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A Day at A Time

A study of unsupported family carers of older people

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August 2003

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Abstract

Informal carers provide the majority of care for older people living in the community. The provision of care can be very stressful and is said to have an adverse affect on caregivers' health. Policy has recognised the need to support carers and a key objective has been to improve service provision for them. Research has shown that service intervention can prevent the breakdown of care and admission to long term care. However, relatively few carers and older people use formal services. While the low uptake of support services is documented, it is not fully understood.

The aim of this study was to explore the experiences of informal carers of older people who received no support services. It focused particularly on the question: why when caregiving is portrayed as being stressful, do carers continue without support from formal service providers?

Purposive sampling was used to obtain a sample of unsupported carers of older people, who were interviewed three times over a period of two years. For this longitudinal study a predominantly qualitative approach underpinned by the principles of grounded theory was chosen with a quantitative component included in the second stage. The study used a range of methods including focus groups, interviews and self-completion questionnaires. The main source of data was individual in-depth interviews, while self-completion questionnaires and literature provided secondary and tertiary sources of data. Data were analysed according to the principles of grounded theory.

The study found that carers were motivated by a strong sense of duty and a desire to maintain their independence and control over their lives and the caregiving situation. They regarded formal services as authoritarian and intrusive. Acceptance of support was associated with feelings of failure and a potential loss of control.

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Joyce Statham
August 2003

Author's Declaration

I declare that this thesis has been composed by myself and has not been presented for any other degree. All quotations are differentiated from my own work and all sources of information have been acknowledged.

Signed

.....*Joyce Statham*.....

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Introduction

The roots of this research lie in the researcher's experience as an informal carer and with her concern for carers as a community nurse. A chance remark from an ex-carer drew the researcher's attention to the way in which her needs tended to be overlooked by professionals. As a community nurse it had become an unthinking routine for the researcher to ask carers when entering their home 'How are *you*?' before asking after the patient. When paying a post bereavement visit to a wife whose husband had recently died, the researcher was told that '*you were the only one who ever asked how I was*'. This particular comment was startling as the woman's husband, was attended by two community nurses, three times a day, seven days a week over a period of three months. This incident was thought provoking and revealing. It highlighted the extent to which nurses, GPs and others from the so-called 'caring professions' overlooked the needs informal carers. The focus of professional concern is the needs of the patient / client rather than the person with primary responsibility for their care. This incident prompted further interest in carers as a specific group.

Informal Carers

The literature on caregiving uses the terms 'informal' and 'formal' to distinguish between the providers of care. Care provided in a family setting is usually referred to, as 'informal or family care' while that provided by statutory, private and voluntary sectors, within both domiciliary and institutional settings, is 'formal care'. Informal carers provide the majority of care for older people living in the community. Current estimates from the GHS put the numbers of carers in Britain at 6 million. Of the 1.7 million carers estimated to be providing personal and or physical care, approximately 1.2 million were caring for older people (Rowland and Parker 1998).

A carer is defined by the Carers (Recognition and Services) Act 1995 as

'an individual who provides or intends to provide a substantial amount of care on a regular basis for the relevant person'
(Carers National Association 1995)

However, the provision of care can be highly stressful for family members and can contribute to long term health and financial problems (Evandrou 1995,1996, Hutton and Hirst 2001). The need to support informal carers has been identified and clearly sanctioned by the policies of successive governments. Formal service interventions have been developed to meet these needs. Whilst putting a monetary value on the cost of informal care is complex, it is nonetheless, estimated that in Scotland approximately 500,000 carers provide care in the community to the value of £5 billion, which is similar in value to the care provided by statutory agencies (Carers UK 2002). Given current demographic trends and an ageing population, these figures suggest that if only a small number of carers were to give up caring, perhaps through lack of support, the economic impact could be substantial.

Supporting Carers: policy context

In relation to older people, policymakers are primarily concerned with the costs of long term care (Royal Commission on Long Term Care 1999). In this context carers are viewed as an important resource, and one which is essential to the success of community care (Scottish Executive 2001). Thus carers are currently placed relatively high on the political agenda and in recent years, have been given increasing recognition in community care policy. Three pieces of legislation, the NHS and Community Care Act 1990, the Carers (Services and Recognition) Act 1995, and the Community Care and Health (Scotland) Act 2001 and the Carers Strategy (Department of Health 1999) have explicitly recognised carers.

The NHS and Community Care Act 1990, brought about a change in the way that welfare services were financed, organised and delivered. It placed a greater emphasis on providing care for older people within the community rather than in institutional settings. The White Paper, *Caring for People* (Department of Health 1989), which preceded this legislation, had highlighted the importance of carers. One of its key objectives was to ensure that service providers made practical support for carers a high priority. Thus the NHS and Community Care Act 1990 acknowledged the need to support carers.

Attention to carers' issues increased with the introduction of the 1995 Carers (Services and Recognition) Act, which was the first legislation to accord carers any rights. This Act has been regarded as the first legislation to recognise fully the role of carers (Tinker 1997,

Lloyd 2000). It gave carers who were providing a 'substantial' amount of care, with a statutory right to an assessment of their needs, which was to be separate from that of the care recipient. However, the assessment could only be undertaken if the care recipient had been offered and accepted an assessment of their own needs.

Whilst the 1995 Carers (Services and Recognition) Act was an important achievement for carers' organisations, its value was more symbolic than real (Parker and Clarke 2002). There is little indication that this legislation made much difference to the level of services provided for frail older people and their carers. That finding is perhaps not surprising given that no extra resources were committed to local authorities to implement the requirements of this legislation. However, since the election of the present government in 1997, resources have been directed specifically at services for carers.

The resources committed to improving service provision for carers was part of a package of measures announced in the Strategy for Carers in Scotland 1999. The Carers Strategy reflected the government's commitment to a reduced role for the state and an increasing emphasis on family care. In some ways, unpaid family carers exemplified New Labour's emphasis on duty and responsibility as key elements of citizenship. Thus the Carers Strategy portrayed a picture of formal intervention that supported but did not take over family care. It was introduced as a '*new substantial policy package*' that reflects a '*decisive change from what has gone before*'. According to the government caring for carers means:

'...Giving them more control over their lives and over the range, nature and timing of services which they need. It will offer real choices about the extent to which they provide care, remain in employment, receive information and are involved in the life of their community'

(Department of Health 1999:62)

The strategy promoted the principles of choice, consumer control, access to paid work and social inclusion, all the hallmarks of the New Labour approach to welfare. The government identified three elements to the strategy: information, support and care for carers. Central to the strategy was a number of assumptions including; a carers' right to choose to care, to be adequately prepared to do so, to receive relevant help at an appropriate stage, and to be enabled to care without it adversely affecting their health or inclusion in society. Another important aspect of the Carers Strategy was its emphasis on the provision of services for carers in their own right. This issue built on the provisions of the 1995 Carers Services and Recognition Act, which accorded carers the right to an assessment of their needs if the person they were caring for was being assessed. According

to the strategy therefore, the system previously limited carers' entitlement to services, undervalued their role and needs and their ability to have a proper say in the kind of provision which best suited them (DoH 1999:57). The Carers Strategy identified key priorities, which included the promotion of new and more flexible services for carers, better and more targeted information for carers at national level, and monitoring the performance of health and social work services in supporting carers.

Building on the intentions set out in the Carers Strategy, recent legislation in Scotland, the Community Care and Health Act 2001 introduced new rights for carers. The Act made provision for the right to an assessment independent of the cared for person. It placed a duty on local authorities to inform carers of their rights and to take account of carers' views when putting together a community care package. Within this legislation carers are now considered as 'key partners' in the provision of care. Thus policy has sought to provide carers with adequate support services which will ensure the continuation of caregiving in the community.

Research: visible and invisible carers

Successive governments' commitment to supporting carers has resulted in a large body of literature whose titles include the term 'carer'. Carers studied in this wave of research were identified through the users of services (see for example Nissel and Bonnerjea 1982, Charlesworth et al 1984, Warner 1995). This sampling strategy was regarded at that time as being appropriate in light of the concern about the adequacy of the support provided by the formal sector. However, the effect of this approach was to define carers as part of the support system of people living in the community who were already receiving health and social care services. This reliance on caregivers known to service providers has meant that policy was related to the apparent needs of such carers. Atkin (1992) called for the needs of different carers to be recognised if appropriate services were to be developed. To that end he distinguished between spouse, parental, filial, sibling, child and non-kin carers but importantly, these continued to be carers who were known to service providers.

Soon after the results of the first authoritative national survey of the population to address the issues of carers was published, the terms 'hidden' or 'invisible' carers began to emerge in the literature. The results of this survey revealed that the numbers of people caring for another person were greater than previous estimates (Green 1988, Parker 1990c).

However, no clear definitions of the terms ‘hidden’ or invisible’ carer have been found. It seems that these terms were initially used by carers organisations to describe carers who did not identify themselves as such. It has also been taken to mean carers who are unknown to service providers and/or carers organisations (Barker and Mitteness (1990, Evandrou 1990, Age Concern 1995, PRTC 1998). Because of this uncertainty about the precise meaning of these terms, the present study uses the term ‘unsupported carer’ to identify individuals who were providing care for another person and who were not in receipt of support from formal service providers.

Service Support for Carers

Support is an inclusive term, which in the present study is taken to mean any service whose purpose is to provide either practical or emotional support for caregiving. Support has been defined as any action, which either helps carers to continue in the caregiver role or to end it (Askham 1998). Formal services are taken to mean those that may be provided funded and/or arranged by statutory and voluntary agencies.

Service support for carers remains problematic, despite more than a decade of campaigning, the raised profile of carers and the policy and practice initiatives that have been developed (Parker and Clarke 2002). These initiatives have been underpinned by an assumption that support services will reduce the negative impact of caregiving, thereby enabling carers to provide quality care for a longer period. This assumption has been supported by research, which has shown that service intervention can prevent the breakdown of care and reduce admissions to long term care (Twigg et al 1990, Allen et al 1992, Wright 2000).

Nonetheless, what is regarded as a service for carers remains unclear (Parker and Clarke 2002, Twigg and Atkin 1994). The best example of a service with the explicit aim of helping carers is carers support groups. There is no ambiguity over who this service is for. However, simply providing services does not ensure their use. Research indicates that relatively few carers and older people use formal services (Curtice et al 2002, McDonald 1999, Taylor and Ford 1994). Spouse caregivers have been identified as being particularly reluctant to use formal services (Parker 1993, Wenger 1990a). Thus the literature documents the low uptake of services by carers but does not explain it adequately.

Exploring Unsupported Caregiving: aims of study

How is this non-use of services by carers to be understood? Why are some carers reluctant or unable to accept available service support from formal providers? Focusing particularly on carers of older people, the present study explores the experiences of caregivers who continue to provide care despite having no support from formal services. Using a grounded theory approach the overall aim of this study is to address the following question:

Why when caregiving is portrayed as stressful do carers continue without support from formal service providers?

The research seeks to understand why and how individuals became carers in the first place and how they cope when others, faced with a similar situation, seek support from service agencies. The study explores their perceptions of the difficulties and satisfaction associated with caregiving. A major concern of this thesis is the role that carers' perceptions of service providers play in their status as unsupported caregivers. Hence, the study explores carers' reasons for having no support, for example, whether it is through choice or lack of knowledge. It examines their interactions with service providers and seeks to determine what triggers if any lead to service receipt.

Informal caregiving is the major source of care, which maintains frail older people in the community. The need to support informal carers has been endorsed by successive policy initiatives, which have directed attention and resources to developing services for carers. The central aim of these initiatives is to ensure the continuance of caregiving in community settings and thus prevent the need for long term care.

However, current policy has been devised with the needs of carers already known to service providers in mind. It is possible that the needs of carers who are unknown to service providers differ from those already identified. If the experiences of unsupported carers remain unexplored, then their needs will continue to be unmet. Moreover, if as research has shown, carers are reluctant to utilise formal service provision, then policy will fail to meet its objectives. Policymakers need to ensure that services for carers are effective, accessible and will make a positive difference to their lives. This entails being aware of the needs of all carers and not just those known to service providers.

Exploring Unsupported Caregiving: layout of thesis

This final section outlines the structure of the thesis. All names in the thesis have been anonymised in order to protect the identity of carers and their friends and relatives to whom they refer. The thesis begins with a review of the literature comprising three chapters. Chapter 1 explores theories of care. It highlights the notion that care is associated with dependency and reviews the literature on the concepts of formal and informal care before concluding with models of caregiving. Chapter 2 examines the literature on experiences of caregiving and centres on the practical aspects of providing care and the consequences these have for carers' employment, health and financial status. The rewards of caregiving and carers' responses to their role are also discussed. Chapter 3 focuses on the concepts of stress and coping and considers the strategies and resources used by carers to manage the demands of caring. These resources include the use of services and attention is drawn to the low level of uptake by carers and older people.

The aim of chapter 4 is two-fold. The purpose of the first section is to review the methodology underpinning this longitudinal study and justify the choice of a qualitative grounded theory approach, with a quantitative component. The second section provides a detailed description of how the study was conducted. The three stages of data collection are outlined and followed by a description of how the raw data was coded firstly, into open codes and finally into core categories which helped to structure the thesis. A detailed profile of carers who took part in this study is also presented in this chapter.

Chapter 5 explores the process of becoming a carer. It discusses the concepts of duty and obligation and describes the pathways that lead to individuals taking on responsibility for the care of their older relative. Chapter 6 begins by discussing carers' experiences of providing personal and practical care, the defining features of caregiving. It continues by exploring the nature of caregiving relationships and the factors such as motivation and reciprocity that structure them. Chapter 7 centres on the concepts of power and control. It describes how by exercising power, control was established and maintained within the relationship between the carer and the person being cared for.

Chapter 8 examines carers' perceptions of stress and their use of coping strategies and resources. It also discusses the role of positive and negative outcomes of caregiving. This is followed by a description of temporal dimensions of caregiving. Chapter 9 documents the process by which carers made the transition from unsupported to being supported by service providers. It begins by exploring carers' reasons for not being in receipt of services

and continues by examining the pathways to service provision. This chapter concludes by contrasting carers' experiences of service provision with their previously held perceptions. Chapter 10 brings together the main ideas developed in the thesis. In doing this discussion returns to key findings and examines these in the context of current policy.

1. Theories of Care

This chapter will explore theories of care. Care is a small word widely used in everyday life but containing a wealth of meaning. As a concept it is ambiguous, difficult to define (Parker 1990c, Twigg and Atkin 1994, Kyle 1995) and is one of the least understood ideas used by professionals (Leininger 1981, 1984, Dunlop 1986, Morse 1990). Whilst it has been suggested that theories of care have been developed in a historical and cultural context (Leininger 1981, Noddings 1984, Tronto 1993, Brechin et al 1995) this review is grounded predominantly in white British culture. The chapter will begin by exploring the notion that care is inextricably linked to dependency. It will then review the literature on the formal and informal concepts of care before considering who within the family provides care and for what reasons. The chapter will conclude with an outline of models of caring.

Care and Dependency

Dependency is defined as a 'state in which an individual is reliant upon others for assistance in meeting recognised needs' (Wilkin 1990). Caring is often linked to dependency, which in turn is closely associated with old age (as defined by the age of retirement) (Walker 1990, Johnson 1981, 1993). The negative image of older people becoming helpless, childlike and dependent on others is a widely held stereotype (Johnson 1993). Moreover, it is common practice for policymakers and economists in particular, to label older people, children and people with disabilities as the 'dependent population'. This is usually done in order to calculate a dependency ratio between this dependent group and those of working age.

However, such a generalisation is misleading in two respects. Firstly, there is no direct link between old age and economic, physical or psychological dependency (Walker 1990, Johnson 1993). Secondly, the nature of dependency in old age differs from that among children or adults with disabilities, although both may be regarded as social constructions (Phillipson and Walker 1985, Phillipson et al 1986, Oliver 1990, Morris 1993, Phillipson 1998, Shakespeare 2000). Elderly people have past life histories of relatively independent living and for them the experience of dependency may be accompanied by a sense of shame and humiliation (Johnson 1981, 1993). There is evidence too that older people attach a great deal of importance to independence (Abrams 1978, Qureshi and Walker

1989, Sinclair 1990, Bond et al 1999). As Johnson (1993) points out, we live in an interdependent society where no individual is truly independent, we are all dependent on strangers who provide goods and services such as food, clothing and transport. He notes that those who are seen as dependent are for some reason unable to contribute to society in an economic way and that they need the support of others to maintain their existence. Thus the words care, caring and caregiving have come to mean the help that is provided to (dependent) people who cannot look after themselves.

Social gerontologists (Phillipson 1981, 1986) and the disability movement (Morris 1991, 1993, 1997, Shakespeare 2000) challenge the assumption that because they need personal assistance, elderly and disabled people are dependent and less able to make choices and take control of their own lives. The disability movement in particular maintains that policy should not endorse dependency through an emphasis on supporting carers. Rather it should underwrite the independence and empowerment of people who receive care. They suggest that this could be achieved through social and economic changes, which would allow disabled and older people control over personal support services, thus removing the need for informal carers (Wood 1991, Morris 1993, 1997). In their view, the focus on the needs of caregivers diverts attention and resources from the real issue, which is the support of people with disabilities irrespective of age (Oliver 1990, Morris 1991, 1993, 1997). This perspective supports the views of older people who value their independence and may not want to rely on their families for care (Sinclair et al 1990, Daatland 1990, McGlone 1994). However, it is criticised on the grounds that it fails to consider those older people who prefer to be cared for by their families rather than pay for formal carers (Parker 1993). Moreover, because some people will continue to provide unpaid care, there will always be a need to acknowledge their contribution and provide support for them as well as the cared for person (Parker 1993).

As a result of pressure from the disability movement, some writers question the concern with carers in academic and policy research (Joseph Rowntree Foundation 1996, Twigg 1998). Indeed, a publication from JRF, meeting the Costs of Continuing Care, fails to mention carers in their recommendations, yet they are mentioned in the main report (JRF 1996). The contribution made by the disability rights perspective to the dependency debate is to ensure that in discourses about caring, the notion of dependency is challenged and a focus on carers is matched by a focus on care recipients. Thus the 'dual focus' of caregiving is recognised and acknowledged as being particularly problematic in terms of service provision for carers (Twigg and Atkin 1995). While service support for carers will

be referred to again in chapter 3, this chapter will now explore how caring as an issue has emerged over the last thirty years.

The Emergence of Caring

The emergence of caring as an analytical and theoretical concept took place mainly in the 1970 and 80s although some writers claim that it is still in the process of being constructed (Dunlop 1986, Kyle 1995, Bytheway and Johnson 1998). As a concept, caring was initially discussed in relation to professional nursing care (Leininger 1981, Noddings 1984). By the mid-70s its meaning had widened to encompass paid care undertaken by social care agencies. Thus while trained carers were called nurses, untrained care staff became known as care assistants, carers or care workers, indicating a difference of status between nursing and caring (Phillips 1993, Twigg 1990, 1998, 2000, Webb 2001).

As it is currently used in relation to informal care, the concept did not emerge until the mid-eighties when it was first used to describe the unpaid care provided by family members (Pitkeathly 1989, 1994 Arber and Ginn 1990) and it was being asserted that 'caring is news' (Ungerson 1987). Prior to this, the term caring did not merit an entry in a dictionary. Yet in his seminal text on the family life of older people Townsend (1957) created an image of how care was provided by relatives within the context of ongoing family life. Thus the role by family in providing care was recognised although it was not termed caring or caregiving. Caring is therefore, a recent social invention (Bytheway and Johnson 1998).

Referring to the '*emergent sense of caring*' some writers claim there is little evidence that caring in the sense that it is now being used is the long standing meaning of the word (Dunlop 1986, Phillips 1993, Bytheway and Johnson 1998). Dunlop claims that the emergent and enriched meaning of the word seems to involve a form of emotion that was not previously used. Dunlop (1986) argues that the term caring and curing share a common origin, the Oxford English dictionary (OED) distinguishes between different origins. According to the dictionary, care comes from the Old English word '*carian*' which meant to trouble oneself, whereas cure comes from Latin '*cure*' meaning priest. This distinction is important as it suggests that the origins of care are embedded in an original class difference in that the higher orders cured while the lower orders cared. Thus while care was linked with love within the private sphere, in the public domain, it was the means by which conditions likely to produce danger, were constantly monitored and kept under control (Dunlop 1986, Webb 1996). The nurse was thus seen as caring for the sick

and preventing conditions detrimental to health. Nursing was the arm of the public health movement, which extended care, in the old sense, into the public or formal domain (Dunlop 1986, Phillips 1993). While the meanings of the terms have developed in their separate ways, the relationship to power has remained, with care continuing to convey a more direct relationship of power and control (Dunlop 1986, Tronto 1993, Fox 1995, Orme 2001).

Care is a concept within which there are divisions of formal and informal care. The literature on the subject uses the terms informal and formal to distinguish between the providers of care. Care provided in a family setting is currently referred to as informal care while that provided by statutory, private and voluntary sectors, within both domiciliary and institutional settings, is formal care.

Formal Concept of Care

The changing context of caring within the formal domain can be illustrated by various definitions. Leininger (1984) for instance, conducted one of the first anthropological studies of care in the early sixties. Practical tasks are central to her meaning of care, which she defined as assistive, supportive or facilitative acts towards or for another individual or group (Leininger 1984: 345). Her concept consists of a number of context-free elements such as comfort, compassion, concern, stress alleviation, support and trust, constructs which she proposes can vary in emphasis and use. To be caring though involves more than a series of helping activities. It also encompasses the manner in which these activities are carried out along with the attitudes and feelings underpinning them (Dunlop 1986, Thomas 1993, Tronto 1994, McFarlane 1997). Noddings (1984) for example, uses a concept of caring which encompasses both feelings and emotions and is similar to what Dunlop terms the emergent concept of caring:

'Caring involves stepping out of one's own personal frame of reference into the others. When we care, we consider the other's point of view, his objective needs and what he expects from us. Our attention, our mental engrossment is on the cared-for, not for ourselves...to care is to act not by fixed rule but by affection and regard'

(Noddings 1984: 67)

Those who view caring as a series of simple 'helping' activities focus on caring behaviours (Griffin 1983). Griffin's concept identifies five general methods of giving help or

assistance, which include acting for, or doing for another person, guiding, supporting and providing an environment that promotes personal development, and teaching another. His model though is unclear about whether supporting is in a practical or emotional sense or perhaps both.

Other professional concepts of care have tried to portray its complex nature by including a number of elements. Kyle (1995) defines these elements as behavioural, moral, cognitive and emotional, with each one also being culturally and context specific. Watson et al's (1979 in Kyle 1995) model of caring identifies two types of expressive activities – those establishing relationships that are characterised by trust, faith, hope, sensitivity, empathy, touch, warmth and genuineness, and those offering support which may include surveillance and comfort. Scott (1995) describes good professional care as 'constructive' care, the achievement of which requires competence in the clinical and technical aspects as well as humanness, sensitivity and compassion. Yet, the variables in these concepts of caring outlined above are not any easier to define, explain or measure than caring itself.

Formal caring tends to be viewed as a therapeutic, interpersonal process that can be effectively demonstrated and practised impersonally (Phillips 1993, Kyle 1995), although some concepts include an emotional dimension (Leininger 1984, Noddings 1984). Research on the care of older people has examined the ways in which feelings and love in particular, can and does enter the formal domain of care. For example, Qureshi's (1990) sample of older people and their carers was derived from the records of service providers in the formal domain. This source of information led her to question the 'sharp opposition' between the worlds of formal and informal care posed by Abrams (1977, 1978). She concluded that carers, whether formal or informal, undertake caregiving with, but sometimes without a caring disposition (Qureshi 1990). The debate over the extent to which emotion features in the formal domain has been reflected in the informal concept of caring.

Informal Concept of Care

The early literature on the concept of informal care contains a debate revolving around the dual meaning of the term. A distinction is made between caring *for* and caring *about* (Parker 1981, Ungerson 1983a, 1990b, Graham 1983, Dalley 1996). In an attempt to clarify the concept, Roy Parker introduces the concept of '*tending to*' in place of '*care for*'.

Viewing the concept mainly in terms of an activity carried out in the informal domain, he uses the word tending to distinguish ‘the actual work of looking after those who, temporarily or permanently, cannot do so for themselves’ (Parker 1981:17). Tending, is he says, the ‘*active and personalised manifestation of care*’ (1981:37). Despite acknowledgement of his argument though there has been no widespread use of the term. Roy Parker's concept has been criticised on the basis that by focusing on care as an activity it reduces caregiving to work and overlooks the emotional element (Graham 1983, Ungerson 1983, 1987, Thomas 1993).

Other informal concepts of caring assume that the two terms, *caring for* and *caring about* are inextricably linked (Ungerson 1983, Graham 1983, 1991, Dalley 1996). Graham's analysis for example, has two analytically distinct but intertwined dimensions in the experience of giving and receiving care. Graham, whose focus has been caring within families, claims that it is considered perfectly natural that in motherhood, caring for and caring about are so completely integrated that it is deemed unnecessary to separate the two. She defines informal caring as:

‘A concept encompassing that range of human experiences which have to do with feeling concern for, and taking charge of, the well-being of others’.
(Graham 1983:21)

For Graham, caring has both material and psychological dimensions. The material dimension includes caring as work, and as labour towards the reproduction of the family (routine housework, childcare, meeting the physical needs of dependants). The psychological dimension encompasses caring as an emotional phenomenon involving feelings of love and affection, and the giving of emotional support. Thus caring involves labour and love, the ‘transaction of both goods and services’ (Graham 1983: 27).

Whilst the language complicates the analysis of care the ‘new vocabulary’ clarifies the idea that caring about someone and caring for them are not necessarily or logically linked; one can care for a person without caring about them (Ungerson 1987, 1990b, Qureshi and Walker 1989). Similarly, one can care *about* them without doing a great deal to care *for* them (Ungerson 1990, Dalley 1996). However, the term caring with its connotations of love and affection is nowadays mainly used to describe a relationship within the private sphere, while the public sphere of caring is treated as the place where skill effectively replaces love and affection. This is what Ungerson refers to as:

'A conceptual dichotomy between public or 'formal' care on the one hand, and private or 'informal' on the other'.

(Ungerson 1990a: 87)

Ungerson claims that a *'false dichotomy'* between the formal and informal domains of care stems from the merging of the meanings of 'caring for' and 'caring about', of labour and love. It is false because it is based on an assumption that the emotional aspect of care is only to be found within the informal domain of caring. Thomas (1993) and Orme (2001) also claim that concepts of care, which include only that which is undertaken by family within the home, are inadequate. They maintain that by removing this conceptual division, analysis of care might be easier (Ungerson 1990a, Thomas 1993, Orme 2001). Ungerson suggests that this might be achieved by having a word or phrase that was equally appropriate to the work of caring within the formal and informal spheres. Such a word would make it possible to think about labour and love in both contexts (Ungerson 1990a, Dalley 1996).

In Scandinavia, Waerness (1984) for example, has coined the term *'care-giving work'* to describe the care of people who cannot look after themselves and who are dependent upon others, irrespective of the location of caregiving. However, Waerness's concept subordinates the affective or emotional elements of care to the tasks involved in the work of caring (Waerness 1984, Ungerson 1990a). Despite Ungerson preference for the use of the phrase *'care-giving work'* and Orme's for *'care work'*, these terms do nonetheless, refer to the individual task orientated relationship between paid / unpaid carers and the cared for person. Not only do these expressions seem harsh, but by subordinating the emotional aspects of caring, they also convey no sense of the warmth and goodwill that permeates both formal and informal care. Thus by adopting the term *care-giving work*, or *care work*, our understanding of the experience of care might continue to be restricted to task based conceptualisations.

Informal caring is closely associated with emotions to a greater extent than caring in the formal domain. Emotion is significant not just because love and other feelings underpin the bonds of obligation, but because caring represents a form of emotional labour in itself (Finch and Groves 1983, Ungerson 1990b, Delphy and Leonard 1992, Orme 2001). As Ungerson and others have pointed out informal care is founded on feelings of love and affection, rather than on logic and the identification of need. Thus it has been claimed that there is an important distinction between caring which is paid labour and that which is unpaid. It is presumed that informal unpaid care based on affection is qualitatively different from formal care simply because the loving feelings contained within it lead to

better care (Abrams 1978, Finch and Groves 1983, Goodman 1986, Ungerson 1990). Only care from the informal sector can make people feel 'cared for' rather than simply serviced (Abrams 1978, Graham 1983). Informal carers have because of this perception, sometimes been variously portrayed as loving heroes or heroines, virtuous and dutiful sons and daughters, or selfless martyrs (Pitkeathly 1989, Coates 1995).

In a review of the literature on the concept of care, Morse (1990) concluded that formal caring is either; an affective response, a human trait, a moral imperative, a therapeutic intervention or an interpersonal interaction. However, these perspectives are as relevant to informal care as they are to professional care. Thus it would appear that there are more similarities than differences between the informal and formal concepts of care. The definitions and meanings discussed above suggest that both domains consist of number of similar dimensions such as attitudes and behaviours, attributes that cannot be easily defined or measured. Moreover, there is a concern in both the informal and formal caring literature that it is the visible, instrumental aspects of care that are most recognised and measured, while the less visible, affective components tend to be overlooked.

There are two main differences between the formal and informal domains of caring. Firstly, it would seem that purpose and emotion are the crucial elements that distinguish the formal from the informal concept of care. That is not to say that formal care is not and cannot be carried out with a caring and concerned approach to the welfare of others. But the range, depth and intensity of emotions invoked through informal care are much more important to the caring situation and their very existence is the reason for carers' involvement (Finch 1989, Qureshi and Walker 1989, Wilson 1989, Graham 1991, Willoughby and Keating 1991). The second difference is that one group has undergone vocational training and is paid while the other is not. There have however, been calls for the 'expertise' of informal carers to be recognised (Bond 1990, 1992, Fox 1995, Nolan et al 1996, 2001). It is argued that family caring should be 'professionalised', not in the traditional sense but to the extent that the skills used by caregivers are valued, encouraged and improved (Bond 1990). Much of what informal carers do could be classified as therapeutic interventions and although they might not use the term, this is often their intention (Nolan et al 1996). Moreover, qualities regarded as essential for professional care are not seen as essential for informal caring. The idea that a family carer has to be competent to provide care is an issue that is rarely addressed in the literature (Nolan et al 1996). A number of studies have, however, found that when given training for their role, informal carers tend to provide care for a longer period of time than those who were untrained (Triantafillou and Mestheneos 1995, Clarke 1995, Marshall 1997).

The concept of caring with all its ambiguities has been discussed above. The conclusion reached is that despite a large body of literature on caring, the concept remains elusive and imprecise. Were it to be otherwise, it might mean that in theory at least, caring could be transformed into a computerised, routine and mechanistic process that would leave carers redundant. In order to explore theories of care further we need to understand exactly who are carers and who within the informal domain provides the care that others have attempted to describe and analyse.

Who Are Informal Carers?

The complexity of caring has led some writers to conclude that a search for a single definition that distinguishes a carer from a non-carer is 'over ambitious and probably futile' (Arber and Ginn 1990). Yet as the concept of care emerged so too did a number of definitions. In one of the earliest definitions of a carer Abrams (1978) called them '*domestic caring agents*' and suggested that their needs should be explored. Another early definition of carers used in a report from the Equal Opportunities Commission (EOC) noted that the majority '*were women, of course*' and described them as '*those adults who are responsible for the care of the sick, handicapped or elderly*' (EOC 1980:1). The author of this report suggested that the term 'carer' was not entirely satisfactory, but was '*probably the best available*'. Later definitions accepted the term carer unquestionably, for example Braithwaite (1990:27) defines carers as:

'People who assume the major responsibility for providing caregiving services on a regular basis to someone who is incapable of providing for him/herself'.

A more recent definition contained in the 1995 Carers (Recognition and Services) Act claims that:

'A carer is an individual who provides or intends to provide a substantial amount of care on a regular basis for the relevant person'
(Carers National Association 1995:6)

Despite these definitions containing relative variations in emphasis, they all focus primarily on issues of responsibility and the instrumental aspects of caregiving. Other definitions arising from major surveys of carers have a wider focus, but they too emphasise the instrumental aspects of care by linking caring to 'looking after' or providing a 'regular service' (EOC 1982, Green 1988). Bytheway and Johnson (1998:249) conclude that the

category of carer was initially an operational concept to assess the impact of community care policies but has now become a social identity enshrined by legislation.

However, carers are not a homogenous group (Parker 1992, Baldwin et al 1990, Twigg 1998). A distinction is often made between carers who undertake 'informal helping' and 'heavily involved caring' (Parker 1992, Twigg 1998). Definitions of heavily involved carers vary with some researchers defining it in terms of whether the carer is co-resident or not (Arber and Ginn 1990, 1991, 1997). Others have defined it on whether the care has sole responsibility or is the main carer (Evandrou 1990). Other approaches use the number of hours spent caring or the type of care that is provided (Parker and Lawton 1990, Parker 1992). This distinction between different caregiving activities has important implications for policymakers since heavily involved carers are more likely to need support from service providers. Irrespective of what definition is used, the term carer used in relation to informal care is usually taken to mean a relative or a close family member. We turn now to explore exactly who within the family provides care?

Who within the family cares?

Recent statistics confirm that the family provides the majority of care for older people (Rowlands and Parker 1998, Bauld et al 2000, Hutton and Hirst 2001). Despite social and demographic changes that may have affected the numbers of people available to provide informal care (Parker 1990, Allen and Perkins 1995), there is little evidence to suggest that the family no longer cares (Wicks 1982, Evandrou et al 1986, Arber et al 1989, Evandrou 1997). Although the provision of formal services to older people has increased in recent years, this has largely been to support older people without families living nearby rather than replace family carers (Arber et al 1989, Nolan et al 2001).

This evidence challenges one of the most widely held misconceptions about contemporary society that holds that the family no longer cares for its older relatives as it used to in the good old days (Shanas 1979, Brody 1981, Litwak 1987, Richards 1996). So persistent and widely held is this belief that policymakers are still influenced by it almost thirty years after Shanas (1979) likened it to a '*hydra-headed monster*'. The evidence however, is overwhelming, family carers look after older people. Although it is obvious from the literature that friends and neighbours are important to older people, the amount of care they provide is limited (Bayley et al 1985, Bulmer 1986, Wilmott 1987, Wenger 1990a,b). Neighbours typically help with shopping and by keeping an eye on older people in the absence of a carer (Wright 1986, Levin et al 1989, Nocon and Pearson 2000).

The literature suggests that factors such as gender, marital status and living arrangements determine who within the family are most likely to become a carer. The carers of older people tend either to be caring for a spouse or parents / parents-in-law but the characteristics of these two groups are different.

A number of studies have confirmed the importance of spouse carers, thus leading to the suggestion that marriage is associated with a responsibility and a duty to care (Arber and Ginn 1989, Chappell 1990, 1994, Parker 1993, Opie 1994). Spouse carers have been identified as being the main source of co-resident care for dependent older people (Arber and Ginn 1990, Fisher 1994, Rowlands and Parker 1998). Moreover, the majority of spouse carers are older than other caregivers and likely to be retired (Arber and Ginn 1990, Parker 1992c). Data from the GHS suggest that over 70 per cent of them are over the age of 65 and 21 per cent were over the age of 75. Men are as likely as women to be a spouse carer, with 48 per cent of men and 52 per cent of women providing care for their partner. They were also more likely than other carers to have the main responsibility for care and to be involved in the most intensive forms of caring. Almost 80 per cent provided personal and/or physical care and three-quarters provide 20 hours or more of care a week. The heavy involvement of spouse carers arises from the fact that they live with the care recipient. Furthermore, local and national studies suggest that many carers in the older age groups are likely to be in poor health and are less likely to ask for help from formal services (Wenger 1984, 1989, 1990a, Tinker 1997). It is only when a spouse carer has not been or is no longer available that children of an older person may become the principal carer (Ungerson 1983a, Aronson 1992, Chappell 1990).

Research has suggested that daughters and daughters-in-law constitute the largest group of informal caregivers in the UK (Charlesworth et al 1984, Qureshi and Walker 1989, Arber and Ginn 1995). Indeed, the traditional image of a carer for older people is that of an unmarried daughter living in the parental home (Lewis and Meredith 1988, Parker 1990). Parker's (1992) analysis of carers of older parents supported this stereotype. She found that the majority were daughters of working age of between 45 and 65. This fitted with other studies that found the average age of carers to be between 55-65 (Bland and Hudson 1994, Fisher 1994).

The living arrangements of married adult children also determine who might become a carer. Unmarried sons and daughters who have never left the parental home are more likely than their married siblings to become a carer for frail parents (Wright 1986, Qureshi and Simons 1987, Arber and Ginn 1990). In their sample of carers, Qureshi and Simons

(1987) found that half the children who were living with their elderly parent had done so all their lives. The remaining children were slightly more likely to have moved in with their parents, for example after divorce, than they were to have had their parents to live with them. Three quarters of Lewis and Meredith's (1988) sample of caring daughters had either lived with their parents all their lives or moved in with them before the onset of major disability. Aronson's (1990) study portrays a similar picture. Living together is thus more likely to be the context within which the need for care arises than a deliberate response to the need itself.

Although sons and older men are more involved in caring than was previously thought (Wright 1986, Arber and Ginn 1990, Fisher 1994), feminist writers claim that women perform most of the caring that takes place in a domestic setting (Finch and Groves 1980, 1983, Baldwin and Twigg 1991, Graham 1991, 1997). However, the 1985 and 1995 GHS found little difference between the numbers of men and women who said they were carers: 12 and 15 per cent respectively, or 2.5 million males and 3.5 million females. (Green 1988, Rowlands and Parker 1998) Yet these similarities between male and female carers are deceiving. In terms of the kind of help and support given, they are completely different.

Arber and Ginn's (1995) secondary analysis of the 1990 GHS data suggests that men and women are equally likely to provide informal care for someone in the same household, but a higher proportion of women than men provide care for someone living in another household. It was also found that women are far more involved in the 'heavy' end of caring, while men have lighter responsibilities and spend less time discharging them (Green, 1988, Parker and Lawton 1994, Arber and Ginn 1995).

A picture of a typical carer at the heavy end of caring has been produced from Parker and Lawton's (1994) secondary analysis. This suggests that a typical carer is likely to be a married woman, aged 46 years or over and caring for 20 hours a week or more for at least 3 years. She is also likely to be the sole or main carer living in the same household as the cared-for person. This analysis certainly lends weight to the assertion that women provide the majority of care but this does not mean that the contribution to informal care made by men is unimportant.

However, recent research suggests that the population of informal carers is constantly changing (Hirst 1998, Hutton and Hirst 2001). Evidence from the British Household Panel Survey (BHPS) show that more than a third of carers either take on or cease caregiving every year, and that heavily involved carers, those caring for more than 20 hours a week,

are even more transient. Whilst these findings suggest that caregiving might be short-lived, a minority of carers provided care for long periods of time. Data from the 1995 GHS shows that 24 per cent of all carers had been caring for ten years or more and a further 23 per cent for between five and nine years (Rowlands and Parker 1998:25). The findings of a recent study examining Crossroads Care attendant schemes were similar. They found that 52 per cent of carers using the service had been carers for at least five years, more than a third had been caring for ten years or more, while 9 per cent had been caring for more than twenty years (CHSR 1997).

Becoming a carer

There appears to be an increasing awareness within policy and academic literature that the transition into a caring role is a crucial phase (Askham 1998, Banks 1999, Brereton and Nolan 2000, Department of Health 1999, Gilles 2000). Linked to this is the notion of choice. The intention of the UK government as stated in the National Strategy for Carers is to 'support people who choose to become carers' (Department of Health 1999). However, the way in which a caring role is assumed has implications for the degree of choice that can be exercised.

The reality is that people do not make an informed or positive choice to become a carer. That is, people fail to fully consider the choices available and the implications that caring may have for them and other family members (Tamborrelli 1994, Twigg and Atkin 1994, Opie 1991, Gilles 2000). Consequently, most carers take on their role in a state of 'initial innocence' (Tamborrelli 1994), with no real idea of the possible demands it will place on them (Twigg and Atkins 1994, Opie 1991). According to these studies many carers 'drift' (Lewis and Meredith 1988, 1989) or 'slip' in to their role, with the transition from non-carer to carer being 'imperceptible' (Murphy et al 1997, Schofield et al 1998). In conditions with an insidious onset such as dementia, taking on a caring role is not a sudden decision. Rather, in the case of spouse carers in particular, it is a continuation of a relationship where the level of dependency had grown progressively (Nolan et al 1996, Gilles 2000). In other situations, the process of becoming a carer happens almost instantaneously when for example, an older person suffers from a sudden and unexpected accident or illness (Qureshi and Walker 1989, Nolan et al 1996, Brereton and Nolan 2000).

Reasons for Caring

Studies of carers found that particularly in crisis situations, the choice to care is often a passive one based either on the belief that there is no one else or that there are no acceptable alternatives (Ungerson 1983, Lewis and Meredith 1988, Motenko 1989, Aronson 1990, Braithwaite 1990). The willingness of families to care in such circumstances is usually taken for granted (Walker 1992, Tamborrelli 1994, Warner and Wexler 1999, Brereton and Nolan 2000). However, a synthesis of the literature suggests that three main factors motivate carers to accept the role; a sense of obligation, attachment and reciprocity.

Care as obligation

While there is in theory, an element of choice over whether or not an adult child assumes responsibility for a frail parent, in reality societal expectations often compel people to accept it is their role or duty. Kinship obligation is the factor that determines an involvement in informal care, and is usually what prevents carers ending or changing their situation (Qureshi and Walker 1989, Finch 1989, Opie 1994). Obligation refers to a situation where caring is performed as a social and moral duty, rather than evolving from a desire to sustain an important caring relationship (Finch 1989, Opie 1994, Orme 2001). The literature confirms that caregiving may take place because of kinship obligation despite the absence of positive emotions towards the recipient of care (Qureshi and Walker 1989, Finch and Mason 1990, 1993 Parker 1993, Tronto 1993, Orme 2001).

Whilst other family members are often regarded as potential alternative carers, it has been shown that once a person assumes the responsibility to care, other relatives retreat, leaving one person as the main or principal carer (Ungerson 1987, Qureshi and Walker 1989, Parker 1993). Qureshi and Walker (1989) claim that a 'caring hierarchy' determines who becomes a carer. Based on a local study of older people Qureshi and Walker demonstrate that decisions about who should provide help to older people are made in accordance with a consistent hierarchy of preferences among available network members. They outline a hierarchical decision model of caregiving, which is underpinned by two powerful normative beliefs within which there is strong pressure on families to conform. Firstly, there is a prevailing belief that children have a general responsibility or obligation to care for their parents in old age. Secondly, there is the assumption of the primacy of women over men and specifically daughters over sons, as caregivers within the family. Because this model of family care is based on the supposition that these are normal obligations to be

fulfilled, many carers are reported to have developed feelings of guilt when they recognise they cannot accept these tasks as part of normal family duty (Parker 1993, Twigg and Atkin 1994, Dalley 1996).

This hierarchical model has been challenged by Finch and Mason (1993). In exploring the manner in which help and assistance is organised within families, Finch and Mason (1993) found no agreement amongst a representative sample of the British population about what obligations or responsibilities are attached simply to being an adult child. They claim that there is no clear consensus about the division of responsibility nor are there universal normative rules. Rather, in their alternative model a delicate and dynamic process of negotiation occurs in which the family history and biography interact, resulting in the development of commitments over time. They identify a number of components to the negotiation process foremost amongst which are reciprocity and balance, which underpin the giving of and asking for help. Finch and Mason conclude that there are no rules of obligation in terms of rights or duty, but rather guidelines for action, based upon responsibilities that have been created over time. According to this model, family members develop different commitments with each other and their response to the need for caregiving will be dependent on the level of commitment established over time rather than a fixed obligation to help based on kinship and gender (Finch and Mason 1993).

