As previously stated, further applied research is required here.

Finally, professionals in the field should be wary of becoming complacent about the level of community services that are available. This research was undertaken in relatively well off areas of the country and yet service provision was minimal. With continuing hospital closures we are relying more and more on community services and they are going to be spread even thinner.

APPENDIX ONE

PILOT STUDY

APPENDIX ONE

PILOT STUDY

I. INTRODUCTION

This appendix describes the pilot study which was undertaken between 1986 and 1987. The measures used, and the results of the study are also presented and discussed.

II. METHOD

Twenty carers participated in semi-structured interviews and several questionnaires were administered. The interview schedule and the questionnaires were then refined on the basis of this and used in the main phase of the project. The carers who participated were all carers looking after a dementing relative in the community. They were identified via two Psychogeriatric Day Hospitals in Lothian and Tayside regions. All primary carers of patients with a diagnosis of an organic dementia were contacted by letter offering appointment times for an interview in their own homes.

The semi-structured interviews were based on twelve standard questionnaires and were administered in the order defined below. Where details have already been given in the main text, they will not be repeated again.

- 1) General Information Questionnaire This included sociodemographic details, information on professional, social, voluntary and financial support networks, carers' views on future care plans and information on the quality of the premorbid and current carer:dependant relationship.
- 2) Stressful Situation Questionnaire Using an adaptation of a technique devised by Folkman and Lazarus (1980), carers were asked to describe a recent incident involving their relative which the carer found particularly stressful or difficult to manage. The carer was then asked how she dealt with or coped with the situation.
- 3) Problem Checklist (Gilleard, 1984) This 34 item checklist was completed by the carer to identify the frequency and severity of dementia related problems
- 4) Ways of Coping Checklist (Folkman and Lazarus,

- 5) General Health Questions -This questionnaire asked the carer to evaluate her own health and the extent to which she felt that it had been affected by her caring duties. Items on persistent health problems from the General Household Survey were also included.
- 6) The General Health Questionnaire 28 items, Goldberg (1978)
- 7) The Beck Depression Inventory 13 items, Beck (1974)
- 8) The State-Trait Anxiety Scales, Spielberger (1970). These are two self-administered questionnaires for measuring state and trait anxiety. Respondents are asked to respond to 20 statements with reference to how they feel 'right now' and a similar 20 with reference to how they 'generally' feel.
- 9) Patient Rejection Scale (Kreisman et al. 1979) Adapted for use in this study by the author.
- 10) Face to Face Weekly contact (Gilleard et al 1984)
- 11) Clifton Assessment Procedures for the Elderly Survey Version (Pattie and Gilleard, 1979)
- 12) Medical Details Patient information from hospital case-notes was gathered to include diagnosis, relevant hospital admissions and medication.

III. RESULTS

1. Demographic details

The carers' mean age was 64.7yrs (range 35-87yrs). Fifteen of the sample were female, five were male. Seventeen were married, two single and one widowed. The sample of carers comprised of 6 wives, 4 husbands, 5 daughters, 1 son and 2 sisters and 2 nieces. The majority were in social classes IV or V and 15 had left school with no qualifications. Only 2 of the carers were employed on a part-time basis, 2 were unemployed and the remainder were either retired or housewives. Thirteen of them were co-resident with their dependant.

The dependents' mean age was 79 years (range 65-88yrs). On the CAPE 16 fell within Grades D and E, indicative of a moderate to maximum level of impairment and dependency. All had a medical diagnosis of an organic dementia. Regarding medication, 7 were on no medication at all. Of the remainder, 8 had been prescribed a neuroleptic, 2 were

on anti-depressant medication, 3 were on minor tranquilisers, 2 received anti-Parkinsonian drugs and there were 8 prescriptions for 'other' medication.

2. Professional and social networks

With the exception of the Home Help service few other professionals visited the carer at home. However, only 3 of the sample stated that they wanted more help and this was backed up by the interviewers own subjective judgement that 13 of the carers were indeed satisfied with the services that they were receiving. In addition, most dependants attended a Day Hospital on an average of 2 days per week. Only 3 had ever had a holiday or respite admission.

Only 4 of the carers had voluntary services call at their home and despite the presence of Relatives' Support Groups at both hospitals only 6 of the carers attended on a regular or occasional basis.

The majority of the carers (n=18) had family living locally and half of them said they received a 'great deal' of practical help from their family and 15 of them did not want any additional help. Twelve received regular social visits from the family. The interviewer rated that 12 were happy with their current level of family involvement while she rated that 8 were dissatisfied. Friends and neighbours also gave help to 7 of the carers and only 1 carer felt that she would like more help from this source.

Regarding financial allowances and housing, 8 of the 20 carers were in receipt of Attendance Allowance, 1 received Invalidity benefit, 1 received Mobility Allowance, 1 drew Social Security and 2 received 'other' allowances. In spite of this low level of financial help, only 6 carers said that they would like more. Sixteen of the carers judged that the housing was suitable for the dependant and 15 thought that their own housing was suitable.

3. Future care and the carer:dependant relationship When asked about their views on the future care of their relative, 11 thought that their dependent would eventually be admitted to long-term care, 3 thought that could cope with a residential home and 5 did not know or would not say what might happen.

Prior to the onset of dementia, 15 of the carers judged their relationship with their dependent to have been 'good' or 'very good', 2 said that it had been 'average' and 3 said that it had been 'poor' or 'very poor'. As for the quality of the relationship at the time of interview, only 9 of the sample judged the relationship to be 'good' or 'very good', 3 thought it

was 'average' and 8 now thought that it was 'poor' or 'very poor'.

4. Carers Health

Nine of the carers judged their health to be 'good' or 'very good', 5 thought that it was 'average' and 6 said it was 'poor' or 'very poor'. Just over half (12) felt that their health had suffered as a result of caring for their dementing relative.

On the GHQ-28, the carers' mean score was 2.84 and only 4 of the sample scored >5 ie. the cut off point for psychiatric morbidity.

On Spielberger's State Anxiety Scale, scores ranged from 20-46 with a mean of 33.7. The mean for a group of working adults between 50 and 69 years is 32.2 (Spielberger, 1970). On the Trait Anxiety Scale, scores for this sample ranged from 23-46 with a mean of 39. The mean on an adult sample of similar ages is 31.8 (Spielberger, 1970).

On the Beck Depression Inventory, the carers' mean score was 4.84, range 0-15. Four is the cut-off point above which the respondent may be at least mildly depressed.

5. Measures of Expressed Emotion

On the Patient Rejection Scale, the carers' mean score was 68 (range 47-99). In a sample of carers of schizophrenic dependants using the non-revised, original scale, McReadie and Robson (1986) obtained a mean score of 61.2.

The interviewer also estimated the extent of emotional overinvolvement in the pilot sample. Almost half (n=9) of the carers were thought to be emotionally overinvolved to some extent. The interviewer also estimated the extent of critical comments made spontaneously during the course of the interview and this too was rated on a 5 point scale. Eleven out of 17 carers rated made at least some spontaneous critical comments.

Regarding the number of hours of face: face contact in the week prior to the interview, this ranged from 3 to 96 hours, the mean being 52 hours. Also during this week, 6 of the 20 carers had gone out with their dependant. Seventeen of the dependants and 16 of the carers had also made trips out in the absence of the other; in the dependants case this was usually to a Day Hospital.

7. Stressful situations and coping

The stressful situations mentioned by the carers fell into 6 categories as determined by the interviewer.

They were, repetitive behaviour, angry behaviour, deluded thinking, specific symptoms of dementia eg. memory, incontinence; refusal to comply, and other. The most frequently mentioned stressful incidents related to the unique problems of dementia eg. disorientation, memory difficulties, repetitive behaviour etc.

When asked how they coped with the specific stressful incident which they cited, several responses were usually made. These were allocated in to 13 categories. These categories were as follows, direct action (non-verbal), direct action (verbal), hope/positive thinking, expression of feelings or emotions, use of tea/cigarettes, turn to other activities, physical distancing, psychological distancing, maintaining dependant's independence, creating dependency, inhibition of feelings, and other.

Most of the carers at some stage took some verbal action, usually by correcting their dependants misconceptions. Implementing some practical solution to the problem was also common eg. using a plastic table cloth to make mess more manageable.

Expression and inhibition of feelings and emotions were equally common and reported by just over half of the sample.

There was also an acceptance of the situation by most carers and this was frequently cited as a way of coping.

On the 66 item 'Ways of Coping Checklist' between 26 and 51 items were endorsed ie. used at least somewhat, by any one carer. The mean number of techniques used was 36. The most frequently endorsed items tended to be emotion focused and passive forms of coping. The least frequently endorsed items were the more practical items eg. 'Making a plan of action and following it'.

The interviewers subjective estimation of coping ability suggested that 12 of the 18 carers were coping either 'well' or 'very well'. Four were rated as average and 2 were thought to be coping 'badly' or 'very badly'.

III. DISCUSSION

This preliminary analysis of the pilot data highlights some interesting points. In terms of the sample

characteristics, they are in many ways similar to other groups of carers, namely, the majority are female, unemployed and from the lower social classes. They are not young themselves, all are of pensionable age and frequently not in good health.