The differences in these two models may be due to the characteristics of each studies sample. While Qureshi and Walker conducted qualitative interviews with a self-selected sample of people who were already caring for an older person, Finch and Mason surveyed 2000 members of the general population followed by interviews with only 80 carers. This suggests that the response of respondents in Finch and Mason's studies are based on anticipated action rather than actual practice. In other words, when faced with a hypothetical situation, people's beliefs about how they would react might be different than when faced with the real thing. The responses of carers in Qureshi and Walker's study were based on actual experience. What the two studies do have in common though was the extent to which relationships were characterised by attachment and reciprocity.

Care as attachment

Bonds of affection or attachment are a motivating factor underpinning caregiving (Ungerson 1983, 1987, Cicirelli 1981, 1986, Braithwaite 1990, Selig 1991, Parker 1993). Attachment theory was originally used by Bowlby (1973) to explain the bonds between young children and their mothers. In later work however, Bowlby concluded that

attachment does not end in early childhood but continues throughout the entire lifespan (Bowlby 1973). Building upon Bowlby's work, Cicirelli (1986, 1992) uses attachment theory to explore caregiving relationships between adult children and their parents.

Attachment is described as a stable internal state within an individual that is inferred from that person's tendency to seek close contact with or to be near the attached figure (Cicirelli 1986). Cicirelli's view of attachment within caregiving suggests that in adulthood, feelings of closeness along with attachment behaviour can be used as proof of an affectionate bond between two people. According to this theory, sons and daughters will visit and communicate more with their parent and undertake caregiving when feelings of affection and attachment are strong (Cicirelli 1986, Selig 1991).

Distinguishing between affection and obligation in caregiving relationships Cicirelli (1986, 1992) maintains that relationships based on obligation alone tend to be perfunctory in comparison to relationships enriched by affection and trust. He claims that whilst cultural norms and expectations play an important part in shaping adult children's behaviour towards their elderly parents, without affection obligation alone was more likely to result in abusive relationships, if care is provided at all. In relationships characterised by a lack of affection and attachment, adult children are more likely to walk away from caregiving. Thus a relative's response to the need for caregiving is determined by the history of the relationship and their attachment to the care recipient (Cicirelli 1986, 1992, George 1986, Selig 1991).

Care as reciprocity

Reciprocity is another main reason for caregiving relationships (Abrams 1978, George 1986, Antonucci and Jackson 1989, Grant and Nolan 1993). Its importance is illustrated by Young and Wilmott's (1964) seminal study into the family lives of people living in London's west end. The study describes the mutual benefits fostered by three generation families. The picture portrayed by Young and Willmott's study is confirmed by others (Townsend 1957, Qureshi and Walker 1989, Nolan et al 1996).

Reciprocity is defined as a social relationship between individuals in which there is a mutually beneficial exchange of goods or services between two parties. Gouldner (1973) describes it as a fundamental principle guiding human behaviour, which decrees that people should help those who have helped them. The norm of reciprocity therefore directs human behaviour as well as reinforcing exchanges within relationships (George 1986).

The concept has been used particularly to explain the dynamics of help and support passing between family members (Gouldner 1973, Abrams 1978, Cicirelli 1986, Antonucci and Jackson 1989, Grant and Nolan 1993, Uehara 1995). Abrams (1978) describes informal care as being produced and sustained by a 'productive balance of reciprocity, affect and trust'. The care given to older people in particular, is seen as the result of an often pre-established relationship in which mutual assistance may have been given and received many times. According to Blau (1964 in Qureshi and Walker 1989) one function of such giving and receiving over time is the establishment of bonds of gratitude and affection which make the exchange more rewarding when carried out with some individuals rather than others. George (1986) claims that when reciprocity is not present, individuals will withdraw from interactions and relationships, which have become unrewarding (George 1986). This suggestion does not fit with other studies that found caregiving takes place in the absence of reciprocity (Quershi and Walker 1989, Finch and Mason 1993). In fact the absence of reciprocity has been cited as an explanation for elder abuse within caregiving relationships (Jack 1984, Cicirelli 1986, George 1986, Biggs et al 1996).

Models of Care

What is evident from the literature reviewed so far, is that informal caring arises as a result of a familial relationship. Yet, theories about caring tend to be dominated by professional conceptualisations, which focus on the more visible instrumental aspects of care. However, some models of care have been devised in an attempt to promote a greater understanding of the informal carer's experience (Bowers 1987, 1988, Tronto 1993, Nolan et al 1994). These models tend to conceptualise informal caring as a dynamic process with temporal and longitudinal dimensions.

Tronto's (1993) analysis of the 'interconnected, but analytically separate phases' of caring describes the process of caring when both the activity and disposition of care are present. Tronto's phases of caring are; caring about, taking care of, caregiving and care receiving. *Caring about* involves the recognition in the first place that care is necessary. It involves noting the existence of a need and making an assessment that this need should be met. Caring about will often involve assuming the position of another person or group to recognise the need. Caring about can be thought of in highly individualistic terms but it can also describe society's approach to problems. *Taking care of*, the next step in the process, involves assuming responsibility for the identified need and determining how to

respond to it. Rather than simply focusing on the need of the other person, taking care of involves the recognition that one can act to address these unmet needs. If one believes that nothing can be done about a problem, then there is no appropriate taking care of which involves the notion of responsibility in the caring process.

Care-giving involves the direct meeting of needs for care. It involves physical work and almost always requires that carers come into contact with the recipients of care. Care-receiving is the final phase of caring which recognises that the recipient of care will respond to the care they receive, for example, the patient feels better or more comfortable. Tronto claims that it is important to include care-receiving as an element of the caring process because it provides the only way to know that caring needs have actually been met. Whilst Tronto's approach takes a very detached objective view of caring, it does nonetheless encourage us to view caring as a dynamic and interactive process. However, the extent to which taking care of and care giving can be analysed separately is questionable. These phases of informal caring are essentially the same thing in that both involve the recognition of and meeting the needs of the care receiver. Moreover, this approach does little to contribute to our understanding of the complexities of care or carers experiences.

It is from within the literature on dementia that the majority of longitudinal models of caregiving have emerged. Bowers (1987) model for example, explores the meanings and purposes of care as defined by informal carers themselves. Data were collected from mainly female adult carers looking after their frail older parents who had recently been hospitalised and who had varying degrees of dementia. Bowers argues that previous typologies were based on the nature of caregiving activities, but that this emphasis did not correspond with informal carers' accounts. She concluded that the process of caregiving was much more complex than these simplistic models of caring suggested and that purpose rather than task should differentiate informal caring.

Bower's typology has been criticised on three accounts. Firstly, that it is confined to carers of older people with dementia. Secondly, that it is not applicable to a wider population of carers. Thirdly, that by failing to adopt a longitudinal perspective it limits certain types of care to the early stages of the caregiving process (Given and Given 1991, Nolan et al 1995, 1996). Yet, the fact that it focuses solely on older people with dementia might help to explain some of her findings. Moreover, some of these criticisms are from others such as Nolan et al (1995, 1996) who have adapted Bower's typology for their own use. Yet despite the claim that their typology of care is applicable to carers of all client groups, their

own extended model, based on Bowers work, was supported by evidence from a number of studies of carers of people with dementia and learning disabilities. Moreover, the following models, whilst conceptualising care as a process, are based on descriptions of the type of care provided rather than the stages of the caregiving process.

Bowers outlines five distinct but overlapping types of informal care. Her first category is anticipatory care. This is based on anticipated future need, with the main notion being 'just in case'. Anticipatory care can begin many years before any actual help is required and as such, it is deliberately kept from the individual who is the focus of attention. It can however, have profound effects on carers' lives as major decisions can be influenced by the anticipated future needs.

The second type of care in Bower's model is preventative care. The main component of this is monitoring at a distance. As with anticipatory care, this does not involve direct observable assistance and therefore the care recipient may remain unaware of its existence. Examples of this type of care are ensuring that medication regimes are being complied with or that adequate food is being consumed.

Supervisory care has been reached when a monitoring role requires more direct intervention, such as help with actually taking or dispensing medication. At this stage, the care recipient is more likely to be aware of the intervention but carers may still try to minimise such awareness. As the need for direct assistance increases and the carer has to 'do for', then the stage of instrumental care has been reached. The care recipient is now largely aware of their need for assistance but carers will often try to maintain an element of reciprocity in their relationship.

Underpinning Bower's entire model is the notion of protective care, the purpose of which is to maintain the self-esteem of those being cared for. This entails maximising the extent to which they still perceive themselves as independent and minimising their awareness of their failing abilities. According to Bowers, carers perceive protective care as the most difficult, the most important and the most stressful. Moreover, it is frequently in conflict with other aspects of caregiving, in particular the instrumental functions. It can for instance, be very difficult both to do something for someone while, at the same time, maintaining their perceptions of independence. Carers would sometimes prefer to ignore certain instrumental tasks in order to preserve protective caring. In a later paper Bower's (1988) replaced protective care with preservative care, which is based on the need to preserve the care recipient's sense of 'self'. Types of preservative activity, which were

intended to help maintain the care recipient's dignity, hope and sense of control, are described.

Although the first three types of care in Bower's typology have been overlooked in previous research, her model illustrates the more complex interactions that take place in the informal domain. Moreover, current literature supports many of Bower's arguments in relation to the notion of anticipation. It has been suggested that the anticipation of caring responsibilities is a feature of ordinary family life. It may occur several years before any care might be needed and irrespective of whether such help is ever actually required (Finch 1989, Aronson 1990, Finch and Mason 1993, Turner and Karasik 1993).

Lewis and Meredith (1988) describe phases of caring that are similar to Bower's (1987) preventative and supervisory care. They call these phases 'semi-care', 'part-time full care' and 'proper care'. They claim that in semi-care there is usually little or no need for physical support but daughter's monitor the situation 'just in case', a term also applied by Bower's to anticipatory care. Semi-care can continue for several years and along with part-time full care, precede proper care. While this study provides support for Bower's typology, others have adapted it.

Nolan et al (1995, 1996) have expanded Bower's model of care by redefining some of the categories of care and adding others not included in the original model. They claim that their reconceptualisation is applicable to a more diverse set of caregiving circumstances. The eight dimensions of Nolan et al's typology are: anticipatory care, preventative care, supervisory care, instrumental care, protective, preservative, (re)constructive and reciprocal care. Although Bowers categories remain central to the typology, they have redefined anticipatory care whilst retaining both protective and preservative care. Two new categories added are reconstructive and reciprocal care. According to Nolan et al these constitute the broad types of care used by family carers. Nolan's description of anticipatory care differs from Bowers in terms of its duration. While Bowers sees this type of care being confined to the early stages of caring, Nolan et al (1996) maintain that it extends throughout the caregiving history and that in fact it changes in character as time goes on. While Bowers sees the main concept underpinning anticipatory care 'just in case', Nolan et al see it as 'what would I do if' or 'what will I do when'.

Bowers saw protective care as being primarily concerned with protecting the care recipient from the knowledge that they are becoming more dependent. Yet in Nolan et al's typology, protective, preservative and reconstructive care are believed to have a temporal

relationship. They argue that while protective care might be functional in the short term, it is nonetheless, of limited value and duration, that there comes a point at which denying dependency is no longer possible. Preservative care has a key and worthwhile role in maintaining the self-esteem of the care recipient, an issue that is of importance to carers. However, as with protective care, preservative care is possible and useful up to a point, past which it becomes potentially damaging. This is the point at which Nolan et al contends that preservative care shades into reconstructive care. Reconstructive care builds on the past but also seeks to develop new roles for care recipients. Informal carers' work hard at preserving and reconstructing the self-esteem of care recipients but the manner in which they respond to their limitations determines the success of a caregiving relationship.

The type of care uniting the various dimensions of the typology is reciprocal care. This, according to Nolan et al (1995, 1996) is the major limitation of Bower's model and is an element in caregiving relationships often overlooked by others. George (1996) for example, assumes that dependency on others means that care is not provided on a reciprocal basis. Whilst direct exchange of the same type and level of care is unlikely, the supposition that there is no reciprocity in caring is based only on the notion of instrumental care. Claims have been made that reciprocity exists in caring relationships at the financial, material and psychological levels (Abrams 1978, Cicirelli 1986, Grant 1986, 2001, Selig 1991, Uehara 1995).

Other models, again from the literature on dementia, explore the sequential stages of the caregiving rather than the type of care provided. Wilson's (1989) work, based on a small-scale study of twenty carers, describes an eight-stage model of care. These stages are; noticing, discounting or normalising, suspecting, search for explanations, recounting, taking it on, going through it, and turning it over. In a later study, Willoughby and Keating (1991) suggest a five stage model comprising of; emerging recognition, taking it on, gaining control, relinquishing control and letting go. This model however, being concerned primarily with admission to long term care, focuses mainly on the processes of 'taking it on' and 'relinquishing control'.

In order to understand how caring changes over time Keady and Nolan (1993, 1995) outline a longitudinal model of the key transition points in caregiving. This model is based on in-depth interviews with fifty-eight dementia carers in contact with formal service providers. The six stages of this model are; building on the past, recognising the need, taking it on, working through it, reaching the end and finally, a new beginning. Rather than concentrating on the beginning and ending of caregiving, this model explores each

stage of the process. The authors contend that caregiving must be conceptualised in this way in order to develop effective, stage-specific service interventions (Keady and Nolan 1993, 1995, Nolan et al 1996). Although this model was developed from a sample of dementia carers, the authors believe that it can be applied to other caring situations.

While the models outlined above have been derived from small-scale studies of service users, they are nonetheless, valuable in encouraging caregiving to be conceptualised as a process rather than simply instrumental activities. Although the models use various terms, there are more similarities than differences in the stages they describe. They all highlight the gradual way in which caregiving evolves over time in response to the care recipients' increasing needs.

Conclusion

From this review it would appear that there are more similarities than differences between the informal and formal theories of care. The concepts and models discussed above suggest that both domains consist of a number of similar dimensions such as, attitudes, behaviours, attributes, types and stages of care, all of which cannot be easily defined or measured. Moreover, there is a concern in both the informal and formal caring literature that it is the visible, instrumental aspects of care that are most recognised and measured while the less visible, affective components tend to be overlooked.

The majority of models of informal caregiving are essentially limited to task based conceptualisations. Even those that claim to demonstrate a more 'sophisticated understanding' (Parker and Lawton 1994) seem to focus on the physical dimensions of caring. However, this instrumental approach fails to portray the interactive nature of informal caring (Given and Given 1991, Nolan et al 1996). Some authors have sought to understand caring by purpose and aspect rather than by task (Bower 1986, 1988, Nolan et al 1996, Wenger et al 1996). Yet these models have emerged from the literature on dementia, a degenerative condition with a recognised pathway. So whilst these models map carers experiences in line with the condition's progress, they fail to address the temporal and dynamic nature of caring for older people without any cognitive impairment, people whose descent into frailty and increasing dependency is not assured.

The lack of temporal and longitudinal models of caring has been noted by a number of authors (Given and Given 1991, Tarborelli 1993, Thompson et al 1993, Opie 1994). Whilst Bowers (1987, 1988) and Lewis and Meredith (1988, 1989) have taken what might be broadly termed a temporal view, their studies use a retrospective approach rather than a longitudinal one. The majority of studies that do adopt a longitudinal design tend to be quantitative, descriptive research, which fail to capture the individualistic experiences of carers (Bauld et al, 2000, Hutton and Hirst 2001).

The need to develop a temporal understanding of the caring process is recognised (Given and Given 1991, Thompson et al 1993, Greene and Coleman 1995, Nolan et al 1996). While the current literature documents the temporal nature of caring for people with dementia, it overlooks the experiences of carers of older people. The current literature fails to address the way in which experiences and relationships of carers of frail older people change over time. There is a need to understand the way in which their experiences and relationships might differ, if at all, from those of dementia carers. What are needed are models of care, which would illustrate the dynamic and temporal nature of their caregiving experiences.

This chapter has explored theories of care. The following chapter will now review the literature on the experience of caregiving.

2. The Experience of Caring

Early studies of informal carers were simple descriptive ones, which focused on the experiences of caring for mentally handicapped and physically disabled children (Glendinning 1983, Baldwin 1985). Increasingly sophisticated explanatory and evaluative studies about the experience of being a carer followed (Nissel & Bonnerjea 1982, Wenger 1984, Ungerson 1987, Glendinning 1992, Twigg and Atkin 1993, Parker 1994). These early studies of informal care emphasised the daily grind and burden that caring placed on the carers (Glendinning 1983, Finch and Groves 1983, Graham 1983, Levin et al 1984). This perception arose mainly as a result of a focus on carers of people with physical disabilities, care recipients whose needs involved help with personal and physical care. More recently however, there has been increasing recognition that caregiving can also be a rewarding experience (Motenko 1989, Grant and Nolan 1993, Cohen et al 1994, Nolan et al 1996). This chapter will discuss the practical aspects and the consequences of caregiving. It will also consider the growing body of literature on the rewards and satisfactions of caring, before concluding with a consideration of carers' responses to their role.

Care as Tasks

There is a widely held assumption particularly in the British policy literature, that family care can be reduced to a series of tangible tasks. An example of this is the practice guidance accompanying the Carer (Recognition and Services) Act 1995. The Act makes provision for carers with a 'substantial and regular' commitment to caregiving to have an assessment of their needs (Social Services Inspectorate 1996). The policy guidance suggests that the interpretation of 'substantial and regular' should include reference to the types of tasks undertaken, the time involved, the associated supervision, and whether this represents a continuing commitment from the carer. The implication is that the number of tasks undertaken is related to carers' commitment. This focus on tasks is misleading because empirical evidence suggests that carers' commitment cannot be adequately explained either by reference to the number of tasks undertaken or the 'dependency' characteristics of the care recipient (Motenko 1989, Nolan et al 1990, Grant et al 1998). Moreover, the purpose of some of the main caregiving tasks is to preserve the dignity and

self-esteem of care recipients (Bowers 1987), outcomes which tend to remain invisible to professional assessments. Thus to focus on the tangible aspects of caring such as the performance of tasks, means that the intangible dimensions are overlooked.

Although the performance of tasks has become the defining feature of caregiving, it has been suggested that informal care involves activities that go beyond the normal reciprocities common between adults (Wright 1986, George 1986, Twigg and Atkin 1993). In practice, informal care involves carrying out tasks such as washing, dressing, feeding and lifting that people cannot do for themselves and that have been described in detail by other studies (Nissel and Bonnerjea 1982, Wright 1986, Lewis and Meredith 1988, Twigg 1989, Parker 1993). Linked to this practical aspect of care is the perception that caring often involves hard physical labour (Graham 1983, Pitkeathly 1989, Twigg and Atkin 1990), and that it is in fact a 'labour of love' (Graham 1983) or what Land and Rose (1985) call 'compulsory altruism'. In an attempt to quantify the practical aspects of caregiving Parker and Lawton (1994) undertook a secondary analysis of the 1985 GHS data in which caring activities were coded into eight main areas. Personal care was taken to mean help with dressing, bathing and toileting, while physical help referred to assistance with walking or getting in and out of bed. Practical help was defined as help with preparing meals, shopping, housework and household repairs. Help with paperwork, keeping the care recipient company, or keeping an eye on them were regarded as separate categories as were taking the cared-for person out, and giving medicines (including injections) or changing dressings. These tasks were used to develop a typology of caregiving activities consisting of six mutually exclusive categories:

- Personal and physical care
- Personal not physical care
- Physical not personal care
- Other practical help
- Practical help only
- Other help

This typology provides a measure for the level of involvement based on caring activity, with those giving personal and physical care being the most involved and those giving other help the least. Based on this typology, 69 per cent of carers providing personal and physical care were caring for 20 or more hours per week. By contrast, types of help not involving personal and physical care were much more likely to be associated with lower levels of involvement, for example, more than 70 per cent of those providing other practical help were caring for less than 10 hours a week. Co-resident carers were more

likely to be providing personal and physical care. The total of 1.29 million people providing personal and/or physical care is close to the estimates of the numbers of carers at the 'heavy end' of caring, produced before the 1985 GHS and also to the estimates derived from disability surveys (Parker 1990).

Parker and Lawton (1994) also found that women were more likely to be involved in providing personal and physical care, while male carers were more likely to provide physical not personal care and practical help only. In terms of the care recipients, males were more likely to receive personal not physical care, while women were more likely to be receiving practical help only. The age of the care recipient and the type of care being provided were strongly associated. Older care recipients, that is aged 65 and over, were more likely to receive practical help. The finding that older people are more likely to be in receipt of practical rather than personal forms of care echoes findings from earlier research that suggested that it is domestic rather than personal care tasks, which present many older people with problems. It also supports research that demonstrates the extent to which older people strive to retain their independence (Wenger 1984, Quershi and Walker 1989, McDonald 1999).

Personal care

The literature is equivocal about whether personal care is more problematic than care of a physical or practical nature. Twigg defines personal care in a simple straightforward way as 'self-care' or 'the things that an adult would normally do for him or herself' (Twigg 2000b:44). However, recent policy documents have used a more flexible and all encompassing definition. The definition of personal care contained in the Community Care and Health Act 2001 is based on the one used by the Royal Commission on Long Term Care. However, it differs in that it takes account of the needs arising from cognitive impairment and behavioural problems as well as physical frailty. It also places importance on counselling and psychological support particularly for people with dementia. Thus the definition of personal care used in Scotland differs from that used by Social Services departments in England and Wales. It defines personal care in terms of six dimensions:

- Personal Hygiene - bathing, showering, hair washing, shaving, oral hygiene and nail care.
- Personal assistance – assistance with dressing, surgical appliances, prostheses, mechanical and manual aids including hoists. Assistance to get up and go to bed.

- Continence Management - toileting, catheter care, skin care, incontinence laundry and bed changing.
- Food and Diet – assistance with; eating, special diets. Managing different types of meal service, and with food preparation.
- Problems of immobility – dealing with the consequences of not being able to move.
- Simple treatments – assistance with medication, eye drops, application of cream and lotions, simple dressings, and oxygen therapy.

(Scottish Executive 2001)

Whilst this definition is deemed to meet the needs of older people in Scotland for personal care services, it essentially describes the range of tasks that might be undertaken by either informal caregivers or home carers employed by formal providers.

Whether or not personal care is perceived as problematic depends on the nature of the caregiving relationship (Atkin 1992, Parker 1994). The relationship between a child and parent sets up a different set of expectations than in other kin relationships. What is acceptable for a parent to do for a child is different from what a child might be expected to do for a parent. So care involving tasks of a personal and intimate nature is less likely to be seen as a natural part of an adult child's relationship with their parent (Wright 1986, Lewis and Meredith 1988), whereas for parents it is a conventional part of their relationship with younger children (Atkins 1992). An adult child's relationship with a parent also differs from a spouse relationship. There is a greater tradition of independence between adult children and their parents, and often each has established separate lives before the need for care arises (Aronson, 1990, Abel 1990, Parker 1992, Twigg and Atkin 1993). There are therefore, greater expectations of privacy, autonomy and separation than in a marriage relationship (Twigg and Atkin 1992, 1994). According to recent research, difficulties with personal care may stem from the fact that it erodes the cared-for person's status as an adult. Carers want to continue experiencing their relative as the person they always knew and that usually meant a fully clothed person who managed their own personal needs, and to whom they related in a sociable way (Twigg 2000).

Cross-sex caring

Cross-sex caring has been identified as being particularly problematic (Wright 1986, Ungerson 1987, Parker 1993). Cross-sex caring of a personal and intimate nature is

awkward because providing personal care for a person of the opposite sex may violate cultural taboos and social expectations (Ungerson 1983, 1987, Twigg 2000). These taboos and expectations mean that what men do for women in relation to bodily contact is more highly constrained than what women do for men. Moreover, personal care is associated with nakedness and touch, concepts that are particularly associated with sexual intimacy. This means that in a social context to be naked usually contains some erotic connotation. The implication of this is that eroticism often conflicts with social expectations about relationships and the kind of intimacy that personal care creates. Nakedness and touch in the course of bathing is not erotic and is therefore more likely to be seen as disturbing (Twigg 2000a). Men have traditionally been seen as the sexually active partner in the sense of being the instigator or predator. Women on the other hand, are seen as being more vulnerable and passive. Thus, as a result of being tied up with sexuality, cross-sex caring appears to be more problematic when provided by men for females than when women provide it for men (Ungerson 1987, Parker 1993, Twigg and Akin 1994, Twigg 2000a). Parker (1993) suggests that providing personal care is easier for some women caring for dependent men because it may be viewed in terms of a mothering relationship.

In contrast, personal care within marriage has been deemed to be less of a problem because of the intimate nature of the relationship (Ungerson 1983, 1987). The marriage relationship, being the prime location of care, particularly for older people (Arber and Ginn 1990, Parker 1993) seems to be associated with an expectation and duty of care. Caring for a spouse tends to be seen as a natural extension of the love and support that is a mutual expectation of marriage (Arber and Ginn 1990, Parker 1993). Marital relationships also encompass privacy within the confines of the home, and a taken for granted assumption of 'togetherness' rather than leading separate lives. Because of these factors, Ungerson maintains that cross-sex caring is not problematic for married partners (Ungerson 1983, 1987). This view has been challenged by others who argue that far from intimate care being unproblematic for spouse carers, it was fraught with even more problems than those faced by adults caring for their parents (Parker 1993, Twigg 1992, 2000). In Parker's (1993) study spouse carers undertaking intimate and personal care found it embarrassing and damaging to the relationship. These difficulties she suggests, stem from the complexities of a relationship where intimacy has often been replaced by personal caregiving.

Consequences of Caring

Another key area of the caregiving experience focuses on the consequences of caring. The consequences of caring in terms of employment, finances and health have been explored by a number of studies (Nissel and Bonnerjea 1982, Joshi 1987, Glendinning 1992, Askham et al 1992, Phillips 1994, Hutton and Hirst 2001). The employment and financial status of carers are closely linked. Studies on the employment and financial consequences of caring are important because as a group carers tend to be economically dependant on the household as a whole, with little more than 1 in 8 having any significant level of economic independence from the household (Warner 1995).

Consequences of caring on employment

Until the late 1980s research on the consequences of caregiving tended to be small scale studies concentrating mainly on full-time caregivers who left the workforce in order to care and who were in receipt of formal services (Nissel and Bonnerjea 1982, Finch and Groves 1983, Levin et al 1983, Joshi 1992). Since then research on the effects of caregiving on the employment and financial status of carers has utilised nationally representative samples of carers and non-carers from larger data sets such as the General Household Survey (Green 1988, Ashkam et al 1992, Parker and Lawton 1994). More recently, Hutton and Hirst have used data from the British Household Panel Survey 1991-1995, the 1985, 1990, 1995 GHS, and the Family and Working Lives Survey 1995. This longitudinal data has allowed researchers to chart trends in the population of carers over time (Hutton and Hirst 2001).

The findings from these studies have been remarkably consistent. In general, carers are less likely to be in paid employment than non-carers (Green 1988, Parker and Lawton 1994, Evandrou 1995, Hutton and Hirst 2001). Among women, both married and unmarried part-time workers are more likely to be carers than full-time workers. This is particularly so as the duration of caregiving increases and where carers are providing 20 or more hours of care a week. For many it is the equivalent of two full-time jobs as 40 per cent of women were at the heavy end of caring and were in paid employment (Phillips 1994). Looking after a spouse or partner also reduces the likelihood of being employed (Askham et al 1992, Phillips 1995, Hutton and Hirst 2001). Among men, the proportion of carers was higher among non-employed than the employed, thus suggesting an association between caring responsibilities and withdrawal from the labour force. Only a third of men aged between 50 and 64 years provided twenty or more hours of care a week and had a full-time job (Parker and Lawton 1994, Askham et al 1992).

Consequences of caring on finances

It is clear from the literature that the economic impact of carers is usually as a result of lost work opportunities. Restrictions in employment affected caregiving daughters and women in general more than any other group (Askham et al 1992, Evandrou 1995, Rowlands and Parker 1998, Hutton and Hirst 2001). Employment was restricted by the need to take time off work to deal with crises, having to substitute a less demanding job for a career, having to work part-time or give up altogether (Lewis and Meredith 1988, Askham et al 1992, Phillips 1994).

Findings such as those outlined above led to further research on the financial costs of caring in terms of earnings and pensions. These studies suggest that as a result of their position in the labour market, carers are financially disadvantaged (Askham et al 1992, Evandrou 1995, Hancock and Jarvis 1994, Hutton and Hirst 2001). Compared to non-carers, carers' incomes from work tend to be less although personal and household income is less affected. Evandrou's study aimed to explore how far receipt of social security benefits compensate carers financially and places them on a par with non-carers. Her analysis showed that it did not compensate carers and that their mean net income was lower than that of non-carers (Evandrou 1995:31). Hence the standard of living in carer households tends to be lower and there is little evidence that carer incomes catch up after caregiving ends (Hutton and Hirst 2001).

Caregiving has long term financial consequences that reach into carers' retirement. Retirement incomes from state and private pensions are lower for both current carers and those who provided care earlier in their lives. This is essentially because they are less likely to make the necessary contribution to pension schemes. By using a secondary analysis of the 1989 Retirement Survey, Hancock and Jarvis (1994) studied the relationship between periods spent caring and periods spent working full or part time. They found there was a distinction between carers who had devoted many years to caring and those for whom caring lasted for shorter periods. Current carers who provide the most intensive levels of care had substantially lower incomes from savings than past carers. Long term past carers tend to have, lower incomes, to be in receipt of means-tested benefits, and spend less time in occupational pensions, than those who had cared for shorter periods. Co-resident women carers over retirement age are particularly likely to be in the lowest income band compared to other pensioners (Hancock and Jarvis 1994, Hutton and Hirst 2001).

Consequences of caring on health

The effect of caring on health is a contentious issue. On the one hand, there is a widely held perception that caregiving has a detrimental effect on the health of the carer (Charlesworth et al 1983, Levin et al 1983, Bowling and Brown 1991, McLaughlin 1994). In Levin et al's (1983) study of carers of older people, whose average age was 61 years, only a third rated their health as good and about half had disabilities which limited their activities. Similarly, in another study of older people, half the carers reported that their health was poor (Charlesworth et al 1983). Furthermore, a survey conducted on behalf of the Carers National Association found that two thirds of respondents said their own health had been affected by caring responsibilities (Warner 1994). Ex-carers have also reported suffering from physical health problems as a result of caring. Some said that their health problems continued or even started after the caring ended but clearly, some of these might have been reactions to the strain that the carers had been under (McLaughlin 1994, Warner 1994).

However, the relationship between health status and caregiving is complex. It is not always clear whether the reported deterioration in health can be attributed directly to the caring role. A review of the literature in this area suggests that caregiving has the potential to affect health in either a direct or indirect way. Direct effects on health include physical strain and musculoskeletal problems, as well as emotional strain from the overall caring experience (Cantor 1983, Levin et al 1989, Evandrou 1996). Caring can also have an indirect effect on health for example, through lower incomes, or where the care recipient lives with the carer, through overcrowded housing conditions. It is thought that the indirect link between health and caring may be influenced by a number of factors such as; the coping strategies adopted, the intensity of caring, the type of caregiving activity (personal, physical or practical), the nature and extent of the care recipient's incapacity, the duration of caring, and whether the carer is co-resident or not (Parker 1990, Evandrou 1996, Nolan et al 1996).

In contrast to these findings, other studies claim that carers can experience better health and functioning than non-carers. Nolan et al (1996) for example suggest that caregiving might have a positive effect on health through increased physical activity and/or mental well being. In another study Taylor et al (1995) found no systematic evidence of the 'deleterious effects' of caregiving on health. Indeed, their longitudinal study on a cohort of 55-year-olds, suggested a tendency in the opposite direction, that is, carers reported better health and functioning than non-carers. The authors suggest that caring is a selective

process in that many carers choose whether or not to take on or give up a caring role. Those who are in poor health or disabled are less likely to undertake caring than those who are fit.

Parker and Lawton (1994) suggest that previous research which has argued for a causal relationship between caring and current physical ill-health may have confounded the effects of caring with those of age and sex, both of which also influence health status. Using nationally representative data from the 1985 and 1990 GHS, studies that took account of age and sex differences, found that the self-reported health of carers as a whole was similar to that of non-carers (Parker and Lawton 1994, Evandrou 1996).

However, distinguishing between levels of caring responsibility and intensity of caring did indicate a relationship to health status. Parker and Lawton (1994) found that among the least heavily involved carers, females were slightly more likely than their peers to report a long standing illness. They suggest that some people may take on low-level caring because they are at home more due to an existing illness or disability that is not particularly limiting (Parker and Lawton 1994). Evandrou (1996) found that co-resident main carers, looking after someone with physical and mental impairments and caring for over 50 hours a week reported less good health in the last year. Being a spouse carer particularly increased the likelihood of reporting ill health (Evandrou 1996).

Recent research using data from the British Household Panel Survey (1991-95) provides new evidence that carers, and women in particular, are at greater risk of mental health problems (Hirst 1998, Hutton and Hirst 2001). Carers were reported to suffer from more anxiety and depression than non-carers. This risk rises progressively with the numbers of hours spent providing care each week. Moreover, distress levels in the carer population increase during the first year of caregiving and do not return to former levels as caring continues. Among those taking on full-time or continuous care, women are almost twice as likely as men to report increasing distress. Whilst the reasons for this are unclear, the authors suggest that differences in men and women's responses to their caring role, the types of care they provide and the support they receive, may all play a part (Hirst 1998, Hirst and Hutton 2000).

The relationship between caregiving and health status is complicated. The mixed results regarding the effects of caring on health have been attributed to a number of factors such as carer self selection and the presence of ex-carers in the non-carer population. However, while caregiving does not appear to have clearly defined effects on physical health, there is

evidence that it causes increased levels of emotional strain (Levin et al 1983, Gilleard et al 1984, Bauld et al 2000, Hutton and Hirst 2001). The literature relating to the mental health of carers focuses primarily on the concepts of burden and stress, which will be discussed in the following chapter. We turn now to consider the more positive consequences of caring.

Caring as a Rewarding Experience

Until recently, the literature on caregiving has focused predominantly on the burdens or difficulties of caring (Nissel and Bonnerjea 1982, Caro 1986, Kahana and Young 1990, Carlson and Robertson 1993). Because of this emphasis the potential satisfactions and rewards from caring have been overlooked. However, there has been increasing criticism of this trend and it has been suggested that a realistic picture will not emerge until the rewarding aspects of caring have been explored in greater detail (Motenko 1989, Summers et al 1989, Walker 1990, Grant and Nolan 1993). Moreover, whilst the evidence supports the view that many carers experience caring as stressful, this does not help us to understand why so many continue to care. There is a need to look for other explanations as to why it is that despite the stressful nature of caregiving, carers are reluctant to give it up (Twigg and Atkin 1994).

A review of the literature suggests that caregiving is not a wholly negative experience. Positive aspects of caring have been included in a number of studies but the definition and measurement of the concept has varied (Motenko 1989, Cohen et al 1994, Coleman et al 1994, Nolan et al 1996). In Coleman et al's (1994) study of co-resident carers of older people, qualitative data were analysed for 'positive and negative effects of the internal and external' caregiving environment. While Motenko (1988) explored the 'frustrations and gratifications' spouse carers derived from caring using quantitative well being measures. Others have analysed the 'hassles and uplifts' of caregiving (Cohen et al 1994).

These studies provide increasing evidence that the majority of carers do experience some positive rewards from their role (Motenko 1989, Clifford 1990, Grant & Nolan 1993, Nolan et al 1996). The percentage of carers deriving satisfaction from caring varies from 55 per cent (Cohen et al) to over 90 per cent (Clifford 1990). Furthermore, it has been claimed that carer satisfaction is related to; improved carer well-being (Gilhooley 1986, Motenko 1989), an increased personal commitment to the caring relationship and a

reduced likelihood of the cared-for person being institutionalised (Gilhooley 1987, Langan et al 1995, Nolan et al 1996, Wright 2000). In other words, the presence of satisfactions may be an important factor in carers' ability to cope (Motenko 1989).

In some of the earliest caregiving literature, the rewards and satisfactions of caring were only occasionally alluded to. Although Nissel and Bonnerjea's (1982) small study of people caring for their elderly parents focused on the difficulties of caring, they nonetheless stated that:

'Underlying the complaints and difficulties there was so often, in addition to a strong sense of kinship, an affectionate relationship with the relative and satisfaction with the caring role'

(Nissel and Bonnerjea 1982:30)

There are some who have been described as 'joyful carers' (Ungerson 1983), or 'enriched carers' (Archbold et al 1992), some who are stoical, and others who are matter of fact about what they have to do (Eagles 1987, Sinclair 1990). Similarly, 75 per cent of Levin et al's (1989) sample identified aspects of their role, which gave them satisfaction. These were thought to result from feeling that they were doing their duty, thankfulness that they were in a position to help, seeing the dependent happy, well cared for and comfortable, and knowing that the care recipient was grateful and appreciative. Other studies have reported similar findings.

Cohen et al (1989) study of caregiving spouses identified four positive aspects of caregiving; gratification derived from the present relationship, from seeing a desirable outcome such as the cared-for staying at home or appearing happy, from the acts of caregiving and from caregiver ideology or the reasons for caring. The most enjoyable aspects listed by caregivers in Cohen et al's (1989) study related to the relationship itself and the desire to see positive outcomes for the cared-for person. A sense of satisfaction with the practical tasks of caregiving was the least frequently identified aspect.

Crookston's (1989) survey of 159 carers of older social services clients, also found that the majority could find something positive to draw from the caring experience. Similarly, in Clifford's study (1990) into the costs of caring, nearly 80 per cent of carers of elderly people in Ireland said they felt that they had benefited from caring, and 70 per cent had learned from it. When asked how they felt they had benefited or what they had learned, they mentioned gaining in understanding, tolerance or patience, satisfaction or fulfilment, or becoming better Christians.

More recent studies whose specific aim was to explore the rewards derived from caring have confirmed that many carers experience high levels of satisfaction. In a nationwide survey, which recruited carers through the National Carers Association, Grant and Nolan (1993) found that more than 63 per cent of carers, who had been caring for more than ten years, identified rewards and satisfactions in caring. A later study, described by the same authors as being the most extensive empirical study on the satisfactions of caring collected, identified three types of satisfaction (Nolan et al 1996).

Firstly, are satisfactions derived mainly from the 'interpersonal dynamic', where the main beneficiary is the care recipient. These satisfactions relate to the nature of the personal relationship and the interaction between the carer and the care recipient. One of the main sources of satisfaction in this category is the 'act of giving'. This referred to small but simple acts that brought happiness or pleasure to care recipients. Another reward is maintaining the dignity of the person being cared for and seeing them clean, happy and comfortable. Maintaining the dignity and self esteem of the care recipient is one of the main purposes of protective, preservative and constructive care described in the previous chapter. Concern about ensuring the dignity of the cared-for stems from the love and affection the carer feels for their dependent and is indicative of a close relationship. Other sources of satisfaction for carers are recognition and appreciation for their work, the fact that caring had brought them closer to the care recipient, and that it had strengthened close family relationships.

Secondly, are satisfactions linked to the 'intrapersonal or intrapsychic orientation' of the carer. This simply means the personal attributes of the carers such as their attitudes, beliefs and their general approach to life. In other words carers derived satisfaction from certain aspects of caregiving because they were the types of people that enjoyed helping others. Moreover, they knew within themselves that they had done the best they could for their relative and therefore, caring stopped them feeling guilty. Some studies have suggested that caregiving provides an opportunity to reduce or eliminate feelings of actual or potential guilt (Ungerson 1987, Nolan and Grant 1989, Kane and Penrod 1995). One of the main sources of satisfaction in Nolan et al's study was derived from being able to repay past acts of kindness. This notion of 'payback' implies a reciprocal relationship whereby carers feel they have a duty to repay past care and as we saw in the previous chapter, a sense of duty underpins carers' reasons for caregiving. According to Nolan et al (1996) the sources of enjoyment derived from the intrapersonal dynamic provide greater levels of satisfaction because they tend to nurture carers' feelings of self-worth and self-esteem. If

carers feel good about themselves they are more likely to view their caregiving role as a positive experience.

Thirdly, there are satisfactions from the 'outcome dynamic'. This refers to rewards derived from the outcomes or consequences of caregiving. These arise from carers' ability to either protect the care recipient from some negatively perceived outcome or to promote positive consequences such as the development of new skills and interests. The most frequently cited source of satisfaction within this dimension suggests that for the majority of carers there is no real alternative to informal care. Carers said that they derived a great deal of satisfaction from being able to keep the person they cared for out of an institution. Both the quality of care and the standard of accommodation available in institutional or long stay care is often perceived as being poor and therefore, regarded by carers as totally unacceptable. Thus, whether that satisfaction is derived from the act of giving, from carers' feelings of self worth or whether it was from positive outcomes, most carers experience some gratification. Nolan et al's (1996) findings are consistent with other studies that found at least 80 per cent of carers experience satisfaction from their role (Crookston 1989, Braithwaite 1990, Clifford 1990).

There is an increasing awareness that an absence of satisfactions may indicate a poor caring relationship and might lead to the abuse of older people (Eastman 1984, Clifford 1990, Biggs et al 1996). However, these concerns are overshadowed by studies that perceive satisfactions from caregiving to be a powerful cognitive coping strategy and a buffer against stress (Summers 1989, Motenko 1989, Nolan et al 1996). This may help to explain why some caregivers are prepared to continue despite experiencing caring as stressful and burdensome. Yet, it has also been suggested that satisfaction and rewards can be a doubled edged sword in that their presence might facilitate coping but at the same time tie carers into caregiving relationships which should perhaps be ended. What is clear is that the potential sources of satisfaction and rewards from caregiving are diverse, complex and subtle (Nolan et al 1996) and their presence may influence how carers respond to the experience of caring.

Carers' Responses to the Role

Some studies have attempted to describe various types of caregiver based on how they respond to their experiences of caregiving. Lewis and Meredith (1989) for example,

distinguish between carers who adopt a *balanced* mode in which they are able to combine caregiving with other important parts of their lives such as employment. They compare this type of carer with those who *integrated* caring into their lives, with caring providing a sense of purpose and of satisfaction. The third category Lewis and Meredith describe is carers who become *immersed* in caregiving, who invest heavily in their role and find it extremely difficult to disengage themselves. According to Lewis and Meredith, the consequences for carers vary depending upon which caregiving mode they adopt. Immersed carers experience the most negative effects.

There are similarities between those categories described above and those outlined by Twigg and Atkin (1994). They distinguish between the *engulfed* carer who subordinates their life to that of the cared-for person; the carer who is able to *balance/set boundaries* and the carers who have a *symbiotic* relationship from which they gain positive benefits. The affective domains described by Opie (1994) also have clear parallels with those of Lewis and Meredith (1989) and Twigg and Atkin (1994). Opie believes that the affective elements or the emotional attitudes that influence caregiving are the most significant factor in carers' responses. She outlines these as *commitment, obligation, dissociation* and *repudiation*. She claims these emotional attitudes are fluid and dynamic and not constrained by such things as gender (Opie 1994:47).