The dependants themselves were a fairly disabled group, more typical of those found in psychogeriatric wards and nursing homes. This maybe says more about this particular group of carers than it does about the waiting lists for long-stay beds as neither hospital concerned had a significant waiting list for continuing care beds at the time of the study.

As has been found in previous studies (Gilhooly, 1984; Gilleard et al., 1984; Whittick, 1988) the extent of professional help given to the carer and dependant was low. However, most carers stated that they did not require more professional help and were unable to specify what sort of additional help might alleviate the burden. It was certainly apparent that help from friends or neighbours was neither desirable nor expected.

The majority of carers had had 'good' or 'very good' premorbid relationships with their dependant and this may have helped to motivate and maintain the ongoing relationship. However, as anticipated, in many cases, the quality of the relationship had deteriorated with the dementing process.

Regarding the carers' psychological wellbeing, this group are unusual in that their mental health is relatively good compared with most previous samples.

From this small sample there does seem to be evidence of hostility and criticism as measured by the Patient Rejection Scale.

Analysis of the coping behaviour at this stage was limited because of the small sample. However, it is interesting to note at this stage that the most frequently endorsed items on the 'Ways of Coping Checklist' tended to be emotion focused. They were very much about the carers' feelings about the situation rather than about practical ways of dealing with the difficulties. It was also interesting that among the least frequently reported techniques were practical, problem-oriented strategies like, 'Making a plan of action and following it' and 'Thinking about how a person I admire would handle the situation and use that as a model'.

The follow-up interviews for this sub-sample were amalgamated with the main phase of data for the analysis.

IV. SUMMARY

This appendix gave a brief presentation and discussion of the pilot study for the main project. There were minimal changes as a result of this and hence the pilot data could be amalgamated with the main phase data for the full analysis.

<u>Footnote</u> Results from this pilot study were published in "Care-giving in Dementia: Research and Applications" G.M. Jones and B.M.L.Miesen (eds). Routledge 1992.

APPENDIX TWO

ADDITIONAL STATISTICAL ANALYSIS

Principal-component Pactor Analysis of the 'Mays of Coping	vais of the 'Mays of Coping	32 Get away from it	191153. 11-11. 11. 11. 60.
Checklist		33 Esting, smoking, medication	
	Pactor	34 Take a big chance	.24 .11011133 .39 .03
Ites	1234567	35 Not act too hastily	14 .0905 .3720 .11 .08
		36 Find new faith	0906 .41 .1528 .23 .21
		17 Pride, stiff upper lip	060509 .61 .00 .14 .07
0) Concentrate on next step	.4707 .07 .042514 .14	38 Rediscover what's important	04 .39 .32 .25 .1402 .19
02 Analyze the problem	03 .47 .13 .28 .11 .1113	39 Change something so alright	17 .48 .36 .1004 .01 .12
0) Work to take mind off things	.64 .09 .25 .06 .06 .1508	40 Avoid being with people	.30 .12 .1107 .3607 .42
04 Time will make a difference	. 29 . 29 . 10 . 07 . 12 . 03 . 13	41 Refuse to think too such	11 .11 .14 .47 .231820
05 Bargain or comprimise	.14 .4506 .23 .160126	42 Ask relative for advice	.04 .47 .380831 .15 .08
06 At least doing something	.54 .2102 .06 .0401 .00	43 Keep others from knowing	11. 12. 31. 72. 6060. 62.
07 Get person to change mind	.20 .09 .1201 .19 .43 .17	44 Make light of situation	.06 .07 .22 .38 .180744
08 Talk to find out more	.11 .60 .25 .0721 .1904	45 Talk about feelings	.20 .01 .280421 .0546
09 Critisize myself	.2215 .04 .1425 .4719	46 Stand ground	01 .19 .08 .05 .0111 .40
10 Try not to burn bridges	.33 .0922 .370917 .07	47 Take it out on others	.60 .12 .130121 .1520
11 Hope for a miracle	.23 .13 .14 .17 .02 .20 .45	48 Draw on past experience	22 .12 .41 .2405 .0506
12 Go slong with fate	.44 .0116 .14 .1409 .22	49 Double efforts	.25 .00 .23 .26 .05 .00 .55
13 Go on as if not happening	16 .08 .05 .53 .3503 .09	50 Rafuse to believe it'll happen	12. 62. 70. 25. 21. 1182.
14 Keep feelings to self	.081144 .37 .21 .14 .23	51 Promise, different next time	.50 .06 .14 .01 .27 .1106
15 Look for silver lining	.01 .10 .41 .51 .08 .08 .22	52 Couple of different solutions	.01 .53 .26 .0601 .1232
16 Sleep more than usual	.17 .11 .1101 .17 .2710	53 Accept 1t	1640 .02 .1812 .0010
17 Express anger	.14070501 .56 .19 .16	54 Don't let feelings interfere	.07 .05 .00 .601207 .04
18 Accept sympathy	.13 .06 .110554 .1209	55 Wish that I could change things	5 .37 .1227 .1414 .18 .06
19 Tell self things, feel better	.22 .06 .43 .3604 .1916	56 Change self	.01 .120124 .05 .6418
20 Inspired to be creative	.07 .08 .5912 .03 .0602	57 Daydream better time/place	.2714 .3203 .27 .27 .07
21 Try to forget whole thing	.10 .07 .15 .10 .570511	58 Wish situation was over	.39041504 .15 .05 .29
22 Cetting professional help	03 .2222 .1427 .4409	59 Fantasies/Wishes about outcome	.21 .21 .37020908 .26
23 Changing in a good way	03 .34 .62 .04 .0503 .01	60 Pray	.0112 .23 .104212 .33
24 Waiting before doing anything	.44 .2417 .0115 .05 .13	61 Prepare for worst	.17 .1701 .161722 .08
25 Apologize	16 .11 .00 .1106 .77 .11	62 Go over in mind saying/doing	.40 .41 .281720 .14 .03
26 Making plan of action	.01 .61 .09 .04 .1604 .06	Use other person as model	.05 .17 .44 .030714 .04
27 Accept next best thing	.0615 .04 .27 .19 .40 .27	64 See things from other view	.10 .52 .04 .241808 .04
28 Let feelings out	.5926 .22120113 .00	65 Remind self it could be worse	.06 .04 .16 .42390103
29 Brought problem on self	.1623 .4312 .24 .1511	66 Jog or exercise	20 .32 .05080710 .10
30 Come out of experience better	.10 .06 .42 .310509 .07		
31 Talk, something concrete	.08 .60110909 .23 .12		

Principal component factor analysis of the 'Ways of Coping Checklist'

Seven factors with eigen values >1.0, accounting for 38% of the variance.

Factor 1

Factor 1 accounted for 10.7% of the variance and included 14 of the 66 items, as shown below.

Ite	<u>Loa</u>	<u>ding</u>
01	Just concentrate on what I have to do	_
	next, the next step	.47
03	Turn to work or substitute activity take	
	my mind off things	.64
06	I'm doing something which I don't think	
	will work but at least I'm doing something	.54
10	Try not to burn my bridges but leave things	
	open somewhat	.33
12	Go along with fate, sometimes I just have	
	bad luck	.44
24	I'm waiting to see what will happen before	
	doing anything	.44
	I let my feelings out somehow	.59
33	Try to make myself feel better by eating,	
	drinking, smoking, using drugs or medication	
	Take it out on other people	.60
51	Make a promise to myself that things will be	
	different next time	.50
55	Wish that I could change what is happening or	
	how I feel	.37
58	Wish that the situation would go away or	
	somehow be over with	.39
	I prepare myself for the worst	.37
62	I go over in my mind what I will say or do	.40

This Factor accounted for 6% of the variance and 16 of the 66 items loaded on this factor, as shown below

<u>Ite</u>	<u>Lo</u> a	<u>ading</u>
02	I try to analyze the problem in order to	
	understand it better	.47
05	Bargain or compromise to get something	
	positive from the situation	.45
80	Talk to someone to find out more about the	
	situation	.60
16	Sleep more than usual	.31
23	I'm changing or growing as a person in a	
	good way	.34
26	I'm making a plan of action and following it	.63
31	Talk to someone who can do something concrete	
	about the problem	.60
	Rediscover what is important in life	.39
39	Change something so things will turn out	
	alright	.48
	Ask a relative or friend I respect for advice	.47
52	Come up with a couple of different solutions	
	to the problem	.53
	Accept it since nothing can be done	40
	I prepare myself for the worst	.37
	I go over in my mind what I will say or do	.41
64	I try to see things from the other person's	
	point of view	.52
66	I jog or exercise	.32

Factor 3 accounted for 5.2% of the variance and 16 of the 66 items loaded on this factor.