Harris (1993) too believes that the affective response of carers is important. She argues that there is little known about the qualitative experiences of male caregivers. Based on in-depth interviews of male carers she identifies four types: *the worker, the labour of love, the sense of duty*, and *at the crossroads*. 'The worker' is consistent with the findings of others who claim that male carers are more likely to see caring as an extension of paid employment (Ungerson 1983, Twigg and Atkin 1994). However, the other types suggest that love and concern are a major part of male caregiving, a finding confirmed by Fisher (1994) and Motenko (1989).

It has been suggested that a number of factors such as the disability of the care recipient might affect carers' experiences of caregiving. Therefore, because these typologies have considerable conceptual differences, they may not be applicable to all carers. With the exception of Harris (1993), they have been constructed using data from predominantly female carers looking after different client groups. For instance, Lewis and Meredith's typology is based on a small-scale study of daughters for whom caregiving had ended. Their typology is based on carers' memories of their caregiving experience. On the other hand, Twigg and Atkin's categories are derived from a larger study with a wider range of

carers including a few males. Their sample, obtained from surveys of the general population, included carers of older people with physical and cognitive disabilities, younger adults with physical and learning disabilities and those with mental health problems. Opie's typology was derived from a study of spouses caring for dementia sufferers. There is no typology specifically based on carers looking after frail older people with no cognitive or physical disability.

Conclusion

Whilst an understanding of the experience of caregiving requires more than an account of the physical dimensions (Nolan et al 1996), the defining feature of informal caring is the performance of tasks. The policy literature in particular implies that the number of tasks undertaken is related to carers' commitment to caregiving. This implication is underpinned by Parker and Lawton's (1994) typology, which gauges the level of carers' involvement by the type of caring activities carried out. Thus those providing personal and physical care are deemed to be the most heavily involved carers. While this typology is a useful analytical tool the focus on tasks obscures the affective dimensions of caring. Yet, the experience of caring at the 'heavy end' cannot be adequately portrayed by a set of mutually exclusive categories. Describing the experience of caring simply as a series of activities overlooks the problematic nature of some of these tasks. Personal and cross-sex care are identified as being particularly problematic. Moreover, a commitment to caregiving cannot be explained adequately by either the types or number of tasks undertaken or by the physical characteristics of the care recipient (Motenko 1989, Nolan et al 1996, Wenger 1996). Nor can it be fully understood in terms of the consequences of caring.

The consequences of caregiving in terms of employment, finances and health have been explored by a number of qualitative and quantitative studies. These studies have concluded that carers are less likely to be in paid employment, are more likely to have lower incomes from state and private pensions and to be reliant on means tested benefits. Thus caregiving appears to have long term financial consequences that reach into carers' retirement years (Hutton and Hirst 2001).

Evidence of the consequences that caring has on health are equivocal. While some studies found that caring had detrimental effects on physical health (Charlesworth et al 1983, Warner 1994), others suggest that carers experience better health and functioning than non-

carers (Nolan et al 1996, Taylor et al 1995). It is thought that those who are in poor health or disabled are less likely to undertake caring than those who are fit. Recent research however, shows that carers, and women in particular, are at greater risk of mental health problems (Hirst 1998, Hutton and Hirst 2001). If caring is as detrimental to health as many studies suggest, why then do so many informal carers continue to care for their relatives?

It has been suggested that a number of factors might influence how caring is experienced. However, because of a predominant focus in the literature on the difficulties, the more positive aspects of caregiving have until recently, been overlooked. Yet, a realistic picture of the caregiving experience and an explanation as to why family carers are reluctant to give up cannot emerge until the positive aspects have been explored. The importance of those positive aspects of caring is becoming increasingly clear. The findings from a number of studies suggest that for some caregiving might be a difficult and stressful experience whilst others view it in a more positive way. Moreover, the majority of carers derive a great deal of satisfaction from caregiving and the existence of rewards has been found to be a coping strategy, to alleviate stress, and to increase the commitment to caring.

A number of authors categorise carers by the way in which they respond to their role. These typologies are derived from the experiences of ex-carers (Lewis and Meredith 1988, 1989), male carers (Harris 1993), spouse dementia carers (Opie 1994), and carers of older and younger people with physical and cognitive disabilities (Twigg and Atkin 1994). There is no typology of carers of frail older people without any cognitive or physical disability. Furthermore, studies exploring the experience of caregiving, its rewards and satisfactions as well as the difficulties have tended to emerge from the nursing and psychological literature. The samples in these studies are predominantly carers of people with dementia (Motenko 1989, Nolan et al 1996) or learning disabilities (Grant and Nolan 1993, Grant et al 1998) and are drawn mainly from the records of health and social care providers. Thus the experience of caring and the prevalence of different types of rewards for families living in different circumstances remains unexplored.

This chapter has explored the experience of care. The following chapter will review the literature on the concepts of stress and coping and the use of formal services.

3. Stress and Coping in Caring

The previous chapter recognises the positive view that caregiving can be a satisfying and rewarding experience. This chapter however, explores the notion of caregiving as stressful. It will discuss the concepts of stress and coping before concluding with a consideration of coping strategies and the use of formal services. Many studies of caring have tended to view caring as stressful and burdensome and consequently, have adopted a stress-coping framework (Kahana and Young 1990, Kahana et al 1994, Kane and Penrod 1995). The sizeable body of literature on stress and coping is mainly from the USA and is dominated by psychological methodology. These studies tend to measure stress and coping in an objective way by using standardised instruments. Moreover, these studies tend to be predominantly quantitative and even those who call for increasing use to be made of qualitative methodology in stress research, use an explicitly quantitative approach (Thoits 1995). Most studies have been conducted with carers looking after people with largely the same type of disabilities, most commonly those with varying degrees of cognitive impairment. Furthermore, in common with other caregiver research, most studies recruit carers through lists of people receiving formal services. This sampling procedure limits the generalisability of the results to all service users. Although there are obviously practical reasons for homogenous samples, there is a need to know more about stress as it is experienced by caregivers who are neither service users nor looking after cognitively impaired persons.

Concept of Stress

The literature provides a considerable amount of evidence to support the view that caregivers of older people, with or without cognitive impairment, suffer stress (Cantor 1983, Gilleard 1987, Kahana and Young 1990). The assumption that caregiving is necessarily stressful is based on the considerable volume of literature detailing the lifestyles, difficulties and sacrifices of caregivers (Cantor 1983, Nissel and Bonnerjea 1983, Gilleard et al 1984, Jones and Vetter 1984, Jones 1986, Kahana and Young 1990, Kane and Penrod 1995). What is stress and how is it defined?

The notion of stress lacks any agreed definition (Rutter 1983, Selye 1985). However, the most widely accepted is one used in the seminal work of Lazarus and Folkman (1984) who define stress as:

'a relationship between the person and the environment that is appraised by the person as relevant to his or her well-being and in which the person's resources are taxed or exceeded'
(p 152)

In other words, situations are perceived as stressful when the demands of a situation exceed the person's resources and endanger their well being (Lazarus 1991, Monet and Lazarus 1991).

Many authors talk in terms of burden rather than stress (Cantor 1983, Nissel and Bonnerjea 1983, Gilleard et al 1984, Jones and Vetter 1984, Kahana and Young 1990). Indeed, the terms *caregiver burden* and *caregiver stress* or *strain* are often used interchangeably (Cantor 1983, Cicirelli 1986, Montgomery 1989, Nolan et al 1990, 1996). Others use the same factors that determine levels of stress to define caregiver burden George and Gwyther (1986). However, despite the literature using these terms interchangeably, stress and burden are concepts that describe different dimensions of the consequences of caregiving and feelings of burden can, in fact, create stress.

Caregiving stress is a *response* to difficulties encountered whilst providing care, which manifests itself in psychological and physiological symptoms such as headaches, anxiety or depression. Burden, on the other hand, is essentially the adverse *impact* that caregiving stress has on carer's personal and social lives that provokes negative feelings. Burdened carers report feelings of overload, of being unable to cope and of perceiving caregiving as a difficult load or weight to bear (Braithwaite 1990, Jutras and Veilleux 1991). Although caregivers' perceptions or appraisal of the situation is central to both concepts, research has shown that while some carers experience caregiving as stressful, they do not necessarily regard it as burdensome or vice versa (Motenko 1989, Burr and Klein 1994, Murray and Livingstone 1998). Burden, therefore, cannot be regarded as a universal caring phenomenon (Braithwaite 1990, Gupta 1999) and should not be used synonymously with stress.

Models of Stress

According to Burr and Klein (1994) research about stress began in the 1940s. These early studies guided by scientific principles sought to identify causal relationships that would determine particular patterns of behaviour. Since then a number of theoretical models of stress have emerged with the ABCX model being one of the most enduring.

The Double ABCX model of stress

Stress theory has its roots in the work of Hill (1949 cited in Summers et al 1989, Burr and Klein 1994), who formulated the ABCX model of stress. This theory postulates that families differ in their responses to stressful events. Hill's theory has undergone many modifications and elaboration since it was first described, but the basic structure remains the same. McCubbin and Patterson (1983) amended Hill's original model to take account of their findings that stress may arise not from a single but rather multiple events and also that it may result in positive and not necessarily negative outcomes. Consequently, the Double ABCX family crisis model (McCubbin and Patterson 1983, McCubbin et al 1993, 1998, Patterson 1993) is an attempt to explain these differential responses.

In this model Factor A refers to events that have had an impact or have the potential to have an impact on the family. Factor B refers to the family's resources to meet the challenge of these events. Factor C, the family's perception or definition of the events, indirectly influences the degree of crisis (Factor X) that might occur in the family. Factor C might also include a cognitive reappraisal of the situation to make it more manageable or to maintain an optimistic outlook or acceptance. Crisis is defined as a change in the family system for which the family's previous patterns of response are not adequate (Patterson 1993, McCubbin et al 1998). In this model, reacting to a stressful event is not seen as a single event or outcome but as an ongoing cyclical process.

Others have used this model in studies of families whose children have learning disabilities (Orr et al 1991, Behr and Murphy 1998). However, the findings from Orr et al's (1991) study suggest that the ordering of the model runs in the direction of A-C-B-X. This finding is important because it implies that the use of coping resources depends not so much on the objective features of the stressor but more on how that particular stressor is perceived and appraised (Dunst et al 1988). Another issue that this model raises is the unit of analysis. The ABCX model perceives the family to be the unit of analysis. Yet many studies on caregiving have found that caring for older people is rarely shared with other

family members (Quershi and Walker 1989, Twigg and Atkin 1994, Kane and Penrod 1995).

Life Events model of stress

This model believes that stress is caused by the cumulative effects of life events such as serious illness or bereavement and if these events occur close together, they are more likely to result in physical or psychological stress than single events (Dohrenwend and Dohrenwend 1978). Brown and Harris (1978:27) describe life events as '*occurrences in people's lives, which require some form of change and adaptation to take place*'. They are distinguished from ongoing difficulties or continuing social roles by their short duration. Perhaps the best known research of this nature was that carried out by Holmes and Rahe (1967) who constructed a Schedule of Recent Life Events. This consisted of events most commonly occurring to individuals that were then rated according to the level of readjustment required. However, this cumulative approach fails to take account of the influence of everyday experiences as stressors. Minor events or 'the hassles and uplifts of everyday life' were found to be a more accurate predictor of psychological symptoms than life event checklists (Pearlin et al 1990).

Whilst Brown and Harris (1978, 1989) support the life events model, they found that rather than stress resulting from an accumulation of many adverse events or experiences over a period of time, it was in fact more related to the meaning of an event as attributed by the individual concerned. So in this model, whilst responses to stress may vary over time, beliefs and values are also considered important. However, this model has been criticised as being irrelevant in understanding how informal carers manage on a day-to-day basis, because stress for many of them is caused by the 'daily grind' of caregiving, rather than major life events (Nolan et al 1996, Patterson 1998).

Transactional model of stress

Similar to the Double ABCX model of stress is the transaction model. In this model developed by Lazarus and Folkman (1984) events or conditions in people's lives are not automatically assumed to provoke stress. Rather, the key issue is how the individual determines or appraises whether the event is stressful in relation to their resources. Stress occurs when the individual perceives a mismatch between the nature of the demand and their ability to respond. Hence, the individual's appraisal of events is the key to stress.

There is growing support for the transactional model in explaining stress and coping (Edwards and Cooper 1988, Nolan et al 1996). It is the most widely accepted explanation of how people deal with potentially adverse and stressful events in their lives. Moreover, studies of carers seem to support the efficacy of the transactional model in understanding stress and coping (Burr and Klein 1994, Nolan et al 1990, 1996) but some are cautious in interpreting their results. Quine and Pahl (1985, 1991) for example, used this model in their study of mothers of children with severe learning difficulties. They reported being able to explain 55 per cent of the variance in stress, with the inclusion of coping responses as a mediating variable. However, in their discussion they note that 'difficult' behaviour can be stressful for mothers, but stress may also make them feel tired and irritable, and less affectionate toward and less able to deal with a child, who in turn becomes even more difficult to deal with. Hence the difficult behaviour may be both a cause and a consequence of stress.

Edwards and Cooper are also wary of the efficacy of the transactional model of stress and suggest that perhaps coping takes place before appraisal (Edwards and Cooper 1988). This they claim would be most likely in sudden situations when there may be little or no time to think first. On the other hand, where routines are already well established, it may be less necessary to appraise what needs to be done before a coping strategy is employed. They also make the point that coping may itself be stressful, in which case the stressful event or condition to be dealt with itself provokes further stress in the coping response required.

Stress as a process

Pearlin et al (1981, 1990) however, perceive stress not as an event or a single phenomenon but as a process. This perspective is in contrast to the early literature on caregiver stress, which tended to focus on discussions of whether stress lay in the event or in the person's response to the event. This process consists of four domains: the background and context of stress, the stressors, the mediators of stress, and the outcomes or manifestations of stress. They claim that stress is an unstable mix of circumstances, experiences, responses and resources that vary considerably among caregivers and that consequently, vary in their impact on carers' health and behaviour. A change in any of these components may result in the change of others. This notion of process directs attention on the interaction of many conditions leading to personal stress and the ways these relationships develop and change over time. This perspective focuses not simply on identifying conditions that may be associated with stress but in understanding how these conditions arise and how they relate to each other.

A finding common to most stress research is that people exposed to apparently similar stressors are affected by and cope with them in different ways (Pearlin et al 1990, Monet and Lazarus 1991, Nolan et al 1996). One possible explanation for these variations relates to the type and number of stressors that individuals are exposed to, that over time one stressor tends to generate others (Pearlin 1991, Pearlin et al 1981, 1990). The primary or original stressor may be an event or role strain which may eventually give rise to other secondary events or strains that then exert their own stress. This stress might be accumulative. Caregiving for example, might result in heightened conflicting demands with children and spouses, in the loss of social networks, the loss of friends and in having to re-arrange living accommodation. Once established, each one of these secondary stressors may act as an independent source of stress. Because stress begets stress, people who are similar with regard to primary stressors, may nevertheless vary widely in the configuration of secondary stressors in their lives. Therefore, one reason that relationships between a given stressor and an outcome may vary is because the stressor may for some people, be the sole stressors they are experiencing and for others a host of secondary stressors may have developed around the primary stressor (Pearlin et al 1990, Eckenrode 1991).

The presence of primary and secondary stressors usually lead to the assumption that caregiving is stressful (Zarit et al 1980, Nolan et al 1990, Jutras and Veilleux 1991). Indeed this assumption underpins many of the instruments used to measure stress. Yet, other studies have found that not all carers perceive caregiving as stressful (Burr and Klien 1994, McKee et al 1999). What then are the determinants of stress?

Determinants of Caregiver Stress

The literature suggest that determinants of caregiver stress include a variety of 'life conditions' and 'environmental factors' (Pearlin et al 1981, 1990, Burr and Klein 1994). These include the volume and type of tasks undertaken with the most heavily involved caregivers experiencing the most stress (Jerrom 1993, Cantor 1983, Jutras and Veilleux 1991, Nolan et al 1996, Murray and Livingston 1998, Schofield et al 1998). Other determinants of stress are related to the care recipients type of impairment (Zarit 1980, Gilhooley 1986, Jutras and Veilleux 1991), and level of functional disability (Cicirelli 1986, Jutras and Veilleux 1991, Murray and Livingston 1998, Schofield et al 1998).

The quality of the caregiving relationship and co-residency are also related to stress. According to a number of studies, the closer the relationship, the more stressful caregiving becomes (Cantor 1983, Gilhooly 1987, George and Gwyther 1986). However, it has been suggested that caregiving stress is influenced by the pre-morbid relationship (Motenko 1989, Qureshi and Walker 1989, Murray and Livingston 1998). Perceiving the continuity of a close relationship is associated with higher morale and lower levels of stress and perceptions of being able to cope (Gilleard et al 1987, Motenko 1989, Williamson and Schulz 1993). Other studies though, have shown that caregiving stress can arise irrespective of the closeness of the relationship (Cicirelli 1981, 1986, Kahana and Kinney 1991). However, such contradictory findings might be explained by the differences in sampling. Cicirelli's study for example, focused on adult children whose motivation for caring might differ from spouses and Kahana and Kinney's sample comprised caregivers of various client groups.

It has also been reported that a factor more likely to increase stress is shared living arrangements (Fisher and Hoffman 1984, Cicirelli 1986). Co-resident carers have been found to report higher levels of stress, provide more hours of care, (Sinclair et al 1990, Parker and Lawton 1994), express more resentment (Murphy et al 1997) and are more likely to suffer from isolation, boredom and lack of sleep (Cantor 1983, Murray and Livingstone 1998).

Other studies have found that the most important determinant of stress is the nature of the carer's response to their role (Nolan et al 1990, Twigg and Atkin 1994). For example, Nolan et al (1990) found that stress is most likely to occur when a carer feels out of control, unable to relax because of worry about caring and experiences guilt about the situation. Stress is heightened when the carer feels that the person they are looking after does not appreciate their efforts and displays problem behaviour in terms of being over demanding, manipulative and failing to help. These findings suggest that stress levels are more strongly influenced by emotional components such as feelings of anger, guilt and worry and are only marginally related to objective factors. Nolan et al (1990) conclude that the physical demands of caregiving are not perceived as stressful until carers themselves perceive a threat to their emotional well being.

Consequences of caregiver stress

A fuller discussion of the effects of caregiving on health, employment and finances based on the sociological literature can be found in the previous chapter. The literature discussed

here is primarily from the field of psychology where the negative consequences of caregiving are conceptualised as stress, which is detrimental to social and emotional well being (Braithwaite 1990, Kahana and Young 1990, Kane and Penrod 1995). Caregiver stress is believed to underlie physical and mental illness in a substantial proportion of caregivers (Appley and Turnbull 1986, Braithwaite 1990, Schultz et al 1990, Murray and Livingstone 1998), and is a factor in the use of formal services (Gilleard 1984, Eagles 1987, Schultz et al 1990, Wenger 1990), and is a predictor of future behaviour (Zarit et al 1980, Brooks 1998, McKee et al 1999).

Increased stress may also reduce the willingness and ability of a caregiver to provide care, thereby increasing the elderly care recipient's risk of admission to institutional care (Jerrom 1993, Brooks 1998, McKee et al 1999, Wright 2000). Thus, stress is regarded as placing the well being of carers in jeopardy and in extreme cases might result in mistreatment, neglect or abuse (Eastman 1984, Biggs and Phillipson 1995). Stress and coping therefore, emerge as issues of concern for families, welfare providers and policy makers.

Concept of Coping

How do individuals respond to stressful events and with what success? There is general agreement in the literature that stress, appraisal and coping are closely related parts of a complex and dynamic process (Appley and Turnbull 1986, Eckenrode 1991, McCubbin et al 1998). Like stress, coping has become a popular and increasingly ambiguous concept (Titterton 1989, William's et al 1999). Although coping is the term used by the majority of authors when referring to the way individuals deal with difficult situations, some suggest that it is misleading. Patterson (1993) for instance, prefers the word 'adaptation', whereas others use the terms 'managing' (Boss 1993, Burr and Klein 1998, Nolan et al 1996). However, in order to reflect accurately the views of authors who are cited, the term coping will be used in the following discussion.

Some authors define coping mainly in terms of the efforts that people use when a perceived demand is seen to tax their adaptive resources (Pearlin and Schooler 1978, Lazarus and Folkman 1984). These definitions however, are rather restrictive in that they focus predominantly on problem solving behaviours. Turnbull et al (1993) on the other

hand, take a more individualistic approach that better reflects the diversity of coping. They define coping as:

'The things people do (acting or thinking) to increase a sense of well-being in their lives and to avoid being harmed by stressful events'
(Turnbull et al 1993:11)

In this definition, coping is not just limited to actions but extends to cognitive attempts to manage stress, irrespective of their effectiveness. However, the most comprehensive explanation of coping comes from Lazarus (1976, 1991) who defines coping in terms of three functions; the modification of the circumstances giving rise to stress, the cognitive and perceptual management of the meaning of the circumstances, and the control and relief of symptoms of distress that results from stressors.

Within Lazarus and Folkman's (1984) transactional model of stress and coping, the key concept is appraisal, which operates in the following way. When a demand or an event occurs a primary appraisal takes place. This essentially involves the individual in determining whether or not there is a need to respond to the event or demand. If they perceive there to be no need to respond then no action is taken. If people perceive that there is a need to respond then a secondary appraisal takes place. In this secondary appraisal, the individual takes account of what resources are available to them. A response or coping resource is then selected to deal with the event. If a person feels they can make an appropriate response this may lead to a fresh approach to coping (Lazarus 1991). If not, a re-appraisal may lead to stress being manifest in the expression of negative feelings (Cicirelli 1986, Braithwaite 1990, Lazarus 1991).

Feedback from the coping process becomes part of a successive appraisal or reappraisal, leading to modified coping, further re-appraisal and so on until the balance is restored or a new one reached or the individual is removed from the situation physically or psychologically. The process of coping can therefore, involve a complex mixture of continually changing strategies. There are difficulties inherent in developing a framework for understanding approaches to coping because of the vast range of strategies involved. Moreover, it is unlikely that individuals simply randomly select a strategy in the hope that it will work. What is thought to be more plausible is that individuals strive to achieve what Antonovsky (1985, 1987, 1998) calls a 'sense of coherence', which reflects a perceived ability to cope with stress. A strong sense of coherence is associated with an ability to cope well with stress through more effective use of the array of resources available to the individual. An individual's sense of coherence determines which events are seen as

comprehensible, manageable and meaningful (Antonovsky 1987, 1993, 1998 Coe et al 1992). While Antonovsky's approach has been mainly used in the area of health care (Antonovsky 1979, 1985, 1987, McCubbin et al 1998, Post-White 1998), it is increasingly being used in the field of caregiving and disability research (Coe et al 1992, 1998 Brooks 1998, Wagenfeld et al 1998).

Another concept implicated in successful coping and which resembles Antonovsky's sense of coherence, is hardiness. Hardiness comprises three dimensions: control, challenge and commitment. The integration of these interrelated concepts represents overall hardiness (Kobasa et al 1982, Huang 1995). According to this view, hardy individuals perceive their encounters as interesting and meaningful. They also believe they have the power to make changes and regard change as an essential stimulus for growth and development. These beliefs and perceptions are beneficial in coping with stressful life events. In contrast, people with low hardiness tend to view experiences as boring, meaningless and threatening. They often retreat from overwhelming situations due to their powerlessness. Thus stressful events are allowed to expand and have a negative impact on a person's wellbeing (Kobasa 1985, McCubbin et al 1993, Huang 1995). Whilst these studies suggest that a sense of coherence or a hardiness framework might be very useful in explaining differential responses to coping, they are nonetheless, general approaches to coping and do not necessarily determine what particular strategies carers might adopt.

Coping Strategies

Coping strategies are concerned with how people adapt or manage a situation. When a situation is appraised as being potentially harmful or stressful, coping strategies are developed and pursued to reduce the perceived threat. There is agreement in the literature that the first step in the coping process is the recognition and understanding of the problem (Lazarus 1976, 1985, 1991, Benner and Wrubel 1989, Eckenrode 1991). According to Pearlin and Schooler (1978) once a problem is recognised and acknowledged, coping behaviour involves efforts to

- either change and alleviate a difficult situation or,
- alter or reduce perceived threats or,
- manage the symptoms of stress arising from the situation.

Various methods of coping have been implicated in successful adaptation to caregiving. It seems that individuals who can draw on a variety of coping strategies are likely to be less stressed (Bramson 1985, Eckenrode 1991, Williamson and Schultz 1993). A number of writers distinguish between problem focused and emotion focused coping (Lazarus and Folkman 1984, Moos and Schafer 1986, Eckenrode 1991).

Problem focused strategies

The majority of problem-based coping strategies revolve around minimising deficits and maximising independence (Folkman et al 1991). They focus on management of problem behaviours and use of medication, for example, the use of sedatives at night, or providing food and fluids and thereby avoiding the hazards of frailty and immobility. If, on the other hand, a loss of personal freedom is the major stressor, accepting respite care is likely to be more beneficial (Beck et al 1992, Murray and Livingstone 1998, Ashworth and Baker 2000)

The use of positive coping strategies such as problem solving has been associated with a decrease in caregiver stress (Bramson 1985, Folkman et al 1991, Bull and Jarvis 1997). Bull and Jarvis's (1997) study on how people coped following hospital discharge describes two phases of coping: '*finding out what worked*' and '*establishing new routines*'. The first phase '*finding out what worked*', was characterised by trial and error and the absence of an established routine for managing care. Although finding out what worked was most prevalent in the early weeks of caregiving, deterioration in the care recipient's condition and re-hospitalisation generally initiated another cycle of experimentation. The second phase '*establishing new routines*' referred to a period, in which people were getting their lives organised and arranging schedules based on what worked. Carers in this study reported how they had learned the importance of having a routine, especially for diets and medication. However, this study seems to focus almost exclusively on problem based coping, no mention is made of the emotion focused coping. Yet, problem focused and emotion focused forms of coping can be mutually facilitative (Lazarus and Folkman 1984, Folkman et al 1991, Monet and Lazarus 1991).

Emotion focused strategies

Emotion focused coping has also been shown to be effective. According to Lazarus and Folkman (1984) emotion focused coping occurs when emotions need to be subdued or altered in order to allow an individual to function. The aim is usually to manage one's

emotions so that one can deal better with the tasks at hand. Emotion focused strategies include cognitive efforts that change the meaning of a situation, without changing the environment, through the use of techniques such as cognitive reframing, social comparisons, minimisation, or looking on the bright side of things. They also encompass behavioural efforts to make oneself feel better, as through the use of exercise, relaxation, meditation, support groups, religion, humour, or talking to someone who cares and understands; and efforts to escape through the use of drugs or alcohol (Lazarus and Folkman 1984, Folkman et al 1991, Cleary 1992). In Williamson and Schultz's (1993) study of carers, coping was sometimes a matter of emotional release, of having a good cry in private. For others, venting their anger and frustration by shouting and arguing was more beneficial – although it could also add to carers' distress. Such things as acceptance of the care recipient's declining health and parents' limitations, have also been shown to be an effective means of coping with unchangeable sources of stress (Cicirelli 1986, Nolan et al 1996, Murray and Livingstone 1998). Clearly there are a number of coping strategies that individuals draw upon if and when necessary. What is not so clear however, is which ones are the most effective.

Efficacy of Coping Strategies

Effectiveness of individual strategies is difficult to ascertain because when active attempts at coping with stress take place, many different cognitive and behavioural strategies are used (Lazarus and Folkman 1984, Folkman et al 1991). In a study using a large representative community sample, Mattlin et al (1990 cited in Eckenrode 1991) studied six types of cognitive and behavioural responses following stressful life events and found that half of the sample reported using virtually all the coping strategies. This finding is similar to that of Nolan et al (1990, 1996) who explored the use of coping strategies using a self-selected sample of 726 carers.

Efficacy of coping strategies depends on the way in which people evaluate the nature and extent of the stresses that are present in their lives. Moreover, the intensity with which the same circumstances are experienced will vary with the meanings attached to the circumstances (Eckenrode 1991, Pearlin 1991). McKee et al (1999) suggest that coping can be considered effective depending upon the extent to which it reduces demand and increases capacity. Whilst this sounds a simple and perhaps straightforward way of

assessing efficacy, it would be difficult to determine accurately the capacity of individuals to cope with stress.

In their early work Pearlin and Schooler (1978) compared the efficacy of coping responses. They argued that the most effective coping responses (defined in terms of stress levels measured by an adjective checklist) occurred when the stressor concerned interpersonal relationships and the least effective took place in the workplace. They considered this mirrored the degree of control perceived as available to individuals in both situations, a finding later confirmed by other studies (Straw and Kendrick 1988 cited in Seymour 1999, Baum 1993, Thompson 1993).

Coping styles and resources

Effectiveness of coping also relies on the use of other resources. It has been argued that coping resources and coping styles are potentially an integral part of an individual's coping framework. Yet, coping resources and styles are not well understood and few studies have attempted to devise typologies of them (Lazarus and Folkman 1984, Moos and Schafer 1986, Nolan et al 1996).

Coping styles may be defined as methods of coping that characterise individuals' reactions to stress either across different situations or over time within a given situation (Stone et al 1988, Titterton 1992). There are few analytical and descriptive typologies of coping styles available. There are though, some studies outwith the coping literature, which come close to providing such typologies. Twigg and Atkin (1994) devised a typology to describe carers' responses to their role. This identifies three distinctive types of carer, which could be said to represent different styles of coping; the engulfed, the balanced and boundary setting and the symbiotic (see chapter 2). In a similar vein, Evers (1984 cited in Titterton 1989) study of the self-perceptions of dependency of older women contrasted two types of vulnerable persons according to their responses. The 'active initiators' are those who see themselves as being in control of their own lives, despite in some cases considerable reliance on others for help with basic care. These are contrasted with the 'passive responders', who see themselves as being largely dependent on others to organise and structure their lives for them, despite in some cases apparently having the ability to lead a relatively autonomous life. Coping styles such as those outlined above refer essentially to the different way that individuals respond to situations and events. However, coping styles do not adequately explain individual variations in the way given sources of stress are dealt with in specific contexts such as caregiving.

Coping resources, on the other hand, refer to the kinds of resources people might call upon in managing situations. It is argued that having appraised the resources available, individuals will actively and consciously select and employ particular coping behaviours (Endler and Parker 1990 cited in Seymour (1999). Lazarus and Folkman (1984) distinguish between 'internal' and 'external' resources. They believe that coping resources are part of an individual's internal or external environment not under direct control; that they lie dormant until called upon in a stressful encounter. Factors considered to be internal resources are personal skills, past life experience, psychological disposition. External resources include such things as income, knowledge, housing, formal services, as well as social support (Lazarus and Folkman 1984, Folkman et al 1991).

Whilst social support is generally thought to play a buffering role in mediating stress (Antonovsky 1989, Carlson and Robertson 1993, Harrison et al 1995, Seymour 1999), it can also generate stress when conflict and criticism are experienced (Gottlieb and Wagner 1991, Monet and Lazarus 1991, Murray and Livingstone 1998). The absence of social support increases vulnerability to stress (George 1986, Dunst et al 1989, Wenger 1990, Given and Given 1991). Carers receiving few visits from other family members reported more stress, resentment and difficulty in coping with behavioural problems (Zarit et al 1980, Carlson and Robertson 1993, Schofield et al 1998). The level of social support is also said to influence use of formal services (Eagles 1987, Wenger 1990). According to Wenger's studies on the support networks of older people, those with no family other than a spouse living locally, are more likely to receive formal services. Formal services are an important coping resource for carers and merit more detailed consideration.

Support from Formal Services

As we have seen, the stress associated with caring for an older person is well documented. The provision of services has been found to reduce carers' stress levels and to improve the quality of carers' lives (Wright 1986, Gilleard 1987, Perring et al 1990, Clark 1994, Levin et al 1994). Moreover, evidence from a number of studies suggests that service intervention can prevent the breakdown of care and subsequent institutionalisation (Challis and Davies 1986, Challis and Bartlett 1988, Twigg et al 1990, Nocon and Quershi 1996, Wright 2000).

However, the relationship between carers and service providers is unclear and ambiguous (Twigg 1989, 1992, Twigg and Atkin 1994). Carers are neither clients nor patients and their position within the service system is simply by virtue of their relationship with the care recipient who may be regarded as a client. As a consequence, carers have until recently, rarely been the direct focus of service intervention. Twigg (1989, 1992) has conceptualised these ambiguities in terms of four models of how service providers relate to carers as; resources, co-workers, co-clients, or superseded caregivers. She claims that providers shift between these various frames of reference according to the individual circumstances of each client/carer. She notes though that carers as resources represent the predominant reality of community care (Twigg 1992).

Carers' position within the service system has been clarified by recent community care policy that has placed support for them high on the agenda. The recently enacted Community Care and Health (Scotland) Act 2001, allows services for carers to be viewed as part of the overall package of care for care recipients, thus legitimising carers' right to support. There are several forms of service provision that have as their primary objective support of informal carers. These include home, day and residential respite schemes, and carer support groups. Carers might also be indirectly supported by services that are aimed at the care recipient or when decisions relating to the care recipient take account of carers circumstances (Twigg 1992, Twigg and Atkin 1994). Despite this provision though, it is becoming increasingly apparent that the link between carers' stress and the use of alternative sources of care is not straightforward (O'Connor 1995, Burholt et al 1997).

Use of services

Simply providing services does not ensure utilisation. Studies have shown that relatively few carers and older people use formal services (DSS 1991, Taylor and Ford 1994, Warner 1995, McDonald 1999). For example, Robinson and Yee (1991) estimate that 1 in 4 carers receive no help from service providers. In Taylor and Ford's (1994) study three quarters of carers were not in receipt of services. In Curtice et al's (2002) study of intensive support packages received by older people, just under half of informal carers in the community sample received some assistance from services. Yet the reasons for the low uptake of services are unclear. While the literature documents the issue and suggests that some carers (Evandrou 1990, Taylor and Ford 1994), and spouses in particular (George and Gwthyer 1990, Wenger 1990, Parker 1993) are reluctant to use formal services, it fails to explain it adequately. Moreover, the issue of low uptake and non-use of services tends to be incidental to the main focus of research.

Whilst studies have examined this issue in relation to people with learning disabilities (Stalker et al 1999, Grant 2001), or ethnic minorities (Blakemore and Bonham 1993, Boneham et al 1997, Gunaratnam 1997), or in relation to mental health services (Albert et al 1998, Clarkson and McCrone 1998), very few have looked at the issue of non-use amongst family carers of older people (O'Connor 1995, Stearns and Butterworth 2001). No published reviews of this theme exist, and even recent studies of services only touch briefly upon the topic (Twigg and Atkin 1994, Nocon and Quershi 1996, Burholt et al 1997, Brereton and Nolan 2000) or concentrate on predisposing factors such as gender, age and disability rather than the reasons for non-use (Boniface and Denholm's 1997).

Concept of need

The literature contains an assumption that service use is determined by 'need'. Yet research has found that there is no association between need and service use (Wister 1992, Chappell 1994, Boniface and Denholm's 1997, Edwards et al 1999, McDonald 1999). For example, one study found that spouses caring for dementia sufferers were significantly less likely to report assistance from formal sources, although they identified the presence of more needs than non-dementia caregivers (Straw et al 1991). Similarly, in McDonald's (1999) study, 40 per cent of those identified as most in need of support did not use services. Thus need *per se*, does not necessarily equate with the actual use of services.

Furthermore, when the concept of need is used to determine the use of services by caregivers, the question arises of whose need is to be considered. Research has found that being married and/or living with someone is predictive of less service use (Arber et al 1989, Chappell 1994, Parker 1994, Boniface and Denholm 1997). This suggests that co-resident status may have some bearing on the decision to use services. However, research has not examined the decision-making process between caregiver and care recipient regarding use of services. In particular, whose need determines whether services will be used.

Views of services

Research examining service use seems to be concerned with evaluating the quality of services by measuring users satisfaction levels (Langan et al 1995, Ashworth et al 1996, Clark et al 1998, Hardy et al 1999, Jarrett et al 1999, Raynes et al 2001). Studies of people's experiences of welfare services has consistently found high levels of expressed satisfactions amongst both service users (Allen et al 1992, Wilson 1995, Ashworth et al

1996, McDonald 1999) and carers (Mudge and Ratcliffe 1995, Myers and McDonald 1996, Ashworth and Baker 2000). These findings make the issue of non-use more perplexing. If users and carers are on the whole, satisfied with the services they receive, why do so few use them?

In some studies where respondents were apprehensive about receiving formal care services, their worries, based on their own and friend's experiences, related to poor standards of care and a dissatisfaction with previously received services (Aronson 1990, Grant et al 1994, Stalker et al 1999). Formal services have also been criticised on the grounds of inflexibility in terms of the type of tasks undertaken and the timing of services (Sinclair et al 1990, Twigg and Atkin 1994, Raynes et al 2001). Other criticisms have focused on a lack of continuity of care (Simpson et al 1995, Curtice et al 2002), low levels of provision (Grant et al 1994, Stalker et al 1999), and communication problems between providers and service recipients (Simpson et al 1995, O'Connor 1995, Myers and McDonald 1996, Boneham et al 1997). These findings suggest that there might be a variety of reasons why individuals who need support from formal services do not utilise them.

Lack of knowledge

Another common reason cited for under-use of services among older people in general and carers in particular, is related to limited knowledge or awareness of services (Wright 1986, Jutras and Veilleux 1991, Sinclair 1994, Schofield et al 1998). This in turn is associated with the availability of information about services. Difficulty in finding out what is available is a recurring theme in research on services within the fields of community care and learning disabilities (Boniface and Denholm 1997, McDonald 1999, Stalker et al 1999). Lack of information, or insufficient or inaccessible information is disabling and dis-empowering. Moreover, it has an adverse effect on carers' ability to establish what support is available and how to access it. Yet, carers do not like to ask for information; rather they want it to be freely available (Simpson et al 1995, McDonald 1999).

Simpson et al (1995) suggests a reluctance to ask for information is possibly because of a perceived imbalance of power between the two groups. From a sociological perspective, service providers are seen as powerful and knowledgeable, and patients /carers seen as powerless and unable to make themselves understood (Hugman 1991, Simpson 1995, Hogg 1999, Twigg 2000). The issue of communication and a lack of information is one of real frustration for carers as they have difficulty in coping with professional jargon and the

aura of power (Hugman 1991, Heyman et al 1995, Simpson et al 1995). Moreover, older people who have long experienced old-fashioned traditions particularly in medical care may have an ingrained awe of professionals. They may also have less of the educational advantages of younger people, which would facilitate a freer exchange of information (Simpson et al 1995, Twigg 2000).

Carers have also expressed difficulty in communicating with service providers when seeking information (Hunter and MacPherson 1990, Clarke 1995, Simpson et al 1995, Stalker et al 1999, Nolan 2001). In Stalker et al's (1999) study, carers who reported communication difficulties had discovered that the best way to find things out was by constantly being proactive and badgering professionals to answer their questions. The language chosen to describe this interaction; 'a fight', 'a struggle', 'a battle', graphically illustrates the way this process is experienced by carers. In McDonald's (1999) study successfully negotiating support with service providers depended on having the right information or contacts. For some people, receiving adequate support from primary care or the social work department seemed to be largely a matter of chance.

Other studies have noted that even with active recruitment, encouragement, and free access to services, nearly one third of carers eligible for services do not use them (Caserta et al 1987, Chapman 1997). However, the authors of these studies do not speculate as to the reasons for this situation. While the findings discussed above suggest that information, knowledge and accessibility are important factors accounting for service use, they do not adequately explain non-use by fully informed individuals.

Previous experience of services

In trying to understand non-use of services, some studies point to the importance of understanding an individual's history of involvement with service providers (Grant et al 1994, O'Connor 1995). In the course of Grant et al's (1994) study on how carers appraised service quality, respondents who expressed a reluctance to contact service providers were questioned further. Of those who expressed reluctance, just over half the carers said it was because they preferred to be self-reliant, 28 per cent because of 'bad experiences' with providers in the past, 24 per cent because they considered service providers to lack resources, and 17 per cent because insufficient help had been received in the past. These reasons are unrelated to need, access, information or knowledge of services. O'Connor's findings are similar to Grant et al's (1994) in that they too suggest non-use of services is a more complex issue than simply a lack of information or knowledge.

O'Connor's (1995) study explores the meanings of service use amongst spouse carers who were in contact with service providers but continued to refuse offers of support. Their reasons were related to notions of independence, distrust of strangers and duty. Carers' determination to be independent and to overcome obstacles was associated with fear of losing control of their environment and perceived inadequacy. Acceptance of services implied a failure to cope, provoked a sense of incompetence and a loss of personal control.

Some of the themes identified by O'Connor have been demonstrated by other studies of carers and older people (Stalley 1991, Parker 1993). Stalley for example, explores older people's reasons for refusing home help services by comparing the experiences of users and non-users. Marked differences are noted between users and non-users of the service. Non-users seem to have a much greater need for control and a desire for independence. The need for control included the need to define the date and the time of the service and to determine what types of tasks would be undertaken. Stalley (1991) concludes that the need for independence and control is vital to non-users' sense of wellbeing and that to force services upon these individuals might have unintended repercussions such as causing unnecessary distress.

The stress associated with caring for an older person is well documented. However, the link between carers' stress and the wish to use alternative sources of care is not straightforward. Simply providing services does not ensure their acceptance. Although there has been recent concern about the non-uptake of services among ethnic minorities (Boneham et al 1997), there is still a paucity of research on this issue in relation to caregivers of older people. The widely held assumption within the literature, that non-use is due to a lack of knowledge and awareness of available services, has been shown to be an inadequate explanation. Moreover, this literature review reveals that few studies are concerned specifically with non-users of services (Eagles 1987, Stalley 1991, O'Connor 1995). Clearly, there is scope for furthering our understanding of carers' reasons for not using formal services as a source of support.

Conclusion

This chapter has explored the concepts of stress and coping and the use of formal services. Much of the literature reviewed on stress and coping is from the USA where studies tend to be predominantly quantitative, which fail to take into account any changes over time

(Pearlin 1990), and in which the use of checklists of life events and coping behaviours is widespread. Whilst there are examples of qualitative methods being used (Brown and Harris 1978) in stress and coping research, some authors claim there is a need for more (Thoits 1995, Nolan 1996, Seymour 1999).

Studies on stress and coping have tended to either treat caregivers as a homogeneous group irrespective of the nature of the disability (Burr and Klein 1994, Warner 1995, Nolan et al 1996), or have focused on carers of people with a particular disability such as dementia (Cleary 1992, Krauss and Seltzer 1993, Murray and Livingstone 1998, Moriarty and Webb 2000). Little research has focused specifically on caregivers of frail older people. Moreover, with few exceptions (Taylor and Ford 1994), the majority of studies derive their samples from the lists of service providers. Thus the extent, to which the findings are applicable to other carers and non-service users in particular, is unclear.

Nonetheless, the literature provides ample evidence to support the commonly held view that caregiving is stressful. Events or circumstances are perceived as stressful when the demands of a situation exceed the person's resources and endanger their wellbeing (Lazarus 1991). Stress is seen as a consequence of the current caregiving situation but it can also be a predictor of future behaviour. Stress reduces the willingness and ability of carers to provide care and increases the care recipient's chances of admission to institutionalised care.