Ite	em.	Loading
14	I try to keep my feelings to myself	44
15	Look for the silver lining; try to look of	n
	the bright side of things	.41
19	I tell myself things that help me feel	
	better	.43
	I am inspired to do something creative	.59
23	I'm changing or growing as a person in a	
	good way	.62
	I realize I brought the problem on myself	
30	I'll come out of the experience better the	nan
	I went in	.42
	Find new faith	.41
	Rediscover what is important in life	.32
39	Change something so things will turn out	
	alright	.36
42	Ask a relative or friend I respect for	
	advice	.38
48	Draw on my past experiences; I was in a	
	similar situation before	.41
51	Make a promise to myself that things will	
	be different next time	.34
57	I daydream or imagine a better time or	
	place than the one I'm in	.32
59	Have fantasies or wishes about how things	
	turn out	.37
63	I think about how a person I admire would	d.
	handle this situation and use that as	
	a model	.44

This factor accounted for 4.7% of the variance and loaded on 12 items, as shown below.

Ite	<u>em</u>	Loading
10	Try not to burn my bridges but leave	
	things open somewhat	.37
13	Go on as if nothing is happening	.53
	I try to keep my feelings to myself	.37
15	I look for the silver lining so to speak;	
	try to look on the bright side of things	.51
19	I tell myself things that help me feel	
	better	.36
30	I'll come out of the experience better than	
	I went in	.31
35	I try not to act too hastily or follow my	
	first hunch	.37
	Maintain my pride and keep a stiff upper li	
41	Don't let it get to me; refuse to think to	
	much about it	.47
44	Make light of the situation; refuse to get	
	too serious about it	.38
54	I try to keep my feelings from interfering	
	with other things too much	.60
65	I remind myself how much worse things could	l be.42

Factor 5

This Factor accounted for 4.1% of the variance and loaded on 9 items.

<u>Item</u>	Loading
13 Go on as if nothing is happening	.35
17 I express anger to the person who caused	. 56
the problem 18 Accept sympathy and understanding from	.36
someone	54
21 Try to forget the whole thing	.57
34 Take a big chance or do something risky	33
40 Avoid being with people in general	.36
42 Ask a relative or friend I respect for	
advice	31
60 I pray	42
65 I remind myself how much worse things	
could be	39

This Factor accounted for 4% of the variance and loaded on 7 Factors as shown below.

Ite	em	Loading
07	Try to get the person responsible to	
	change his or her mind	.43
09	Criticize or lecture myself	.47
22	I'm getting professional help	.44
25	Apologize or do something to make up	.77
27	I accept the next best thing to what I want	.40
34	Take a big chance or do something risky	.39
56	Change something about myself	.64

Factor 7

This Factor accounts for 3.6% of the variance and loads on 10 items as shown below.

<u>Item</u>	<u>Loading</u>
04 I feel that time will make a difference;	
the only thing to do is to wait	.33
11 Hope a miracle will happen	.45
32 Get away from it for a while; take a rest	
or a holiday	51
40 Avoid being with people in general	.42
44 Make light of the situation; refuse to	
get too serious about it	44
45 Talk to someone about how I am feeling	46
46 Stand my ground and fight for what I want	.40
49 I know what has to be done so I double my	
efforts to make things work	.55
52 Come up with a couple of different solution	ns
to the problem	32
60 I pray	.33

Correlation Coefficients (Pearson's r) between coping Factors and psychological and physical well-being.

BDI	GHQ	Zung	Kutner Morale	Carers Health Rating
F1 .320**	.323**	.441**	 066	243*
F2052	.118	.079	.005	004
F3 .042	.218	.212	.004	281*
F4069	.097	.064	.130	112
F5 .185	126	.056	034	 123
F6 .365**	.436**	.370**	 065	316**
F7 .210	.199	.142	.023	 156

*p<.01 **p<.001

Correlation coefficients (Pearson's r) between coping factors and relationship and EE variables.

	Patient Rejection Scale	Prior Relationship	Current Relationship
F1	.404**	124	401**
F2	.105	.035	086
F3	.035	.083	.054
F4	023	.131	046
F5	.230	157	265*
F6	.134	.030	144
F7	242*	.256*	.116

*p<.01 **p<.001

Stepwise multiple regression analysis - predictors of Factor ${\bf 1}$

	Adjusted <u>R2</u>	<u>Beta</u>	<u>F-value</u>
Variable entered on Step Number 1. Patient Rejection Scale	.21	.47	20.29***
Variable entered on Step Number 2. Zung Anxiety Scale	.31	.34	17.61***
Variable entered on Step Number 3. Current Relationship	.36	33	15.17***
Variable removed on Step Number 4. Patient Rejection Scale	.36	.42	21.61***
Variable entered on Step Number 5. Hours Face:Face Contact	.42	26	18.61***

*p<.01 **p<.001 ***p<.0001

APPENDIX THREE

COVERING LETTERS

APPENDIX_THREE

COVERING LETTERS

I. LETTER TO POTENTIAL SUBJECTS FOR INITIAL INTERVIEW

Hospital letterhead

Dear

I am currently carrying out some research about caring for dependent relatives at home. It was (Sister Grant, at the Pinel Centre) who suggested I contact you.

I know that you are very busy and your time is limited, but I would be most grateful if I could visit you at home and discuss with you about the care you give your (father), Mr (Smart).

May I call at your home on (Wednesday, 27th April at 1.30pm?) and I will explain more about the project then? I enclose a stamped addressed card for your reply and I look forward to hearing from you.

Yours sincerely

II. LETTER TO CARER AT FOLLOW-UP IF DEPENDANT STILL IN COMMUNITY

Hospital letterhead

Dear

You may remember I visited you at home a year ago when you kindly agreed to help me with my research project about carers. In order to complete this work I need to gather information about your situation one year on.

I understand that you are still caring for your (mother, Mrs Smith), at home and I hope you are still managing the situation.

I would be most grateful if you would help me by completing the enclosed questionnaires and returning them to me in the stamped-addressed envelope provided. If you have any questions about the project or if there is something you think I should know but would rather tell me about in person or over the 'phone, please do not hesitate to contact me at the above address.

Thank you once again for all your help.

Best Wishes.

Yours sincerely

III. LETTER TO CARER AT FOLLOW-UP IF DEPENDANT NOW IN INSTITUTIONAL CARE

Hospital letterhead

Dear

You may remember I visited you at home a year ago when you kindly agreed to help me with my research project about carers. In order to complete this work I need to gather information about your situation one year on.

I understand that your (wife, Mrs Jones), is now in long-term care. I hope that this is making life easier for you although I am sure it will take some time for you to adjust to the change.

I would be most grateful if you would help me by completing the enclosed questionnaires and returning them to me in the stamped-addressed envelope provided. If you have any questions about the project or if there is something you think I should know but would rather tell me about in person or over the 'phone, please do not hesitate to contact me at the above address.

Best Wishes.

Yours sincerely

IV. LETTER TO CARER AT FOLLOW-UP IF DEPENDANT DECEASED

Hospital letterhead

Dear

You may remember I visited you at home a year ago when you kindly agreed to help me with my research project about carers. In order to complete this work I need to gather information about your situation one year on.

I was sorry to hear that your (sister, Miss Scott) had died. That must have been a great loss for you and I am sure it will take some time for you to adjust.

I would be most grateful if you would help me by completing the enclosed questionnaires and returning them to me in the stamped-addressed envelope provided. If you have any questions about the project or if there is something you think I should know about but would rather tell me in person or over the 'phone, please do not hesitate to contact me at the above address.

Best Wishes.

Yours sincerely

V. LETTER TO CARER AT FOLLOW-UP IF NO RESPONSE FROM PREVIOUS LETTER

Hospital letterhead

Dear

I wrote to you a few weeks ago and asked if you would complete some questionnaires as a follow-up to our interview on carers a year ago. I was wondering if you had received the letter or if there was some reason that you preferred not to complete them.

If you did not receive them, I have enclosed further copies along with a stamped, addressed envelope for their return. If you do not wish to participate, please accept my apologies for bothering you again.

Yours sincerely

VI. THANK YOU LETTER TO CARER AFTER INITIAL INTERVIEW

Hospital letterhead

Dear

Just a note to thank you once again for taking part in my research project about carers. Your time and honesty were greatly appreciated and hopefully the results will help carers like yourself in the future.

I would be most grateful if I could contact you again in a years time and perhaps send you some questionnaires.

Best Wishes.

Yours sincerely

VII. LETTER TO CARER ON RECEIPT OF FOLLOW-UP INFORMATION

Hospital letterhead

Dear

Just a note to thank you for returning my questionnaires. I know you are busy and I am most grateful to you for all the time you have given to my project.

Your honesty was greatly appreciated and hopefully the results will be used to assist carers like yourself in the future.

Best Wishes.

Yours sincerely

APPENDIX FOUR

QUESTIONNAIRES

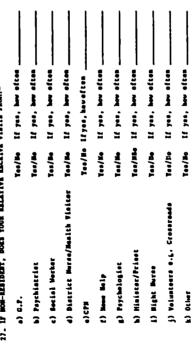
21. LOU LONG MAYE YOU BEEN THE HAIN GARER?
RELATIONERIP LOCAL NELP TISIT CONTACT NO CONTACT
23, MON BATTEFIED ARE YOU WITH THE UKLP TOO RECEIVE FROM OTHER FAMILY?
CONFLICIT AATISFIED AATISFIED AATISFIED
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a) G.P.	b) Paychiatrist	c) Social Vortor	d) District Merss/Realth Visitor	•) Cha	() Noce Help	g) Psychologist	b) Historer/Priest	() Hight Beree	j) Volumteers a.g. Cressrands	L) Other

27. IF HOM-RESIDENT, BOES TOUR RELATIVE RECEIVE VISITS FROM:-



26. NOW SATISFIED ARE YOU HITH THE PROFESSIONAL HELP YOU RECEIVED



29. WOULD TOU LIKE HORE EXIL PROM PROPESSIONAL SERVICES? . Tee/No

If You, what!

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30. INTERVIEWER TO RATE SATISFACTION UITH PROFESSIOUAL NELP	
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31. DOES TOUR EXLATIVE ATTING DAY HOSPITAL? Tee/Mo If Tee, how many days per week?

PLEASE AND PLICEBOOM

34. BO TOO RECEIVE MELP IN CARING PRON FRIEINS AIR MEICHBOURS? Tes/No

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ohat.	
If Tee, who, what and how efter!	
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35. WOULD TOU LIKE INKE WILP FROM: FRIENDS AND MEIGHBOURS? Tes/No If Yes, what?

36, DO TOU VISIT OR SEE FRIEIDS SOCIALLY? Yes/110

If Yes, who and how often?

TIME TO METE

37. DO TOU RECEIVE:-

Yes/to	Yes/io	Yes/I.o	Yes/! "	(tel/: 0	Tes/Ito
					e pension)
a) Attendance Allowance	laveladity benefit	Al lovence	reutity	went Senefit	f) Other (ercluding state pension)
a) Attendance	b) lavelidit	c) liability Allowence	d) Social Se	e) Unersploys	f) Other (er

18. HOGID TOU LIKE HORE FIRANCIAL MELP? INDICATE BOW 13578

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39. HOW SUITABLE IS PERSONT BOSSING FOR YOUR

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4-	ADEQUATE	
	VERY	SULTABLE

40. NOW SUITABLE IS PRESENT MOUSING FOR YOUR RELATIVES

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2 - Abrouate
VERY SUITABLE

TETEL CALL

41, WAST DO TOU THIME WILL MAPPEN TO TOOK RELATIVE IN THE PPTURE! Tick below

a) Long-torm boopital care	b) Assidential care	e) Live independently	d) Live with other relative	e) Will continue as long as able	f) Snable to say	g) Other

PAST ARP PRESENT BELATIONSHIP

42. OVERALL, MOU HOULD TOU RATE THE QUALITY OF YOUR RELATIONSELP REFORE YOUR RELATIVE DECAME ILL!

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43. OFTRALL, NOW WOULD TOO BATE THE QUALITY OF TOOR RELATIONSHIP NOW!

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CAMERS' REALTH

44. OVER THE PAST 12 HORTES HAS YOUR MEALTH BEEM:

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•	-	AVERACE		
•	_	POOR		
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45. MAYE TOU BEEN TO TOUR DOCTOR AMOUT TOUR OWN WEALTH IN THE PAST 6 IDENTIST

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44. ALE YOU CONLEMENT TAKING MEDICATION? Yes/No

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If Yee, when?

Tes/Bo

46. DO TOD TRIME TOUR MEALTH MAS BUPPERED BECAUSE OF MATHE TO CARE FOR TOUR RELATIVE?

-	A CREAT DEAL
2 –	BONEWNAT
	NOT AT ALL

49. IF TES, IN UNAT MATT

APPLITIONAL INFORMATION

13.7

COPIEC QUESTIONSAIRE

1. Please describe on incident which hoppesed recently (past 4 weeks) concerning your relative which you found etransful.	2. What did you do in the olimition? Bow did you needed	 In general, was the elivation one (tick one); that you could change or do something about? that must be accepted or got used to 	c) that you needed to know more about before you could act d) in which you had to hold yourself back from doing
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below is a list of ways parple have of coping with a vi.a welvery of streachil events. Please indicate by circlist, the appropriate manar the strategies we solve in dealing with a specific <u>extendial event.</u>
(The help keep the situation is mind): I am talking about the eltoution in which

	Dose wat apply and/or and used	111	11:	įįį
1. Just concentrate on want I have on do next — the next stay.	•	~	•	-
2. I try to analyze the problem is order to understand it better.	-	^	-	-
), han to with or admittate activity to take my and off chimps.	-	•	-	-
4. I feel that than will note a difference	-	•	-	4
5. Bergain or compromise to get amething praitive fros the scheetion.	-	~	•.	-
6. I'm doing earsching which I don't think will work, but at least I'm doing earsching.	•	•	•.	-
1, fry to yet the perem responsible to change has or ner aund.	-	~	•.	-
6. Talk to experts to find out enre about the attuction.	-	~	•	-
9. Criticize or lecture myself.	•	~	- .	<u> </u>
 fity not to been my bridges but leave things open extractor. 	-	~	-	-
11. ispa a miracle will nappen.	-	~	^	-
12. On along with fate; emertimes 1 just neve bod luck.	-	^	_	-
1). On on we if mothing is hyppening.	-	~	٠,	۔
14. I uy to hamp my feelings to syself.	-	~	-	-
 Lant for the silver lining, on to epont; try to lank as the bright side of things. 		4-	•	-
16. Sleep ence then usual.		~	- .	<u>-</u>
 I espress anger to the personnis) who caused the problem. 	•	٠.	- .	
16. Accept sympathy and understandlong from screens.	•	"	•	-

	Loars not apply and/or are used	113	137	1 2 1
19. I tall syself things that help as feel tector.	-	~	-	~
26. I ap implied to do accerching crantive.	-	~	-	-3
21. Try to forget the arole thing.		~	-	-
22. I'm getting professional fielp.	•	~	•	~
2). I's cheeçing or growing as a person in a gond way.		~	-	-
is, I a waiting to see what will happen before oning apprising.		~	•	_
25. Applicative or do consecuting to make up.	-	~	-	<u></u>
26. I'm making a plan of action and following it.	-	~	-	_
27. I accupt the ment west thing to what I went.	-	٠,	-	-
18. I let my feelings out moneton.		~	•	_
25. Realize I brought the problem on sycalf.		~	~	-
36. Fill come out of the experience better then went I went to.	-	٠.	•	-
 This to envente who can on something concrete about the problem. 		^	-	-
32. Get many from it for a while; it; to rest or take a vacation.		^	•	_
 Try to make myself feel better by enting, drinking, menking, using drugs or medication, etc. 		٠	-	
14. Take a bly chance of do emething fiety.		,	-	
 I er, not to act ton heatily or follow my first hanch. 		~	•	-
36. Fins new faith.		~	-	_
17. Haintain my pride and beep a stiff upper lip.	-		-	-
30. Bediscover what is separtual in life.	-	۲.	-	-
39, Change schetching on things will turn out all right.	-	^	-	
48, Avnid being with people in general.	-	~		
4). Dravit let it get to am; refuse to think ton much about it.		•	-	-
62. Ask a relative of friend I respect for advice.			-	
4). Keep nivers from knowing how bad inings are.	•	۲-	-	-
44. Hoke light of the situation, refuse to get the serious mout it.			•	-
45, Talk to ermetrie about Now 1 am feeting.			-	_

- -

Come not lived lived by the part of the pa 55, have fentueses or visites about him things buth out. 65. I remind eyes! frow much worse things could be. 6), I think about this a person I achire would becals this situation and use that as a model. 12. I go over to ay aind what I will any or do. 46. Stand by ground and flight for what I went. 54. I try to long my teelings from interfering with other things too faces. 51, hate a primise to myself that things will be different sent timm. 46. Dries on my past experiences, I was in a similar estandien before. 55. nish that I one change what is happening or lens I feel. 67. I try smething entirely different from any of the Above. (Please describe.) 65. I here west has to he done, as I am doubling my efforts to make things with. 5), I oxydraen or langina a better time nr place then the one 1 on in. Su. Mish that the situation usual go many or externa to ever with. 5). Accept 1t, since nothing can be done. 66. I try to see things from the ctner person's print of view. 52. One up with a chapte of different enlucions to the problem. M. Becare to believe it will begren. 61. I prayers syself for the wrest. 36. Overge ermething about eyealf. (). Take 10 eat on other people. 66. 1 ym or exercise. 4. 1 pray.

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PROBLEM CHECKLIST

Loading after searched with some dagree of indimaly is racely on east test. This questionmairs is for you to any which of the following altestions affect you at the someof.

Pirace po through sock of the situations described in this list. The first part south year indicate how often end situation specifies, behavior activate seven to coccusions of the end of

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ON OCCASION BUCK OR ALL OF THE TOP 1.4. Onable to dress without help b. If the person cities eccusionally or much of the time is smalls to deseat these tales, do you Wild William.

A GLAST PROBLEM A SPALL PROBLEM

2.5. Panando attention 1803 OR ALL OF THE TING ON COCASIONS

b. If the percen either eccessesily or mach of the time demands attention to you find it....

ED PROPER

A GLESS PROPLEM A SPALL PROBLEM

HECH OR ALL OF THE TIPE ------

b. If the person olther eccusionally or man of the time to emake to get in one out of a chair values in its, to you find it.... **G** COCASTON

NO PROBLEM A CREAT PROBLEM A PARIL PROBLEM

MECH OR ALL OF THE TIPE ON OCCASIONS 4.a. Bose bad language

b. If the person either eccasionally or much of the time man bad language, to you find ti....