Coping has a very specific meaning within the literature. It is seen as the mechanism employed by individuals responding to stressors. The most widely accepted theory is Lazarus and Folkman's (1984) transactional model of stress and coping. The transactional approach to stress has been useful in explaining variations of stress amongst large samples of caregivers as well as exploring their individual circumstances. Because the transactional model focuses on understanding how events are interpreted and appraised, studies using this approach have suggested that 'life conditions' and 'environmental' factors are important in understanding caregiver stress and coping. The efficacy of coping strategies depends on the way in which people evaluate the nature and extent of the stress in their lives and also on the availability of coping resources such as social support and formal services. Stress is a key factor in carers' use of formal services (Eagles 1987, Twigg and Atkin 1994).

Service support for carers is usually justified in terms of its effectiveness as a means of supporting frail older people in the community and preventing institutionalisation. In this

context, concern with the stress experienced by carers is warranted because of its reputed effect on their willingness to continue providing care. Development of formal support services aimed at reducing the stress associated with caregiving has been the focus of recent policy. However, simply providing services does not ensure utilisation. Research documents the low uptake of services by carers, but fails to explain it adequately. Reluctance to use services does not necessarily indicate a lack of need for them. Contrary to widely held assumptions, neither need, knowledge, awareness nor availability of services are good predictors that services will actually be used. There is a need for further research to determine why some carers are reluctant to use formal services.

Gaps in the literature

This literature review has shown how the emergence of caring as a policy issue has led to a considerable volume of literature trying to describe, analyse and quantify informal caregiving. The first chapter explored theories of care. It considered both the formal and informal concepts of care and also explored who, how and why individuals within a family became carers. The second chapter reviewed the literature on experiences of caring, focusing particularly on practical and personal caregiving and its consequences in terms of employment, finances and health. Also considered was caregiving as a rewarding experience and typologies of carers based on their responses to their role. The final chapter explored the literature on the concepts of stress and coping and the use of formal services.

As a result of this review three gaps in the existing literature on caregiving have been identified. Firstly, much of the literature, particularly about stress, coping and models of care is based on studies of people with dementia. Moreover, by focusing on the physical dimensions of caring, these studies tend to map carers' experiences in line with the progress of this degenerative condition. They fail however, to address the nature of caregiving for older people without any cognitive impairment whose progress towards frailty and dependence is uncertain. There is a need to understand the way in which the experiences and relationships of carers of older people, might differ, if at all, from those of dementia carers. The models of dementia care fail to illustrate the dynamic and interactive nature of care provided for frail older people.

Secondly, research tends to overlook carers who are not supported by service providers. Carers most likely to be in receipt of formal services are reputed to have high stress levels and to be the most heavily involved by providing personal and physical care for more than 20 hours a week. It has been shown though, that many carers do not receive support from formal service providers and are in fact, reluctant to do so. Yet with few exceptions (Taylor and Ford 1995), the vast majority of studies draw their samples from the lists of service providers. Respondents are therefore, either current or previous users of services. The literature almost completely ignores the issue of non-use of services by carers.

Thirdly, due to a lack of qualitative, longitudinal studies, the current literature fails to capture the way in which individual experiences and caregiving relationships may change over time. The few temporal and longitudinal studies of caring that exist tend to be quantitative, descriptive research, which identifies trends rather than explain individualistic experiences (Bauld et al 2001, Hutton and Hirst 2001). Moreover, studies on caregiver stress and coping are also predominantly quantitative. These studies fail to explain why, if caring is as stressful as many studies suggest, do so many informal carers continue caring for their relatives without support from formal service providers?

The current study aims to fill some of these gaps in the caregiving literature. By adopting a qualitative longitudinal approach, it seeks to further our understanding of the process of caring for frail older people without dementia. It will also explore the dynamic and temporal aspects of caring from the perceptions of non-service users. Such a study has important implications for the development and delivery of community care services.

The last three chapters have formed a review of the literature, which has informed the research design of the current study, which is described in the following chapter.

4. Research Design

This chapter will discuss the research design of the study. It will review the methodology underpinning the study as well as the methods used to collect and analyse data. The research was designed to be a predominantly qualitative study, guided by the principles of grounded theory, which further incorporated quantitative and longitudinal components. The chapter begins with a discussion of the study's methodological foundations, which is followed by a detailed narrative of the methods employed in data collection and analysis.

Quantitative versus Qualitative Research

The selection of a research design for this study was guided by its purpose, which was to further our understanding of the experiences of informal carers. In particular, it sought to explore the experiences of caregiving from the perspective of informal carers. In selecting the most appropriate design various research traditions were considered.

The literature distinguishes between two approaches to research, namely quantitative and qualitative. These approaches are sometimes said to represent divergent and opposing research traditions described as positivistic versus interpretative (Giddens 1976 cited in Gilbert 2001). These traditions differ in the philosophical assumptions they make about the nature of social reality and the relationship between the researcher and those being researched.

The positivist tradition holds that there is an objective, external social world that exists independently of human perception and is suitable for quantitative measurement. Knowledge of this world is gained through a scientific mode of enquiry similar to that employed by the natural sciences. The positivist tradition aims to develop valid and reliable ways of collecting facts about society, which can then be statistically analysed in order to explain how the social world operates. The researcher is seen as maintaining an objective stance by using tools and methods such as structured questionnaires and systematic sampling techniques. These tools are intended to prevent bias by limiting the amount of personal interaction between the researcher and the researched. It is claimed

that these tools produce precise, objective and scientifically sound analyses of the nature of social life (Bryman 1988, 2001, Sarantakos 1998).

In contrast to positivism, qualitative research within an interpretivist tradition rejects the notion of a single objective reality or truth, which can be discovered by scientific investigation. Interpretivists believe that the social world consists of multiple, subjective realities, that individual and groups construct their own vision of reality and therefore, reality is a much more elusive concept. Furthermore, the interpretivist or qualitative perspective emphasises the concept of naturalism. In its broadest sense, naturalism asserts that social phenomena are so fundamentally distinct from physical phenomena that they cannot be understood by applied scientific methods from the physical sciences. Thus the interpretivist tradition uses qualitative methods and tools such as observation and unstructured interviews as a way of getting close to the data and studying social interaction in its natural settings. This is in marked contrast to the quantitative approach where the rules of scientific method exhort the researcher to adopt a position of scientific detachment (Bryman 1988, 2001, Sarantakos 1998).

Qualitative Research

It was decided that a mainly qualitative approach following the interpretivist tradition and guided by the principles of grounded theory would be the most suitable approach for exploring carers' experiences of caregiving. A wholly traditional, positivist approach was considered inappropriate for a study whose overall aim sought to understand carers' subjective interpretation of events and experiences. Positivist approaches can exclude information that is considered to be too subjective and beyond the control of the researcher. This can result in valuable dimensions of the social world being overlooked (Bryman 1988, 2001, Sarantakos 1998).

A qualitative approach was selected for three reasons. Firstly, qualitative research studies phenomenon in their natural settings and is concerned with obtaining people's own accounts of their behaviour, attitudes and motivations. Secondly, qualitative research offers a rich description of individuals' perceptions, beliefs and feelings as well as the meaning and interpretation given to events and behaviour (Bryman 1988, 2001). Thirdly, it allows the researcher to gain an insight to the nature of the research problem as it is understood and experienced by those involved, in this instance informal carers. This

approach therefore, aligns itself with the aims of the present study, as do the principles of grounded theory. The following section will outline the main elements of grounded theory and explain why it was used in the present study.

Grounded Theory

Grounded theory was developed by two sociologists, Glaser and Strauss (1967) and presented in their seminal work 'The Discovery of Grounded Theory'. Grounded theory is an ambiguous term in that it refers to a research methodology as well as describing the type of theory that is generated by the methodology.

As a methodology, grounded theory is an inductive approach to research, which was developed as an alternative to the hypothetico-deductive approach of positivism. The hypothetico-deductive method depends on the existence of theory from which hypotheses are deduced. This drives the collection of data, which either confirms, rejects or refines the hypothesis in order to bring it nearer the 'truth'. In contrast to this approach, grounded theory depends on the existence of data from which hypotheses or propositions are induced. This leads to further data collection from which theory emerges. The theory is therefore, said to be 'grounded in' and 'emerges from' the data (Strauss and Corbin 1990). Thus when using a grounded theory approach the researcher does not begin a study with a preconceived theory or framework in mind unless their purpose is to elaborate and broaden existing theory (Strauss and Corbin 1990, 1998). Rather, they begin with an area of study and allow theory and the framework to emerge from the data.

Grounded theory offers a complete methodological package in which the theoretical framework and method are integrated. This methodology prescribes a rigorous set of procedures with which to systematically collect and analyse data. The main procedures are based on data collection, theoretical sampling and coding. These procedures are similar to those of other qualitative approaches but they differ in that in a grounded theory study they are undertaken simultaneously rather than sequentially.

Data Collection

In the grounded theory approach data collection is a broad term that is taken to mean searching and establishing access to sources and finally studying and collecting

information. It begins with only a cursory literature review. It is claimed that a comprehensive review at this stage is impossible because it is impossible to guess what issues and concepts will emerge from in the course of the study. It is claimed that familiarity with the literature that is closely related to the research topic might constrain the coding of concepts and categories that emerge from the data (Strauss and Corbin 1990, 1998). Reading widely is recommended only once a specific research topic is identified in order to establish the background and importance of the study.

Data collection is a cyclical process that is interwoven with analysis, generating new propositions, writing theoretical memos about emergent issues, collecting new data again and further analysis. The process ends according to the principle of theoretical saturation. Saturation entails the continued analysis of data until all available information has been obtained. Saturation is reached when new information is unable to effect a change in the interpretation of the existing data.

Theoretical Sampling

Theoretical sampling is a defining property of grounded theory (Bryman 2001). It is concerned with sampling in terms of what is relevant to and meaningful for the evolving theory. Theoretical sampling is similar to purposive sampling in that they both deliberately select respondents who are most likely to contribute reliable and valid information about a particular situation. Theoretical sampling differs from probability sampling in that it is an ongoing process rather than a distinct and single phase. Also it is not just people that are sampled. Places, people, events and situations that will maximise opportunities to confirm categories, refine ideas or discover new data can also be theoretically sampled.

Coding Process

The coding process is central to the analysis of data and the generation of grounded theory. Coding refers to the iterative process of asking questions of the data in an accurate and systematic way. During this process analytical memos relating to emerging codes and categories are written. Their purpose is to explore and develop themes and ultimately to contribute to the final analysis.

Coding is one of three types: open, axial and selective. Open coding refers to the process of closely examining the data in order to identify and classify significant words, phrases or paragraphs. During this process, words such as 'carers allowance' or 'pension' might be

coded as 'finances' and phrases like 'she came for a visit and just stayed' as 'residency'. Phrases such as 'giving up work' might become an 'en vivo' code, which means that it is taken directly from the words as spoken by the respondent. Incidents, objects, words or events can be assigned more than one open code.

The process of axial coding is concerned with the relationships or connections between the codes established in open coding and the formation of categories and their properties. Categories subsume more than one code and describe generalised processes, which occur in more than one empirical case. For example, open codes of 'conflict', 'fights', 'arguments' and 'power' might be axially coded to create a category termed 'control'. As a category 'control' is an overarching term that embraces other open codes. Finally selective coding determines which categories are core or important for the emergent theory and which can be discarded as being irrelevant.

Coding is conducted in accordance with the concept of constant comparisons. Constant comparison is a procedure whereby incidents in the data are literally compared with each other and to the literature in order to develop codes, categories and their properties. As Strauss and Corbin (1990) state, the discovery and specification of differences and similarities among and within codes and categories is crucially important and lies at the heart of grounded theory. A detailed description of how the process of coding was undertaken in the present study can be found in the following methods section.

Why Grounded Theory?

The use of grounded theory for qualitative research has become increasingly popular across a wide range of academic disciplines. This rise has been attributed to its relevance (Bryman 2001, Dick 2002, Pandit 1996). The grounded theory approach is relevant to other fields because it has the advantage of having no pre-determined theoretical framework (Strauss and Corbin 1990). Grounded theory guides the collection and analysis of data, but it does not prescribe the particular perspective which researchers should adopt. Thus it is possible for sociologists or psychologists to use perspectives from their own disciplines to study phenomena using the grounded theory method as it is not 'discipline-bound' (Strauss and Corbin 1990). The emerging theory is driven by the data not by a theoretical framework. Corbin and Strauss (1988) used symbolic interactionism in their attempt to describe the hospital care of dying patients.

The decision for the current research to be guided by the principles and procedures of grounded theory was based on the perceived advantages of this approach. It was anticipated that these advantages would help to achieve the research objectives. The first perceived advantage is that grounded theory is a procedure that focuses on processes. For that very reason it is a suitable approach with which to study the process of caregiving. Secondly, this approach is particularly relevant for areas about which little is known, such as certain aspects of caregiving. Furthermore, the main purpose of a grounded theory approach is to understand the nature of human behaviour. Thus, because it is drawn from data, a grounded theory approach is said to offer insight into the ways that individuals and groups make sense of something. It explores the reality of situations rather than preconceived notions of what should or ought to be happening. Hence it is argued that an emergent theory derived from data is more likely to resemble 'reality' than one derived either from piecing together a number of concepts or through speculation (Glaser and Strauss 1967, Strauss and Corbin 1990). This focus on reality should aid our understanding of carers' behaviour and the nature of caregiving.

Thirdly, grounded theory offers a complete methodological package, which makes it practically accessible to the novice researcher. Its proponents claim that it is flexible and adaptable to the changing demands of the research process. Furthermore because it has no pre-ordained theoretical framework, a grounded theory approach is unlikely to restrain the researcher and likely to show a good fit with participants' perspectives (Strauss and Corbin 1990, 1998).

Finally, a grounded theory approach was selected because of the researcher's experience as a community nurse and her familiarity with the field of informal care. Being a participant observer or even a worker 'in the field' itself is apparently a strength as far as this approach is concerned and means that the researcher enters the research process with some 'theoretical sensitivity' to the needs of carers (Glaser 1978, Strauss and Corbin 1990). This enables the researcher to enter the field more quickly as they do not have to spend time becoming familiar with surroundings or events. Thus from the start the researcher was 'immersed' in the context of caregiving and had already developed a 'contextual sensitivity' to and an 'empathetic understanding' of the research area (Strauss 1987, Strauss & Corbin 1990). Other writers support this view that it is advantageous for researchers to be sensitised to existing conceptualisations so that their enquiries are focused and can build upon the work of others (Bryman 2001).

Critique of Grounded Theory

Since its introduction more than thirty years ago, grounded theory has evolved into three different strands. These debates within contemporary grounded theory vary according to different beliefs on the nature of knowledge and the methods for attaining it. The founding fathers of grounded theory, Glaser and Strauss, have developed this methodology in different ways. Glaser's approach to grounded theory is called 'traditional', Strauss and Corbin's 'new positivist' and Charmez's 'constructionist' (Dick 2002).

For the most part all these approaches continue to promote the goal of grounded theory as being to formulate a theory which must emerge from and be grounded in data that is systematically gathered and analysed. However, Glaser (1998) believes that Strauss and Corbin (1990) grossly misrepresented the most important features of grounded theory. The crux of the difference between grounded theory as advocated by Strauss and Corbin (1990) and that of Glaser (1998) is about the extent to which the theory is allowed to 'emerge' from the data as opposed to being 'forced'. Strauss and Corbin describe a detailed and rigorous set of procedures for coding and analysing the raw data from open codes to core categories. According to Glaser (1998) this defined set of procedures 'forces' the data into determined frameworks rather than allowing it to emerge naturally. Glaser thus describes a more flexible and less rigorous process of coding which identifies 'categories' as opposed to the open codes derived from Strauss and Corbin's procedures. Also in Glaser's approach high priority is given to the use of analytical and theoretical memos, which are eventually used to select the categories that are important to the emergent theory. This process Glaser refers to as 'sorting' but in fact it is similar to what Strauss and Corbin call 'axial coding'.

Charmez (2000 cited in Bryman 2001) has extended the grounded theory debate further by her critique of both Strauss and Glaser's approaches. She claims that the grounded theory associated with Glaser, Strauss and Corbin is objectivist in that it seeks to identify a reality that is unaffected by social actors. Her alternative constructionist version holds that social reality does not exist independent of human action. Thus the categories and theoretical concepts in grounded theory emerge from researchers' interaction within the field and questions about the data. Charmez's position is in contrast to earlier writing on grounded theory which inferred that categories and concepts are inherent in the data and wait to be uncovered by the researcher.

The differences in the three schools of thought outlined above, might seem minor but taken together have important implications for the way research, including the present study, was conducted. The existence of these competing accounts of grounded theory does not make it easy to describe or establish how to use it. Nonetheless, grounded theory is regarded as being the most influential general strategy for conducting qualitative research, although how closely the approach is followed varies between studies (Gilbert 2001, Sarantakos 1998). Its core processes such as coding and the notion of allowing theoretical ideas to emerge from data have been widely adopted.

The present study used a modified grounded theory approach, which adhered more closely to Strauss and Corbin's approach. This decision was made because to the novice researcher, Strauss and Corbin's detailed description of rigorous coding procedures was more reassuring than Glaser's more abstract guidance. In the present study, literature was accessed both prior to the start of fieldwork and as necessary in the course of the study. The present study also used purposive sampling rather than theoretical sampling, although both are similar in that they aim to deliberately choose who or what situations to include in the study on the basis that those selected can provide the necessary data. Thus in the present study the principles and procedures of grounded theory were mainly applied to data analysis, which proceeded according to the principles of constant comparison and theoretical saturation. A detailed description of this process can be found in the following section on methods.

Longitudinal Approach

Aspects of grounded theory that are deemed important include a focus on processes. This aspect is of particular relevance when considering the overall aim of this study since caregiving is acknowledged as being a dynamic process, which evolves over time (Nolan et al 1996). Thus it seemed appropriate that data about caregiving should be collected at intervals in order to capture any change that may take place.

Furthermore, despite a considerable body of literature on caregiving emerging in the last twenty years, little is known about the temporal dimension of caregiving. Few studies have considered the stages or processes of caring (Willoughby and Keating 1991) and as a consequence, there has been a failure to explore or develop longitudinal models of caregiving (Opie 1994, Taraborrelli 1994). This has resulted in a failure to understand how

caregiver attitudes, beliefs and behaviours change over time. Thus a longitudinal approach was selected as being an appropriate component of the research design.

Because of the time and the costs involved, small-scale longitudinal cohort studies are rarely used in social policy research (Gilbert 2001). Nonetheless, it was anticipated that a longitudinal approach would have several advantages. Firstly, this design would provide an insight into the progress and processes of the caring role. Secondly, it would allow any changes or continuity in circumstances to be explored. Finally, it would produce a more complete picture of a caring career rather than a snapshot of circumstances at a particular point in time.

Longitudinal studies are intended to study change at the individual level but the most common difficulty reported with this strategy is the attrition rate (Hakim 1987, Magnusson et al 1991, Sarantakos 1998). However, it was decided that possible sample attrition due to death or admission to long term care would be treated as a key event and appropriate information collected wherever possible. According to Hakim (1987), despite the problems of sample attrition a longitudinal study is unique in its ability to provide a basis for substantiated explanatory theory and in this respect it fits well with either a qualitative or quantitative approach.

Quantitative Research

When described in their purest forms, quantitative and qualitative approaches to research seem to be incompatible. Their underlying philosophical assumptions are not only different, but they also appear to be mutually exclusive. However, by successfully combining quantitative and qualitative research methods within the same study, researchers have proved that they are not necessarily incompatible (Qureshi 1995 cited in Gilbert 2001, Critcher et al 1990) and are particularly effective in policy-orientated research (Gilbert 2001). Furthermore, quantitative and qualitative research may be relevant at different stages in the research process (Bryman 1988). Gross et al's (1971 cited in Bryman 1988) study for example, shows how quantitative and qualitative research may achieve different types of fit with various stages of a longitudinal study.

Despite an emphasis on a qualitative approach it was decided to include a quantitative component. There were a number of reasons for this decision. Firstly, it was anticipated

that the inclusion of a quantitative approach would supply reliable numerical data, which would be used to confirm and strengthen findings from the qualitative data (Bryman 1988, 2001). It would for example, suggest how many carers experienced similar difficulties or indicate the frequency of use of particular coping strategies. Secondly, it was expected that by gathering two types of data a more comprehensive picture of caregiving would emerge. The purpose of the overall qualitative strategy was to study processes within caring and to allow access to the perspectives of carers, whereas the quantitative data would allow for the exploration of specific issues, thus shedding more light on particular aspects of caregiving. It would also allow for an exploration of sensitive issues in a detached way. Issues such as the changing nature and quality of relationships and the difficulties and satisfactions that can arise, which carers are reported to have difficulty in articulating (Motenko 1989).

A quantitative approach was used to identify the most prevalent problems and causes of stress, coping strategies and satisfactions related to caregiving as perceived by caregivers. In order to explore these aspects of caregiving the researcher had to choose from a wide range of tools. Whilst stress and coping are often measured with validated instruments, satisfaction derived from caring is rarely assessed (Motenko 1989). However, many of the validated instruments used do not necessarily take account of carers' perceptions. Coping for example, can be measured by the Ways of Coping Questionnaire (Matson 1994), which contains 40 items that detail the ways in which carers cope. Stress can be measured by validated instruments such as the Rutter Malaise Inventory (Rutter et al 1970) or the Kosberg Cost of Care Index (Kosberg and Cairl 1986), which assess the adverse effects stress is deemed to have on caregivers' mental health.

These instruments are designed to show the impact of caregiving on the mental health of carers. The Malaise Inventory in particular, has been used in a number of studies of caregiver stress in the field of learning disability (Patterson 1993, Quine and Pahl 1985), as well as with carers of older people (Bauld et al 2000, Nolan and Grant 1989, Wright 1986). The authors of these studies suggest that it is a valid and reliable instrument that illustrates clearly that caregiving has a negative effect on carers' mental health. However, these instruments do not specifically ask respondents whether or not they perceive the items listed in the indexes as stressful. Rather they are underpinned by the assumption that the difficulties and restrictions caused by particular caregiving tasks are stressful in themselves. Yet other studies have found that caring is not necessarily stressful. In McKee et al's (1999) study of carers 28 per cent reported experiencing 'no stress at all' and 14 per cent 'hardly any stress'. Furthermore, these instruments score respondents

according to how many affirmative answers they give to a series of questions. The number of affirmative answers is taken as the total score. Thus the summative nature of these tools obscures the relative contribution that particular items make to the overall score. Although the Kosberg Cost of Care Index attempts to overcome this problem by using factor analysis, it too is underpinned by the assumption that because caregiving imposes restrictions for example, on the social lives of carers, then this in itself is stressful.

An earlier study by Grant et al (1990) which explores stress in a self-selected sample of carers sought to overcome these conceptual and methodological problems. This study was concerned with identifying the problems of caregiving as perceived by carers themselves and exploring the relationships between stress levels, perceived sources of stress and the objective circumstances of the caregiving situation. This study developed and used a new instrument that was not underpinned by an assumption that the presence of difficulties necessarily leads to stress. Grant et al (1990) and Nolan et al (1990) used the Rutter Malaise Inventory together with a newly designed instrument, the Carer Perceived Problem Checklist (CPPC) to measure caregiver stress.

It is claimed that this instrument is not underpinned by an assumption that the presence of difficulties necessarily leads to stress (Grant et al 1990, Nolan et al 1990). However, the assumption that it does seem to make is that the presence of stress necessarily leads to feelings of burden. Yet, the instruments used in this study did not ask carers if they perceived certain aspects of the situation to be burdensome. This study is commendable in that it allows carers to determine how much stress a particular situation generates. Nonetheless, by taking carers' perceptions of stress to represent feelings of burden, the study is underpinned by an assumption that the difficulties and restrictions caused by caregiving translate directly to feelings of burden. Although the concepts of stress and burden are similar, we have seen from the literature review that they are not synonymous. Grant and Nolan and their colleagues further developed the CPC into the Carers Assessment of Difficulties Index (CADI) that was used in the present study. This index however, is not underpinned by an assumption that feelings of burden translate directly to stress. Rather, it allows carers to express which circumstances or events they experience as stressful.

Standardised instruments

The instruments used to capture quantitative data were utilised only in the second wave of data collection. These validated instruments were indices developed by Nolan and his

colleagues (1994, 1996) as tools with which to conduct a comprehensive assessment of carers' unique circumstances. These indices can either be administered by the interviewer or completed by respondents. In the present study carers were invited to complete them themselves. The indices used were the Carers Assessment of Satisfaction Index (CASI), Carers Assessment of Difficulties Index (CADI), and the Carers Assessment of Managing Index (CAMI). The items contained in these indices were derived from research with carers. The items are therefore empirically based, being generated from factors identified by carers themselves (Nolan et al 1996).

Carers Assessment of Difficulties Index (CADI)

CADI was designed to assess the range of problems carers face and their existing level of knowledge and expertise. It provides a way of identifying the most prevalent problems in a particular caring situation and the ones that are perceived to be stressful. It consists of 30 statements that carers have made about the difficulties they face. In completing the index carers were asked to read each statement and say whether it applied to them and if it did, to say whether they found it; not stressful, stressful or very stressful. (See Appendix II)

Carers Assessment of Managing Index (CAMI)

This tool determines the frequency of use and the perceived effectiveness of particular coping strategies. Coping strategies and their efficacy were primarily measured by carers' perceptions and supported by the data collected by means of the Carers Assessment of Managing Index. (CAMI). The purpose of using this tool was to explore as fully as possible the way that carers cope with the challenges they face and the coping measures and strategies they adopt. CAMI comprises 38 statements about coping strategies. When completing the index, carers were asked to read each statement and indicate whether they did not use this approach, whether they used it but did not find it helpful, used it and found it quite helpful, or used it and found it very helpful. (See Appendix III)

The Carers Assessment of Satisfaction Index (CASI)

The Carers Assessment of Satisfaction Index (CASI) (Grant and Nolan 1993) was devised to explore the range and diversity of rewards that carers derive from caregiving. It consists of 30 sources of satisfaction as identified by carers. As mentioned in chapter two, a carers role is frequently portrayed as being difficult and stressful and satisfaction is an overlooked aspect of caregiving (Motenko 1989, Grant and Nolan 1993). So this tool was expected to

be useful in eliciting carers' feelings of satisfaction about their role. In completing the scale carers were asked to read each item and indicate if it did not apply to them, applied but did not provide a source of satisfaction, applied but provided quite a lot of satisfaction, or applied and provided a great deal of satisfaction. (See Appendix IV)

It can be seen from the above discussion that the selection of these instruments was congruent with the overall aims of the research in that they were designed to explore different aspects of carers' experiences.

Methods

This section contains a detailed description of the methods used in the current study to collect, code and analyse data. The main steps in grounded theory research are similar to those of other qualitative models, for example, thinking about the research issues, searching for material, asking generative questions, entering the field, making observations, interviewing, and analysing the data. The key points of such research are data collection and analysis. However, in grounded theory study these steps are taken simultaneously rather than sequentially although they are often, as in this thesis, reported as separate processes.

There were several reasons for the specific selection of data collection methods of interviews, questionnaires and literature. First, it was anticipated that these methods would allow for the collection of detailed information reflecting complex social phenomenon. The use of in-depth interviews in particular as the primary source of data was expected to provide the research with rich information. Secondly, it was thought that the use of multiple methods would provide diversity and would be more likely to reflect a broader picture of caregivers' experiences.

Focusing the Research

The research process began with a preliminary review of the literature. This was conducted as recommended by Hart (1998) to identify the scope, range and type of previous research, and to establish the background and importance of this particular study. As the study progressed, the literature was accessed as it became relevant, in order to further understanding of related concepts and emerging categories. The next step was

narrowing the focus of the research. What Glaser & Strauss (1967) refer to as the 'substantive area' of research was easily identified because of the researcher's personal and professional interests but as a research topic it required some refinement. In an attempt to do this a series of focus groups were arranged with carers.

The primary objective in conducting focus groups was to further explore the dimensions of caregiving as a topic and refine the research questions. When conducting focus groups, participants should be selected because they have been involved in a particular situation and display a degree of homogeneity (Tynan and Drayton 1988, Morgan 1995). In this case the particular situation that participants had in common was providing care. Although focus groups have been criticised on the grounds that they do not generate 'hard data' (Clough and Nutbrown 2002), in this instance they were utilised in order to explore the issues of importance to carers. Focus groups were chosen for this purpose because they have the advantage of stimulating discussion through interaction with others and eliciting a range of views within a relatively short space of time (Frey and Montana 1987, Morgan 1991, Henderson 1995).

Focus groups were arranged with the help of community workers and voluntary groups in north Glasgow. A sample of carers were recruited using three different approaches. Firstly, the staff in a day centre agreed to distribute a pro forma return and a letter explaining the study to persons attending the day centre. The letter invited carers to take part in a discussion group about the needs of carers. Secondly, the Social Work Department contacted a number of people who had expressed an interest in attending a carer's information day to ask if they were carers and if so, for whom. Once their status was confirmed, carers were invited to participate in the study. Finally, contact was made with the organisers of support groups run by both statutory and voluntary agencies who were asked to invite their members to a focus group.

The number of groups was determined by the availability of carers willing to participate. The final sample consisted of carers who looked after people with dementia, with learning difficulties, with physical disabilities, with drug addiction problems, and resident and non-resident carers of older people. Carers of people with mental health problems were invited but declined to participate. For the convenience of participants, two groups met in the morning and four in the evening. It is recommended that groups should be small when participants are likely to have a lot to say on the research topic and that this is most likely to occur when participants are very involved in or emotionally preoccupied with the topic (Scott 1983, Morgan 1995). Each group therefore, consisted of between six to eight carers.

The method used in discussions with carers was the Nominal Group Technique originally devised by Delbecq and Van de Ven (1968) and more recently modified by Fitzpatrick and Taylor (1994). This technique enabled carers to focus on a single statement, to generate ideas and reach consensus through a structured process. This process began with the opening question:

'What would make life better and easier for you as a carer?'

Each member of the group was given a pen and paper and asked to record their own answers. The individual answers were subsequently transferred on to a flip chart that everyone in the group could see. Each item on the flip chart was discussed at length. Members were then given blank cards and asked to study the flip chart in order to choose the ten items, which they considered the most important. They were asked to record each item on a separate card. With the cards displayed in front of them, group members were then asked to choose the most important and award it 10 points. The exercise was repeated with the remaining cards until each item had been given a descending score. Finally each score was transferred onto the flip chart, the totals counted and the issues ranked according to the highest score.

Findings from the focus groups suggested that carers were not a homogenous group. Their needs were determined by the illness and/or disability of the person being cared for and their living arrangements. So some needs were specific to a particular client group, others were shared but given differential importance. The needs shared by three or more groups of carers were for information, practical and emotional support, service improvement and respite care. Needs unique to particular groups were crisis intervention and recognition. Crisis intervention was identified as a need by carers of people with dementia and drug addicts. Both groups experienced most problems during the night when statutory services were not readily available. Carers of people with dementia wanted an overnight home support service while carers of drug users wanted practical help at night in the form of a local crisis centre. Recognition was a need unique to non-resident carers who felt that their role was undermined and unacknowledged by service providers. Non-resident carers experienced particular difficulties in communicating with service providers and GPs. They believed that this was due to lack of recognition.

A theme running throughout the focus groups was mistrust and criticism of health and social care agencies, which carers perceived to be unhelpful and unsupportive. They expressed a particular need for information on what services were available and help with

the practical aspects of caregiving. Carers in the focus groups found services difficult to access and the referral process a difficult and lengthy one. Many of them, irrespective of who they were looking after had little or no contact with service providers. They seemed to be unknown or 'hidden' from the gaze of service providers.

It was these findings from the focus groups that determined the initial perspective adopted by the current study. These findings served to generate a number of questions for example, was the relative obscurity of carers in the focus groups simply a stage in a caring career such as that described by Nolan et al (1996)? Or did these carers possess personal qualities that allowed them to manage successfully with a situation which others in a similar position found difficult if not impossible to deal with on their own? Did the experiences of these carers differ significantly from those who received support from formal service providers? These issues were felt to be interesting and intriguing aspects of caregiving worthy of further investigation and led to the formulation of a research question. Subsidiary research questions were not compiled because in grounded theory the researcher starts with a broad area and allows issues and concepts to 'emerge' from the data. To have formulated additional research questions means that the data would have been 'forced' into pre-determined frameworks which is contrary to grounded theory and the point of Glaser's (1998) article about emerging versus forcing. The research question was:

Why when caregiving is portrayed as being stressful do carers continue without support from formal service providers?

The focus groups had highlighted intriguing issues and effectively helped to narrow the focus of the research. However, the problem of who or which group of carers to study remained. It was eventually decided that carers of older people without dementia or a pre-existing disability should be the focus of the study. Whilst not all older people are in need of care, there is little doubt that it is amongst the older population that the greatest need for care exists. Of those in receipt of care, almost 79 per cent are aged 65 and over and 20 per cent are over the age of 85 (BMA 1995). As a group, older people aged 65 and over, comprise 15.7 per cent of the total UK population and are the main users of health and social services (Tinker 1997, Walker 1995). In relation to the sample, the minimum age of 65 was decided upon as it is the most commonly used definition of 'older people' (Tinker 1997).

Carers of client groups other than older people were considered and discounted as a potential sample. For example, carers of children or young people with learning or

physical disability were discounted because data from the focus groups and the literature suggested that their situation is often regarded as normative. In other words, parents are expected to look after their children without formal support from welfare agencies (Glendinning 1983, Twigg and Atkin 1994). Carers of people with dementia and/or a terminal illness were also discounted. In both these circumstances, the amount of care required is generally expected to increase in line with the deterioration of the recipient's condition. Hence caregiving is not expected to last indefinitely and in the case of terminally ill people in particular, is expected to end with the death of the person being looked after. Moreover, the literature suggests that these carers experience specific problems due to the nature of particular medical conditions (Clarke 1995, Gilhooley 1986, Keady & Nolan 1995, Rodgers et al 2000).

Negotiating access

Negotiating access is one of the key phases of any research project and as recommended by Blaxter et al (1996:143), a 'reasoned, planned and modest strategy' was adopted. As there is no suitable sampling frame for a study of this kind, problems in obtaining a sample of unsupported carers were anticipated from the outset. Gaining access was not simply a 'continuing and demanding process' (Blaxter 1996: 144), it was in fact, extremely difficult. It is estimated that approximately two thirds of carers are not known to formal service providers (Taylor & Ford 1994), and that approximately one third receive no help at all (Robinson & Yee 1991). Therefore, since relatively few carers are known to statutory services (Taylor & Ford 1994) it was decided to enlist the help of a range of voluntary groups and carers organisations. Many of these voluntary organisations undertook outreach work and were thought to be in a position to identify and contact carers who were not receiving support from formal service providers. The Princess Royal Trust for Carers, Strathclyde Carers Forum and the Glasgow Council for Voluntary Services supplied lists of names, addresses and contact numbers of carers and users groups.

From these lists, two older people's organisations, a carers support group and a local minister were approached. A letter, which introduced the researcher, outlined the purpose of the study, and explained that their help in identifying carers was being sought, was sent to key individuals. The letter also stated that the researcher would telephone them in a few days in order to discuss the study further. A series of meetings was set up with the managers of these voluntary organisations during the follow up phone calls, the purpose of which was to gain the co-operation of gatekeepers.

It was essential that those involved with the study felt that it was beneficial and worthwhile. Therefore, at these meetings, the reasons for doing the research, why it would be of value and what the outcomes might be were explained. A report based on the study's findings to assist with service planning was also offered as a further enticement. Finally, gatekeepers were asked if they would be willing to identify carers of older people, who did not suffer from dementia, who seemed to be providing care without help from formal service providers.

The managers of the two older people's groups and the minister were very supportive. They took relatively little time to contact carers, explain about the study and ask if they were willing to participate and if so, give permission for their names and contact numbers to be passed to the researcher. Managers from the older people's groups provided the names of 15 carers willing to participate in the study, of which 4 subsequently refused to be interviewed. The carers support group supplied the names of 6 carers, of whom 5 were found to be receiving services from both health and social care agencies. The minister supplied the names of 4 carers of which 3 refused to be interviewed. Carers' reasons for not wanting to take part in the study were in some cases, related to issues of timing or a reluctance to become involved. Some carers said that they were either about to go on holiday, were in the midst of redecorating their homes, or were simply too busy to participate. Others said that when asked, for example, by the minister that they did not like to refuse him but it was apparently easier to refuse a complete stranger.

When it became apparent that suitable numbers of potential respondents were not materialising, contact was made with other groups and individuals throughout the following six months. For example, a health visitor with responsibility for carer support within a particular GP practice was contacted and provided the names of 3 carers, 2 of whom participated in the study. Two pensioners clubs located in different areas supplied the names of 9 carers who all agreed to participate. A carers group in the north west of the city supplied 2 names of carers, as did the manager of a community centre, all of whom participated in the study. In total 41 carers were approached of whom 28 agreed to participate. However, when contacted to arrange an interview 2 subsequently declined, one because he was going on holiday and the other because their parent was in hospital and not expected to return home.

Asking gatekeepers at the right time was found to be important; when approached, one centre manager was conducting her own research and was reluctant to help. She did not want the carers in her area to be '*hassled*' by too many researchers at the one time.

Although she expressed her willingness to help in identifying carers once her own study was completed, when she was contacted some months later no assistance was forthcoming. The description above portrays a picture of a relatively straightforward process that was in reality, arduous, time-consuming and frustrating.

Sampling strategies

Purposive sampling was used to identify a suitable sample of carers. This type of sampling guides the selection of participants, events and situations that are considered relevant to the research topic. The aim is to purposely choose subjects who in the opinion of the researcher are the most likely to provide valid and useful information (Sarantakos 1998). Participants were selected because of their status as carers of older people aged 65 and over without dementia or other existing disabilities, and who received no support from formal service agencies but were caring for 20 hours a week or more. Carers who provide care for 20 hours a week or more are regarded as being at the 'heavy end' of caring (Parker 1990). This assumes that they are the most involved carers providing both personal and physical care resulting in high levels of stress and in most need of support services. Because of practical and resource considerations, it was decided that participants should live within the city of Glasgow. The study included respondents living in the west, north and south-east of the city, areas which had similar socio-economic characteristics. The characteristics of respondents are outlined in more detail in the following section.

Data Collection

The intention was to interview carers on three occasions with a minimum interval of three months between interviews. However, due to the difficulties in accessing a sample of carers and combining fieldwork with other responsibilities, the actual interval between interviews varied from approximately 4 - 6 months between the first and second interviews and an interval of between 9–12 months between the second and final interview. This protracted period of data collection began in February 1998 and finished in April 2000.

Carers were contacted by telephone and during the ensuing conversation the researcher introduced herself, reminded the carer that they had agreed to their name being passed on, outlined the aims of the research and sought their agreement to participate further. Once a mutually convenient time and place for the interview had been agreed, a letter confirming the arrangements was sent to each carer. The majority of carers were happy for the interviews to be conducted in their own homes. Only on two occasions were interviews

conducted elsewhere. The very first participant was interviewed in his workplace with the agreement of his employer. He worked as a driver for a community centre and on the evening in question had agreed to work later in order that young people with physical disabilities could attend a social function. Thus he had to time to talk in between picking up and returning people to their own homes. To ensure privacy, his employer had arranged for the use of room and provided tea and biscuits. On another occasion a carer did not wish to be interviewed with his mother present but had suggested that he meet the researcher at his house. The interview was subsequently conducted in a local lounge bar. Unfortunately, because of the level of noise in the premises, an attempt to record the interview was abandoned. This participant was subsequently excluded from the study because the researcher felt sufficient discomfort that it was decided not to seek further interviews. Although no other interviews were arranged this carer telephoned the researcher on a number of occasions. The purpose of the calls was unclear but they justified the decision to exclude him from the study.

Interviews began with a personal introduction by the researcher, who described the purpose of the study and stressed the importance of carers' contribution to the research. Respondents were assured about their anonymity and the confidential nature of the study. It was anticipated that each interview would last about one hour but in fact some lasted almost two hours and on some occasions longer than that. The interviews were in-depth and unstructured although a simple topic guide was devised to act as an 'aide memoir' for the interviewer. The questions were open-ended and subsequent ones were asked in response to the issues introduced by the respondents. The aim was to allow issues and themes to develop freely in order to gain an insight into carers' experiences and feelings. All interviews were tape recorded and subsequently transcribed. The three phases of interviewing are discussed below.

Phase One

A total of 26 carers were interviewed in the first phase of data collection. This phase was concerned with exploring issues in relation to carers' experiences. These interviews started with questions, which confirmed the respondents' demographic details. By having these personal questions at the very start of the interview rather than at the end, as often recommended by methodology text books (Blaxter et al 1996, Gilbert 2001), it was immediately and clearly established that the focus of the interview was the carer and not the person being cared for. With sensitive probing the conversation was guided from general description to specific details. Invariably respondents gave detailed descriptions of

how and why they became carers. Carers also talked about the quality of their relationship with the person being cared for and some expressed regret at the changes that had occurred. Some found this initial interview a painful and emotional experience and for many carers it was the first time they had told anybody their 'story'. Emergent themes were explored further in subsequent interviews (Glaser and Straus 1967, Strauss and Corbin 1990).

Phase Two

During the second phase of data collection 21 carers were interviewed. This phase was concerned with exploring emergent themes such as changes in the caring situation, carers' perceptions of stress and coping. Both qualitative and quantitative approaches were used. Interviews began with an open invitation to carers to tell the researcher about any changes that might have taken place since the last meeting. It was at this stage that the quantitative approach was used with carers being asked if they would mind completing three self-completion questionnaires. The purpose of the questionnaires CADI, CAMI and CASI, which were described in the previous section, was explained and carers were instructed on how to complete them. Essentially carers were asked to read each statement in the questionnaires and say whether or not it applied to them and if so, to what extent did they find it stressful, helpful or satisfying. All respondents completed these indices without difficulty.

Phase Three

Interviews were conducted with 17 carers during the third phase of data collection. This phase used an exclusively unstructured approach and in-depth interviews to explore any changes that had taken place since the previous interview. Emergent themes such as the triggers and pathways to service provision and carers' perceptions and experience of service providers were explored. Respondents appeared more relaxed and open to an exchange of confidences during these interviews. Thus, as predicted by Fielding and Thomas (2001) the openness of interviews increased once an atmosphere of 'sympathetic understanding' had been established. On completion of the final interview carers were once again thanked for participating and assured that in due course, they would receive a summary of the study's findings.

In the following section the characteristics of carer who took part in the study are presented.

Profile of Carers

The following table illustrates the individual characteristics of carers and care recipients who participated in the study. It describes their gender, age, relationship to care recipient, gender and age of care recipient, living arrangements, the duration of caregiving and the number of stages each carer participated in.