NO PROPERTY. A SHALL PROBLEM A GLANT PROBLEM

2.6. Shable to get do and out of hed bed without help

MICH OR ALL OF THE TIME ON OCCASIONS

b. If the parson either accasionally or such of the time is unable to get in one on of hed ulthout help, do you find it....

NO PROFES A GLAST PROBLEM A SPALL PROBLEM

6.4. Merupis personal

MODEL OF ALL OF THE TIME OF COCCASTORS

b. If the person either eccationally or much of the time disrupts personal secial life, do you find firm.

ME PROPERTY A CREAT PROFESS A GIVIL PROBLEM

2.4. Smalls to make

Ē MUCH OR ALL OF THE TIPE ON OCCASIONS

b. If to person either accessionally or much of the time to smable to wash without help, do you find it....

A CREAT PROBLEM A SMILL PROBLEM

2.6. Physically aggressive MDCI CR ALL CF THE TIME ON OCCASIONS

b. If the person either occasionally or much of the time to payeleally aggivestry, do you find it....

NO PROBLEM A SHALL PROBLEM A GRANT PROBLEM

2.t. Heads help at

MECH OR ALL OF THE TIDE ON OCCASIONS

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11.a. lacentiames - setting MICH ALL OF ME THE CH COMMISSION MOTHER.

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LEGAL THORE A SALE TORES A

11.0. Creates personality maca on ALL OF THE TIME OF OCCUSIONS HOTHER b. If the person either occasionally or mach of the time creates personality classes, to you find if....

A GRANT PROFESSION A SPINIL PROFESSION OF SPINISH

13.4. Porgets things which many in All or the tree on consisted more than harm begins the scene many of many and of the first forgets takes which have happened, do you'llist little.

A STAFF THOSE A SHALL PROBLEM TO PROFILE

14.a. Temper sections to make an ALL or yang TDB on conceasing serving to the person cliber sectionally or make of the liber best temper outbursts, do you find it.....

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19.0. Rude to visitors 10001 OR ALL OF THE TARE ON OCCURIOR 1870B.

b. If the person eliber gassilmelly or mach of the line is take to visitore, to you find it....

A GREAT PROBLEM. A SHALL PROBLEM. NO PROBLEM

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- person either accessmally or mach of the time to weekle to meaning.

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as beneat, do you fine first

A GREAT PROBLEM A BRALL PROBLEM IN PROBLEM

If the person either eccusionally or much of the time to make to bold a penalthe conversation, on you find it.... Amable to beld a MICH OR ALL OF THE TIME ON OCCUSIONS HETER A SILAY PROJECT A SHALL PROSECT UD PROGEST

24.4. Soley, shouting b. If the person either occasionally or much of the time is noisy, obserting, do you find it.... HECH OR ALL OF THE TIME ON OCCASIONS

A GENT PROBLEM A SWILL PROBLEM IN PROBLEM

25.0. Incentional - writing INCO OR ALL OF THE TIME ON OCCUSIONS MYTH. b. If the person either occasionally or such of the time to incustorest writing, do you find it....

26.a. Shows we concern for personal bygirms HOOM ON WITH CALLER LINE CALOUCYSTONE MANNE A GENT PECKEN A SMILL PROBLEM SO PECKEN

b. If the person either occasionally or much of the titus obsess us concern for personal bysics , do you find it....

A GLAST PROBLEM A SMALL PROBLEM NO PROBLEM

27.n. Bartrady m foot b. If the person either accusionally or much of the time is unstrady on feet, do you find it.... MICH CHALLY THE THE CH COCALIDIS SEVER

A GLAT PROBLEM A SMALL PROBLEM IN PROBLEM

Mr. allege sellig b. If the person either accessmally or much of the time is always soling questions, do you find it.... HOCH OR ALL OF THE TIME ON OCCASIONS HAVE

29.0. Quably to take part in family con-If the person either occasionally or much of the time to wooble to take part to family conversations, do you find it.... THICK OF WIT OF JUST LIVE ON COUNTY AND INC.

A GLAST FROM A SHALL PROBLEM IN PROBLEM

A COLUMN TANKS A MATERIAL AND ANCHORY

A TANKE TO FREE HECH OR ALL OF THE THE OF OCCUPIONS HEAVY

b. If the person either accretionally or much of the time to weathe to cook management, negations, etc., do you find it....

A GLAST PRODUCT A SHELL PROBLEM TO PROBLEM

21.0. Site present b. If the person either eccessimally or much of the time site around delay matring, do you find $\overline{\Gamma_1,\ldots,\Gamma_n}$ HECH OF ALL OF THE THE ON OCCUPIONS. HEAR

A GRAFT PROBLEM A SMILL PROBLEM IND PROBLEM

12.0. Dang as faltrest to men shout friends and retailings

b. If the person either occusionally or much of the time shows an interest in oran about friends and relatives, do you find it.... THE SECRETARY OF SELL SELL OF STATES

A GREAT PROBLEM A SMILL PROBLEM NO PROBLEM

23.0. Quable to match and follow television (or radio) b. If the person either excessionally or much of the time do models to extens and fellow television (or redst), do you find it.... HEALT OF WIT OIL BALL BALL ON TOWN TO THE

A GLASS PROBLEM A SMALL PROSCESS IND PROSCESS

M.s. Smalle to secure If the person either accessionally or much of the time to emable to occupy blaze if Accessif Andrey world inlaye, do you find it.... HICH OR ALL OF THE THE OR OCCUSIONS HEVER

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Kutner Morale Scale

i Now often do you feel that there is just no point in living? Often Sometimes.	2 Things just keep getting worme and worme for me ms I get older Agree Disagree	3 How such do you regret the chances you sissed during your life to do a better job of living? Bot at all Somewhat Somewhat A good deal	4. All in all, how much unhappiness would you say you find in life today? Almost none Some, but not very much	5. On the whole, how satisfied would you say you are with your way of life today? Very satisfied Fairly satisfied Not very satisfied	6. How much do you plan ahead the things you will be doing next week or the week after? Would you say you make Many plans A few plans	7. As you get older, would you say things seem to be better or vorse than you thought they would be? Better Better worse than you thought they would be?
-						

81 SHORE

Instructions

This is a questionnaire. On the questionnaire are groups of statements. Please read the entire group of statements in each category. Then pict out the one statement in that group which best describes the way you feel today, that is, right mov! Circle the number beside the statement you have choosen. If several statements in the group seem to apply equally well, circle such one.

He sure to reed all the statements is each group before making your sholog.

' I do not feel sad
i I feel sad or blue
I am blue or sad all the time and I can't snap out of it
i am so sad or unhappy that I can't stand it

ë

5

I don't feel I look any worme than I used to
I am worried that I am looking old or unattractive
I feel that there are preminent charges in my appearance they make se look unattractive
I feel that I am ugly or repulsive looking

_

I make decisions about as well as ever
ity to put off making decisions
I have great difficulty in making decisions
I can't make decisions at all any more

۲,

I can work about as well as before
It takes attra effort to get started at doing something.
I have to push myself very hard to do snything
I can't do any work at all

I me not particularly possimistic or discouraged about the future 2 I feel in here nothing to look forward to 1 I feel that the future is hopeless and that things cannot improve 1 feel that the future is hopeless and that things cannot improve

I do not feel like a failure
I feel I have failed more than the average person
As I look back on my life, all I can see is a lot of failures
I feel I am a complete failure as a person (parent, husband, vife) ຜ

I am not particularly dissatisfied
I don't enjoy things the wey I used to
I don't get satisfaction out of anything anymore
I am dissatisfied with everything ė

I don't feel particularly guilty
I feel bad or unvorthy a good part of the time
I feel quite guilty
I feel as though I am very bad or worthless

I don't have any thoughts of harming myself
I feel I would be better off dead
I have definite plans about committing suicide
I would kill myself If I had the chance don't feel disappointed in myself am disappointed in myself am disqueted with myself hate myself

Ξ.

Taken from Paychological Memaurements in Paychopharmacology, Mod. Probl. Pharmacopaychist., vol. 7, pp. 191 – 169, ed. F. Pichot, Paris (Karger, Basel 1974). Assessment of Depression : The Depression inventory or 70 m. 70 m. 71 m. 10 m. 10 m. 10 m.

ě

My appetite is not as good as it used to My appetite is not as good as it used to My appetite is much worse now I have no appetite at all any more

I don't get any more tired than usual
I get tired more easily than I used to
I get tired from doing anything
I get too tired to do anything

Per 2

i I have not lost interest in other people
i I am less interested in other people than I used to be
I have lost most of my interest in other people and have
little feeling for them
I have lost all of my interest in other people and don't
care about them at all

Thank you very much for your on operation	refer			
Hove you necently				
A1 - been faciling perfectly real and in good health?		1	200	Much worse than usual
A3 - been hading is and of a good	2 E	No more	Rether mere	Much mere
bank?		Name usual	than sexual	then vested
A3 - been feeling run down and out of	3 5	No more	Rather more	Much mere
parts?		Shan usual	than usual	then secuel
A4 - felt that you are III?	11	No more than sevel	Redher man	Much mare Non usual
A5 — boon gording any paint in	11	No more	Resher more	Much mare
your head?		Man usual	than usual	then usued
A6 - boen getting a feeting of higheness	3 5	No more	Rether mera	Much more
or presents in your head?		Men usual	than wested	than usued
A7 – been having het er eeld spells?	7 K	No more then usual	Rather more then usual	Much mare then usual
B1 - lest much along over werry?	1 2	No more then usual	Rether more then usual	Much more than usued
82 - had difficulty in staying solves	2 %	No more	Rether more	Much more
ones you are off?		than usual	than usual	then usual
B3 - Ish sensionly under strain?	7 %	No more	Rether more	Much more
	2 %	then usual	then usual	then usual
D4 - been getting edgy and	2 S	No more	Rather more	Much more
bed tempered?		then usual	than usuel	than usual
95 - been gotting seared or peniahy	2 2	No more	Rather more	Much more
for no good recean?		then usual	than usual	then usual
B6 - found everything getting an	2 T	No more	Rather more then usual	Much more than usual
B) - been leading nervous and	2 4	No more	Rather more	Much more
serung up all the dates		then usual	then usual	then usual
			•	

Monso	Sharps Outcher Shart usual	de parametra deba galente des	ness settlefted with the way More not very task? settlefted	More as useful More as galgets	More so Menueual	More so Then usual	been thinking of yourself so a Not sentitions person?	full that life is entirely hepeless? No:	felt that the lan't wanth thing? Not	thought of the peculbility that you Definitely might make every with yourself? not	reverd of times you couldn't do Not prything because your nerves at all prers too bod?	bound yourself wishing you ware No.	found that the idea of taking your Delinitely given life hapt consists into your mind? not	
	2 2 2	About	About seme	Senate to the se	Series S	Some se usual	No more then usued	No more than usual	No more than usual	I don 1 Ihma so	No more then usual	No more than usual	l don'i Ihank so	
Reflection Permission	Longer then usual	Loss week	Less semsted Much less then usual sexisfied	Less useful Then usual	Less so than usual	Leas so Then usual	Rather more than usuel	Rether more then usuel	Rather more than usual	Hes crossed my mand	Rather more then usuel	Rether more then usual	Has crossed my mind	107A
Much less than usual	Much longer then veuel	4	Much less seniafied	Much less useful	Much less capable	Much less than usual	Much more then usual	Much more then usual	Much more than usual	Defuntely heve	Much more than usual	Much more than usual	Definitely has	



Bases Artis Bates artistis securi (1435)

		A Method	of the time	To the All
1. 1 feel	I feel nore nervous and marrows than wewel			
2. 1 feel of all	feel afraid for no recom-			
7. 1 get u	l get upot eastly or feel passedy			
1 1001	I feel like I'm falling spart and going to pieces			
f. 1 feel that	l feel that everything to all right and nothing bad will happen			
6. ly area treeble	arms and lags shake and			
7. 1.0	I as bothered by bredaches, nock and book pains			
9. J feel	I feel week and got thred meetly			
9. 1 fee]	I feel cals and can old			
30. 1 cm boots	I can feel my beart beeting fast			
11. 1 en k	as bothered by dissy			
12. 1 boy feel	I have faicting opells or feel like it			
.5. 1 cc.	I car breathe in and out			
14. I get and ti	I get feelings of nucheese and tingling is ay fingers, toes			
.5. 1 ac	l ar bothered by stomach- aches or indigestion			
ié. I bev	I have to empty my			

	Man or A Linite	Som of the time	Good part of the time	A Little Sem Good part Nest or All of the time
17. By hands are sevelity dry				_
16. Ry fuse gets hot and				
15. I fall saloop easily and got a good might's rest				
20. I have nightmares				

that happen to me. It is impossible for me to believe that chance or luch plays an important role in my life.

People are lonely because they don't try to be friendly. There's not such use in trying too hard to please people, if they like you, they like you

Many times I feel that I have little influence over the things

It is hard to know whether or note person really likes you. Now many friends you have depends upon how mice a person you ere.

Most people don't realize the extent to which their lives are controlled by accidental happenings. There really is no such thing as "luck".

As far as world affairs are conterned, most of us are the vicins of forces we can neither understand nor control. I taking an active part in political and social affairs the people can control world events.

In my case getting what I want has little or mothing to do with luch. Heny times we might just as well decide what to do by flipping

who get to be the boss eften depends on who was lucky enough to be in the right place first. Cuting people to do the right thing depends upon ability; luck has little to do with it. In the long run the bad thing that happen to us are balanced by the good ones. Host misfortunes are the result of lack of ability, ignorance, lasiness, or all three.

With enough effort we can wipe out political corruption. It is difficult for people to have much control ever the things politiciens do in effice.

 \Box

Sobetizes I can't understand how teachers arrive at the grades

they give. There is a direct connection between how hard I study and the grades I get.

IOMS: of the paired statements below please tick the one		Many of the unhappy things in people's lives are partly due to bad luck. People's misfortunes result from the mistakes they make. One of the major reasons why we have ware is because people.	don't take enough interest in politica. There will always be ware, no matter her Ard people try to prevent thes. 1 is the lase run people set the respect they deserve in this	world. Unfortwately, an individual's worth often passes parecegnized no matter her hard he tries.	The idea that teachers are unfair to students is nonsense. Most students don't resilise the extent to which their grades are influenced by accidental happenings.	Without the right breaks one cannot be an effective leader. Capable people who fail to become leaders have not taken advantage of their opportunities.	No matter how hard you try some people just don't like you. People the can't get ethers to like them don't understand how to get along with others.	I have eften found that what is going to happen will happen. Trusting to fate has mever turned out as well for me as making a decision to take a definite course of action.	In the case of the well prepared student there is rarely if ever such a thing as at unitary rest. Hany these same quotions ford to be so unrelated to course work that studying is really useless.	Becoming a success is a miller of hard work, luch has little or or nothing to do with it. Getting a good jub dene depends mainly on being in the right place at the right ince.	The average citizen can have an influence in government decisions. This world is run by the few people in power, and there is not ruch the little guy can do about it.	when I make plans, I he slengt certain that I can make them work. It is not always wise to plan too far slend because man; things turn out to be a maiter of good or bad fortune anyway.	what happens to my is my one doing. Sometimes I feel that I don't have enough control ext. the direction my life is taling	wast of the tire i chi't wicirstand thy politicians betwe the say they do.	In the long run and propie are responsible for the contracts of the national as well as on a local level.
	ě		Ϊį												

 I am very disappointed with (X).
 (Now often do you feel that you are ...)). I don't expect much from (R). (Now often do you teel that you ...) Alvaya Almost alvaya A lot of the time Sometimes Once in a while Almost mever Alect always
A lot of the time
Sometimes
Once in a while
Mener
Hear Alvays
Almost slvsys
A lot of the time
Sometimes Almost alvays A lot of the time Sometimes Once in a while Almost never Never Once in a while Almost never 6. I love (I) very much. It is sometimes difficult to live with people who are confused and families of-ten have mind feelings about the patent who lives with them. I'm going to read you now abstracts other families have made and I'd like you to tell me if you have been feeling that way about (I). Here is a card that you to be use to tell me how eften you feel that way. (PRESENT CARD B). It gets easier to understand $\{\chi\}$ as time goes on. Do you feel this way ... 3. (I) could get better if (I) would only try. Do you feel thin way ... READ RESPONSES UNTIL RESPONDENT UNDERSTANDS TASE 1. Always
2. Almost always
3. A los of the time
4. Sometimes
5. Once in a while
6. Almost mever
7. Hever
9. WA Almost alvays
A let of the time
Sometimes
Once in a while
Haver

(X) se an suportant part of my life

RELATIONSHIP TO PATIENT: MAPE OF RELATIVE

DATE OF INTERVIEW HAME OF PATIENT

7:4

Almost slusys A lot of the time Sometimes

Once in a while Almost never Mever

8. I'm tired of having to organise my life around (X).

Alvays
Alsost always
A lot of the time
Sometimes
Once in a while
Almost never
Never

1. I enjoy being with (X)
Do you feel this way ...

9. (X) to driving me med.

Alvays
Almost alvays
A lot of the time
Sentimes
Occes in a while
Almost mover

10. It makes me happy to do things for (X).

Alace alvays
A let of the time
Sometimes
Oute is a while
Almost meet

11. I have to treat (E) like a little child.

Alvaye

1. Almost elvaye

5. A let of the time

6. Sometime in a while

6. Almost mever

7. Hever

12. I can belp (I) get better.

1. Always
2. Almost sluays
3. A lot of the time
4. Sometimes
5. Once in a while
6. Almost meet
7. Hevet

13. (X) is not grateful for what we do for (X). (Now often do you feel that (X) is ...)

Alvays
Alsoct slusys
A lot of the time
Sometimes
Once in a while
Almost mever
Mever ----

if. I get more affaitated with (X) as time goes on.

Always
Almost slunys
Almost slunys
Alet of the time
Souttanes
Ouce is a while
Almost never
Mever

15. (X) to precty easy to get along with.