Table 1: Characteristics of carers and care recipients (n=26)

Carer						Cared for		
<i>Name</i>	<i>Age</i>	<i>Gender</i>	<i>Relationship to cared for</i>	<i>Residence</i>	<i>Duration of caring in years</i>	<i>Age</i>	<i>Gender</i>	<i>Stages participated in</i>
Brown	40	M	Son	Co-resident	6	85	M	I, II, III
Morrison	58	F	Daughter-in-law	Co-resident	8	81	F	I, II, III
Ireland	63	F	Sister	Non-resident	5	73	M	I, II, III
Welsh	62	F	Daughter	Non-resident	3	86	F	I, II
Macrae	63	F	Daughter	Co-resident	11	92	F	I, II, III
Yuill	75	F	Wife	Co-resident	4	78	M	I
Watson	38	F	Daughter	Co-resident	2		M	I, II, III
Kearns	36	F	Daughter	Co-resident	2	87	F	I, II, III
Murphy	65	F	Wife	Co-resident	8	77	M	I, II, III
Thomson	41	F	Daughter	Co-resident	6	78	M	I, II, III
Currie	83	F	Wife	Co-resident	20	86	M	I, II
Black	47	F	Daughter	Co-resident	8	79	F	I
Smith	50	F	Daughter-in-law	Co-resident	13	91	F	I, II, III
Peters	47	F	Daughter	Co-resident	6	84	F	I
Davidson	68	F	Wife	Co-resident	6	78	M	I
Veitch	69	F	Daughter	Co-resident	13	90	F	I, II, III
Tierney	68	F	Wife	Co-resident	7	76	M	I, II
Downs	76	M	Husband	Co-resident	6	76	F	I, II, III
Gordon	63	F	Daughter	Co-resident	20	87	M	I, II, III
Cranston	56	F	Daughter	Non-resident	6	78	F	I, II, III
Roberts	65	F	Wife	Co-resident	3	75	M	I, II, III
Duncan	47	F	Daughter	Co-resident	0.5	74	F	I, II, III
Beaton	51	F	Daughter	Co-resident	8	82	F	I, II, III
Bennet	67	F	Daughter	Co-resident	2	94	F	I, II, III
Clark	50	M	Son	Co-resident	1	83	F	I,
Paul	63	M	Husband	Co-resident	4	74	F	I, II

Carers varied in age from 36 to 83 years. The age distribution as set out in Table 2 shows that they were almost equally divided between those who were above and below 60 years, the pensionable age for women. The average age of carers was 58 years. The age range with the greatest representation was 60 – 69 with 11 carers, but the upper range extended to include 3 people over the age of 70. The age profile of unsupported carers' highlights the role of middle aged and elderly women in providing informal care.

Table 2. Carers: age and gender (n=26)

Age of carers	Female	Male
30 – 39	2	-
40 – 49	3	1
50 – 59	4	2
60 – 69	11	-
70 and over	2	1
Total	22	4

This profile mirrors those of other studies focusing on the carers of older people in the community. For example, Bland and Hudson (1994) and Fisher (1994) found the average age of carers to be between 55–65 years. On the other hand, larger surveys of carers of various client groups such as the 1995 GHS found the peak age for caring was 45–64 years (Rowlands and Parker 1998).

Length of time caring

Table 3 outlines the length of time carers had been providing care. It shows that for the majority, unsupported caring was not a short-term commitment.

Table 3. Primary carers: length of time providing care (n=26)

Length of time caring	Number of carers
Less than 1 year	1
1 – 4 years	8
5 – 9 years	12
10 or more years	5

The majority of respondents said that they had been caring for their older relative for more than a year. The actual length of time varied from 6 months to 20 years with the average being 6.88 years. There is no clear correlation between the relationship of the cared-for and the length of time the carers had been providing assistance. Spouse carers' did not appear to have been providing care for a longer period than adult child or sibling carers. The data provided examples of both siblings and spouse caring for more than ten years. Caring for the longest time was a professional woman who had been looking after her father since the death of her mother 20 years earlier. One person had been caring for her mother for six months.

The findings of a recent study examining Crossroads Care attendant schemes were similar to the present one. They found that 52 per cent of carers using the service had been carers for 5 years, more than a third had been caring for 10 years or more, while 9 per cent had been caring for more than 20 years (CHSR 1997). The 1995 GHS found that 24 per cent of carers had been looking after their dependant for at least 10 years, and a further 23 per cent had been caring for between 5 and 9 years. Of carers who lived with their dependants just under a third had been caring for them for at least 10 years (Rowlands and Parker 1998).

Relationships

Table 4 illustrates carers' relationship to the person being looked after. The nature of assistance required by frail older people means that it is usually close family members, a spouse, followed by children and siblings of the older person, who are willing to provide support.

Table 4: Carers: relationship to dependant (n=26)

Relationship to carer	Number of carers
Spouse	8
Daughter	13
Daughter in-law	2
Son	2
Sister / sister-in-law	1
Total	26

The single largest group of women (n=15) was daughters or daughter-in-laws. This finding mirrors those of other studies, which recognise the substantial contribution made

by daughters and daughters-in-law to the care of older people (Brody 1981, Charlesworth et al 1984, Qureshi and Walker 1989). Spouses were the second largest group and on the whole tended to be older than other carers. In this study the proportion of spouse carers is smaller than that found by others. The 1995 GHS for example, found that there was no difference in the proportion of husbands and wives devoting 20 hours a week or more to caring (Rowlands and Parker 1998). Furthermore, just over half of co-resident carers were looking after a spouse and only a fifth were caring for a parent or parents-in-law (Rowlands and Parker 1998).

Of the 16 carers in the study who were married or in permanent long-term relationships, only 8 were married to the person they were caring for. Five carers were divorced and 5 had never been married. The divorcees and unmarried carers were all caring for parents, and all but two were females. Three single females had always lived at home. In contrast, the two single men had both had their own homes, one had subsequently moved in with his mother and one brought his father to live with him.

Living Arrangements

The majority of respondents' (n=23) in the present study were co-resident carers. Only 3 carers were non-resident but they all lived in the same locality as the person they were caring for. The living arrangements of 9 carers were pre-existing with 4 having lived with their relative for more than 10 years. For this group co-residency was not a product of becoming a carer. The living arrangements of 8 were not pre-existing and were initiated by the dependant's need for care. Pre-existing was defined as co-residency predating the older person's need for care. The high proportion of co-resident carers in the present study is in contrast with other larger studies of carers. For example, the 1995 GHS found that just over a third of carers were caring for someone in the same household (Rowland and Parker 1998).

Employment

Of the 26 carers participating in the study, only three who had no younger dependants living at home, were in full-time employment. Four had given up work to care on a full time basis. Three carers on long-term disability benefits had health problems that were present before they became carers. Carers who had young children were either employed on a part-time basis or not at all. At the first interview only, two carers worked on a part-time basis, one as a homehelp and the other as an interviewer for a market research

organisation. One carer had never been in paid employment since her marriage 28 years ago and had looked after a number of relatives.

This profile provides an overview of the characteristics and circumstances of carers who participated in the study. The following section describes the process of data analysis.

Data Analysis

The use of computer software greatly facilitated the management and analysis of data. Computer software programmes used included Microsoft Word, ATLAS.ti and Excel. The main advantage of using a computer programme is that it simplifies the storage and organisation of information in a way that facilitates effective retrieval and analysis (Dey 1998, Sarantakos 1998). It also reduces the time taken to mechanically sort data, so leaving the researcher more able to concentrate to a greater extent on the creative aspects of theory building. The computer does not make conceptual decisions, such as which words or themes are important to focus on. These analytical tasks are still left to the researcher.

Quantitative data was analysed using the computer programme Excel that was already available on the researcher's computer. Excel is a spreadsheet and database package that performs many different types of calculations for nominally scaled data. In using Excel, the purpose of the process was to summarise, count and compare data. It was decided that advanced statistical analysis was unnecessary given that the sample was small and the focus was on the individual rather than on the characteristics of the group. Thus the added expense of obtaining a statistical package such as SPSS was deemed unnecessary.

Qualitative data were analysed using the computer software programme ATLAS.ti. This is a powerful and very 'user-friendly' package that operates in a similar manner to the popular Microsoft Windows software. ATLAS.ti was developed by Muhr (1993) a German scientist and is firmly based on the principles of grounded theory generation. There are two modes of data analysis within ATLAS.ti. Firstly, at the 'textual level' analysis focuses on the raw data and includes activities such as text segmentation, coding and memo writing. The second mode of analysis is at the 'conceptual level' which focuses on building a framework of inter-related codes, concepts and categories to form theoretical networks (Muhr 1993, 1996).

The principles and procedures of grounded theory guided the analysis of data. Thus all data were analysed according to the principles of theoretical saturation and constant comparisons. The concept of saturation means that analysis continues until all available information is obtained. Saturation is reached when additional data provides no new information (Strauss and Corbin 1990, 1998).

Constant comparison is a procedure whereby incidents in the data are literally compared with each other and to the literature in order to develop codes, identify their properties and ultimately formulate core categories. During this procedure the researcher asked questions of the data such as, how often is a particular concept or incident emerging and what does it look like and how does it vary, what are the consequences? Constant comparisons are made not only to classify data but also to stimulate thinking about the properties and dimensions of codes and to guide the formation of core categories.

Analysis, which is basically the process of making sense of the data, began as soon as the first data were collected. Interview tapes were transcribed on to a personal computer. Although this process was a slow and tedious one, it nonetheless provided an opportunity for identifying themes as tapes were transcribed. Following transcription a printout was obtained and the tape replayed whilst the researcher made notes on the transcript. These notes included comments about tone of voice, the demeanour of respondents and potential codes.

The Coding Process

Coding was facilitated by the use of ATLAS.ti and was one of three types: open, axial and selective as described in the previous section. For clarity, the following discussion of coding describes it as distinct and separate procedures but in practice the process is cyclical and flexible with considerable movement between the different levels.

Open coding

The first stage in the coding process was open coding. This involved a close examination of the first interview transcript and fieldnotes, which were organised into themes or examples of events and codes assigned accordingly. Quote marks were used around some codes to remind the researcher that they were derived from the actual language used by the respondent. Codes were thus derived from short phrases, individual words or whole paragraphs. At this stage in the analysis there was a great deal of uncertainty about the

amount of detail that needed to be taken from the data and represented in individual codes. So the researcher noted, commented upon and labelled everything that was considered interesting or significant. Some data had more than one code assigned to it.

The following example of open coding illustrates how the words in bold type ‘decision’ and ‘give up work’ were classified as codes on the first examination of the data. But during the process of constant comparison, when the data was being examined yet again, it was noted that the word ‘decision’ also suggested the notion of choice that had arisen in other transcripts. So the same word was assigned two codes, ‘decision’ and ‘choice’ and the entire passage coded as ‘sense of duty’ because the respondents feelings of responsibility seemed to reflect that. It will be shown below how these codes were related to others during the process of axial coding.

*‘It was a **decision** that had to be made – that wasn’t really difficult because I knew where my priorities lay – you know that was the thing, I didn’t kind of agonise over it, it was my responsibility, it was just the case I knew it wasn’t possible... I had to **give up work**’*

(Mrs Ireland, 63 year old carer)

Another example illustrates how on the first trawl through the data the following passage was coded as ‘residence’ to indicate that it was about living arrangements. Continued analysis subsequently related it also to the codes of ‘resources’ and ‘power’ and to the core category of ‘control’ because the flat referred to was a resource, which was used to gain power and control over the caregiving situation (see chapter 8).

*Well, he lives with me. There’s a subtle difference in that kind of thing. When you have a parent **come to stay with you** or when you go to live with a parent. There’s different pressures apply...there’s a big difference between you going and moving in with your parents. **I’ve got a ground floor flat** and that’s no bother because everybody knows that **he stays with me** and I don’t stay with him. The mortgage is my mortgage’*

(Mr Brown, 40 year old carer)

Codes generated during open coding all had equal status. As codes were ascribed analytic memos were also written. Analytical memos were simply notes written by the researcher to explain about codes and concepts, how they were defined and how they changed. Memos also included the researcher’s own initial thoughts about the nature and significance of the data.

Once a list of codes relating to the first transcript had been generated, the next step was to test and develop this framework by examining the remaining transcripts or data. Analysis

proceeded by means of the process of constant comparisons. Constant comparison is a procedure whereby incidents in the data are literally compared with each other and to the literature in order to develop codes and categories. Thus the second and subsequent transcripts were coded with the first interview in mind. As coding progressed, in order to facilitate the process of constant comparisons, all the collected quotations within one code were printed out and respondents' responses compared in this form. This process highlighted the patterns, similarities and differences that linked carers' experiences together.

For instance, carers spoke about having to organise their time or organise work. These sentences were tentatively coded as 'organising' and 'routines' because it was through the use of routines that carers organised their time and work. Examination of other transcripts noted that while these codes appeared frequently, differences in carers' ability to organise their time or work became apparent. Some carers found it difficult to organise their work around caregiving and so 'gave it up'. Thus the code 'organising' was related to another code 'giving up work'. Comparing the code 'organising' to the literature revealed that 'organising time' and 'developing routines' were some of the most frequently used coping strategies cited by carers in other studies. Also that having to give up employment in order to provide care was an experience common to many carers. During the process of constant comparison theoretical ideas were noted down and expanded or referred to again as analysis continued.

Axial coding

The next step was axial coding, which took data to a higher conceptual level. Whilst open coding deconstructs the data, axial coding can be viewed as putting it together again in new ways (Strauss and Corbin 1990). Whilst axial coding was based on the codes created during the open coding phase, the main focus was on the relationships between categories. During the process of axial coding, codes, memos and transcripts were reread in a more purposeful way. The researcher looked for codes or categories that linked together whilst thinking about the causes or consequences of the processes to which the data referred. Particular events or situations were considered and tentative associations examined and compared against other data until saturation was reached.

The first strategy used to establish networks of relationships between codes was a mind or network map. Such a map places the main idea at the centre of the paper and a series of lines with arrows linking related codes are placed around it. Relationships identified in

this way were substantiated by use of the paradigm model developed by Strauss and Corbin (1990) to assist with axial coding. This paradigm, which describes questions to ask of the data, was found to be very useful for establishing relationships between codes.

The components of the paradigm are conditions, actions/interactions or strategies and consequences. Conditions are the circumstances within which the phenomenon is set. Actions and interactions are the responses made by individuals to issues, problems or events that happen under these conditions. Consequences or outcomes are the results of these action/interaction or strategies. Thus questions asked of the data related to these components. In other words the researcher was looking for the answers to questions that began with words such as why, where, how, when and with what results. For example, why do people become carers, why do carers move house, also why some don't, how does it happen, when does it happen and what are the consequences? Other questions asked of the data during this phase included: Can similar codes be grouped together into a more general category or do should some categories be sub-divided? Can any categories be put into a sequential or temporal pattern? The following description of how axial coding was conducted reveals how some words or terms were initially open codes, which during the process of axial coding became core categories. Open codes that were not 'well connected' to others retained that status.

As axial coding proceeded some categories were found frequently in the data and to be connected to many other codes. These categories became core categories. For example, by using the paradigm model as advocated by Strauss and Corbin (1990) the open code 'becoming a carer' was related to other codes and eventually became a core category. The code 'becoming a carer' was one of the central ideas or phenomenon being studied. Codes such as 'accident', 'breaking a leg' and 'illness' were related to 'becoming a carer' because these were some of the events leading up to the development of the phenomenon. Other codes such as 'choice', 'pace', 'duty' and 'obligation' were specific properties relating to 'becoming a carer'. 'Co-residency', 'location of caregiving', and 'relationship' were codes that related to the conditions which had a bearing on 'becoming a carer'. Other open codes such as 'moving house', 'give up work', and 'living together' were actions aimed at managing the phenomenon of 'becoming a carer'. 'Difficulties', 'stress', 'coping' and 'satisfactions' were other open codes related to 'becoming a carer' in that they were outcomes of the actions such as 'giving up work' taken to manage the situation. Whilst these codes were initially subsumed under the core category 'becoming a carer' it was decided that because 'coping' appeared frequently in the data and could be related to other codes such as 'stress', 'depression' 'difficulties' and 'crying' that it should become another

core category. Thus during axial coding the relationships between codes were identified and established and those found to be well connected to others became categories.

Selective coding

Selective coding was the final step in the coding process. Selective coding was based on the categories created during the axial coding phase. The purpose of this process was the deliberate selection of categories, which illustrate major themes that emerged during axial and open coding. These core categories are central to grounded theory in that they explain variations in behaviour and are the nucleus around which a theory may evolve. According to Strauss and Corbin (1990, 1998) core categories help to integrate and saturate a grounded theory.

During this process codes, memos and transcripts were reread and compared in light of the categories developed during axial coding until saturation was reached. Only data that related to the categories developed during the axial coding phase was re-examined. Care was taken to ensure that the categories selected possessed the power to explain carers' experiences and behaviour. Categories such as employment and finances that were rarely mentioned and were difficult to relate to others were discarded. Examples of categories and their properties, which were selected to become core categories, are given below.

Central Category: Circumstantial dimensions of caregiving

Category: *Becoming a carer*

Properties: as choice: as no choice: as sudden: as protracted

Category: *Nature of caring*

Properties: quality of relationship, motivation, type of care

Category: *Control*

Properties: as conflict: as power: as resources

Category: *Coping*

Properties: as stressful, as strategies, as resources, as adaptation

Category: *Transition*

Properties: as circumstances, as pathways, as triggers, as service intervention

The categories above are unified with a central category that is termed 'circumstantial dimensions of caregiving'. This central category is the key issue around which all other categories are integrated. According to Strauss and Corbin (1998:146) the central category consists of '*...all the products of analysis condensed into a few words, which explain what this research is all about*'. 'Circumstantial dimensions of caregiving' was interpreted as being the central category because of its ability to pull the other categories together to form an explanatory whole. It also has the ability to account for considerable variation within core categories.

As will be seen the categories outlined above serve to structure the thesis. Each of the following chapters focuses on the circumstances pertaining to the core categories. The theory that is 'grounded in' and 'emerged from' the data explains why when caregiving is portrayed as being stressful, carers continue without support from formal service providers.

Reflections

Whilst the overall approach of this study, grounded theory, provided a complete methodology and a rigorous set of procedures for the novice researcher to follow, it was not without its problems. Grounded theory demanded certain qualities of the researcher. Qualities such as confidence, creativity and experience would have been particularly beneficial. Coding in particular, was a period of great uncertainty and slow progress, although it rapidly became more efficient as the process evolved. The sheer volume and complexity of data generated was quite daunting although the use of computer software aided matters considerably. Thankfully, there did come a time when after much patience and persistence things became much clearer. While the above description of coding might suggest that it was almost a mechanistic process, in fact many of the steps and decisions were taken almost intuitively. For example, before moving to axial coding a sense of how codes might relate to each other began to develop during open coding. In this respect some data such as that relating to 'becoming a carer' were relatively straightforward to code but it was more difficult to establish the relationships of others such as 'control'. Interpretation of the complex relationship between the codes 'conflict', 'fights', 'arguments' and 'behaviour' was challenging. However, a discussion with supervisors and using the literature as another source of data helped to make sense of the actions and behaviour of carers and care recipients and facilitated interpretation. Nonetheless, throughout the coding process the researcher continually reflected upon her decisions and her interpretation of events and confidence increased as the study neared completion.

Conclusion

This chapter reviewed the research design of the study. In order to explore the experiences of informal caregivers a qualitative approach underpinned by the principles and procedures of grounded theory with longitudinal and quantitative components, was chosen for this study. The decision to use a qualitative approach was based on several reasons but guided by the overall aim of obtaining detailed information on carers' experiences. Reasons included issues related to the study's interpretative orientation, the compatibility of a mixed method approach, the nature of the research topic, and the actual methods used to gather data about carers' experiences. A qualitative approach allows for the inclusion of rich detailed information that would traditionally be omitted from positivist research on social phenomenon.

The study used a range of methods including focus groups, interviews and self-completion questionnaires. The main source of data was individual interviews, while self-completion questionnaires and literature provided secondary and tertiary sources. The use of in-depth interviews as the primary source of data produced detailed perspectives on carers' experiences. Data were analysed according to the grounded theory principles of constant comparisons and theoretical saturation. The coding process began with open coding, proceeded with axial coding and finally selective coding. Each stage took the data to a higher conceptual level until at the final stage, core categories were selected for their explanatory properties. Core categories were collected together under the central category: 'circumstantial dimensions of caregiving'.

This chapter has reviewed the research design and the methods used in the present study. The following chapter describes the process of becoming a carer.

5. Becoming a Carer

Men and women of all age groups provide informal care but the process of becoming a carer and the choices available to them may vary. This chapter seeks to determine how and why individuals became carers. The chapter will consider the concepts of 'duty' and 'sense of obligation' before discussing the pathways that lead to caring. It will continue by considering the relevance of two theoretical models of caregiving to the present study.

The assumption that it is natural to feel a sense of obligation to one's kin informs much of contemporary social policy (Finch 1989). In her study of family obligations, Finch (1989) uses the term 'duty' synonymously with a 'sense of obligation' to describe the belief that people should be prepared to assist their relatives. People feel 'duty bound' or morally compelled to help members of their family. Although kin relationships are marked out distinctively by this sense of obligation, Finch (1989) argues that this does not imply that caring is 'naturally' part of family relationships. She claims that the notion that the family should be the first port of call for people who need help, does not reflect what actually happens in practice. Finch (1989) argues that whilst kin support is reliable in the sense that people believe they can fall back on close relatives if all else fails, it cannot be assumed that assistance will be given automatically. According to Finch (1989) people confuse notions of duty with feelings of affection. Duty she claims, is a prescriptive concept rather than an empirical description of what happens in practice. Yet in the present study powerful notions of duty and obligations underpinned people's accounts of how they became carers.

How do people become carers? Early research seeking to determine how people became carers found that, in general, people do not make an informed and positive choice to become a carer. That is people failed to fully consider the choices available to them and the implications that caring may have for them and other family members. According to these studies the majority of people gradually 'drifted' into caring (Ungerson 1987, Lewis and Meredith 1988, Qureshi and Walker 1989). As we will see, these findings are similar to those of the present study, which found that the majority of people did not make a positive choice to become a carer.

Pathways to Care

The data from the present study revealed that there were two main pathways to becoming a carer. Individuals became carers either by default or via a positive pathway. The key difference between these pathways was the degree to which the concept of choice was present. The positive pathway featured a degree of choice available to individuals who were free to exercise that choice and decide whether or not to accept the responsibility of looking after their relative. On the other hand, the default pathway featured a distinctive lack of choice. Pathways to caring were precipitated by critical incidents such as a deterioration in the health of the cared-for, the death of a spouse or parent, or an accident and subsequent discharge from hospital. These pathways will be discussed in turn starting with the default pathway.

Default Pathway

For the majority of carers in the present study, entry to caring was 'by default'. This pathway was characterised by the absence of positive choice and was applicable to co-resident adult children and spouses. In other words, for those who became carers 'by default' it was because they were already living with the older person who needed care and their willingness to assume the role was taken for granted. Individuals became carers 'by default' by virtue of their co-resident status, which reduced or removed the element of choice. The co-resident status of these carers was a pre-existing arrangement and not a consequence of the dependent person's need for care. These carers expressed a strong sense of duty and felt that they had no choice other than to accept the responsibility for care. Virtually all spouse carers expressed a feeling of having no choice that it was their duty and responsibility to care for their partner. They believed that to care was an inherent part of their marriage contract.

Marriage in our society is regarded at an ideological level, as the supreme caring relationship (Ungerson 1987, Parker 1993). Marriage vows, to which many spouses referred, reinforce the idea that one of the fundamental responsibilities of marriage is to care 'in sickness and in health'. Thus spouses were carers by default because they were simply fulfilling their ascribed role as spouses and to do otherwise would have perhaps undermined their relationship.

Mrs Murphy for example, believed it was her duty to care for her 72-year-old husband. Not only did she feel responsible for his care, she also felt responsible for his deterioration.

Having lived for most of their married life in a four apartment house with a large garden, Mrs Murphy was determined to move to a smaller, more easily kept flat once they had both retired. Her husband had reluctantly agreed to the move. Mrs Murphy dated her husband's deterioration and his increasing need for care from this time. She took her marriage vows seriously and felt that it was her responsibility and hers alone. She said:

'We moved down here in 1994, he didn't want to move ... and sometimes I feel a bit guilty because I think since then he just slowly went down ... It's my duty to look after him ... I feel the family shouldn't have to do it. I just think well, for better for worse. I mean I don't think I'm a martyr. I just feel we've been married for years and it's a case of in sickness or in health'
(Mrs Murphy, 65 year old carer)

Mrs Currie, another spouse carer dated her caring for her husband from the day that he retired from work. Affection for her 86 year old husband and her sense of responsibility was articulated quite clearly when she said that:

'Well, he's my husband and I love him as much today as the day I married him. So therefore, he's my responsibility. He's mine and that's it ... It was after he retired from his work that his legs started to give him problems. So you might as well say that since he's been the age of 65 I've been more or less kind of looking after him'
(Mrs Currie, 84 year old carer)

Atkin (1992) claims that two specific expectations govern informal care within spouse relationships. First, care given by spouse carers is often seen as an extension of the love and support that is a mutual expectation of modern marriage. Secondly, the assumption of being and remaining together is implicit in marital relationships. This view suggests that love and affection motivate spousal caregiving but in this study this was not necessarily the case. For Mrs Teirney for example, it was '*a sense of responsibility*'. Caring for her was an unwelcome trap that had prevented her from leaving her 76-year-old husband. It seemed to be a sense of responsibility rather than love, which kept her chained to her husband's side for 35 years of marriage. Their relationship had apparently always been problematic because as she put it '*he could be nasty*'. Talking about why she looked after him she said:

' Well, I stuck with him at the beginning because of the kids. This was my ambition, when they were kids no longer, I'd be on my way. And then as time went on I felt, "Well, I've put a lot into the home and I worked hard". Then I thought "Why should I go and leave him everything?". Then as I got older he got worse, "It's too late now". He doesn't take any responsibility ... It's like being in a trap and there's no way out. I mean to be honest the only escape is when he dies. It's not a very pleasant way of living your life'
(Mrs Teirney, 68 year old carer)

Duty as a reason for caring was not unique to spousal caregiving relationships. Adult child carers also expressed feelings of having had no choice. Their accounts featured an underlying sense of duty or obligation to elderly parents. Whilst a few child caregiving relationships were based on love and affection, others were not. Daughters were caring for parents whilst admitting they had little or no affection for them. In one case Mrs Gordon was unsure of her motivation, whether it was duty, need circumstances or social pressure. She knew her caring role was not motivated by love, an awareness that caused her to feel guilty and trapped by her obligations. Whilst her actions were motivated by duty rather than affection, her feelings for her father were rooted in past events.

Mrs Gordon had never anticipated having to look after her father despite having cared for her mother who died twenty years previously. In order to facilitate caring for her mother, Mrs Gordon had moved with her husband and young children into a house large enough to accommodate two families. Now with her mother long dead, her children grown up with homes of their own, widowed and divorced from her second husband, there was no-one else to look after her 87 year-old father. The onset of caring for her father was a gradual process spanning a number of years. In response to a question about how she became her father's carer and how she felt about it Mrs Gordon explained:

' My mummy died. [that left] My dad and I ... He's never had to do anything for himself and I think I just slotted into that ... I had no choice in the matter. Not really, because there wasn't anybody else... I think I'm doing this because it's my duty, or I've been made to feel this is my duty. I don't know. I've got ambivalent feelings about that ... Sometimes, yes I think it is your duty and if it was ... well you've just got to get on with it ... I mean now I would admit to feeling trapped, I feel terribly trapped at times. I didn't ever feel that when I was younger. There's always a guilt trip there. As a carer, if you don't feel one hundred per cent of the time 'I should really not be minding doing this', you can feel guilty... It's awful because there's part of me doesn't like my dad basically. It's like you hear mums say when their kids are naughty, I love you but nobody has to say I like you. And I think there's a wee bit like that with me'

(Mrs Gordon, 63 year old carer)

Mrs Gordon had not planned on having to care for her father, preferring to overlook the issue in the hope that events would overtake the need for a decision.

'This isn't what I planned to do in the beginning...I thought he would've passed away. I sometimes feel guilty about that...but my dad and I don't talk about these kinds of things, we never have. But what can I do. You can't, in this situation, you can't walk away'

(Mrs Gordon, 63 year old carer)

In another case where duty was more powerful than feelings of affection, the onset of caring was swift and unexpected. Ms Bennett who had always lived at home had just retired from her job as a home help organiser. Her mother's sudden accident caused her to reconsider her carefully laid plans for her retirement. Whilst she was quite resentful of the position in which she found herself, she felt nonetheless, that she had no choice, that she was morally obliged to care for her 94-year-old mother. Talking about why and how she felt about being a carer she said:

'Mother fell. She was still quite active at that time and she had gone into town to get some wool and the bus turned the corner and she fell and broke her leg. I had just retired and I just had to take over because ... I suppose of my working class upbringing and because I've got a conscience. I had no choice You've got to support and look after your parents ... I don't know why I do it. I don't know whether I'm trying to salve my conscience because I don't love her. I suppose I see it as my duty ... I feel pretty resentful. Nobody prepares you for this. They don't tell you that you're going to have to take over and you're going to be busier than you ever were'

(Ms Bennet, 67 year old carer)

Chappell (1990) claims it is only when a spouse has not been or is no longer available that the children of an older person may become the principal carer. This was certainly true for daughters who happened to live in the same household prior to the death of a spouse. For instance Mrs Kearns, a daughter who became a carer by default following the death of her father, felt she had no choice but to care for her mother simply because she was already there when her services were needed. Mrs Kearns and her husband had moved into her parent's home two years previously. This move was originally viewed as a short term temporary arrangement to allow them to save towards a home of their own. But since the death of her father it was taken for granted by the family that Mrs Kearns would take over the care of her 87-year-old adoptive mother. Unfortunately mother and daughter had never had a particularly close relationship and this seemed to cause some problems for Mrs Kearns who expressed feelings of resentment. She said that:

'When my father died I took over this role, it was just circumstance. At the time it didn't really sink in, the responsibility that you had ...I have actually been looking after mum 6 years now since my father died. He did all her shopping, he helped her in and out the bath, started to do the cooking because her eyesight had failed by this time ...My mum has deteriorated a lot since then, I've had to do a lot more. I suppose to a certain degree I do resent it especially with the attitude of the family. They could do a lot more, but they don't ... It was just my father dying that caused all this. That's where it all kind of came from ... It wasn't my choice it was just circumstance, just because I was there at the time. When it happened it naturally progressed. It wasn't a decision we took, it was just the circumstances that were given to us'

(Mrs Kearns, 36 year old carer)

The pace of the default pathway can vary in rapidity from sudden to gradual. The pace was usually determined by the nature of the critical incident that gave rise to the caring role. For example, in some cases the onset of caring was swift due to sudden and unforeseen events outwith the individual's control. On the other hand, for the majority of people who became carers by default, the pathway into caring was a gradual process that took place over months or in some cases, years. A slow deterioration in the health of the cared-for was the reason why they began providing assistance in the first place. This gradual process was distinguished by a steady increase in the amount of care given, where as the cared-for person became more frail or immobile, the other partner in the household, be they spouse or daughter increasingly undertook practical tasks and personal care. Carers said that they had '*always looked after each other*' or had '*always been together*'.

For some co-resident carers their parents increasing need for care was hardly noticeable at first. Only as the demands placed on them took up more of their time did carers become aware of how much care they were providing. For example, Ms Peters a single adult daughter assumed responsibility for her mother after her father's death nearly twenty years before when her mother was at 64 years, still relatively young and independent. It had only been in the last six years that she had had to undertake any personal care on a regular basis. Commenting on how she gradually became her mother's carer Ms Peters who had always lived in the parental home said:

'My dad died in 1979 and I've really taken care of my mother since then. I took her on holidays when she was able, we always took her abroad. It was just over the last few years that she's got slower... it has all stemmed from 1992 really. It was so gradual. You know I just started doing things for her and you never really noticed it and then - suddenly you realise that you're doing everything. Most of the time it is ok. You want to do it, but sometimes you just think, you know, why me?'

(Ms Peters, 47 year old carer)

Most spouses in the present study also described their entry to caring as a gradual process where as the cared-for became less able the other partner increasingly undertook practical tasks and personal care. The account of Mrs Roberts's caring for her 75 year-old husband illustrates this gradual process. Whilst Mrs Roberts firmly believed it was her duty as a wife to look after her husband, this did not prevent her feeling angry and cheated. Mrs Roberts had taken the opportunity to retire early from her job in nursing when voluntary redundancies were sought. Not for a minute did she think she would have to care for her husband. They had planned to enjoy their retirement by travelling abroad. Now their plans would never come to fruition. Talking about how she felt Mrs Roberts said:

'We had lots of plans. My husband started off ill with a bad chest that was all. He took chronic airways disease and he was really bad. Oddly enough that kind of tapered out, he's not so bad with that. Still takes lots of medication ... About 3 years ago he was getting very shaky and at first we put it down to the pills he was taking... then one day I looked at him ... this dependent person that needs, almost turned into a child, although thank God, he's not demented. ... I felt angry, cheated. I'd stopped work, I'd cared for people all my life in a professional way. I felt we had planned to do things, go places and all that was whipped away. That made me angry and I thought I've just swapped a well paid caring job to look after my husband... Oddly enough I was angry at him, isn't that weird, I was angry at him for being ill then I knew that was ridiculous and I suddenly thought he can't help it so we'll just muddle along as best as we can. Which is what we've done, But it's difficult. Some days are hellish'
 (Mrs Roberts, 65 year old carer)

Rarely did spouse carers in the default pathway find themselves *suddenly* cast in the role of carer. Mr Paul was the only one who found that he was suddenly expected to look after his 74 year-old wife and this unexpected role reversal seemed to cause him great angst. Being more than ten years younger than his wife and married for only eight years, this first marriage for Mr Paul was not turning out the way he expected. Whilst in hospital recovering from a diabetic coma, Mrs Paul fell out of bed fracturing her arm and shoulder, an injury that seemed to have left her permanently disabled. Before his marriage, Mr Paul had lived with and looked after his mother for a short time before she moved into a nursing home. When faced with the possibility of being his wife's carer, Mr Paul considered briefly the possibility of long term care and quickly dismissed it. Mr Paul's decision, despite his doubt and hesitation, was clearly influenced by what he perceived to be a moral and legal obligation to his wife. Talking about having to care for his wife after her discharge from hospital Mr Paul was bitter at the perceived lack of support from the hospital and the assumption that he was willing and able to look after his wife. He described his feelings and how he considered his options:

'I had a wee miniature of whisky and I drank it and I thought whit the hell dae I dae noo. It wis a take it or leave it situation. If I leave then, Cath would end up in a home or hospital or something 'because none of the family is in the situation where they could take her on. It wis down tae me really. That's the way it goes. I widnae see her going into a home and a kent whit that meant so I said it's not really on so I'll just dae it. I felt because it wis my wife I had to dae something ... I didn't feel chuffed about it. It was a new lifestyle ... The hospital didn't say a word and she was in that ward day after day and still naebody came forward and said 'by the way'. There wis no doctor there to advise you – nothing- one hundred per cent on your own ... She wis on tablets and couldn't sit up. At that time I had to do everything for her'
 (Mr Paul, 63 year old carer)

Mr Paul's case was unusual in that for a spouse in this study, the onset of caring was so quick. His sentiment that *'it wis down to me really'*, was shared by adult children who became carers by default who firmly believed that they had little alternative but to care. Their belief stemmed from the unavailability of others to assume the responsibility and from *'being there'* when the need for care arose.

In cases where a daughter was not available, the son's wife assumed the responsibility and daughters-in-laws appeared to be treated in a similar *'taken for granted'* manner. Mrs Smith for example, became a carer by default for her mother-in-law who had lived with her and her husband for long periods throughout their married life. In the early days of their marriage, her mother-in-law moved between relatives staying with each for some months before returning to her son's home. By the time she needed regular care Mr Smith an only child, believed that other relatives were too old to be able to take care of *'mum'*. Mrs Smith explained that:

'She has actually lived with us on a permanent basis for about 13 years. She's needed day to day care for the past six years I would say. But she has actually lived with us on and off all of our married life ... that started from the day we got married, practically from when we came home from our honeymoon ... I think you don't have a choice though. The choice is simple if someone's not living with you'

(Mrs Smith, 50 year old carer)

Adult children who became carers by default were similar to spouse carers in that they were both co-resident and whose ability and willingness to care was never questioned. It was taken for granted that they would look after their older relative. Whilst their co-resident status meant that they were *'on hand'* when the need for their services arose, they were nonetheless, motivated by the belief that they had a moral responsibility to care. In contrast to carers on the default pathway, individuals on the positive pathway were not *'on hand'* nor were they initially co-residents.

Positive Pathway

The positive pathway was characterised by the presence of choice. This was the path taken by non-resident adult children who were free to exercise choice and who had to face a decision about the future care of their parent. Carers who had felt that they had made a positive decision to care expressed fewer negative feelings about caring than those who felt they had had no choice. Decisions to care were influenced by a variety of reasons such as affection, reciprocity, preventing admission to long term care, compassion for the lonely

and sympathy for the bereaved. These reasons, prompted by powerful notions of moral obligations, were strong enough motivation for some carers to form shared households with their parent or parent-in-law.

The majority of carers who travelled the positive pathway described a deterioration in the health of the cared-for person as the reason why they began providing care. Some said they had begun helping when it became obvious that the cared-for '*could no longer cope on their own*'. Many were motivated by their desire not to see their loved ones end their days in long term care, a reason with strong links to notions of familial obligations. As the health of elderly parents deteriorated carers often believed that the only realistic alternative was long term care. This was taken to mean residential or nursing home care which carers collectively referred to as 'homes'. Carers held rather negative views of residential or nursing homes, usually doubting the quality of the care given.

It was her determination that her mother should not have to go into residential care that led to Mrs Duncan decision to give up her job and return home to look after her ailing 74-year-old mother. Mrs Duncan had married and moved away to live in London a number of years before. Pressure had been put upon her by her aunts who lived near her mother and who were finding it increasingly difficult to combine caring for their sister with their responsibilities to their own families. Her mother's increasing need for care was recognised almost a year before Mrs Duncan actually moved in when her aunts suggested that the solution would be a nursing home. The decision-making process was a lengthy and protracted one. This was a major upheaval for Mrs Duncan who said that what motivated her was:

'She was on her own a lot and I didn't want my mother in a home or a nursing home because I thought she would just go down hill faster, I mean I think she's still got good innings in her yet ... With me being here all the time I know she's getting well looked after ... I think the fact that she was on her own and her sisters couldn't cope with it anymore... I decided to move back. It was purely my own decision. I didn't give it a tremendous amount of thought, I just did it and that was that ...I don't think of it as a sacrifice'

(Mrs Duncan, 47 year old carer)

The second main reason that prompted individuals to decide to become carers was the death of the previous carer. In the present study three women became carers following the death of a parent. The decision tended to be motivated by the perceived importance of the close and affectionate relationship between the new carer and the cared-for. For instance, Mrs Ireland the only sibling carer in the study, had always had a close relationship with her older brother who lived a couple of streets or '*two minutes away*'. A sense of moral

obligation combined with love underpinned her decision to look after her brother following the death of their mother who had been his main carer. As if that wasn't enough, she also 'looked out for' an elderly neighbour and her mother-in-law. Mrs Ireland's sense of duty was so strong that she had actually given up her part time job in order to make time for her caring responsibilities. Asked why she chose to care for her brother she said simply that:

'I love him, he's my brother and I love him ...I had to give up work when I was 58. It's a decision that had to be made – that wasn't really difficult because I knew where my duty lay, you know that was the thing. I didn't agonise over it, it was just the case that I knew it wasn't possible to keep on. You've just got to be there for him'

(Mrs Ireland, 63 year old carer)

Mrs Watson had also chosen to become a carer following the death of her mother. Her decision was motivated by a deathbed promise made to her mother with whom she had shared a close relationship. It was this promise rather than feelings of affection or compassion for her father that was at the root of her decision to accept responsibility for her father's care. Whilst they knew that this was what their mother wanted, the family had never fully and openly discussed the issue. What Mrs Watson had discussed prior to her mother's death was the purchase and future ownership of the parental home. Mrs Watson's mother had bought their council house using her daughter and her son-in-law as guarantors for the mortgage. Her mother's share of the house was then left to Mrs Watson in her mother's will. A few months after her mother's death Mrs Watson and her family moved into her parents' home to care for her father. It seemed that her deceased mother had used homeownership as a way of ensuring that her wishes would be complied with. Mrs Watson, a middle child in the family, explained though that the fact she inherited her mothers half of the house was not the reason she was looking after her father. She said that:

'I moved in after mum died ... My mum knew that I would look after my father. I was closer to them. We were all close to her but she would probably say I was the closest - I was round every day or I phoned every day ...and she decided that she was going to buy the house because if anything happened to her that I would give up my home. So she bought the house and she left her half to me and if anything happened to her then my father's share would come to me. That's not the reason I'm here, it's not because I own half the house. The reason I'm here is because it's what my mum wanted. It's what she wanted, not what... I knew this. I mean she had said to me we'll buy the house ... like my husband and I stood guarantor for the house because of their ages and because of their health problems, they would never have got a mortgage unless someone stood guarantor. So we stood guarantor and she spoke to the rest of the family and she told them what she was doing, like if anything happened that we would be moving in here'

(Mrs Watson, 38 year old carer)

Mrs Watson expressed no strong feelings about her role as her father's carer, she simply accepted that she was doing her mother's bidding. She said

'I didn't feel anything you know. I just sort of took over where my mum left off. I didn't have any thoughts about it'.

While this response may have been due to the grief that she clearly experienced following her mother's death, by the third interview, two years later, she continued to express no strong emotions. Asked why she continued to care for her father Mrs Watson was still motivated by her mother's wishes and a sense of responsibility.

Mrs Morrison on the other hand agreed to become a carer because it was what her husband wanted. Compassion and affection for her mother-in-law influenced her decision. Mrs Morrison's father-in-law had looked after his wife for a number of years but following his sudden and unexpected death a decision had to be made. Mr Morrison was one of two children but his sister Pearl, was less than willing to look after her mother. Mrs Morrison who seemed to have an ambiguous but affectionate relationship with her mother-in-law was consulted about the situation and was assured by her sister-in-law that she would be fully supported if she agreed to 'take on' mother. The promised help never materialised and Mrs Morrison admitted that she had not fully appreciated what her caring role would entail. Her own sister had tried to forewarn her not to do it but she chose to ignore the advice. Mrs Morrison believed that her sister-in-law Pearl, the only daughter in the family should look after her mother rather than her or at the very least she should help in some way. She firmly believed that families should look after their own. Having looked after her 81-year-old mother-in-law for six years Mrs Morrison said:

'If the choice were there again I wouldn't do it. No, I would not do it again. My sister warned me that I didn't know what I was letting myself in for. She said you're tied in, you are tied. You don't have the same freedom, if you were to have your mother-in-law there, you cannot go out when you like, you just can't leave her Iris ...I would never do it again. I said that to Andrew [husband] I mean it was through my husband I took her in, it wasn't me. I was told at the time I would get all the help and all the rest of it and I'll come up Iris and I'll take over. It never materialised. Pearl told me that'

(Mrs Morrison, 58 year old carer)

At times her feelings of resentment at her position were evident but her affection for her mother-in-law was also apparent when she admitted that she would miss her if she were not there. When asked at the third interview why she was still caring after eight years Mrs

Morrison's affection for her mother-in-law was apparent. Despite the frustrations of looking after her she said:

'What else can I do? I can't put her into a home ... The funny thing is I would miss her. I mean I am being quite honest with you here about my feelings. I have said to Andrew, the queerest thing is Andy, if you mother dies, I think I would take it pretty bad if any thing happened to her, but I know it's going to come eventually. She might live for another ten years, I mean I don't know ... Aye I think I would take it pretty bad because I have looked after her and I know her pretty well. It doesn't mean that I really - love her. Not really. She's been good to me my mother-in-law, ever since I met my husband. We got on so well, I mean we respected one another put it that way'.