1. Always
2. Almost always
3. A lot of the time
4. Sometimes
5. Once in a while
6. Almost meer
7. Hever

16. It would be better if (I) lived somewhere else.

1. About along
2. About along
3. A lot of the time
4. Sometimes
5. Once in a while
6. Almost never
9. M/v

It's hard to tell what (X) is going to do next.
 (How often do you feel that ...)

Alvays
Almost siveys
a lot of the time
Sometimes
Once in a while
Almost mever
Kever

18. (X) acts so 1f (X) doesn't care about me.

Almost always
Almost always
A lot of the time
Sometimes
Once in a while
Almost mever

.-19. If (E) leaves me alone, I leave (E) alone.

1. Always
2. Almost always
3. A lot of the time
4. Sentimes
5. Once in a while
6. Almost meet
7. Hever

20. I don't case what happens to (X) asymore. (Now often do you feel that you ...)

1. Always
2. Anner, Slowys
3. A lot of the time
4. Sentines
5. Once in a while
6. Almost never
7. Bever
9. B/A

21. (X) makes me happy.

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CLIFTON ASSESSMENT PROCEDURES FOR THE ELDERLY ICAPE)
SULVEY VERSION

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Rema Corrent address' pheatment Date of burn	lerier methant/Ortanacten	3	}	••0	Was Pacs	Prynted dissability	1. When belong is drawing he/ the tequities	2. With regard to methors haven	inger to table special or and and an architecture and at the control of the contr	4 He interes in leng during the day land does neet include couch server in ever- en experiences according to the contraction of the contractions and the contractions of the contraction	1319 Ancheroseg easel brussia yeek bris elektris besultag a ake eH . § 3 Hayan Lebusa 3 Erebes Holling -	6 Whan left so has been devices hat the appropriate scotters and exhaust nevel desired and exhaust nevel desired persons and exhaust scotters.	

9

CAPE Survey Score (I'O Pd)

9

(Pilot study only)

SELF-EVALUATION QUESTIONNAIRE

Developed by Charles D. Speelberger

**Contract R. Louten R. Lubber F. R. Mg. and L. A. Jacobs

**TAT forms 1.1

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DIRECTIONS: A number of varience is which prouple have used to describe themselves are given below. Read each varience and then blacker in the appropriate usefu to the right of the varience to indicate how vool restriction. Unit in this immense in Piete are not right or wrong answers. Do not spend too much time on any one varience hou give the answers which seems to describe your present refinits best	1 testadin	2 Helwine	1 June 12 th	1 Tred stanked	e Hilatia	b Hechiper	Change where you make any factor of the second seco	x I hel and hel	ા દિવસ દાષ્ટ્રીયાનમાં	10 Test contourable	II I feel will conduct to	12 Thelmerons	13 Lampaters	11 Trefunkersie	fy fam glaved	th Tretoment	17 Jam worked	14 That contaxed	19 Thebreads	20 I tech phasam

SELF.EVALLATION QUESTIONNAIRE

ard -

M. Leake disapproximents so keenly that Leant puritien out of my III. I get in a state of reason or inclined as Uthink over no recent convenienting 17 Some unapportant thought consideringly on mond and bothers one 28 The Urban delle observer polong up without a most overcome them dexing themselves are given below. Read each statement and it en blacken in the appropriate curie to the right of the varienten to in all alast bows one arcredit feed Here are noright of wrong an wery. By now yeard too much time on any one statement but give the answer which years to dexirbe how you generally teel. DIRECTIONS A number of careness which people have used to 29 I want to man hower something that it the desert matter at a man transfer as bapty weathers were technical 27 fram calm cool and collected 22 The Universand restry 11 I have districting thoughts 21. That suished sub-modified Mercennesses de la Marie de la the Lamaskads person 12 Hack will confidence 25 The History 5 The Inadequate 21 I hed pleasant 26 Theliand M. Lam content H Halven and micrests addry our 1 og

tperioripones to extend the Spekesy of Rosenberry policies and perioriberry. Energieses de or effecte mexical to the teneral period of

Consulting Psychologists Press

CENTRAL TEALTH OUTSTIONS

1. Over the last 12 months, has your health beens

Very 600d		
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905	 - 	
Average		
Poor	_	
7 Poor		
C		

There are some .inde of health problems that eep recurring, and some that
people have all the time. From this list, can you tell me raw health
problems that you yourself find lesp recurring or that you have all tha
time.

	Bronchi tie	Arthritis or Ehemsetiss	Solatica, lumbago or recurring bac'ache	Persistent skin trouble (s.g. screen)	Asthma	Ray fever	Recurring stomsch trouble	Deing constipated all or most of the time	711se	Blood Pressure	Beart frouble	Persistent foot trouble (e.g. bunions, ingrowing toensils)	Trouble with variouse veins	Herwone trouble or gereistent depression	Disbetos	Persistent trouble with your gumes or mouth	(Trouble or pain with periods/menopeuse/the change)	NOTE OF TRESE
71C FINE				1		ļ											1	

3. Be you have any other health problem not on the list that keeps requiring or that you have all or most of the tists.

specify:	
please	
If yes, please specify:	

i. Do you think your health has suffered because of having to care for wour relative?

A CHEAT	DEM!
 	4
OF AT	¥F.

CODE

SILWANALII TVILIA	IN-NOTICE TYPE - OUT THE PROTECT AND THE PROTECT OF	1f 'more' or 'less', what has changed'
CALEE DETAILS	DEFEUDANT DETAILS	
LA E	EA.E	
ADM ESS	ADV.153	4. KILT DO YOU THINK WILL NAPPEN RECARDING YOUR RELATIVES' CAPE II. THE FUTURE?
		LOIG TERN HOSPITAL CARE
1. 1: GIII'AL, 101 IS THE OVERALL ST	1. IS GITTAL, TOT IS THE OVERALL SITUATION DOV., COLPALED " ITH WEST I LAST \$4.2	RESIDENTIAL (PART IV) CATE
YOL / YEAR ACO?	ĺ	LIVE WITH OTHER RELATIVE
INCP SETTER		I WILL CONTINUE TO CAME
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J.NS		j
120 SE 1 UCH HOLES		5. CM PARED LITH THE LAST THE I SAW YOU, HOW ALF YOU COPING?
		1 UCh BLTTCP
2. COPPATIE VITE THE LAST THE 1 SAN YOR, AND UTHER	YOU, AFF UTLE FALILY MELPING OUT LOFF?	BETTER
11CC 1201		SALE
1.01] 35 10n
א נ	. <u>. </u>	I-INCI 1.0RSE
LFSS I UCH LESS		PLLASE INDICATE NOT YOU FELL YOL AKE COFING IN' TY CIFCLING THE APROPRIATE POILT
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If 'i ore' or 'less', what has cliented?	DF-667	Very Bauly Average tell Very
		6. COI PARED 1 ITH THE LAST THEE 1 SAL YOU, FOL LAS YOUP OFF PHYSICAL MEALTH STEEL
		ויחכוו ונדונף ן ""ן
3, CO' PLPED VITT THE LAST TILL I SAV YOU, APE YOU I, SACOULL SERVICEST	i'' YUL, APE YOU GETTING PO'E HILP FLUI PLO-	BETTER
- I UCL . 101.1	_	SANE
		LOTST
SAIE		ווהבו ומו 35
- 1 5971		-11
- L.		

?. COLPAKEE WITH THE LAST TILE I SAK YOU, BOW HAS YOUR OWN LIENIAL HEALTH BEEK?	PLEASE CIRCLE A POINT OR THE SCALE BELOK WHICH SWOUS NOT YOU FEEL TOLANDS	NT OF THE SCALE BELOW	. WHICH SHOUS MOI	YOU FEEL TOLARDS
I'WE BETTER	YOUR RELATIVE MOL			
711137		- 13		- <u>;</u>
	val angry	Angry		Angry
7540n	12. CARERS OFTER FEEL ANCIT AROUT THE CAFE THEY CIVE. COI FARED VITH: THE LAST THE I AS THE TOVE NOW ANCIT DO YOU FEEL ABOUT THE CARE YOU CIVE TO YOUR RELATIVE?	HCIY AZOUT THE CAFE 1 ANGRY DO YOU FEEL A	THEY GIVE, COLF.	ARED VITH THE LAST GIVE TO YOUR RELA-
	5.	FUCH HORE APCIT []		
6. PLFAST IEDICATE BY CIFCLING A POITT OI. THE SCALE NOV YOUR OUL CEIERAL HEALIV HAS BEER OVER THE ASS YEAR.	SLICHT	SLICHTLY FORE ANGRY		
		SANE		
Very Very Poor Average Good Very Poor	\$110HT	SLICHTLY LESS ANGRY		
ED LITE THE LAST TILE I SA:. YOU, HAVE YOUR FEELINGS TOFAL f charged?	ויים	LUCH LESS AIKERY		
, sy	PLEASE CIRCLE 1. POILT OI TIE SCALE BELOV WITC'I SWOWS NOI YOU FEEL ABOUT THE Cafe you give you rilative ham	T OF THE SCALE BELOW	EFTER SHOWS LOI	YOU FEEL. ABOUT THE
93	_	_	_	-
_!	Lot at	Sluttly	Antry	Very
If 'Yes', in what ways?				(-9
	13. I FOULD EFFLEXAET FOR THAT FOR A TANKEN STUGATION, ATD HOS IT FAY HAVE CHACEE SILCE & L. LAST LIT. PLEASY UST 111 SPACE ELEOV FOR ALVIHIGG I SHOULD ILGO, ABOUT HOW FOR FEEL ALD HOW YOU ALL COLLING	TO NEAL LOSE KEELL A AST LET. PLEAS' U M'YOU FEEL ALD NOV Y	FOLK SITUATION: AN SP 111 SPACE BELV FOL ALL COLLING	D HOG IT FAY HAVE OU FOR ALYTHILG I
II. PLIAST LOGI AT THE LOFUS BLLOL AND ULDEFLIFT THOSE TLAT DESCRIBE NOL YOU FILL AFOUT YOUR PLLATIVE				
Jovin, sas suilty critical annoyed devoted affectionate irritated				
lostile wars. provoked carsns, nepative friencly harred positive				
any ry fund infuriated protective examperated resentful				
11. CAIFTS OFTLE FFFL ALGTY TOE ARDS THE FILATIVE THEY CALE FOR. COFPARED WITH THE LAST THE 1 SAM YOU, HOW ANGRY DO YOU FEEL TOEAKDS YOUR GELATIVE?				
I'UCI HOI E ANGRY				
SLIGHTLY HAIE ANGRY				
5ME	THAIR YOL FOR YOUR HELP	HELP		