(Mrs Morrison, 58 year old carer)

For other carers it was the imminent discharge from hospital of their parents following an accident that caused them to consider whether or not to become a carer. The powerful belief that family has a responsibility to care for their older relatives can cause families to overlook childhood experiences. In the cases discussed below, both carers had been estranged from their fathers for many years, mainly because of the breakdown of their parents marriage which involved problems with alcohol abuse and violence. In both situations, feelings of responsibility combined with compassion led to carers bringing their fathers to live with them. The other factor in their conscious decision was the belief that because of their age and condition, the cared-for person did not have long to live and the caring role was expected to last for only a matter of months. They did not feel as though pressure had been put upon them to look after their fathers as neither family nursing or medical staff had suggested that they should. However, the health of both fathers had shown a marked improvement and they had in fact survived a lot longer than originally expected. For Mrs Thompson the realisation that she had a choice and that she was not being coerced into any particular course of action made a difference to her decision. Now a co-resident carer having looked after her 78-year-old father for four years, Mrs Thompson explained when and how her caring role began:

'My dad had an accident and that's how it happened. My caring role started when my dad was sent home from hospital with the understanding, this sounds terrible, that he wouldn't last weeks. So rather than let him go to a nursing home to die, which I think is a bit cruel,, I brought him home. I thought ok he's been a pure basket through his years but we'll give him a bit of dignity. He stayed in his own house but came to me because I'm the only one that will really take him. My mother and father are separated and my sister can't forgive him for the problems that he caused when we were young ... I think because I had the option, I had the choice. That's what it was. I felt I had the choice, do I want to do it or do I not want to do it and that felt good because you seem to feel that you're not in control of your life. Someone else has taken control of it. The control was back in my court... and I like to control my own

destiny. The control was there and I could basically carry through with it. '

(Mrs Thompson 41 year old carer)

Mr Brown in a similar position stated quite clearly, that he did not necessarily regard caring for his father as his duty. He nonetheless, felt that it just '*wouldn't be right*' to let his father go into a home. He outlined the events the led to his decision to care for his father six years previously.

'I went up to see him. I hadn't intended on taking him home, I had no idea what was going to happen to him, I didn't know how bad he was and it wasn't in the forefront of my mind to look after him because I knew it could be quite heavy, but I thought some more about it. I spoke to the nurses and eventually I went and spoke to a professor about him and what was going to happen to him ... It was a straightforward case of he would go down to Lightburn Hospital if nobody else would have him and I thought why do you want to go in there because it's a grotty place and I thought I can accommodate you. I had the room... I had an idea of what I was letting myself in for because I once worked with folk with dementia. I had already had the insight, I knew what could go wrong. He's a different kind of guy now, he's a different person, denies that he ever drank.

(Mr Brown, 40 year old carer)

For Mrs Thompson and Mr Brown their reasons for caring were a complex interplay of factors such compassion and family obligation. Despite having a childhood dominated by their fathers' alcohol abuse and the breakdown of their parents' marriage, both found it in their hearts to forgive their parents. Once their decisions had been made, their entry to the practicalities of caring was relatively swift.

The way in which carers in the positive pathway described their experiences often suggested that the onset of caring was rapid. However, in reality the pace of the positive pathway varied with some carers making a quick decision and a relatively quick entry into caring. For others, the decision making process was slow and protracted while they considered the available options. Once the decision had finally been made, putting it into effect varied from weeks to, in one case, more than a year. Thereafter, actually undertaking practical and personal care was rapid.

For example, in Mrs Duncan's case her words '*I didn't give it a tremendous amount of thought, I just did it and that was that*' suggest that she made a swift and almost hasty decision. But in fact, her decision making was a long and protracted process that took almost a year to put into effect. Mrs Duncan admitted that she was aware of her mothers increasing need for care a year before she took up her caring role. She was nonetheless, aware of the consequences her decision may have for her life, her job and her future. She

described how she had considered taking her mother down to London to live but felt that it would be unfair on her mother to move her to a place where she knew no one. Mrs Duncan's account illustrates the difficulties she faced when trying to decide how to reconcile her mother's need for care with her need to work and fulfil her familial obligations. She explained that the decision making process started:

'Last year really it was becoming increasingly obvious that she needed care. I knew my mum couldn't stay on her own and I thought actually taking her down there but I wouldn't take her to a place where she didn't know anyone. I knew this was not going to get any better, it's going to get worse ... I can't say it was spur of the moment decision. I mean I didn't decide to do it one day and say I'm going up to look after my mother. I mean my aunts, they said to me did I realise what I was doing and all the rest of it. I did think about it. In fact it took me nearly a year. I put my flat on the market and it was just about to go through when the buyer pulled out, so that gave me all that time to start thinking again. One of the things that did worry me was the fact that I didn't know how long I was going to have to care for my mother. I mean I have no intention of living like this for the rest of my life. The original idea was for me to work, that's what I thought at the time but when I actually came up here I realised there was no way I could keep a job down and look after my mum. Anyway I moved out of my flat and moved in and stayed with a friend for a few months and then eventually moved up. I thought that I would have really missed that flat because I was in it for a number of years. But I put the keys through the door and never looked back ... I just think of this as a new chapter in my life'

(Mrs Duncan, 47 year old carer)

In cases where entry to caring was provoked by sudden rather than a gradual event, the positive pathway was negotiated with greater speed. For example, in the cases of Mrs Thompson and Mr Brown discussed above, it was believed that their fathers did not have long to live following a sudden accident. If these carers had decided not to look after their fathers, the alternative would have been long term institutional care. However, their decision, were not taken quickly or lightly. It was only after a great deal of thought and discussion with family, medical and nursing staff, did they decide to take their fathers from hospital into their own homes. Mrs Thompson explained that her immediate reaction to her father's need for care was to find him a nursing home. It was only in the few weeks of searching for a suitable home did she start to contemplate the possibility of doing it herself. She said:

'I had spoken to the nurses in the hospital. I had saw Dr McColl, I went to my own GP. I went to see Dr Leslie and he's what you need. I go to him when I need like that kind of support. He says the problem's going to be there. So I actually sat down with my husband and family and told them about it. And they says what do you want. So we went round the nursing homes to look for a good home and to be quite honest, I couldn't find one. I couldn't find a district

council that would give me a single room. We went round to see some of the private ones and they were ok but ...I do care. So I wanted somewhere I could be quite happy with. But in between the weeks doing all that I started getting myself in a more positive attitude. But now I was in a position to say oh I can do it'

(Mrs Thompson, 41 year old carer)

The above account of how Mrs Thompson's became a carer suggests that the decision making process was simple and straightforward. Yet the process was actually a lengthy procedure. Her father's accident occurred in the December and it was not until the July that she actually started looking after him. Seven months in which she and her family considered the options.

In contrast, other carers were not in position to take her time over a decision. For Mrs Veitch entry to caring was hasty as her mother, after breaking her leg in a sudden fall was about to be discharged from hospital. Her decision was to have mum to stay with her and her family on a permanent basis. However, this decision was motivated more by duty than affection as Mrs Veitch had never had a particularly close relationship with her mother but she had always had a strong sense of familial responsibility. Being the eldest of three children, responsibility for family affairs had always fallen on her shoulders since the death of her father thirty years previously. She had at that time, taken over the running of the family business until she married and moved to the west of Scotland. Her elderly mother was in the habit of visiting each of her three daughters for a few months of each year. Traditionally she came to stay with Mrs Veitch and her husband over the festive period and stayed until the end of January. One year however, during her usual visit, Mrs Veitch's mother had an accident which prompted family discussions about her need for care. Mrs Veitch's husband agreed that they were in a position to take her mother. Mrs Veitch did not work and was at home anyway. Furthermore, they had a suitable house, being large and spacious with accommodation on the ground floor that could be easily converted into a bed-sitting room and most importantly of all, a ground floor bathroom. Thus it was agreed that mother should stay with in the west of Scotland rather than return to her own home in the east where her other daughter who worked full time would have had to shoulder the burden of care. Mrs Veitch, a carer for thirteen years explained simply that:

'Mother came to stay for a few weeks and while she was here, she fell and broke her leg. So she just ended up staying. Events forced a decision although it had been thought about ... I don't regret it. I think I might have regretted it if I hadn't done it'

(Mrs Veitch, 69 year old carer)

Mrs Veitch's decision meant that her mother, who came for a holiday, ended up staying with her on a permanent basis. This change in living arrangements was a common feature of all positive decisions to care. For nine out of ten adult children a positive decision to care for a parent entailed a change in the living arrangements of either the carer or cared-for. In the present study, the decision to move back home or invite parents to live with them was never made while the parent was still in good health. This concern with living arrangements was sometimes the reason that the pace of the decision making process was protracted and complicated.

It was easy and relatively quick for some carers to put their decisions into effect. This was particularly the case where parents had suitable accommodation and there was little difficulty in giving up their tenancy of their own house. For instance, according to Mr Clark his decision and subsequent move took about three weeks although his motives were not completely altruistic. Mr Clark's reasons for moving into his mother's home were twofold. His marriage had broken up and he had to move out of the marital home and, at the same time, his mother's need for care was increasing. She came to stay with him every weekend and it was her suggestion that he move in with her. The issue was discussed with his mother over a period of only three weeks leading up to the expiry of his tenancy. Mr Clark said:

'Mum used to come and stay most weekends and when I had to get out of the flat, mum suggested that I move in with her. I thought, well why not. I felt that because we got on well together coupled with the fact that mum needed more care, that it would work out ok'

(Mr Clark, 50 year old carer)

Mrs Duncan, on the other hand owned her flat and the speed at which she could move from her own flat to her mother's home was determined by the London property market. Mrs Duncan was not alone in moving house in order to care for her mother. Mrs Macrae's decision to form a combined household with her mother in order to look after her was motivated by a close relationship and the fact that they did not live near each other. This move involved both parties relinquishing the tenancy of their respective homes when another house large enough to accommodate three people became available. Mrs Macrae explained how she was *'always one for her mum'* and how the care her mother needed increased as her sight deteriorated. She worried about her 90-year-old mother living alone and believed that it would be easier and cheaper for them to live together. She explained that:

'It was my choice to look after mum. Well it had to be. You couldn't let your mother go to a home, could you? No, I'd feel guilty because she was a good

mother. Then she took the blindness. So then she fell and she phoned, she'd broken her arm, then it was her ankle. So then I decided we'd be better with the one big house and we'll all be together. I says look we'd be as well in the one big house as two houses, because I used to go up and clean as well and my mum would be here, I wouldn't need to be phoning. Because maybe you'd phone her and not get a reply and I ended up getting in a taxi which I could hardly afford, and I'm saying oh mum will be behind the door. So this is how, we came here because there's no way my mum could manage. And she could never have managed sheltered [housing] because she needs attention... It's quite a lot of hard work now [but] I couldn't put my mum in a home. I'd feel guilty because she was a good mother'

(Mrs Macrae, 63 year old carer)

Mrs Macrae's decision was motivated by her close and affectionate relationship with her mother. She was not co-resident nor did not live near her mother but she nonetheless chose the positive pathway to caring which led to her becoming a co-resident carer. In some cases the pathway which carers travelled were not always clear cut.

The positive and default pathways were not always clearly defined. In some cases, the boundaries between them were indistinct. There were some carers who did not 'fit' neatly into one category or the other. Some non-resident carers began giving care as the need arose, at a time when they believed that they had choice in the matter that no one else would do it. As time went on though and the task became more onerous, the longer they were involved in the care of their mother, the harder it was for them to put a stop to their caring role. Their difficulty in drawing a line on their caring activities was essentially because of the close and affectionate relationship they enjoyed with their mothers. '

Mrs Welsh for instance, who lived in the same district as her mother described how her mother's need for care increased as her mobility and her blindness gradually worsened. Her caring role evolved so slowly that she had no clear idea of when it started. Only when the demands placed on her became more time consuming did she realise how much care she was providing.

'I felt as if - before you knew it, you were doing it - I can't remember when I started doing it or any specific day or what had happened. I think just over the years my mum was getting weaker and I just started getting her messages for her and from there it just went on'

(Mrs Welsh, 62 year old carer)

A crucial point in this caring relationship was reached when Mrs Welsh's mother was hospitalised after collapsing at home. This was the point at which she had to decide whether or not she was willing and able to continue being her mother's main carer. Mrs Welsh viewed her responsibility to her mother as a commitment, which was founded upon

close contact, shared activities and reciprocity. The two women had always maintained a close and affection relationship, which predated the caregiving one. While she believed that it was her duty to look after her 88-year-old mother although she had other sisters who could do it, she referred to her caregiving activities as 'pay back time'. She felt that she was paying back her mum for all the help and support that she had given her throughout the years that she was struggling to bring up her own family and hold down a job at the same time. When faced with the possibility of someone else taking over the care of her mother Mrs Welsh's made a positive decision to continue being her mother's main carer. Mrs Welsh rationalised her decision by saying that:

'It was just pay back time. Well she was my support during all these years when you couldn't get help, you couldn't run to any house, the way battered wives do nowadays. I mean I had to support my family. I had to work. So I feel it's just. I know what my mum likes and dislikes over the course of the years with just being with her constant ...I think that it is probably through choice that I'm doing it. It was gradual at first but it is choice now. But I can see a time when it might be ... she has to go in'

(Mrs Welsh, 62 year old carer)

Mrs Welsh's case illustrates how a few non-resident carers began providing a small amount of care although there were other family members who could have done the same. A close relationship between the carer and the care recipient seemed to determine who within the family would provide the care. Ungerson (1987) though claims that despite reasons given by carers for why they became one, they are in important ways selected. She argues that they are selected, first and foremost, according to 'dominant, normative and gendered rules of kinship' (Ungerson 1987:61). Secondly, they are selected according to how they and other members of their family negotiate an agreement that caring is compatible with other demands on them from the family. In other words, becoming a carer is a process of negotiation among immediate family members. Yet the data from this study indicated that very little discussion takes place among family members about who is going to accept responsibility for caring. This process of negotiation certainly happened to an extent in the positive pathway where carers took a positive decision to become a carer. Negotiations among family members were less apparent in the default pathway where carers expressed a feeling of having 'no choice' and that 'no one else would do it'. Nonetheless, a model of caregiving that supports Ungerson's (1987) claims that carers are chosen according to dominant and normative rules of kinship will now be considered.

Models of Caregiving

Other family members and siblings in particular are often regarded as alternative carers or as an additional network of support (Ungerson 1987). However, studies have shown that once a person assumes the responsibility to care, other relatives retreat, leaving one person as the main or principal carer (Ungerson 1987, Qureshi and Walker 1989).

The question of who else might have cared confirms the existence of a caring 'hierarchy' (Qureshi and Walker 1989). Qureshi and Walker demonstrated that, irrespective of the quality of relationships, decisions about who should provide help to older people are made in accordance with a consistent hierarchy of preferences among available network members. Their hierarchical model of caregiving is underpinned by two powerful normative beliefs with which they claim there is strong pressure on families to conform. Thus children accept a general responsibility for the welfare of their parents. Secondly, there is the assumption that daughters rather than sons should be caregivers.

Finch and Mason (1993) who argue that such fixed obligations are not 'naturally' part of family relationships have challenged these assumptions. They found no agreement amongst a representative sample of the British population about what obligations or responsibilities are attached simply to being an adult child. Their alternative model views these responsibilities as commitments which are built up over time between specific individuals through contact, shared activities and particularly through reciprocity in giving and receiving help. According to this model, family members develop different commitments with each other and their response to the need for caregiving will be dependent on the level of commitment established over time rather than a fixed obligation to help, based on kinship and gender (Finch and Mason 1993).

How do these models of caregiving relate to the findings of the present study? The findings of this study suggest that both models are in operation and that it is not simply a case of either one or the other. Qureshi and Walker's (1989) model of caregiving claims that there is a prevailing belief that children have a general responsibility to ensure the welfare of their parents in old age. The data from this study confirms the existence of this belief. Firstly, carers' accounts were underpinned by a strong sense of responsibility to their parents. Even in cases where carers such as Mrs Gordon or Ms Bennett had little or no affection for their elderly parent, their sense of responsibility overruled their dislike. This suggests that the decision to care was not always equated with the desire to do so. Secondly, in cases such as Mrs Kearns and Mrs Morrison, the responsibility fell to

daughters in the absence of a spouse. In both these cases, sons were in theory, available to care but were never considered as possible carers. For the two male carers looking after a parent, Mr Brown and Mr Clark, no daughters or indeed daughters-in-law were available. Moreover, Mr Brown and Mrs Thompson despite being estranged from their fathers for many years accepted the responsibility to care. Their decision to care was not a commitment that was built up over time and based on close contact, affection, and reciprocity. Their decision was a compassionate one based on a strong sense of obligation to kin. The data therefore provides evidence that supports Qureshi and Walker's (1989) hierarchical model of caregiving.

Nonetheless, some carers viewed their responsibilities as described by Finch and Mason's model (1993). For instance Mrs Welsh and Mrs Macrae both viewed their responsibilities to their mothers as a commitment, which was founded upon close contact, affection, mutual support and reciprocity. Their accounts were remarkably similar in that both had other family members who could have taken on the caring role. They had always maintained a close and affection relationship with their mothers that predated the caregiving one. In their younger days when their marriages broke up, both women had received support from their mothers in the form of childcare. This childminding allowed them to hold down jobs that involved working unsociable hours so it would have been almost impossible for Mrs Welsh and Mrs Macrae to obtain help from other sources. Mrs Welsh worked full-time as a bus conductress. And when she wasn't a '*dancer on the stage*', Mrs Macrae worked part-time as a barmaid. That their mothers' support allowed them to maintain their independence and pride was never forgotten.

Another carer whose experience could be summarised by Finch and Mason's commitment model was Mrs Watson. She was a middle child who described herself as being the one closest to her parents. Her commitment to her parents was different to that of her siblings in that her decision to care was determined by her promise to her deceased mother. Her relationship with her mother was one, which was established over time and was based on close contact, reciprocity and shared activities.

Thus the data provides evidence to suggest that both the hierarchical and the commitment models were in operation. Neither one nor the other was predominant. The nature of the relationship between the carer and the cared-for was an important determinant of who became a carer. On the whole carers tended to have a close and affectionate relationship with the cared-for person. Those who had a difficult and distant relationship were in the minority and tended to have become carers by default. No one in the positive pathway

described their relationship with the person they cared for as difficult and distant. Thus the data provides evidence to suggest that caregiving relationships evolve in accordance with both models. Where there is a close and affectionate relationship between both parties and alternative carers are available, Finch and Mason's (1993) model is apparent. On the other hand, in the absence of a close and committed relationship with kin, Qureshi and Walkers (1989) hierarchical model which believes that children have a general responsibility to ensure the welfare of their parents in old age, is relevant.

Conclusion

The data from the current study revealed that there were two pathways into caring. The default and positive pathways were characterised by either the absence or presence of choice. The default pathway in which there appeared to be little or no choice was relevant to spouse and daughters. Adult daughters who became carers by default were similar to spouse carers in that they were both co-resident before the onset of caring and their ability and willingness to care was taken for granted. Carers on the default pathway firmly believed that they had had little alternative but to care. The majority of carers drift into caring via the default pathway rather than making a positive decision. The positive pathway where choice was present was relevant to adult sons and daughters. Moreover, a positive decision to care often involved a change of living arrangements for either the carer or the cared-for. Thus the decision to assume responsibility to care had important implications for people's living arrangements.

Carers travelled both pathways with varying degrees of rapidity. Entry to caring could be either gradual or sudden. Furthermore, geographical proximity and living arrangements seemed to influence which pathway carers travelled. Carers who had always lived in the parental home or nearby were more likely to have gradually drifted into caring than those who had moved away from the area. For those living at a distance from the care recipient's home a gradual drift into caring was almost impossible. For the majority of carers in the default pathway, it was usually a slow deterioration in the health of the cared-for person that led to a gradual increase in care given. In a few cases, such as Ms Bennet and Mr Paul entry to caring was rapid due to the sudden nature of the critical incident that provoked the need for care.

The positive pathway to caring was usually prompted by similar incidents that caused co-resident children and spouses to become carers by default. In the positive pathway entry to caring could be gradual too but for the majority of carers who took this path it was the

decision making process rather than the onset of caring that was a slower and more protracted exercise. Once the decision had finally been made, putting it into effect varied from weeks to months and in Mrs Duncan's case, more than a year.

Carers' decisions were influenced by a variety of reasons such as affection, reciprocity, preventing admission to long term care, compassion for the lonely and sympathy for the bereaved. These reasons were strong enough motivations for some carers to ask their parents or parent-in-law to form a combined household. It was clear though that no matter what pathway to caring carers travelled, their motivation was underpinned by a strong sense of duty and familial responsibility.

Although the data from this small scale study illustrates the importance of spouse carers, it remains the case, that where there is no husband or wife available, caregiving often falls to a member of the close family and in particular to a daughter or daughter-in-law. This finding mirrors earlier research that claimed that children, especially daughters and daughters-in-law, are the mainstays of informal care (Qureshi and Walker 1989, Atkin 1992). However, as stated earlier, the evidence suggests that there is not a predominant model of caregiving. Caregiving relationships evolve in accordance with both Finch and Mason's (1993) and Qureshi and Walker's (1989) model.

This chapter has focused on how people became carers. The following chapter explores the nature of caregiving.

6. The Nature of Caring

This chapter seeks to understand the nature of caring. The chapter will discuss carers' experiences of providing practical and personal care before considering the nature of caregiving relationships. It will continue by discussing the factors that structure the relationship between the carer and the cared-for person.

The early literature on informal care tended to use the term carer/dependant relationships (Finch and Groves 1983, Glendinning 1983, Baldwin 1985). In the following chapter an attempt has been made to avoid the use of the term 'dependant'. Avoidance of this term is out of respect for the dependency debate that has been propounded by the disability movement (Morris 1993, Shakespeare 2000) and social gerontologists (Phillipson 1981, Phillipson et al 1986). The dependency discourse challenges the assumption that because they need personal assistance, disabled and elderly people are 'dependent' and less able to make choices for themselves. This discourse argues that the term 'dependant' negatively portrays the disabled and elderly as passive recipients of care and a burden. Furthermore, the disability movement argues that to talk about carers and dependants ignores the extent to which disabled people themselves provide care. As the majority of older people and those with disabilities lead independent lives the use of the term is misleading and disempowering (Morris 1993, Shakespeare 2000). Where the word dependant appears in this chapter, it is because the author whose work is being cited uses the term.

Nature of Caring

The performance of personal and practical care tasks has become the defining feature of caring. Much of the early literature on informal care focused on carers of people with physical disabilities (Glendinning 1983, Baldwin 1985), people whose needs involved help with lifting, cleaning and feeding. In the present study, the tasks performed by carers of frail older people were similar to the personal and practical care described by other studies (Nissel and Bonnerjea 1982, Glendinning 1983, Wright 1986, Lewis and Meredith 1988, Parker 1993). Care recipients usually needed some degree of help with getting in and out of bed, bathing, toileting, dressing, walking, taking medication and household chores. While carers in the present study were at the 'heavy end' of caring; that is they were caring

for twenty hours a week or more, not all of them undertook the full range of personal and physical care as described by Parker and Lawton's typology (1994).

Personal care defined as 'self-care' or the things that an adult would normally do for him or herself (Twigg 2000:44) seemed to be more problematic than care of a physical or practical nature. Personal care, that is washing and bathing, are usually thought of as mundane, ordinary actions, so routine and obvious that they have required little explanation or analysis. Yet in the present study, although carers tended to accept that providing care of that nature was part of their role, this aspect of caregiving caused a mixture of emotions ranging from embarrassment to distress and disgust.

Two factors, relationship and gender, mediated carers' experiences of personal care. Relationships tended to be underpinned by different sets of expectations. It appeared that what was acceptable for a parent to do for a child was different from what a son or daughter, even as an adult might be expected to do for a parent. Providing care of a personal and intimate nature was less likely to be seen as a natural part of the child-parent relationship. Moreover, it seemed to be rendered more embarrassing because of the gender of carer and cared-for. On the other hand, the marriage relationship, being the prime location of care, particularly for older people (Parker 1993) seemed to be associated with an expectation and duty of care. Personal care within marriage has been deemed to be less of a problem because of the intimate nature of the relationship (Ungerson 1983,1987).

Relationships

For the majority of spouse carers providing personal care for their partners was not particularly problematic. During their interviews they tended to make direct reference to their marriage vows and viewed caregiving as part of their marriage contract. For them, caring was simply a way of expressing their love for their partner. Mrs Currie for example, regarded caring as synonymous with love and marriage when she explained that:

'Well, he's my husband and I love him very very much. I love him as much today as the day I married him. So therefore he's my responsibility. I don't look on him as a chore. I look on him, he's mine, he's there and to be very honest with you, as long as I come in that door and see him sitting there, I don't care what I have to do for him. He's mine and that's it'

(Mrs Currie, 83 year old carer)

While not experiencing personal care as particularly difficult, some older spouse carers said that initially, they found it embarrassing to perform intimate care for their partners.

Mrs Yuill for example, had to overcome her embarrassment at carrying out personal care for her 78-year-old husband. She described how when he was in hospital she worried about having to wash and dress him when he came home. Despite her concerns though she was anxious for him to be discharged. Once he was home, she used humour to lighten the situation and detract from their feelings of awkwardness and embarrassment. She said that:

'When he came out at first I thought how am I going to manage – he'll be embarrassed, I'll be embarrassed and I worried about that. Although we're not really embarrassed now. I try to make it fun. When I put him into bed at night I have to help him and I'll say I'll bloody choke you and he just laughs because he knows I'm not going to choke him. I says I've got you at my mercy now. So I try to make light of it. I try to laugh and make it fun'

(Mrs Yuill, 75 year old carer)

Mrs Roberts was too concerned with preserving her husband's dignity to be embarrassed. Having previously worked as a nurse she was more accustomed to undertaking personal care. Like Mrs Yuill she used humour to lighten awkward situations or ones that her husband found embarrassing. Mrs Roberts explained that:

'We turn some of the bizarre things into a joke. If he falls in the shower he won't let me call my sons. He'll say no don't call anybody, it's too humiliating – which it is and so we struggle and laugh about it. I mean what else can you do? If you didn't have a sense of humour you would definitely go down. If you couldn't see the funny side of things you may as well shoot yourself. There's got to be a lighter side to it. You've got to treat it in a light-hearted way'

(Mrs Roberts, 65 year old carer)

The account above reveals Mrs Robert's concern and that despite difficulties caused by her husband's need for personal care she responded with sensitivity to his embarrassment. Her collusion with her husband also suggests that providing personal care may bring a greater degree of closeness to some relationships.

Mrs Teirney was exceptional in that she was the only spouse carer in the study who discussed openly her distaste and distress at having to carry out tasks of a personal and intimate nature. Because of her difficulty with this aspect of care, her son came to the house at least twice a week to bathe and shave his father but between visits she tried to encourage her husband to do as much for himself as he could. She admitted however, that on days when she felt she just couldn't cope with him, he remained unwashed and dressed in dirty clothes.

Distress at having to perform personal and intimate care was greater among sons and daughters than among spouse carers. While accepting that intimate care was generally a normal part of caregiving, sons and daughters expressed acute embarrassment or discomfort at having to undertake personal care for their parent. A few of carers expressed not just distaste but revulsion at the thought of having to help their parent with personal and intimate care. These carers had little inclination to touch their parents' naked body never mind wash or bathe them. Mrs Bennet for example, stated with feeling that:

'I can't bear to touch her, oh no! I mean she can wash her face and hands, but Sheila [carer's friend] helps to do all that. She's slightly incontinent but she's not smelly'

(Mrs Bennet, 67 year old carer)

Difficulties with personal care were directly related to the child-parent relationship rather than an aversion to the actual tasks involved. Mrs Gordon's distaste of undertaking personal care was compounded by her father's '*filthy habits*' and she admitted that his need for personal care was one of the main reasons that she would possibly consider accepting help to look after him. Her account of her reaction when she had to help him out of the bath reveals revulsion to the task in hand. She said that:

'There have been occasions when I have had to houw [pull] him out of the bath a couple of times. I know before, I would have thought oh no. I don't particularly like my dad but I couldn't allow someone else to come in and bathe him. I would need to do that. And I would put my hand up to you and say the thought of it kind of repulses me. The thought of having to do that. I would need to find this defence mechanism that made me not think about what I was doing...part of what you are doing is almost a pretence, isn't it, you are sort of acting a role. My dad's dirty habits are very alien to my own personality and his dirty habits are becoming increasingly worse. And I am finding it increasingly difficult to... cater for that'

(Mrs Gordon, 62 year old carer)

Mrs Gordon's account reveals the technique that she had developed to help distance herself from the bathing experience. This strategy of '*acting a role*' seemed to help her cope more easily with the intimacy of the situation. Her response, like those of other daughters and sons appeared to be a mixture of distaste and embarrassment caused by the intimate nature of the task and the shifting boundaries of the child-parent relationship. In having to perform personal care they seemed to be constrained by the normative expectations concerning the child-parent relationship. According to Twigg and Atkin (1993, 1994) in the relationship between children and their parents there are greater expectations of privacy, autonomy and separation than in a marriage relationship. In other words, children are generally expected to receive care from their parents rather than give it and to leave

home and lead independent, separate lives. So what is acceptable for a parent to do for a child differs from what children might be expected to do for their parent. Thus because carrying out personal and intimate care is less likely to be seen as a natural part of a child-parent relationship, it creates difficulties for some adult child carers (Atkin 1992). Marriage relationships however, contain a different set of expectations to those of child-parent relationships. Caring for a spouse is seen as a natural extension of the love and support that is a mutual expectation of marriage (Parker 1993). Marital relationships also encompass privacy within the confines of the home, and a taken for granted assumption of 'togetherness' rather than leading separate lives. Thus, in the present study, the type of relationship accounted for the differential experiences of spouse carers and sons and daughters.

Gender

Gender also mediated the experience of caregiving. Daughters and sons who were caring for a parent of the opposite sex reported difficulties caused by the need for personal care. Because of the intimate nature of personal care, it seemed to challenge normative conventions about what men and women should see and touch in relation to each other. Personal and intimate care was a particularly embarrassing and unacceptable part of caring for some carers. The difficulty arose, not from the type of care required but rather from the gender of the care recipient. Mrs Thompson for example, only washed or bathed her father during occasional periods of poor health when he tended to become incontinent and needed more frequent help with personal hygiene. She explained that she had bathed her father '*at the beginning*' when he was quite ill and she believed that he was only going to live for a few weeks. Now that death was no longer imminent she found it increasingly difficult to undertake personal care. The intimate and private nature of these tasks meant that like other carers in a similar situation, Mrs Thompson resolved the problem by turning to her family for help. She was fortunate that her sons were more than happy to regularly undertake the personal care their grandfather required. Mrs Thompson explained that:

'When's he's having a bath or a wash my sons attend to that for me. When he was just home from hospital I could do it then. I did everything for him because at that time it was like a case of well this is only going to be for a few weeks. Now when it's a permanency, well my sons take over, they see to him'
(Mrs Thompson, 41 year old carer)

While Mrs Thompson did not regard herself as a '*prude*', neither did she feel it was proper for her to bathe her father. She conceded that her reactions would probably be different if her mother needed the same type of care. Cross-sex caring also presented difficulties for

Mr Clark, a male carer looking after his 83 year-old mother. Mr Clark's mother suffered from slight urinary incontinence and whilst he was extremely reluctant to assist her to wash and bathe, he recognised that she increasingly needed more assistance with personal hygiene. At the first interview his mother's incontinence did not present too much of a problem. He simply reminded her to wash properly and ensured that clean underwear was available for her every morning. As time went on though, her increasing frailty and poor eyesight made it more difficult for her to keep herself clean. She steadfastly refused to accept help from her son who admitted that he would be too embarrassed to bathe and toilet his mother.

In contrast to carers who would prefer not to be involved with personal care, Mrs Watson undertook all intimate care for her father despite having a husband and brothers who could help. The amount of personal care her father required increased as his physical condition deteriorated. For instance, at the first interview he required supervision rather than assistance with washing but by the third interview, she was bathing him on a daily basis, carrying out bowel and bladder management, and even inserting suppositories. Mrs Watson accepted that personal and intimate care was part of her role, which she saw essentially as a nursing rather than a caring one. She said that:

'I do everything for my dad. Everything. Get him up, shower him, toilet him, dress him, everything because he can't do it himself. He'll ask me to toilet him and I know tonight, he'll ask me to put that cream on his piles again ... He doesn't like anybody else washing him because he says that they don't clean him right, they don't wash between his groins... He gets lotions in to his head, his head is in a mess, it's all white scale and everything. I do everything for him, everything, I cut his hair and see to his catheter'

(Mrs Watson, 38 year old carer)

Mrs Watson was exceptional in her ability and willingness to undertake intimate and personal care for her father. This willingness may be explained by the fact that she had once been an auxiliary nurse in a geriatric hospital and was not entirely inexperienced in these tasks which she alluded to as '*total patient care*'. So while Mrs Watson was unperturbed by her daily routine of personal care, other carers preferred not to perform tasks of an intimate nature except when necessary. Mrs Watson's previous experience in nursing seemed to enable her to perform personal care tasks with an ease that was unique among adult daughters caring for a parent of the opposite sex. On the whole though, sons and daughters were more likely to experience personal care as problematic when caring for a parent of the opposite sex.

Carers looking after a parent of the same sex reported few difficulties in providing personal care other than those caused by size and poor mobility. Mr Brown for example, made light of the difficulties he encountered when bathing his father. He said that:

'It's not easy to bath him in here – the bath is too small and 18 and half stones is a lot of weight, and he's not that mobile. But it's no a problem to me because I'm used to him and we stick to the same routine. Tuesday night is bath night. Other than that he gets a good wash every morning'

(Mr Brown, 40 year old carer)

So for carers like Mr Brown personal care was problematic only in terms of the time it took and the practicalities of helping an older immobile person in and out of a bath, rather than the intimate nature of the task. Thus while cross-sex caring presented some difficulties in relation to personal care, same sex caring seemed less of a problem.

According to recent work by Twigg (2000) difficulties with personal may care stem from the fact that carers want to continue experiencing their mother/father/brother as the person they always knew and that usually meant a fully clothed person who managed their own personal needs. Evidence from the present study did not support this view. Rather, in the current study carers' difficulties with personal care were rooted in the intimate nature of tasks such as bathing and the gender of the cared-for person.

Twigg (2000) describes personal care as being associated with nakedness and touch, concepts that are particularly associated with sexual intimacy. This means that in a social context to be naked usually contains some erotic connotation. The implications of this for personal care are that it often conflicts with social expectations about relationships and the kind of intimacy bathing creates. Nakedness and touch in the course of bathing is not erotic and is therefore more likely to be seen as disturbing (Twigg 2000). This account lends support to Ungerson's (1983, 1987) explanation for the difficulties encountered by carers in relation to personal care.

According to Ungerson, cross-sex caring of a personal and intimate nature is problematic because it may violate cultural taboos (Ungerson 1983, 1987). This taboo means what men do for women in relation to bodily contact is more highly constrained than what women do for men. As a result, cross-sex caring appears to be more problematic when provided by men for females than when women provide it for men (Ungerson 1987, Parker 1993, Twigg and Akin 1994). Parker (1993) further suggests also that providing personal care is easier for women caring for dependent men because it may be viewed in terms of a mothering relationship, as was the case of Mrs Ireland, or a nursing role as in the case of Mrs Watson. Evidence from the present study then seems to support these conclusions.

Sons either found it more difficult to undertake cross-sex caring than daughters or felt more justified in refusing to do it. For example, Mrs Thompson performed personal care when her father required it, if no one else was available to do it. Mr Clark on the other hand, who was uncomfortable about undertaking such intimate tasks for his mother absolutely refused to wash her although they had no other source of help. By objecting to her son's attempts to help her with intimate care, it would seem that perhaps it was also unacceptable for Mr Clark's mother to have care provided by a man and her son in particular.

Parker (1993) and Twigg (2000) have challenged the view that cross-sex caring is unproblematic for married partners (Ungerson 1983, 1987). They argue that far from intimate care being unproblematic for spouse carers, it was laden with even more tension than that faced by adults caring for their parents. In Parker's (1993) study spouse carers undertaking intimate care found it embarrassing and that ultimately, it changed the nature of the relationship. She suggests that these tensions arise from the complexities of a relationship where intimate personal care has replaced the intimacy created by loving sexual relationships.

In the present study, very few wives caring for their husbands reported problems with providing personal and intimate care. This would seem to support Ungerson's (1987) point that cross-sex caring poses few problems for married partners. Only two carers in the present study were husbands caring for their wives. Both seemed to perceive the provision of personal care as problematic. Although Mr Paul made it clear that whilst he didn't particularly enjoy having to bathe his wife it was less of a problem than having to cook her meals. Mr Downs on the other hand, found it undignified and embarrassing to have to perform personal care such as bathing. He said that he did not mind supervising or assisting his wife to have a bath but that he did not like having to actually wash her. In an attempt to maintain his wife's independence and dignity, he had bought a very expensive and sophisticated bath with a door at the side, a Jacuzzi and a shower attachment. By the final interview though, despite having spent almost a thousand pounds on this equipment, he still had to help her bathe. In these particular cases it was difficult to determine the exact reasons why Mr Paul and Mr Downs responded the way in which they did. Both men seemed to be uncomfortable in discussing this aspect of caregiving and refused to be drawn on the difficulties of providing personal care. We can therefore, only speculate that perhaps their difficulties arose, as Parker (1993) suggested, from the complexities of a sexual relationship that had been replaced by a caregiving one. Parker's (1993) findings therefore, are also similar to those of the present study where spouse such as Mr Paul and

Mr Downs found personal care problematic. While they carried out intimate and personal care they did so with some reluctance and a degree of embarrassment. Thus while evidence from the present study appears to support both Ungerson's (1987) and Parker's (1993) explanations, it seemed to be husbands more than wives who experienced difficulties with providing personal care.

The needs of care recipients in this study were similar in that they all required help with personal, physical and practical care. On the whole, the need for personal care seemed to be more problematic than care of a physical or practical nature. In attempting to meet common sets of needs, carers experienced similar types of difficulties yet their responses to and perceptions of their experiences varied. Sons, daughters and husbands for example, were more likely than wives to perceive personal care as being particularly problematic. It is unclear though why some carers perceived caring to be more problematic than others despite the similarities in their situations. In order to fully understand this phenomenon these experiences need to be set in the context of the relationship between the carer and the cared-for person.

Nature of Caregiving Relationships

In the present study an important determinant of carers' experiences was the quality of their relationship with the cared-for person. It appeared that the quality of the caregiving relationship conditioned carers' perceptions of caring. For example, carers who had a strong and emotionally close relationship with the cared-for person were more likely to perceive the caregiving situation as unproblematic. The relationship with the care recipient was usually a positive one in which the cared-for person was treated with respect and viewed as a valued member of the family. This did not mean that these caregiving situations were completely free of difficulties, but rather that in the context of a good relationship, they were not perceived as being a problem. For example, some wives said that the hardest thing about caring was the constant feeling of responsibility. These women now had to deal with household bills and maintenance, things that were once the responsibility of their husbands. They also worried constantly about their husbands' welfare especially when they were apart. Yet they continued to perceive caring as a positive and unproblematic experience. When talking about her relationship Mrs Murphy, a spouse carer for over eight years, said that:

'I'm happy to look after him, he's my husband after all. I worry about leaving him. We've been married for 40 years. I mean I don't think I'm a martyr and I don't think of him as a burden. I just feel well for better or for worse. I take great comfort from knowing that I'm able to look after him. It's not a problem. We're close and I feel ok about it'

(Mrs Murphy, 65 year old carer)

Close, loving, and positive relationships were not confined to spouse carers. Adult children also enjoyed emotionally close relationships with the parent they were caring for. Mrs Black for instance, explained how she had *'always been close to mum'* and how even after she moved away to college they maintained a close relationship. Talking about her relationship with her mother she said that:

'We've always been close, we always got on pretty well, even when I went to college and I suppose it's [the relationship] become closer - because your doing so many personal things for her. I mean it's hard, but you look at her sometimes and you think she needs you. So I'm there for her'

(Mrs Black, 47 year old carer)

Mrs Black's relationship with her mother structured her perception of caregiving. Mrs Black's mother had difficulty negotiating stairs but she insisted that she be helped to the toilet upstairs rather than have to use a commode placed beside her bed downstairs. Yet despite facing problems such as these on a daily basis, Mrs Black tended not to view caregiving as problematic because of the close and affectionate relationship she shared with her mother. A relationship that she was committed to maintaining.

It cannot be assumed however, that because an adult child looks after an elderly parent that they share an emotionally close relationship. Where carers did not share a close and loving relationship with the care recipient, caregiving was more likely to be perceived as difficult and problematic. In these situations the caregiving relationship was more likely to be a tense, strained and emotionally distant one in which the cared-for person was neither respected nor valued and carers expressed resentment. An example of this type of relationship was Mrs Watson who had been particularly close to her mother but her relationship with her father had always been volatile. Fights and disagreements characterised this relationship and caused her to view caregiving as problematic. Yet in the previous section we saw that Mrs Watson was unique in that she had few qualms about undertaking personal and intimate care for her father, tasks that other carers found difficult. She explained that:

'I was close to her. I mean I was here every day with my mother. I could argue with my dad when my mum was here. He'd tell me to go out and not come

back. My mother used to know that I was always really angry with him because I used to swear at him, I used to call him a dirty b. and things like that. We still fight and shout. I get myself up to high doh about my father. There's none of the [practical] aspects of looking after him that's difficult if only he would learn to keep his mouth shut'

(Mrs Watson, 38 year old carer)

Other carers were similar to Mrs Watson in that they too were caring for a parent with whom they had a strained and emotionally distant relationship. Mrs Bennet for example, perceived caring as a difficult task and expressed resentment at having her well planned retirement disrupted by the demands of caring for her 94-year-old mother whom she thought would have died before reaching her nineties. Caring for her mother out of sense of duty rather than love, Mrs Bennet admitted candidly that neither did she love her mother nor did she particularly like her as a person. She explained that her relationship with her parents had been neither close nor affectionate:

'I wouldn't say I had a close relationship with my mother. I mean we didn't do things together. We never have. We never even went on holiday together...My mum never had an affectionate nature. Not at all. Neither of them was demonstrative, no very undemonstrative. I don't remember them showing affection. But funny enough I'm a very demonstrative person but not to my mum. I don't love my mother. I see it [caring] as my duty. If you don't feel it you can't force it. There's no use in forcing it...I'm not a tolerant person'

(Mrs Bennet, 67 year old carer)

The cases outlined above illustrate how the quality of the relationship seemed to shape carers' perceptions of caring. On the one hand there were carers who were committed to maintaining the close and positive relationship they shared with the person they cared for. They were more likely to treat their loved ones with warmth, kindness and respect. Their positive relationship with the cared-for person seemed to enabled them to perceive caregiving overall as a positive and unproblematic experience despite the existence of difficulties. On the other hand, other carers perceived every difficulty as a major problem. This suggests that without a strong and close emotional tie, these carers were more likely to react negatively to the caring situation and perceive it to be problematic.

Mediating Factors: personality, history of relationship, motivation

The nature of the caregiving relationship has been shown to be central to the experience of caring. But what is it exactly that determines that relationship? A variety of factors seem to structure the caregiving relationship. Three of these factors, the personality of

individuals, the history of the relationship, and the motivation of carers will be discussed below.

Personality

The first key factor in structuring caregiving relationships was the personality of the cared-for person. In close and affectionate caregiving relationships there was a tendency for carers to describe the cared-for person in positive terms such as 'easy going', 'undemanding' or 'good-natured'. When talking about their relationship carers implied that the personality of the care recipient made their job easier. For example, Mr Brown who enjoyed an affectionate and positive caregiving relationship with his father said that:

'For me it's a dawdle. He's no really any bother, my old man, because he'll do more or less anything that I ask him. He doesn't want for much, he doesn't ask for much, he doesn't need much. Sit him in front of the telly and he's happy. Give him a beer and he's happy. To me, he's no bother really'

(Mr Brown, 40 year old carer)

That he experienced caring as unproblematic, Mr Brown attributed to the fact that his father was an undemanding man whose needs were easily met. The accounts of spouse carers also suggest that their husbands' personality made them easy to care for. Mrs Yuill for example, when describing her husband's good nature started talking in the present tense and switched to the past tense. This suggests that while he remained a 'lovely person' his sense of humour had disappeared. She said that:

'He's a lovely person, really nice. He had a very dry sense of humour. He was so funny, he'd make a cat laugh. He could see the funny side of life all the time. He's not a bother. He accepts it [limitations] very well. I'll say do you not get fed up, not at all he'll say'

(Mrs Yuill, 75 year old carer)

The accounts above suggest that a common factor in positive caregiving relationships is the placidity or good nature of the care recipient. Conversely, where the nature of the cared-for person was described in negative terms such as 'difficult', 'demanding' or 'manipulative', the caregiving relationship tended to be emotionally distant and caring perceived as problematic. Some carers described their mothers as unkind and selfish women. Mrs Veitch for instance, said that her mother seemed to be happy living in her son-in-law's house but did not appreciate what was done for her. She claimed that her mother saw herself as being 'no bother' but that she was really a demanding, ungrateful and difficult old lady. Mrs Veitch sounded quite bitter when she said that:

'She looks and acts like a lovely gentle old lady when anybody is in but she changes when talking to me. If things are missing then she points her finger at me and speaks nastily. She's a very ungrateful woman – a very controlling, demanding person. I've given her my home, my life and my time and I get no thanks, no appreciation for what I and my family have done'

(Mrs Veitch, 69-year-old carer)

Mrs Kearns also used characteristics with negative connotations to describe her mother. That she perceived caregiving as difficult, Mrs Kearns ascribed to her parent's demanding and strong-willed nature which did nothing to improve their relationship. She explained that:

'She's normally a strong willed person and I that's where a lot of the problems come from. She can be difficult and she's very moody. She can lose her temper easily. I find that she's far more pleasant with everybody else than she is with me. I get all the grumps and the moans and the bad moods and the tempers'

(Mrs Kearns, 36 year old carer)

Mrs Kearns' account reveals how she attributed her problems to her mother's personality. Although she had admired her father's ability to look after his wife, she blamed her mother's demanding nature on the fact that he had *'done absolutely everything for her'*. Mrs Kearns felt that if her father had done more to encourage her mother's independence she would have been a less demanding person. In the accounts above both Mrs Veitch and Mrs Kearns failed to consider that their parents' nature and behaviour might be a result of frustration at their increasing frailty and dependency. By drawing on their intimate knowledge of their parents, carers such as Mrs Veitch and Mrs Kearns were confident that their parent's nature had changed little over the years. Thus in caregiving situations such as those discussed above, the emotional distance or closeness that characterised the relationship was maintained rather than dismantled by the personality of the cared-for person.

History of relationship

The history of the relationship between the carer and the cared-for person was another factor that conditioned the current caregiving relationship. In strong, positive caregiving relationships, the history of the carer and the cared-for person usually revealed a long-standing close association where a good rapport had been established prior to the need for care. This was as true for spouse carers as it was for sons and daughters. Some carers claimed that caring had, in fact, brought them closer to the person they were caring for. For instance, for Mrs Morrison caring was a positive experience that had brought her closer to her mother-in-law and strengthened a good pre-existing relationship. In the first

interview Mrs Morrison said of her mother-in-law that *'they had always got on well'*. By the third interview two years later, she felt that caring had brought them closer and their relationship had developed into one of companionship. Mrs Morrison, unable to hold down a paid job because of an old back injury and high blood pressure, spent a great deal of time at home even before she started looking after her mother-in-law. Her affection for her mother-in-law was apparent when she admitted that she would miss her if she were not there. She explained that:

'I quite like her in a funny way. You can sit and have a good conversation with her and she's alert. There's a funny side to her - she can sit and talk about her family, her mother came from Russia, and it's nice when she opens up like that and we'll sit and talk away about things. Sometimes I'm glad she's here because the quietness in the house drives me round the bend. The funny thing is I would miss her. I mean I have said to Andrew [husband], the queerest thing is Andy, if you mother dies, I think I would take it pretty bad but I know it's going to come eventually. Aye I think I would take it pretty bad because I have looked after her and I know her pretty well. It doesn't mean that I - love her. Not really. She's been good to me my mother-in-law. We have always got on well but now I think we're closer. We respect one another put it that way'

(Mrs Morrison, 58 year old carer)

Mrs Morrison enjoyed and derived a great deal of satisfaction from her close relationship with her mother-in-law. Thus where caregiving relationships were of a good quality, living in close proximity to the cared-for person tended to pose fewer problems for carers.

On the other hand, in negative caregiving situations, the history of the relationship tended to reveal an emotionally distant association, which was problematic before the need for care arose. The emotional distance experienced by some carers began in their childhood and continued into adulthood. In Mrs Bennet's case, we have seen already how she recalled the lack of affection during her childhood and how her family rarely shared leisure activities, hobbies or even holidays together. In adulthood, her mother's disapproving and critical attitude towards her ensured that the emotional distance characterising their relationship was maintained rather than being dismantled. Similarly, Mrs Gordon's dislike of her father stemmed from her disapproval of his behaviour during her childhood. She could neither forgive nor forget his past behaviour because it caused both her and her mother so much anguish and humiliation. She explained that she found him difficult to deal with because:

'There's a part of me doesn't like my dad basically. I know if anything happens to him I will be distraught but there's a lot of me that doesn't like him. I remember all the times he was with other women. We were sitting up at night wondering where he was. I can remember that clear as a bell and I've never

forgiven him for it. That and the fact that he chatted up every school friend I ever brought home. You don't lose that and I feel bad that part of me is stuck at that ...I sometimes feel guilty that there isn't more affection between us'

(Mrs Gordon, 63 year old carer)

Carers' accounts suggest that childhood attachments and events shaped the quality of caring relationships. Exceptions to this were Mr Brown and Mrs Thompson whose childhood was marred by domestic violence and alcohol abuse. Despite this though, they had forgiven their fathers for past hurts and now enjoyed amicable relationships. Thus the evidence from the present study suggests that while the quality of the relationship is the key to the experience of caring, personality and history help to structure the relationship.

Motivation

The third factor that conditioned caregiving relationships was motivation. What was it that motivated carers to continue caring? In the present study carers were motivated either by affection, reciprocity or obligation. We have already seen in this chapter how some relationships were characterised by either an emotional closeness or distance. In the last chapter we saw how notions of reciprocity and obligation were given as reasons for individuals choosing to become carers. In this section it will be shown how these concepts structured the caregiving relationship. Although different motivations will be discussed as separate entities they are not mutually exclusive concepts. In reality the boundaries between them are hazy and overlapping and carers may be motivated by one or more factors. Nonetheless, carers tended to be motivated primarily by one or other of these concepts. Therefore, it cannot be said that carers who were motivated by reciprocity did not feel affection for the person they were caring for. Nor can it be said that carers motivated by affection did not feel a sense of obligation to their relative. However, these concepts remained potent in that they seemed to provide an incentive to care.

Affection

Carers in the present study, who had a strong attachment to the person they were caring for were more likely to be motivated by affection rather than reciprocity or a sense of obligation. Their relationships tended to be close with a strong emotional bond, which carers allude to. Thus the majority of spouse carers in the present study, who as we have already seen, tended to have strong, close relationships, were motivated by the love and affection they felt for their long-term partner. But affection for and attachment to their relative also motivated sons, daughters and sisters. When discussing their motivation for

caring, these carers tended to mention the love and affection they felt towards the person they were caring for. Mrs Ireland for example said:

'He's my brother and I love him. It's as simple as that.'

(Mrs Ireland, 63 year old carer)

Affection for and attachment to their parent motivated carers even when they lived a distance away. Carers spoke of how they would keep in close contact with their parent in an effort to maintain the relationship. Mrs Duncan for instance, lived in London and kept in touch by phone calls and by letters to her mother. Holidays from work were also spent visiting her mother on a regular basis. As her mother became frailer the frequency of her visits and phone calls increased until Mrs Duncan eventually realised that they were not sufficient. Rather than manage her mother's care from a distance, she chose to give up her job and return to Glasgow to look after her herself. She was motivated primarily by the affection she felt for her mother and her desire to maintain their close relationship. She explained that:

'I've always been close to my mum. We've always had a very close relationship. Even although I've been away twenty odd years I still had a close relationship with her and I didn't want that to change. I didn't like to think that somebody else was looking after her. I would have wondered and worried if things were alright'

(Mrs Duncan, 47 year old carer)

Mrs Macrae, another daughter who like Mrs Duncan was motivated by a deep affection for, and a strong attachment to her mother, explained how she had *'always been one for her mum'*. She differed from Mrs Duncan in that caregiving had become the reason d'être of her life whereas Mrs Duncan maintained her own interests outwith caring. Mrs Macrae centred her whole life around her mother, her mother's friends and her mother's daily activities. Having enjoyed a long, close and very affectionate relationship with her 92-year-old mother, her sole purpose now was to make her *'feel good'*. If she managed that then she was quite happy. Her account reveals that by maintaining close contact with her mother even after her marriage, their deep emotional bond remained intact. She said that:

'I feel good when she [mother] feels good. When they are nice and that you feel sorry for them and you try to make them happy. I was always one for my mum. She was a good mother... Every day, all day is spent trying to make her happy. If everything is ok and my mum is feeling good -aye that's nice and I'm happy too. I've always tried to be good to her. I used to always be the one for helping her in the house when I was a single girl. Then [after marriage] I used to go up and down to my mums, didn't go up every day but I phoned her every day, I

used to go out and phone her from the phone box'

(Mrs Macrae, 63 year old carer)

By visiting her mother on a regular basis and keeping in touch by telephone, even though she had to leave the house to do so, Mrs Macrae had made determined efforts over the years to maintain her attachment to her mother. It was this deep affection that provided the impetus for her caregiving and caused her to simply accept her mother's irritable and demanding nature. When her mother was being difficult Mrs Macrae blamed it on her age, or on her blindness that meant that she could no longer read or watch the television. Mrs Macrae's devotion to her mother was exceptional in that she allowed it to dominate her entire life to the extent that she rarely left her mother alone. She only left the house to collect '*the pensions*' and even then she took a taxi to the shops in order to minimise the time spent away from her mother.

Mrs Cranston was similar in that she too had made every effort to maintain her affectionate relationship with her mother. But in contrast to the harmonious relationships of other carers with their mothers hers was much more volatile. Having moved away from the area in which her mother lived, Mrs Cranston had travelled back daily to ensure her mother's wellbeing, in addition to phoning her at least two or three times a day. Despite having siblings who lived near their mother, she preferred to see to her mother needs rather than rely on others. Eventually Mrs Cranston and her husband arranged to move into a flat at the same address as her mother. Whilst this move made it easier for her to provide the care that her mother needed, she regretted it because now she frequently rowed with her mother. Rows and disagreements were usually caused by Mrs Cranston disapproval of her mother's drinking habits or as she put it '*her fondness for a wee drink*'. When her mother was drunk Mrs Cranston was usually subjected to tirades of verbal abuse which led to the two women falling out. Despite this however, Mrs Cranston refused to withdraw from caregiving. She explained that:

'I feel that I know her better than the others (siblings) because from when I was four I've done things for my mother. It was always me. She trusts me with her bank books and things too ...At one point I was so bad through her drinking I nearly had a nervous breakdown. When she's on the drink I get it – with her mouth ... But I just keep going because at the same time she is my mother and when she's not drinking she's quite a character. She tells people how much I do for her and how much she appreciates it – but she never apologises. For all that, if anything happened to her, I don't know what would happen to me. I never bothered when my father died but when it comes to her, God knows what state I'll be in'

(Mrs Cranston, 56 year old carer)

This relationship was marked by ambivalence whereby Mrs Cranston displayed feelings of affection and dislike for her parent on different occasions. But a strong underlying bond of affection kept the two people together and her account revealed her concern about how she might react when her mother eventually dies. Carers motivated by affection were more likely to show great concern over their relative's comfort, their health, their appetite, their daily routine and sleep patterns. In other words, these carers demonstrated a deep and genuine concern for all aspects of their loved ones health and well being and many of them put the needs of the cared-for person before their own. Their caregiving seemed to be characterised by a profound attentiveness and solicitude.

Some carers who were motivated by affection could have been described in terms of Twigg and Atkin's (1994) typology as 'engulfed' carers. Caring had become the centre of their lives and their needs were subordinate to those of the cared-for person. Finding it hard to recognise never mind articulate their own needs, meant carers such as Mrs Macrae and Mrs Cranston had difficulty in establishing autonomy for themselves and their own interests. Their sense of responsibility was so total that they found it hard to share even with their siblings. Yet unlike Twigg and Atkin's engulfed carers, caring was for them a demanding yet satisfying role.

The actions and behaviour of carers such as Mrs Macrae, Mrs Cranston and Mrs Duncan are similar to those described by Cicirelli's (1986) model of attachment outlined in chapter 1. In this model attachment is associated with a tendency to seek close contact with or to be near the attached figure. The concept of attachment implies that in adulthood, attachment behaviour with feelings of closeness suggests the presence of an affectionate bond or attachment between two people (Cicirelli 1986). Attachment does not end in early childhood but continues through the entire lifespan, along with its related proximity-seeking, exploratory, and protective behaviour. In infancy, attachment involves periods of exploratory behaviour alternated with 'proximity seeking', that is attempts to restore contact with the mother (Bowlby 1973). In adulthood, separation from a parent is inevitable as the child establishes independence and develops new attachments with others. Exploratory behaviour then gives way to protective behaviour, which is concerned with preserving or restricting the threatened existence of the attached figure rather than merely maintaining or restoring close contact (Cicirelli 1986). This protective behaviour is similar to the 'preservative' care described by Bower's (1987) typology.

Attachment behaviour in adulthood is defined as any action to maintain psychological closeness and contact. These behaviours involve communicating, even over a distance, to

maintain an emotional closeness and periodic visits help to re-establish physical contact. Attachment behaviour includes living near the parent, telephoning, letter writing, and sending messages through others as well as actual visiting. Protective behaviours that are related to the attachment are according to Cicirelli (1986) manifest by the son or daughter providing care to the parent. When the adult child perceives the emotional bond to be threatened by their parent's illness or incapacity, they will provide care to maintain their survival and to preserve the attachment. Thus according to Cicirelli's (1986) model of attachment sons and daughters will visit and communicate more with their parent and undertake caregiving more readily, when feelings of affection and attachment are stronger.

We can see then how the actions of daughters in the present study matched the attachment behaviours in Cicirelli's (1986) model of attachment. Carers described how they kept in touch by phone and paid regular visits to their mothers. Moreover, in order to establish closer proximity to their mothers when the need for care arose, these carers moved house. Mrs Duncan moved into her mother's home while Mrs Macrae and her mother formed a shared household in a new house. Mrs Cranston did not move into her mother's home but to a flat above thereby sharing the same address but occupying separate households. The behaviour and actions of these carers provide evidence of affection for their mothers with whom they had a strong, positive relationship with a deep underlying bond of affection.

Reciprocity

Some carers in the study, who had good quality, close caregiving relationships tended to be motivated by reciprocity. Reciprocity as discussed in chapter 1, is defined, as a social relationship between individuals in which there is a mutual exchange of goods or services that benefit both parties (Gouldner 1973, George 1986). According to Gouldner (1973) the norm of reciprocity decrees that people should help those who have helped them. The norm of reciprocity is a value, which underpins human behaviour and exchanges within relationships (George 1986).

Although the notion of reciprocity was not usually referred to or articulated directly by carers, in the present study, good caregiving relationships were more likely to be based on the idea of an exchange of services. By making reference to how their relative had previously cared for or supported them, some carers viewed caring as payment for prior nurturing, care or support. We saw in the last chapter how some carers such as Mrs Welsh, Mrs Macrae and Mrs Beaton were motivated by the notion of '*payback*' to accept responsibility for their mother's care. As single parents at a time when support services

were virtually non-existent, these women had relied on their mothers to provide childcare. As their jobs had entailed working shifts and unsociable hours, they believed that it would have been impossible to obtain help from other sources. These carers felt indebted to their mothers because their practical and financial support over the years had allowed them to combine employment with parenthood. Mrs Welsh for example, never forgot that her mothers support allowed her to escape from an abusive marriage and maintain her independence. When her mother's increasing frailty made caregiving more difficult it was memories of past support and the notion of repaying a debt that motivated her to continue caring. Her understanding of the reciprocal nature of family relationships was clear when she said that:

'It was payback time. She was my support during all those years when I couldn't get help. You couldn't run to any house the way battered wives do nowadays. Because I used to get beatings – years and years ago when you never got any help and there was no sheltered housing or places to run. I had three children to support but my mother looked after my kids to let me out to work. So I feel that it's just'

(Mrs Welsh, 62 year old carer)

In some caregiving relationships the notion of 'payback' or reciprocity was often very similar to notions of doing the right thing or duty. Spouse carers especially, tended to regard caring for their partner as a natural part of their marriage, but they also saw it in some sense as a repayment for their partners having been a good husband or wife. Although the majority of spouse carers referred to the reciprocal nature of their relationship with their partner, the best example comes from Mrs Currie who held firm views on the role of men within marriage. Referring to the reciprocal nature of her relationship, Mrs Currie told how when she was very ill many years before, her husband had nursed her at home for a number of months until she made a full recovery. She was indebted to him that during her prolonged illness he managed to hold down a job as well as 'seeing to the house'. She explained that it was her responsibility as a wife to care for her husband:

'Well after all, he's been my husband now for coming up to 60 years and I feel that's well my responsibility - because he's been good to me. Who else would look after him? He's been good to me... When I was very ill - I was at death's door years ago. I had a big heart operation and I was in the Royal for 18 weeks. I needed Jimmy when I came back out. He was always there, I never felt alone. He was on the go the whole time. He had to do more or less everything in the house... He's not able to do anything now because he's so bad with the arthritis'

(Mrs Currie, 83 year old carer)

Having given up work when she married, Mrs Currie seemed to believe that her husband's role as breadwinner should not extend to household chores. Housework she regarded as her responsibility while the financial upkeep of the household was his. That he was willing to undertake housework when required signified to Mrs Currie that he '*was a good husband*'. Now that he was unable to do things for himself, Mrs Currie regarded the care she gave her spouse as being in some sense, a repayment for him having been a '*good husband*'.

Whilst Mrs Davidson also regarded caring as part of marriage, she too saw what she did as being in some sense, a repayment for her spouse having been '*a good husband*'. One reason for this view that he used hand her his weekly pay packet unopened. Mrs Davidson also appreciated the support her husband had given her when she had previously cared for her mother and her sister. She recognised that without it she would not have been able to nurse them. Mrs Davidson, like Mrs Currie, clearly had a very close relationship with her husband and never questioned that her role as a wife also meant caring for her husband. She said simply:

'Well, he's my husband and he was good to me. He would have done anything for me - and he always brought home his pay packet unopened...He helped me look after Bella [sister] and my ma. He was great with them. Now it's his turn'
(Mrs Davidson, 68 year old carer)

In the cases outlined above, Mrs Currie and Mrs Davidson clearly regarded their present activities as some sort of repayment for care their husbands had bestowed on them in the past. In their eyes, their husbands had earned their present care by being good husbands. Thus carers' accounts suggested that exchanges of goods and services in relationships might not necessarily be recent or equal but they were expected.

Carers' accounts were underpinned by expectations of giving and receiving care. For example, Mrs Morrison's account reveals how the notion of payback shaped both carers and care recipient's expectations. Having looked after her mother-in-law for six years Mrs Morrison explained that:

'She knows I look after her very very well...She's been good to me my mother-in-law, ever since I met my husband. She's the type though that if she does anything for you - she expects payback ... But I just look at life and think well, if you can help somebody I don't want something for doing it. I think everything goes full circle. You get all these things back'
(Mrs Morrison, 58 year old carer)

Mrs Morrison's account reveals her expectation that the care she currently provided would be repaid sometime in the future. She recognised that repayment would not necessarily take the same form of help or come from her mother-in-law but from some other source. Whilst she stated that she did not expect or want payment in exchange for caregiving she did nonetheless, gain some reward for her efforts, albeit not a financial one. We saw earlier in this chapter how caring brought Mrs Morrison closer to her mother-in-law and changed their relationship to one of companionship. Mrs Morrison therefore, derived a positive benefit from her caregiving role. Moreover, her account suggests that the care she currently provided was in exchange for past support from her mother-in-law. This pattern of behaviour accords with the norm of reciprocity and supports the point made by others, that where an element of reciprocity is present, caring can result in improved caregiving relationships (Abrams 1978, Bulmer 1986, Grant and Nolan 1993).

In the cases outlined above, whether they were spouses or adult children, carers seemed to feel that because their partner or parent had played by the unwritten rules of social interaction they had a responsibility to do the same. Expectations of repayment underpinned carers' incentive to provide care for their spouses, parents or siblings. Thus the evidence from the present study supports the point made by others that relationships are characterised by a trust that the relationship will involve equitable exchanges over the long run and periodic departures from reciprocity will be tolerated (Gouldner 1973, Cicirelli 1986, George 1986). According to George (1986) relationships can develop and be sustained only if both members find the interaction reciprocal. When reciprocity is not present, individuals will withdraw from interaction, which has become unrewarding (George 1986). However, data from the present study contradicts this assertion. It suggests that in contrast to the cases discussed above, spouses, sons and daughters will continue to provide care, despite the absence of reciprocity.

Obligation

Some carers in the present study were motivated by a powerful sense of obligation rather than reciprocity or affection. Caring allowed them to fulfil their sense of duty. Carers in this situation tended to feel that their relationship with their relative had always been poor and they were the ones most likely to make reference to the lack of affection in their relationship. Nonetheless, they tended to believe that they had a moral obligation or a duty to provide care for their relatives. It was obligation rather than affection that motivated Mrs Kearns who at the age 36 years was the youngest carer. She had a somewhat complicated family history, which may have contributed to the complex array of emotions

she expressed towards her 87-year-old mother. Having been adopted at the age of six, Mrs Kearns had only recently discovered that her mother was in fact her great aunt and that her natural father, her adopted mother's nephew, was still alive and living in Canada. Mrs Kearns was aware of her family's expectation that she should look after her mother. Whilst she resented this expectation and felt she was being manipulated, she nonetheless felt obliged to care for her. Mrs Watson was torn between the demands of her adopted mother, a woman to whom she had never felt close, and those of her husband and young children. She was very conscious of the generation gap when she explained that:

'My mum is my adopted mum but she's actually my great aunt. It's not that I don't love her, I do, I think. But we've never been close, I was closer to my dad but at the same time all my problems come from my mother. It's a very difficult situation. I feel we are too young to have all this thrust upon us, but the attitude of the family is that ... well we're just expected to do it. It's very difficult trying to please an older person. So you are not the most tolerant in these circumstances. And because I'm not out [working] I'm at home a lot with her and it's very difficult'

(Mrs Kearns, 36 year old carer)

Carers whose sense of obligation would not allow them to physically withdraw from caregiving, did so emotionally. For instance Mrs Bennet, a recently retired woman looking after her 94-year-old mother viewed caring as problematic and unrewarding. There were traces of bitterness in her voice when she described what it was like to grow up in a household with strict parents who showed little affection towards their children.

'She's never been a mother to me. She never showed me any affection, or my brother for that matter. She didn't criticise directly but everything that happened was wrong somehow. It's all this negativity. She's always moaning no matter what...I don't love my mother. I see it [caring] as my duty'

(Ms Bennet, 67 year old carer)

Mrs Bennet's account suggests that her incentive to continue caring was a strong sense of moral obligation towards her mother rather than affection or reciprocity. Spouse carers such as Mr Paul and Mrs Teirney who had poor or fragile relationships with their partners were also more likely to be motivated by obligation rather than affection. Mr Paul for example said:

'I felt that because it was my wife I had to do something'

(Mr Paul, 63 year old carer)

Mrs Teirney, having looked after her 78-year-old husband for nine years, described him as a selfish, bullying man who had been a strict disciplinarian with their sons. Although she

had worked full-time most of her life, even when her children were small, her husband had never helped her with childcare or domestic chores. She explained that:

'He never lifted a finger for any of his kids. He never showed us any affection. I've put a lot into it [marriage] and I worked hard. You know, I actually worked harder than him. I got no help with anything... Sometimes I think that he's fitter than what I am yet I'm responsible...It's too late now. What's the point, it's too late. This is my life and that's it'
(Mrs Teirney, 68 year old carer)

Mrs Teirney's words clearly suggest that in her marriage, any help or support given was a one way flow. It was difficult for onlookers to understand that she remained with her husband, whom she spoke about in such derogatory terms, out of a sense of obligation rather than love or affection. Mrs Teirney had certainly considered leaving him but she felt that at the age of 68 years, she had left it 'too late' to set up a new home for herself. It is not surprising that Mrs Teirney trapped in a poor quality, emotionally distant relationship perceived caring as problematic and unrewarding. She hadn't had the courage to leave her husband when he was fitter and now that he was in need of more care she felt duty bound to look after him.

For some carers, their sense of moral obligation stemmed from their position in the family. Being the eldest they were expected to assume responsibility for caregiving. Mrs Veitch for instance, expressed an almost overwhelming sense of obligation to continue caring for her mother although her two other sisters indicated their willingness to take over. Her sense of moral obligation stemmed from the fact that she was the eldest daughter and the one her mother had 'always depended on'. That other family members regarded her as capable was illustrated by the fact that she was asked to assume responsibility for the family business after her father's death. Furthermore, she was the one her sisters turned to when they needed help. It was this sense of obligation rather than anything else that motivated her to continue caring for her mother, with whom she had a difficult relationship. She explained that:

'I have always had a difficult relationship with my mother – because I had always had to do for her all over the years. But at the same time she depended on me and when you are dependent on someone – at the same time you will favour someone else who is doing nothing but the one who is doing it all has all the faults. I do what I have to do instead of getting on with my own life... I don't think people should have to be in a place like that [a home] when they have daughters'
(Mrs Veitch, 69 year old carer)

Despite having a poor relationship carers continued to provide care in the context of a difficult relationship despite the absence of affection or reciprocity. In doing so, however, they undertook as little as possible for the person they were caring for. They were motivated primarily by a sense of moral obligation. Thus data from the present study suggests that neither present nor past reciprocity is a necessary condition for caregiving. In the absence of reciprocity, carers who could or would not physically withdraw from the relationship did so emotionally. For example, some carers had longstanding and emotionally distant relationships with their relatives but while they continued to provide care the nature of their interaction ensured that the emotional distance was sustained rather than eroded. Most of these carers expressed and then quelled their longing to withdraw from their caring responsibilities. A powerful sense of moral obligation and family loyalty kept them in unrewarding caregiving relationships. Distinguishing between affection and obligation in caregiving relationships Cicirelli (1986) concluded that relationships based on obligation alone were more likely to be perfunctory in comparison to the qualitatively richer interactions of affection based relationships. He claims that whilst cultural norms and expectations play an important part in shaping adult children's behaviour towards their elderly parents, without an affectionate relationship, obligation alone was likely to result in minimal caregiving effort, if it was carried out at all. Evidence from the current study supports this view. Accounts of the care given by those motivated by obligation, suggest that it was often, if at all, carried out in an routine and cursory fashion. Moreover, carers motivated by obligation were more likely to be inattentive and indifferent to the needs of the person they were caring for, compared to those motivated by affection. As we have seen in the present study, relationships based on affection were qualitatively different to those based on obligation.

Conclusion

In this study of family carers, the provision of personal and physical care was the defining feature of caring. The need for personal care seemed to be more problematic than care of a physical or practical nature. Providing personal care was especially difficult for sons and daughters looking after a parent of the opposite sex. Wives looking after their husbands seemed to experience fewer problems with personal care other than initial embarrassment. The responses and perceptions of carers varied although they experienced similar types of difficulties. It appeared that carers' perceptions were structured by the nature and quality of the relationship between the carer and the person being cared for. Whilst no caregiving

situation was completely free of difficulties, carers who had a strong and emotionally close relationship were more likely to perceive caring as unproblematic. In contrast to them, carers who had a fragile and emotionally distant relationship with the cared-for person tended to view caring as difficult and beset with problems.

Caregiving relationships were structured by a variety of factors including the personality of the care recipient, the history of the relationship and carers' motivation. The personality of the cared-for person and the history of the relationship seemed to determine its quality. In close and affectionate relationships carers tended to describe the care recipient in positive terms and implied that their personality made caring for them easier. Where caregiving relationships were emotionally distant and caring perceived as problematic, the nature of the care recipient was more likely to be described in negative terms. The history of the relationship also revealed that in strong, positive relationships, there had usually been a long-standing close association where a good rapport had been established before the onset of caring. On the other hand, in fragile negative associations, the history tended to unveil an emotionally distant relationship that was problematic before the need for care arose. Thus any problems in the relationship caused by the personality of individuals were of long standing and not easily resolved. Similarly, affection in caregiving relationships had developed over time and was not easily diminished by the problems encountered in caring.

Affection, reciprocity or obligation motivated carers. Carers motivated by affection were highly motivated and committed to maintaining their relationship with the care recipient. Their caregiving was underpinned by a strong emotional attachment and they seemed to be very attuned to needs of the care recipient. Carers who were motivated by reciprocity also tended to have good quality relationships but were less committed than those motivated by affection. Wives were the exception, in that affection, reciprocity as well as duty motivated them. In the absence of a loving attachment and reciprocity, a sense of moral obligation tended to motivate carers who had fragile and poor quality relationships. Their caregiving appeared to be qualitatively different to that provided by carers motivated by obligation in that they seemed to be less attentive to needs of the care recipients and less committed. Although some carers expressed the wish to withdraw from caring, their sense of moral obligation to their parent was so powerful that it forced them to accept rather than act upon their inclination.

This chapter has focused on the nature of caring, on the quality of caregiving relationships and the factors that structured them. The next chapter explores issues of control and power in caregiving relationships.

7. Control within Caring

This chapter will examine how control in caregiving relationships was established and maintained. It will begin by discussing the concept of control and continue by exploring the ways in which control was gained and upheld in caregiving relationships. Previous research has focused on the relationship between service providers and service users and carers (Twigg and Atkin 1994, Twigg 2000). Here the focus is on the relationship between carer and care recipient.

Concept of Control

Caregiving has been acknowledged as a relationship in which either one or the other of the parties has more control (Orme 2000, Twigg 2000). Control, defined as the ability to exercise power in order to direct or manage the caring situation, was an important issue for carers in the present study. Power, the tool used to achieve and maintain control, can be defined as domination, as legitimate authority, or as an act of will (Lukes 1986). Weber's definition (1922 in Haralambos and Holborn 1995) is perhaps the most appropriate for the present study. He defined power as the probability that a person in a relationship would be able to carry out his or her own will in the pursuit of goals regardless of resistance. Weber's definition includes the notion of agency, that is an individual achieving or bringing about goals that are desirable. He claimed that there are differences in interests between the powerful and the powerless and that when power is exercised over other individuals it may involve resistance and conflict as well as restrictions and deprivations for those subjected to domination.

Establishing and Maintaining Control

In the present study control was established and maintained through ownership of material resources such as the house where care was being delivered. A widely held belief was that homeownership conferred a degree of authority that enabled the homeowner to control the situation. Carers who had brought their older relative to live with them, tended to believe

that because caring was taking place in their house, they had the authority to make rules and establish boundaries. Exercising power in this manner enabled them to take and maintain control of the situation. Mr Brown for example, having taken his father to live with him explained why the issue of homeownership was important. He said that:

'Well he lives with me. There's a subtle difference in that kind of thing. When you have a parent come to stay with you it's easier than when you go to live with a parent. There's different pressures apply. There's a difference because people treat you different. It harder for people to care I think if you move into a parent's house... When I moved I brought my father with me and that's no bother. Everybody knows that he stays with me and I don't stay with him'

(Mr Brown, 40 year old carer)

Mrs Smith also placed importance on homeownership, believing that the homeowner had the authority to establish 'ground rules' and who 'called the tune'. Having previously cared for her mother and brother she claimed that:

'I've always said that as a carer, they stay with me. I do not stay with them. It makes a difference if you start that way. If someone is living with you, you've got to have a set of ground rules to start with and if things get worse or alter, you have to change the rules. You have to be quite firm about that because it is quite hard. The people I care for live with me, I don't live with them. I think it makes a difference because it means that you can still have your own life'

(Mrs Smith, 50 year old carer)

These accounts suggest that carers who brought their elderly relative to live with them found it relatively easy to establish their authority. On the other hand, carers who choose to move into their parent's home found it difficult to establish their authority in someone else's home. For example, Mrs Gordon had formed a joint household with her parents almost forty years before when she was in her twenties. Yet despite having lived together for that length of time and the house now being in her name, she continued to view it as her fathers home rather than hers. Consequently, she felt obliged her to consider how any decisions she might make would affect her father. She explained that:

'He doesn't take kindly to being told what he can and can't do. It's his home so I'm very conscious that I don't make too many rules. But for everyone's safety there have to be rules ... The house is mine anyway, this is where I have stayed and although it had been between my dad and myself at one point, he signed over to me when he was 65. So I have this big house, but still I feel that I can never just do anything spontaneously, I've always got to think how will it affect my father. It's been his home now for nearly forty years, so it's a long time'

(Mrs Gordon, 63 year old carer)

Mrs Gordon's co-resident status was not a consequence of her father's need for care. Moreover, their relationship was not marked by a power imbalance. When decisions had

to be made, Mrs Gordon avoided the possibility of conflict by involving her father in the decision making process. Thus Mrs Gordon and her father lived in relative harmony compared to other carers who had moved into their parent's home in order to facilitate their caring responsibilities.

In contrast, Mrs Watson's relationship with her father was fraught with tension. As we have already seen, Mrs Watson and her family had moved into her father's home in order to look after him following the death of her mother. That the move had not been entirely successful Mrs Watson blamed on her father's behaviour and his attitude to her family. Her father had, according to Mrs Watson, always been a selfish, demanding man who was now trying to manipulate and control her life. Mrs Watson's husband had expressed reservations about moving from their own home into her father's in order to care for him. He predicted that because of her father's possessive and domineering nature, looking after him might not be a pleasurable experience. But determined to keep her promise to her deceased mother, Mrs Watson suppressed her misgivings and tried to reassure her husband. The roots of the problem lay not only in the forceful nature of her father but also in the issue of who '*ruled the roost*'. Mrs Watson explained that:

'My husband said what have I let myself in for. As the time was getting nearer, it was getting harder to leave our own house. My husband said – this is your father's house as far as he's concerned, it's not anybody else's, it's his and that's it. It's his telly, his remote control, it's his furniture, according to him, everything is his. I says oh that will all change – but it's not changed at all. He still rules the telly, still rules the remote. And if any of our friends come in he'll ask what are they doing here? It seems that it's only him that's got rights'
(Mrs Watson, 38 year old carer)

The account above reveals the concern felt by Mrs Watson and her husband about her father's possessive nature and their belief that homeownership conferred certain rights. Although she legally owned half the house, Mrs Watson's father acted as though she had no rights of ownership and therefore no authority. Mrs Watson's father tried to maintain control of his household by exercising his power in a number of ways. For example, he often agreed to baby-sit for his other daughter, knowing full well that he was incapable of doing so himself. Mrs Watson would often come home and find she had to care for her father and her niece without being consulted on the matter. Whilst this situation annoyed her intensely because she continued to regard the house as her father's home rather than hers, Mrs Watson felt powerless to do much about it except remonstrate with her father. Whilst she said that she did not regret giving up her own house to move into her father's home, she did nonetheless feel that she was no longer in control of her own life. The

assumption of parental authority combined with homeownership made it very difficult for carers to view the house as *their* home. Consequently, they found it much more difficult to be assertive and were unable to establish rules of the relationship. In other words the parent whose house it was *'called all the shots'*.

Some carers, who like Mrs Watson had moved into their parent's home in order to facilitate their caring responsibilities, expressed regret at their decision. For instance, Mr Clark had agreed to move into his mother's home when his marriage broke up because his mother was becoming quite frail and needed more care. His mother tried to control the situation by the straightforward assumption of parental authority. He explained that:

'Mum used to come and stay most weekend and when I had to move out of the flat, mum suggested that I come and live with her. I felt that because we got on well together coupled with the fact that mum needed more care, that it would work out ok. But it's been a disaster. I wish I had never agreed to it'

(Mr Clark, 50 year old carer)

Mr Clark did not appreciate that his mother's attitude might change once he had moved in with her. That the house was hers was a fact she frequently reminded him of. Mr Clark came to the realisation that when his mother had stayed in his home, she reacted in a different way. She acted and was treated like a guest who made few demands on her host. In her own home however, she became more assertive and demanding, reverting perhaps to the previous parent-child relationship. She made sure that her son knew that he was there on her terms and that it was she who was firmly in control of the situation. For Mr Brown, moving into his mother's home led to a loss of power, independence and autonomy. The relationship had changed from one of dependence to one of interdependence.

The issue of home ownership was also important for non-resident carers. Some anticipated the effect that residency might have on the balance of power. Mrs Welsh for instance, was adamant that she would not give up her home to live with her 93-year-old mother but she felt that it was expected of her. She believed that if she gave up her own home she would lose her autonomy and independence. Whilst she stated that it hadn't actually been discussed, she expressed her fear that if she moved in she would constantly be at her mothers *'beck and call'*. Whilst she expressed feelings of guilt at not living with her mother, she recognised her own need for independence and her own physical space. She admitted that this issue was always at the back of her mind when she said that:

'I'll not give up my house and go and stay with her. She's still got a bit of independence and so have I. I don't want to be always at her beck and call.'

You just feel sometimes you should, but I couldn't give up my own home... but at the back of my mind it does lurk'

(Mrs Welsh, 62 year old carer)

The accounts above portray carers' beliefs that homeownership bestowed certain rights on the owner; rights, which seemed to enable the homeowner to exercise power over the other person in the caring relationship. Another way of exercising power was by having control of financial resources. In Mr Brown's case for instance, the cared-for person was never consulted about any issues even when they directly affected him nor was he aware how much money he was paid in pensions or how it was spent. Mr Brown had full control of his father's income and spent it as he saw fit, although any goods bought with the father's money usually benefited both men. Whilst Mr Brown talked in terms of 'we', his father was not in a position either to decide how to spend his money or on what it was spent. Mr Brown justified his control of joint finances by viewing it as a 'family thing' and implying that he would eventually inherit the money anyway. Moreover, despite being eager earlier in the interview to establish his ownership of the home, when it came to finances Mr Brown was keen for the house to be viewed as 'ours'. He said:

'Basically his money is my money is the way we look at it. I mean it's a kind of family thing, you know. He's got the money and he'll just say you can't take it with you. The rest of my family, my mother and brother don't want to know. They don't want money off him. So whatever money is left I get and I spend on me or on the house, our house. That's how we can afford to renovate the flat. The money is there ... and it benefits him as much as it benefits me. Technically it was his money but he can't take it with him and when he dies I get it anyway. So I am as well spending it as I get it. That's the way I look at it'

(Mr Brown, 40 year old carer)

In this instance the carer exercised power over the cared-for person by controlling their financial resources. Whilst this was the most common pattern of behaviour there were instances of the cared-for person maintaining control of their own financial resources and using that as a means to manipulate their carer. An example of this was the case of Mr Paul whose 74-year-old wife, the care recipient, controlled the household finances and attempted to use this to manipulate her husband. Mrs Paul's wife, being ten years older than her spouse, was in receipt of a generous occupational pension as well as a state pension. He on the other hand, having been made redundant just as his wife's need for care increased, had never sought another job and was dependent on state benefits. His only source of income was the carer's allowance, a means tested benefit of (at the time of the interview) £37 per week. Thus in this particular caregiving relationship financial issues were the source of a power imbalance which resulted in a degree of conflict.

Mrs Paul seemed to be a domineering individual who insisted on being present when her husband was being interviewed and who constantly interrupted his responses. That feelings ran high over this issue was clear when the couple proceeded to argue when it was being discussed. Mrs Paul maintained that her husband would be financially better off if he were to claim sickness benefit rather than the carers allowance. However, he believed that his relatively good health did not warrant making such a claim. As a proud man, reluctant to be viewed as a 'sponger' he was determined that unless his GP suggested it, he would not claim sickness benefit. Moreover, he seemed to be determined not to acquiesce to his wife's demands that he 'go on the sick'. Since his wife had the greater income Mr Paul was dependent on her financially which meant that she had to give him money with which to buy food and anything else that was required.

Nonetheless, Mr Paul had discovered a way of redressing this power imbalance through his control of food. While his wife controlled the amount of money spent, he controlled what food was actually bought and served as meals. His wife had a good appetite and had previously enjoyed cooking. Now that she was unable to undertake domestic chores, cooking was her husband's province. While his wife lamented over the loss of such tasty dishes such as '*mince and tatties*' and '*home-made soups*', Mr Paul explained that he neither enjoyed cooking nor was he any good at it. His way of resolving the cooking problem was to buy in pre-packed convenience foods that only needed to be heated up in the microwave oven. So determined was he not to develop his culinary skills that he had sold their conventional gas cooker and replaced it with a large and powerful microwave oven. When his wife remonstrated with him about the meals he served, she was told that '*it's the best I can do*'. He explained that:

'I had to do the cooking I use the microwave and there's such a variety of stuff now that there's never a shortage of things to eat. The only thing I don't do is feed her – she can feed herself'

(Mr Paul, 63 year old carer)

Mr Paul clearly did not like cooking but he appeared to derive some gratification from the fact that his wife missed the home cooked food that she had been used to. Whilst she was talking about the kind of food that she missed, Mrs Paul, facing away from her husband, failed to see the smile hovering around his face.

In this relationship, despite his attempts to redress the power imbalance by maintaining control over another facet of their lives, Mr Paul's wife maintained financial control. Thus, despite her dependence on her husband for practical care, her ownership of financial

resources gave her power that she deployed when it came to making decisions. For example, when the local council made them an offer of another house in a different area, Mrs Paul decided that they should accept it despite her husband's objections. She also seemed to make the decisions in relation to issues such as holidays and childminding. She would decide where and when they would have a holiday and would agree to baby-sit for her daughter without consulting her husband. Yet, he was the one who had to take care of the children because his wife's condition precluded her from doing so. This finding of a link between control of finances and decision making is similar to that of other studies. For example, in Pahl's (1989) study of power within marriage, it was found that power lay with whoever controlled the money and those who controlled the finances had greater power in decision making. In Pahl's study it was usually males rather than females that controlled the money and therefore had greater power in decision making the principle remained the same. Decision-making was therefore, another way in which control was maintained in caregiving relationships.