Very	REES OFTEN FEEL ANCIT AROUT THE CAPE, THEY GIVE. CON PARED WITH THE LAST HIT I SAL YOU, NOW ANCRY DO YOU FEEL ABOUT THE CARE YOU GIVE TO YOUR RELA- VE?	
Antry	THEY GIVE. CABOUT THE CARE	
Slightly	ANCIY AZOUT THE CAFE IU ANCRY DO YOU FEEL	SLICHTLY FORE ANGRY
Hot at	KERS OFTE! FECL / HF I SAL YOU, NO VE'	ארוכו

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	Angry	
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	Lot at	•11 engry

13. 1 YOULD GE PLEASEF TO HEAT FOLF AFULT YOUR SITUATION: AID HOW IT HAY HAVE CHAIGE SINCE LE LAST LET. PLEASY USE JII SPACE BELOY FOR ALYTHING I SHOULD FLOW. ABOUT HOW YOU FEEL ARD HOW YOU ALL COLING
LOV FOR
TLATIOE / SPACE BE COLING
1 S E
rs S
I VOULD GE PLEASEF TO HEAF FOIR AFULL YOUR SITUATION CHALGEG SILCE LE LAST FIT, PLEASY USF THE SPACE SHOULD FLOI. ABOUT HOY YOU FEEL ARD HOW YOU ALL COLING
A1 101 F.T.
F TO HE LAST HOY YO
PLEASE ICE LE ABOUT
1.0 EE 511
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PLI AST/

CODE

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2. NAS IT FADE YOUR SITUATION HUCH SETTER	SITUATION HUCH BE			
	SAJIÉ 1'OKSÉ			
) nci:	THE ROLL		
II 'brtter' or 'worse', please say in what ways	rse', please say	in what ways		
3. COTPARET WITH THE LAST THE 1 SAN YOU, MAY ALE YOL COPINCT	HE LAST THE 1 S	AL YOU, HUN' ALE Y	OL COPINCI	
	RUCI BETTER			
	BETTEL			
	8 A. E	 		
	VOF SE			
	1 UCII 1'01 SE	<u>[]</u>		
PLIASE IPDICATE Poliat	HO' YOL FEEL Y	PLIASE II'DICATE NO' YOL FEEL YOU ARE COPINC NOU BY CIRCLING THE APPROPRIATE POINT	BY CIRCLING THE	APPROPETATE
_	_	_		-
Very Dadly	Vices		11.01	

÷	4. COMPARED VITH THE LAST TIPE I SAY YOU, HE	VITE	186	LAST	111	I SAI	You.	301	PAS.	roce	OT!	HOW HAS YOUF OUR PHYSICAL HEALTH	*
	E.												

	PUCH BETTER I		
	SA E	,-	
	LORSE		
	T DCH VORSE	-,	
S. CO' FAPED WITH THE LAST TIME I	HE LAST TIME I SAN	SAL YOU, HOY HAS YOLF OVE	F OVT LIELTAL HFALTI BEEL?
	HUCH BETTER	·	
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	SALE		
	LORSE		
	ו הכו ישוצל		
6. PLEASE INDICATE EY CIRCLIIG NAS BEEI OVEN THE PAST YEAI	PLEASE INDICATE EY CIRCLIIG / PCINT OF THE NAS BEEL OVEN THE PAST YEAL	T 01 T11 SCALE IN	SCALE HON YOUR OUR CERTEAL HEALTH
	-		
600			
7. COI PAPED VITI TY RELATIVE CHAIGED?	TYE LAST TI'E 1 S D?	AI 101, 171. YO	COLPAPED VITI THE LAST TI'E I SAN NUN, 177. YOUN HEELINGS TONARDS YOUR RELATIVE CHANCED?
	res i	·	
	<u> </u> _ 2	- <u>-</u>	
If "Yes", in what ways?	nat ways?		
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7. COFPARED WITH THE LAST TIME I SAW YOU, HOW HAS YOUR OWN KELIAL HEALTH BEEN?

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GENERAL HEALTH QUESTIONNAIRE GHQ 28 Devid Goldens

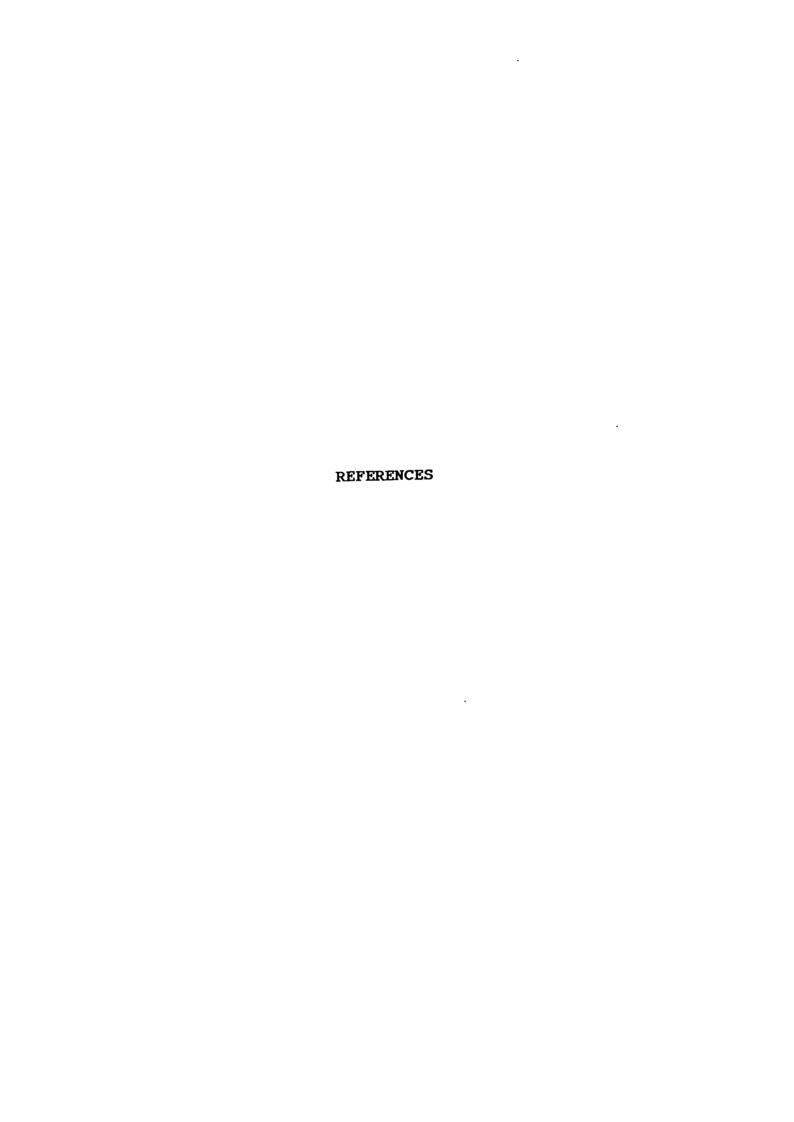
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03 – felt that life lan't werth living?	7 T	No more than usual	Rather more then usual	Much more than usuel
D4 - thought of the pessibility that you make make with yourself	Defaulaty	I don 1 Thank so	Hes crossed my mund	Definitely
D6 - found et times you couldn't de enything because your nerves were tee bed?	5 5 2 5	No more then usual	Rather more than usued	Much more than usual
D6 - found yourself wishing you were deed and ewey from it all?	5 K	No more than usual	Rather mora than usual	Much more then usuel
B) – found that the idea of taking your even life hapt coming into your mind?	Delimitaly	I don 1 thank eo	Has crossed my mind	Dehmhely hee
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