By deploying power in decision-making both carers and care recipients attempted to control the situation. In some cases, carers in an effort to protect their own interests persuaded the person being cared for to accept a situation, which they didn't particularly want. The most common examples of this were carers' decisions to make use of day care or respite facilities. For instance, being in control of the situation was important for Mrs Smith, who by stage two of the study, was determined that caring was not going to take over her life. In order to devote more time to her own interests she decided that the best solution would be for her mother-in-law to go to day care. Having had previous experience of day care when her father was alive, Mrs Smith knew whom to approach for help. Without consulting the person she was caring for, she contacted a local voluntary organisation who agreed to take her mother-in-law in to their day centre. Mrs Smith also took it upon herself to transport her mother-in-law to the day centre rather than have her collected by the centre's minibus. Initially, she attended the day centre five days a week but by the third stage of the study this had been reduced to two days a week at Mrs Smith's request. What was important to Mrs Smith was that this was her choice and events were under her control. It appeared that Mrs Smith did not relish her newly found freedom as much as she thought she might. She explained that:

'She actually went there five days a week which gave me a lot of time. She started going five days, then the four days, three days and then two. But it is my choice for her to go only two days a week. I only need two days a week now anyway...So I decided that she would not go'

(Mrs Smith, 50 year old carer)

The events described above may imply that the cared-for person agreed to go to the day care centre, but in reality she was never given any choice. In the above accounts carers were responsible for making all decisions relating to the care of their parent. This suggests that financial dependency may reduce the power of the cared-for person to such an extent that they are forced into a position of compliance. In some cases diminished power combined with a docile nature, meant that care recipients offered little resistance to the carers' domination and control of both finances and decision-making.

Power theorists claim that power is directly related to decision-making (Lukess 1974, 1987). Thus to explore power relationships within the family, researchers have focused on decision making as determined by power (Lukess 1974, 1987, Pahl 1989, Abbott and Wallace 1991,). We have already seen that in the present study power was exercised by whoever took responsibility for decision-making. However, by focusing solely on decision making, this approach fails to recognise that resistance may also be an exercise of power.

Resistance

Despite appearing powerless there were instances of care recipients who challenged their carer's authority by either refusing to comply with their decisions or by making their opposition known. This resistance often resulted in conflict or a battle of wills between the carer and the cared-for person. For example, Mrs Ireland's brother was in a similar position to that of Mrs Smith's mother-in-law in that day care had been organised for him without him being consulted. In other words he was given no choice or say in the matter. His sister had taken the decision to send him to a local day centre because she felt that she needed a break. In this case, the centre minibus collected Alex five days a week and returned him home again in the late afternoon. This meant that Alex's daily routine changed and he was unable to watch his favourite programmes on daytime television. It was not long before Alex made his opposition to this new routine known. When the minibus came to collect him, as well as telling his sister that he wasn't going he also became belligerent towards the driver and other passengers. Once he reached the centre however, he calmed down and seemed to enjoy the company and activities available. The problem was eventually resolved by Mrs Ireland and Alex negotiating a compromise. Whilst Mrs Ireland made it clear to Alex that he had to go to the day centre she reluctantly agreed that he could as she put it '*have a day off*'. Thus Alex, by asserting his own limited power, ensured that his wishes were taken into account and his attendance at the day centre

was reduced to three days a week. Knowing that he did not have to go to the day centre every day seemed to make a difference to Alex who settled well thereafter. Talking about her decision to make use of the day centre, Mrs Ireland said:

'It was a decision that had to be made. I felt I had to. All these years looking after him – things became quite bad because he needed more help. I was getting him ready in the morning to go and he'd be saying I'm not well and I can't go. I said he had to go to help me. He can either be aggressive or emotional and he was getting quite emotional. It upset him and he was shouting and we had right billy-oh [fight] about it. Now he goes Monday, Wednesday and Friday. He likes to have a wee break. They would have him every day of the week – but it didn't work out. He started getting agitated'

(Mrs Ireland, 63 year old carer)

In this case as in others, the competing interests of the carer and the cared-for generated conflict. Yet, despite the compromise negotiated with her brother, Mrs Ireland was still able to ensure that her decision in relation to day care was upheld. By exercising her power over her brother in this way Mrs Ireland was able to maintain control of the caregiving situation. This instance illustrates how despite challenges to their authority, in many cases, control remained in the hands of the carer because they had the power. There were however, instances of carers being dominated and controlled by the care recipient. The most striking example of a relationship in which the cared-for person exercised more power and control over decision-making than the carer was that of Mrs Watson and her father.

We have already seen how Mrs Watson believed that homeownership conferred certain rights, which allowed her father, to exercise power over them. In the previous account a reference to *'his telly, his remote control'* revealed that both Mrs Watson and her father regarded these items as belonging to him. Thus Mrs Watson's father exercised the authority vested in him by ownership of the house and the television by deciding what programmes were watched. He managed this by ensuring that the television remote control was always by his side. When Mrs Watson or her husband seemed interested in a particular programme he would switch channels without warning, maintaining that he could watch what he wanted because it was his house. This action, always guaranteed to cause an argument was described by Mrs Watson who said that:

'He tells you exactly what programmes are coming on. In other words, that is what he is watching. You can be sitting here watching something and he turns it over and he'll say I'm going to watch this. And if you say you were watching that he'll go oh great, and starts cursing under his breath and says things like you can't watch anything in your own house'

(Mrs Watson, 38 year old carer)

But attempts at exercising his power were not confined to controlling the television. Mrs Watson's father deliberately tried to manipulate both his daughter and her husband by causing trouble between them. His favourite ploy was to imply that his son-in-law was unaware that events such as a night out had taken place. He referred to conversations about these events in Mr Watson's hearing thus hoping to cause trouble between husband and wife. This became an established pattern of events that usually resulted in both men shouting at each other. When the tension and petty squabbling became too much for Mrs Watson she would withdraw physically and emotionally from both men. She described a typical altercation saying:

'There was a fight in here on Monday night and now I'm not talking to him. I'm not talking to my husband either. Robert was sitting there having his dinner and my daddy said what about your night out - what time are you going out at. He twists things ...I said I was only going to B&Q. I was going to get tiles for the bathroom floor - that's not much of a night out is it? Then he started swearing and Robert said that's enough, the wean's there and she's picking everything up. He [father] said who are you talking to - come on over here till I punch you and Robert's saying no come on over here till I punch you. And he's shouting I'm a man and what are you, you're a wimp. This is the kind of things he's shouting at my husband. I told the two of them to stop it and I went -oh I'm not having this. At half past six at night I got that wean ready and went out and left them. I thought I'm not having it, that's it.

(Mrs Watson, 38 year old carer)

Control of the television seemed to symbolise Mrs Watson's father's attempts to control his household and the caregiving situation. The extent to which the cared recipient in this case controlled the situation was unusual but was apparently made possible by his belligerent and forceful personality which overshadowed that of his daughter's. By opposing her wishes, Mrs Watson's father seemed to successfully wield power and hence control over his daughter.

A tactic used by some carers to redress the balance of power was the use of threats. For example, one of the problems Mrs Ireland had to cope with was her brother's nocturnal incontinence. He was continent during the day and therefore she reasoned he should be able to keep himself dry during the night. That he wasn't she attributed to his laziness rather than any medical reason. In an attempt to persuade her brother to comply with her request to keep his bed dry she resorted to the use of threats. By threatening him with admission to a care home she knew she was playing on his fear that he would end his days in such an institution in the same way that his mother had. She described a typical threat to her brother:

'I said there's a lady coming next week and if this bed isn't dry between now and then, I said it'll be a home you're going to and you wouldn't like that'
 (Mrs Ireland, 63 year old carer)

Sometimes the threat worked and Mrs Ireland's brother would be dry for a few nights but then he would revert to his habit of not going to the toilet during the night. Mrs Ireland had in fact been offered incontinence pads that her brother could use during the night and thus save her having so much laundry. Mrs Ireland adopted a boundary setting approach by refusing to use the pads because although they might solve her problem, using them would make demands on her time in the evenings. Her evenings were precious because that was the only time she was able to relax and either indulge in her own hobbies of reading or watching television, or spend time with her own family, without having to worry about her brother. She explained that:

'He doesn't use night pads. The reason for that being is I would have to come down here about half past ten or that every night to put it on him – which means more of my time as well. I feel I've neglected my own family because of having to do this. So therefore it's a case of having the bed well protected and it means every morning I've got to strip it'
 (Mrs Ireland, 63 year old carer)

Despite threatening him Mrs Ireland displayed a great of affection towards her brother and had no intention of putting him into a home. She suspected that her brother realised that and played upon her good nature. Nonetheless, issuing threats and placing boundaries on her caring activities was Mrs Ireland's way of exercising power over her brother in order to control a frustrating situation. Mrs Ireland's brother, by refusing to comply with her request to get up to the toilet rather than wet his bed, was exerting his own albeit limited power. He had the choice and chose not to get out of his bed during the night. This case also illustrates how recipients of care may use small and repetitive actions, which irritate their carer in an attempt to redress the balance of power.

Mrs Watson also used threats as a means by which to limit her father's power and control his demanding and difficult behaviour. At the first stage of the study Mrs Watson's father seemed to be firmly in control of the situation in that his wishes dominated the activities of the entire household. However, by the third and final interview she had discovered that the threat of institutionalisation was enough to modify his behaviour. Between interviews Mrs Watson's father had been hospitalised on four occasions. On the last occasion plans were made, without consultation, for Mrs Watson's father to be admitted to long term care. When she discovered this Mrs Watson refused to allow her father's transfer to long stay care to proceed. While Mrs Watson felt that her relationship with her father, not good to

begin with, would improve if they lived apart, she felt she could not agree to his admission to a care home. Her feelings of guilt at not keeping her deathbed promise to her mother, along with a continuing sense of moral obligation rather than affection for her father compelled Mrs Watson to refuse the offer of long term care. She explained that:

'Although I say I don't care where he's going, at the same time, I do care. So while at times he could go to hell as far as I'm concerned, at the same time I don't want to see him getting in a state ...It's a responsibility and I keep trying. At night sometimes I talk to my mammy. I say oh mammy I'm sorry if I've got to do what I've got to do but I can't keep going on the way it's going on'
(Mrs Watson, 38 year old carer)

That she had prevented him from going into a home was subsequently used as a threat by Mrs Watson to ensure her father's good behaviour. She warned him that she could easily arrange his admission by simply contacting the GP. The passage below illustrates the changes in Mrs Watson's approach to caring and how she was now more in control of the situation than previously. She explained how her father tried to revert to his old ways after he came home from hospital and how she dealt with his behaviour.

'I am harder with him. I have threatened him. I told him he would go back into hospital if he started again. He said, I promise I'll no start again. I was ready to smother him. He was acting the pig again. It's as if he's saying I'm going to see how far I can push her. I told him that it could be taken out of his hands. I said when you were in hospital, they were going to send you to away, and they never even told you. He knows that it just takes one word from me and he's off. My doctor said to me, just say the word and we'll get him in somewhere'
(Mrs Watson, 38 year old carer)

The threat of long term care seemed to be effective in that Mrs Watson's father had since modified his behaviour. Although his acquiescence may have been due in part, to his increasing frailty. Nonetheless, Mrs Watson seemed to have gained the upper hand by establishing a new routine and a set of rules by which her father had to abide. This new regime included her father retiring to his own bedroom earlier in the evening. There he could watch his own television whilst his daughter and her family were free to watch whatever they wanted in the sitting room. By her own admission Mrs Watson was becoming 'harder with him'. She said that:

'He's a bit more amenable these days. Well he tries to be. He goes to bed at quarter to seven at night, which at last is a good bit better. I think because he knows that I need, that I just cannot, he takes over everything. You are sitting there watching something and the telly gets turned over. It doesn't matter what you're watching. Aye, he's mellowed a wee bit. But I think it is because he knows all the problems he's given me, that's he's mellowed'
(Mrs Watson, 38 year old carer)

Despite the new routine and the threats of institutionalisation Mrs Watson's father still seemed determined to control what television programmes were watched whilst he was in the sitting room. By accrediting the changes in her father's behaviour to his increased awareness of the problems he had caused Mrs Watson played down the effect her threats had had on him. The accounts of the experience of caring discussed above, show how in caregiving relationships power was exercised in order to encourage one person to conform to what the other regarded as acceptable behaviour. Threats were used by one person in an attempt to both force the other to comply with these unwritten rules of behaviour and to redress the power imbalance in the relationship.

Power has often been associated with public institutions such as the state rather than private institutions such as the family and interpersonal relationships. Yet within the family it has been claimed not only that women hold power over children (Abbott and Wallace 1991) and dependent relatives but that dependency may change or reinforce existing power differences in relationships (Parker 1993). In the present study we have seen evidence of both change and reinforcement. For example, in Mrs Watson caregiving relationship, a change in the balance of power occurred as her father's increasing dependency entailed a gradual loss of his power despite his ownership of material resources. In contrast to this, Mr Paul experienced a loss of material power when he was made redundant and was forced to rely on his wife the care recipient, for financial support. In this case, whilst his wife's increasing dependency made her physically powerless her possession of greater material resources ensured she retained a measure of power and control although he was physically more powerful. On the other hand in Mrs Smith and Mr Brown's cases, the carers' ownership of material and physical power enabled them to maintain control and reinforced power imbalances in the caregiving relationship. As power was exercised over individuals in an attempt to gain control, pursuing competing and conflicting interests generated conflict in the caregiving relationship. Thus caregiving relationships in the present study conformed to Weber's (1922 cited in Haralambos and Holburn 1995) view of power in that they involved dependence and interdependence as well as resistance and conflict.

In the current study, carers on the whole seemed to hold more power and hence control of caregiving than the care recipient. Dowd (1975 cited in Phillips 1986) explains this position by viewing power as being synonymous with dependence. For example, in his theory of social exchange, Dowd claims that power is based on the inability of one of the parties in the social exchange to reciprocate a rewarding behaviour. As people age, they have less access to power resources and progressively less ability to perform services. The

person then who is less dependent and is perceived as contributing most to the power relationship has the power advantage. When the dependent person has no choice about continuing the relationship, the other has what has been called 'fate control'. Fate control is converted to 'behaviour control' whenever the controlling person uses his or her power advantage to manipulate the behaviour of the dependent person. Whilst this theory contributes to an explanation of why carers in the present study tended to hold more power than care recipients it does not account for the relationships in which the cared-for persons held the power advantage. More useful in explaining and enriching our understanding of the complex and contradictory nature of caring are post-modernist analyses of power.

Foucault's Post-Modernist Analysis of Power

Power has traditionally been viewed, as a negative and oppressive entity possessed by institutions or groups of people who use it for their own ends or to effect certain outcomes. Foucault, whose work was influenced by Marx and Weber, challenges this notion of power. Foucault does not see power as centralised or possessed by a ruler, government or state. In his writings, power is seen as being exercised rather than possessed and as having useful regulatory and productive function rather than negative or repressive effects. According to Foucault, power is fluid and operates in a capillary-like fashion. This means that it is increasingly fragmented and dispersed throughout society and exercised at micro-level within such apparently non-political institutions as families, schools or hospitals. According to Foucault:

'When I think of the mechanics of power, I think of its capillary forms of existence, of the extent to which power seeps into the very grain of individuals, reaches right into their bodies, permeates their gestures, their position, what they say, how they learn to live and work with other people'

(Foucault 1977 quoted in Watson 2000:68)

In a later publication he expanded on his view of power by saying:

'Power is everywhere; not because it embraces everything, but because it comes from everywhere ... Power is not an institution and not a structure; neither is it a certain strength we are endowed with; it is the name that one attributes to a complex strategical situation in a particular society'

(Foucault 1979: 92-92)

Power relations are therefore, present in all encounters, not just between labour and capital or citizen and the state. Power relations are to be found in all social interactions for

example, between husband and wife, parent and child, or in the present study, between carers and care recipients. Thus power is not given or possessed but is exchanged or exercised in social and/or caregiving relationships.

However, for Foucault, where there is power there is also resistance.

'Points of resistance are present everywhere in the power network'
(Foucault 1979:95)

Not only resistance but a '*plurality of resistances*' which are an essential part of the exercise of power. Power, according to Foucault, is not about something done to people over which they have no control. People are not victims of power in the way that is sometimes suggested by Marxist and feminist analyses. Foucault claims rather that since people are always striving to gain some control over their lives, resistance movements do emerge, but there is no guarantee that these will lead to new bases of social power. He implies that in power relationships there are innumerable points of confrontation and instability and numerous possibilities for tactics and strategies of resistance. These '*plurality of resistances*' were evident in the present study. For example, Mrs Watson's father clearly tried to resist his daughter's attempts to establish her authority by controlling the television and by trying to manipulate her actions. His behaviour caused numerous confrontations in the household. At the same time, Mrs Watson tried to challenge her father's domination by using threats of institutionalisation. In Mrs Ireland's case, her brother resisted her domination by objecting to going to the day care centre and by continuing to wet his bed rather than get up to the toilet during the night. Mr Paul resisted his wife's attempts to exercise power over his life by maintaining control over one of the few pleasures she had left, namely what food was purchased and eaten. While Foucault terms this type of behaviour as '*strategies of resistance*' they are in other words, attempts by individuals in the caregiving relationship to redress the balance of power. Thus power in caregiving is rarely total, rather it is limited because of the types of resistance described above.

For Foucault, one important consequence of these forms of power was the growing importance of decisions (Foucault 1979:144, Dreyfuss and Rabinow 1982, Gutting 1994). Together with surveillance, Foucault believed that control of decision making had become an instrument of power. As we have seen in the present study, decision making was one way that power was exercised. Moreover, especially for co-resident carers, caregiving involved almost constant surveillance of the actions and health of the care recipient. The

notion of decision making as a dimension of power has been encompassed in an increasingly influential view of power.

This radical model of power, proposed by Steven Lukes (1974, 1987) claims that power has three dimensions or faces, rather than just one. Lukes sees the first face of power in terms of decision making, where different individuals or groups express different preferences and influence the making of decisions over various matters. However, he believes that it is misleading to concentrate entirely on decisions taken, for power, he claims, can be exercised in less obvious ways.

Hence, Lukes' second face of power focuses on non-decision making. Power may be used to prevent certain issues being discussed, or decisions about them from being taken. From this point of view individuals or groups exercising power do so by preventing those who take a decision from considering all the possible alternative sources of action, or by limiting the range of decisions they are allowed to take. The relevance of this model of power to the present study can be illustrated by the example of Mrs Ireland who offered her brother the opportunity to decide what days he would like to go to day care. Her brother appeared to have power, for he had been given the opportunity to reach a decision. In reality, however, the power rested with Mrs Ireland the carer, who limited the options open to the cared-for person. Her brother, the cared-for person, was not free to decide whether or not he actually went to day care, nor could he choose to reject it completely.

Lukes claims that the third face of power can be exercised by 'shaping desires', by manipulating the wishes and desires of individuals and social groups. Individuals or social groups may be persuaded to accept, or even desire, a situation, which is harmful to them. For instance, care recipients may be persuaded to accept day care even when the effort to do so may cause their own physical or mental health to deteriorate. Lukes concludes that power can be defined by saying that A exercises power over B when A affects B in a manner contrary to B's interests. In other words, he argues that power is exercised over those who are harmed by its use, whether they are aware they are being harmed or not.

However, Lukes view has to be challenged. By using again the example of Mrs Watson, we can see from her account how her father's domination caused her a great deal of anger and distress to the extent that she would physically and emotionally withdraw from the situation. Yet, in cases such as Mr Brown and Mrs Smith, carers who clearly held the balance of power, it is more difficult to determine the ways in which their power and control caused harm to their parents. So while it cannot be denied that one person in the

caregiving dyad held more power than the other, and it is ultimately a matter of opinion what is in a person's best interests, it is therefore, difficult to relate Lukes' conclusion to the present study.

Conclusion

In the current study of family carers, we have seen how power was deployed in order to gain control of the caregiving situation. Power and subsequently control, was related to ownership of and access to resources. Ownership of material resources such as homes and money conferred power and authority on the owner, irrespective of whether they were the carer or the care recipient. Thus, power imbalances in caregiving relationships arose from access to resources.

Carers who brought their parent to live with them were more likely to feel in control of the caring situation. By exercising power within their own home, carers were able to control the situation by establishing rules and boundaries and determining what was acceptable behaviour. In contrast to them, carers who had moved into the home of the cared-for person were less likely to be in control of the situation. They seemed to find it difficult not only to take control of caregiving but also to feel 'at home' in another person's house, even although the cared-for person was their parent. Indeed some co-resident carers who had moved into their parent's home felt constantly at the 'beck and call' of the cared-for person and expressed regret at their perceived loss of freedom. In these cases carers seemed to have lost their power and independence in the face of parental domination. Exceptions to this were where the elderly homeowner was unable to exercise their power due to frailty or ill health. Thus some relationships were characterised by power imbalances whereby the person who exercised more power over the other seemed to gain control of the caregiving situation. The experiences of carers who gained and maintained control differed from those who were in a less powerful position.

This chapter has focused on issues of control and power in caregiving. The next chapter will explore carers' experiences of stress and coping.

8. Coping with Caring

The findings discussed in this chapter have emerged mainly from analysis of the qualitative data from in-depth interviews but is supported by the quantitative data gathered by the standardised instruments CADI, CAMI and CASI (see chapter 4). For the full results from CADI, CAMI and CASI please see the tables presented in Appendices V, VI, and VII. This purpose of this chapter is to explore carers' perceptions of stress and their coping behaviours. It will begin by considering the causes of stress and the coping strategies and resources utilised by carers. It will discuss the role played by the outcomes of caring before concluding with a description of certain temporal aspects of stress and coping.

Literature on family caregiving has focused predominantly on the difficulties and the stress caused by caring (Nissel and Bonnerjea 1982, Baldwin 1985, Kahana and Young 1990). Indeed many writers equate caregiving with stress. Opie for example claims that '*to care is to experience stress*' (1994:39). Yet the results of stress research would challenge this assertion. It has been noted in stress research that people exposed to apparently similar stressors react to them in different ways (Pearlin et al 1990). Thus according to the transactional model of stress, events in a person's life cannot be assumed to be stressful (Lazarus and Folkman 1984, Lazarus 1991, Pearlin 1990). Rather, an individual determines whether the event is stressful in relation to their resources. Stress occurs when the person believes that they do not have the ability or the resources with which to respond to the demands placed upon them by the situation (Pearlin et al 1990). Events are perceived as stressful when the demands of a situation exceed a person's resources and/or endanger their wellbeing (Lazarus and Folkman 1984, Pearlin et al 1990). According to this model, the interpretation and appraisal of events is the key to understanding individual reactions to and perceptions of stress (Lazarus and Folkman 1984, Nolan et al 1990).

Studies of caregiving have suggested that stress may also be a positive experience, which can help people to cope (Motenko 1989, Benner and Wruebel 1989, Opie 1994, Nolan et al 1996). As we shall see, these findings mirror that of the present study in which the existence of positive outcomes mediated carers' experience of stress.

Causes of Stress

The majority of carers in the present study said that caring was stressful. This perception seemed to be unrelated to either the stability or quality of the caregiving situation or to the age of the carer. Stress was measured primarily by carers' own perceptions and supported by analysis of the Carers Assessment of Difficulties Index (Nolan et al 1990). Stress was caused by the provision of personal and intimate care as discussed in chapter 7, but it was also caused by the behaviour of the care recipient, tiredness and having to negotiate with service providers and government agencies. Less visible activities of caregiving such as the constant monitoring, supervision and planning were also a source of stress. While these issues are discussed below the full results of CADI are presented in Appendix V.

Behaviour

Analysis of CADI showed that 86 per cent of carers found that the behaviour of the person they cared for either stressful or very stressful and 85 per cent said that the person they cared for could play them up. A range of care recipient behaviours caused the greatest levels of stress. These included demands for attention, incontinence and a lack of concern over personal hygiene. Demands for attention fell into two categories, the reluctance of the care recipient to be left alone and aggressive attention seeking. In some cases care recipients displayed a reluctance to be left on their own even for a short while. For example, Mrs Beaton and Mrs Duncan's mothers insisted on being able to see their daughters at all times and took to following them around the house. Both women found this reluctance to be on their own for even a short time very frustrating and time consuming. Mrs Beaton's mother wanted to have her daughter in view at all times even when she was hanging out the washing, putting out rubbish or gardening. But living in an upper cottage flat meant it was difficult for her mother to negotiate the stairs. For her mother to accompany her downstairs was a time consuming and painfully slow process which transformed a relatively simple task like hanging out washing or shopping into a major logistics operation. What increased the stressfulness of this behaviour was that Mrs Beaton regarded tasks like hanging out washing and gardening as an opportunity to have a break from her mother's constant demands. Yet if she left her mother in the house when she was outside her mother would sit and cry and call for her until she returned. That she could no longer take these times to herself without causing her mother great distress placed her under increasing pressure. As she sat in her garden surrounded by the flowers she had hastily planted, Mrs Beaton explained what it was like to live under this stress:

'She's like a baby now, aye, like a baby and I'm the mother. That's it in a nutshell. They rely on you and you alone and nobody else. And if you say one wrong word to them it's like scolding a baby. There's nothing you can do about it except grin and bear it...But I've got to have time for me – just even to sit here and sunbathe, whereas when she wants to come down, I can't do any gardening or anything. I had her down last week but you have no sooner brought her down and she wants the toilet. I thought I can't handle this. I want the toilet she says again. So I had to drag her up the stairs and make her a cup of tea. I let her finish that. Do you want to lie down? No, I want to go back down. You got to stay within sight of her. She's got to be able to see you. I'm gardening so that's fine she sitting watching but if come round here [back of house]- it's don't leave me...You've no life and no privacy. For privacy I go into the bedroom and phone John [partner] or Gail [daughter] because there's things I don't want my mother to hear. I mean you could murder her at times – it depends on your own mood. I never knew it could be like this. I could sit and scream. It makes you browned off actually. Browned off. It's like being chained to somebody, chained really'

(Mrs Beaton, 51 year old carer)

This account illustrates clearly how stressful the constant demand for the carers' presence can be and the effects it has on their emotional state. While 67 per cent of carers reported that their emotional wellbeing had suffered through caring, only 29 per cent said their physical health had (see appendix V). The account also suggests that the reversal of roles within this relationship contributed to the stress experienced by Mrs Beaton. Although in the account above she said *'there's nothing you can do about it except grin and bear it'* this was exactly what she was unable to do. Throughout this and other interviews Mrs Beaton cried incessantly. It was as though talking about her life and her experiences brought home to her how trapped she felt by the responsibilities of caring and by her love for her mother. Moreover, their parent's constant demand for their presence meant that some carers had little privacy or time to themselves and added to the restrictions caring had already placed on their lives. The lack of private time caused by caring was reported by 62 per cent of carers to cause them stress and 67 per cent said that it restricted their lives. Having little privacy or time are factors that have been found by other studies to induce high levels of stress (Pearlin 1990, Nolan et al 1990, Given and Given 1991, Twigg and Atkin 1994). Reluctance on the part of care recipients to be on their own is often associated with dementia (Gilhooly 1987, Marshall 1997). Yet care recipients in the present study, did not have dementia or other cognitive disabilities. Their reluctance seemed to stem from their own feelings of insecurity, which tended to increase with their frailty. So the stress associated with this type of behaviour increased rather than lessened with time.

The other type of demand for attention was aggressive attention seeking. In these cases care recipients made constant demands for attention but did so in an aggressive and

sometimes confrontational manner. Carers (76 per cent) in this situation were more likely to comment that the person they cared for demanded too much of them. Mrs Kearns for example, described her mother as a *'strong willed woman'* who competed with her grandchildren for her daughter's attention. Her demands for attention had increased since the onset of major building work in the house, the purpose of which was the creation of a self contained flat that she would ultimately occupy. Being blind Mrs Kearns's mother needed help to move around the house since it was no longer the home she was familiar with. If she did not get the attention she sought she would react in a negative way. Mrs Kearns's description of a typical incident was similar to that described by other carers. She explained that:

'When she's having one of her days it's do that, or do this. If I don't she has tantrums and screams or stamps about muttering under her breathe. I just treat her like one of the kids to a certain degree. That's the only way to deal with her. There was times when she had me in tears and I felt really stressed. I felt that I couldn't go on like that. Now I do what's best for the family. I can handle her better now. I just leave her to calm down. When I go back in later she's talking to me again'

(Mrs Kearns, 36 year old carer)

Another behaviour that caused a great deal of stress was incontinence. We have already seen in a previous chapter how some carers found the need for personal care stressful because of the gender of the care recipient as well as the intimate nature of the cleaning task. Mrs Teirney for example, found her husband's incontinence and uncaring attitude towards his personal hygiene very stressful. Her approach depended on how she felt and alternated between washing him herself and leaving him dirty. Other carers (68 per cent) found incontinence very stressful because it often led to broken sleep, mess, unpleasant smells and damage to furnishings. Incontinence was particularly stressful when carers believed that it was being used by the care recipient as a legitimate reason to make demands on their time. Mrs Watson for example, found it very stressful and difficult to deal with because she was uncertain whether or not it was a deliberate act designed to attract her attention and cause maximum inconvenience. She described her father's demanding and manipulative behaviour:

'I was crying all the time. My scalp was all broken out and the doctor said that it was stress. If anyone spoke to me about him I was crying because he was shouting for me during the night and he was shouting for me in the morning. I was ready to smother him. I was crying quite a bit when I said to the nurse that he was incontinent again. He was shouting and it was all over the bed and he was blaming me. He said that if I had got him up when he shouted it wouldn't have happened. But as I said to Sandra [community nurse] it wouldn't have happened in the bed, it would have happened all over my floor. It's carpeted in

here and it would have been worse. This morning he's telling me that it was just an accident. In other words, he didn't want me to tell the district nurse what had happened because she would tell the doctor. He wasn't incontinent in the hospital. But the minute he's back home again he's incontinent...He'll ask me when I was going out and he'll say well will you put me on the toilet before you go. So I'll put him on the toilet. Then I'll say right I need to go now. He'd ask just as I was having my dinner, just finished my dinner or just about to have it, he would start on about the toilet'

(Mrs Watson, 38 year old carer)

Mrs Watson said she was unable to cope with her father's incontinence despite support from district nurses and her GP and he was subsequently re-admitted to hospital for further investigations. On his discharge the problem seemed to have been resolved with bowel management techniques. That he was co-operative with nursing and medical staff strengthened Mrs Watson's view that her father had used his apparent incontinence as a way of manipulating her. While Mrs Ward discussed this problem with her GP and district nurses, other carers were too embarrassed to draw attention to it. Mr Downs for example was concerned about his wife's embarrassment whereas Mrs Cranston was embarrassed to admit that her mother's incontinence was due to an excess of alcohol.

Tiredness

Another stressful aspect of caring reported by 80 per cent of carers was sheer physical tiredness. Tiredness caused by undertaking direct care tasks was often exacerbated by the physical impairments of the cared-for person. Mobility problems for example meant that carers had to physically help the cared-for person to walk, to negotiate stairs and constantly be on hand in case their assistance was required. Tiredness was also the cumulative result of sleep disturbances caused by the care recipients' need for assistance during the night. Even when direct help was not required, hearing the care recipients' movements in the quiet of the night often awakened carers. Mrs Macrae for instance, had her sleep disturbed regularly. It wasn't that her mother needed help to get to the toilet but the noise of her movements as she scuffed her feet along the hall to the bathroom were loud enough to waken her. Attempts at resolving the problem by using sedation were unsuccessful and hadn't been repeated. Referring to her disturbed nights Mrs Macrae explained that:

'That's been weeks now and I'm dead beat in the mornings. Because when she's up it's not a case of putting my head on a pillow and going back to sleep again. Sometimes you can do it. If it's maybe three in the morning and you hear her and you turn over in bed it's not so bad. But the likes of this morning it was 4 o'clock and I was still awake at 5. And I'm in bed trying to get back to sleep and you're just getting back to sleep when you hear her again. When you get up you have a tension headache as soon as you step out of bed. You just get

so tired with it all. Last week in the afternoon the sun was streaming and I'm in bed... I broke my heart. I thought I need to get help from somewhere because if I don't I'm either going to murder her or take an overdose... I said [to the doctor] you'll need to give me something for her because she is getting up too many times during the night. She gave me melleril for her. It knocked her loopy. She was getting up an hour later wide awake and talking gibberish. I don't want to have to depend on sleeping pills for her but there will come a day when I need to.

(Mrs Macrae, 63 year old carer)

Weeks, months and years of disturbed sleep made coping with the demands of caring during the day increasingly difficult. This was a vicious circle because stress as a result of tiredness and other factors, often manifested itself in an inability to sleep well. The majority of carers (75 per cent) said that they found it difficult to sleep at night and 57 per cent said they couldn't relax because of worry about their caring responsibilities. Yet they appeared to be in relatively stable caregiving situations where there had no improvement or deterioration in the condition of the person the cared for. Their experiences highlight how the effects of stress are neither straight forward, easily identified nor are they necessarily caused by difficult behaviour.

Behaviours such as those discussed above have been described in Gilhooly's (1987) study of carers of people with dementia, as 'acts of omission' and 'acts of commission'. Included in 'acts of omission' was a lack of concern for personal hygiene, apathy and disinterest in conversation and not eating. 'Acts of commission' included such behaviours as attention seeking, incontinence, constant repetition of questions and wandering at night. Of these categories of behaviour Gilhooly found that 'acts of omission' were much less stressful for carers than 'acts of commission'. We can see that stress inducing behaviours in Gilhooly's study were similar to those in the present study, with a lack of concern for personal hygiene, attention seeking and incontinence being common to both sets of carers. However, the findings of both studies differ in that carers in the present study did not report behaviours such as apathy, disinterest, poor appetite and constant repetition of questions as being stressful. However, the night-time wandering of people with dementia in Gilhooly's study was similar to the nocturnal trips to the toilet described by carers in the present study. Although these behaviours had a different cause they were nonetheless, a source of stress and resulted in the constant tiredness of carers. Causes of stress such as tiredness, incontinence and demands for attention were directly related to tasks of caregiving.

Monitoring and supervision

Studies of caregiving stress have generally focused on the direct tasks of care, which have been defined in terms of assistance with the activities of daily living or the performance of practical tasks related to cooking, cleaning and management of finances (Brody 1985, Archibold 1992, Parker and Lawton 1994). Focusing on the direct tasks of caregiving draws attention away from the less visible activities of caring such as monitoring, supervision, planning and organising that must also be undertaken. In the present study, this type of activity usually arose as consequences of care recipients' medical conditions and seemed to generate as much stress as the direct activities of caregiving

Carers did not generally view the medical condition of care recipients as a cause of stress. Rather it was the consequences of these conditions that posed problems and created stress. Elderly care recipients often suffered from chronic conditions such as diabetes, cardiovascular disease, arthritis and osteoporosis. A clinical description of these frail older care recipients would include sensory deprivation such as loss of sight, peripheral neuropathy (no feeling in hands and feet), poor mobility and personality changes. For example, it was not the loss of sight that was stressful for the carer but the inability of the care recipient to see obstacles and other hazards. Poor mobility was not always seen as a problem but carers perceived needing help to go to the toilet during the night as being problematic and stressful. Thus as a consequence of the care recipient's medical conditions and physical impairments, carers had to be constantly monitoring their movements, supervising their activities, planning preventative action and organising domestic routines and furniture to meet the needs of the person being cared for. Many carers (56 per cent) found these constant and indirect aspects of caring very stressful. Mrs Gordon for example said that:

'I have to be organised at all times. I can't do anything without considering how it will affect my father. I have to plan well in advance if I'm going out no matter if it's a trip to the shops, a holiday or just a visit to friends. Even if the plumber's coming or the heating engineer, I have to think how that will affect my father. It's a constant responsibility'

(Mrs Gordon, 62 year old carer)

Mrs Gordon's account suggests that the all encompassing nature and constant feeling of responsibility was stressful. Others like Mrs Gordon disliked going out and leaving the care recipient unattended because they constantly worried about them. Some carers described how before they went out in the evening they would ensure the person they cared for was in bed where they felt little harm could befall them. Immediately on their return they would enter the bedroom to ensure that they were all right. Alternative arrangements

for the care recipient were required if the carer was going to be absent for any length of time. This constant and pervasive feeling of concern and responsibility meant that activities outwith the home such as shopping, visiting friends and even going to church had to be planned well in advance. This lack of spontaneity was very stressful for some carers (54 per cent) who tended to have a more spontaneous nature. Mrs Black for example said that while the constant worry and responsibility was difficult it was the lack of spontaneity in her life that she found most stressful. She claimed that:

'I would just love to get up in the morning and jump on a bus into town if I felt like it. But I can't. I've got to organise someone to look after mum for me and by that time it's not worth the bother'

(Mrs Black, 47 year old carer)

The accounts above illustrate how the less visible activities associated with caregiving such as planning and organising were experienced as stressful. The need for this type of activity tended to prevent carers from acting on a whim or making spur of the moment decisions. In other words they contributed to the restrictions on carers lives.

Negotiating with service providers

Negotiations with service providers and government agencies were another major cause of stress for carers in the present study. At the beginning of this study carers were not in receipt of services and tended not to be in regular contact with service providers. At stage two of the study 84 per cent of carers believed that professional workers did not seem to appreciate the problems that they faced and 45 per cent said that they did not get enough help from service providers. Both issues were reported as being very stressful (see Appendix V). By stage three of the study, the majority of carers had had some encounter with service providers and government agencies such as the Department of Social Security (DSS). Some carers felt that service providers had failed them at a time when they were most needed. For example Mr Brown wanted very little in terms of support from statutory agencies but his futile efforts at obtaining it caused a great deal of stress and at times despair. Since he had last received respite care for his father, the local social work office had closed and his father's records transferred to another office. He said cynically that:

'My stress levels are certainly up for the simple reason that it's outside agencies that wind me up. It's people like the social work that wind me up. The stress thing arises when I discover that I can't get two weeks respite because of the incompetence of the social work department. There seems to be too many people involved. You don't get a social worker now – you get care assessors and home care teams. I don't think I am asking for the earth, just a couple of

weeks in the summer for respite and they are just totally ignoring my pleas and say they have to do a community care assessment because he's not been assessed by this office. That'll be the third time he's been assessed. And as I say his condition hasn't changed. He's much the same as he was'

(Mr Brown, 40 year old carer)

Mr Brown's frustration with the social work department may have been due to his lack of understanding of how they operated. Although the assessment procedure had clearly been explained to him, he had not been reassured sufficiently for him to book his holiday. Mrs Peters' reactions were similar to Mr Brown's when she found herself having to deal with the Department of Social Security (DSS). Having given up work to care for her mother, this was her first experience of dealing with welfare agencies such as social work and the DSS. She also resented having to ask for help, which she felt they were entitled to. She said it was dealing with the bureaucracy of the system that caused untold stress and feelings of total frustration and helplessness. She said that:

'What I find stressful is that you have to fight for things. People don't know how to go about fighting for things. I didn't know. I went about my normal life never giving these kind of things a thought. I thought benefits came easily but they don't. I'm used to being in control of my finances and of my own life. It's the little things, stupid things that are stressful. We go to this course and we have to put down that we're unemployed because if we don't we have to pay for it. I am not unemployed through choice and that really bugs me. If I go for my prescription I've to put down that I'm on income support. Now I'm on income support but not through my own choice. Things like that really bug me now. It might seem stupid but that's what really stresses me. You're not getting recognised, you're just classed as being on benefits –unemployed and that's it. I feel as though I have lost my independence – what it boils down to I suppose is being reliant on the government'

(Mrs Peters, 50 year old carer)

Encounters with official agencies tended to leave carers feeling powerless, demoralised and resentful. Unfamiliarity with their procedures along with a feeling of being let down by what was called '*the system*' caused a great deal of stress and anger amongst carers. Furthermore, they tended to feel that by their dependency on 'welfare' they were losing control of their lives and as people who had always valued their privacy found the intrusion difficult to accept. Eighty one per cent of carers said that they felt helpless and not in control of the situation (see Appendix V). A fuller discussion on carers' views and experiences of service providers can be found in the following chapter.

There is agreement in the literature that the first step in the management of stress is recognition and understanding of the problem (Lazarus 1976, Antonovsky 1987, Boss

1993). As we have seen, carers had no difficulty in recognising the main causes of stress in their lives but how did they cope with it?

Coping with Stress

How do carers cope with the stress of caring? The term coping is taken to mean the things carers do or think to increase a sense of well being in their lives and to avoid being harmed by stressful events (Turnbull et al 1993:11). Coping behaviours serve two main functions. Firstly, the management or alteration of the person–environment relationship that is the source of stress (problem-focused coping) and secondly, the regulation of stressful emotions (emotion-focused coping (Lazarus and Folkman 1984). Coping behaviours are made in response to the experience or appraisal of stress. A combination of behaviours such as the use of coping strategies and resources and recognising the positive consequences of caregiving provided the means for carers to cope. While these elements of coping will be explored individually they do not operate in an isolated way. Rather they continuously interact with each other to produce differential experiences amongst carers facing similar stressors. The main component of coping is the use of coping strategies.

Coping strategies

Coping strategies are behaviours that are concerned with how people manage difficult situations. Carers' use of coping strategies was ascertained by analysis of qualitative data and supported by the Carers Assessment of Management Index (CAMI). CAMI is a 38-item index developed by Nolan and Grant (1992) which contains a series of statements carers have made about the coping strategies they use (see Appendix II). Analysis of CAMI revealed that on the whole, carers in the present study tended to employ a wide and diverse range of coping strategies. Those used fell into three categories; problem solving and practical solutions, cognitive responses and behavioural responses. For the complete results please see Appendix VI.

Problem solving and practical solutions

The majority of problem based coping strategies revolved around minimising the effects of the care recipient's limitations and maximising their independence. Problem solving and practical solutions included measures such as the use of routines (72 per cent), talking over

problems (81 per cent), planning in advance (77 per cent), getting information (67 per cent) and establishing priorities and concentrating on them (91 per cent). Mrs Gordon for example was rapidly approaching retirement and initially she dreaded the prospect of being with her father all day every day. But she eventually adopted a positive proactive approach by planning for her retirement, by introducing a new routine and by making her father do more for himself. She also described how she was able to 'switch off' a strategy frequently used by carers. She explained that:

'I'm coping ok. I had got to the stage where I couldn't cope. Now I would say that I was coping better. I don't know if it's because I'm planning ahead and although I don't see a clear road to go down, I've not allowed myself to think oh my god, this is just going to get worse, which I used to do. Because I wasn't planning I wasn't looking for a way out. All I could see was doom and gloom and my dad and I, and my dad and I, and my dad and I and that was it. I think because I am either consciously or subconsciously saying, no it won't be how I'd like things to be in my life but I'm going to find ways of making it a bit better. That has made things easier, but I don't feel like that constantly. There are times when I still get really, really pissed off with it all ... but I don't stand for any of his nonsense now. We've got a routine now and we stick to that. I think sometimes I haven't done him any favours because I have allowed him to be dependent. Now if he goes into a huff I just think well tough...I find it easier now to switch off from him. And I think I cope great.

(Mrs Gordon, 63 year old carer)

Mrs Gordon's account suggests that she used both problem-solving strategies and cognitive responses. She recognised that the problem was not going to disappear and so she changed the way in which she viewed it. Whilst problem-solving strategies have been found to be the most effective method of coping (Boss 1993), changing a perception of the cause of stress seemed to be equally useful.

Cognitive responses

Changing a perception of the cause of stress was among strategies based on cognitive responses. These responses encompassed such other measures as taking things a day at a time (100 per cent), or just getting on with it (86 per cent), using humour (77 per cent) drawing on religious beliefs (43 per cent), counting your blessings, acceptance or minimising problems. Mrs Macrae for example, who looked after her 93-year-old mother said that her ability to cope 'varies depending on the situation'. She coped by reframing the problem and explained that:

'I don't think about things being a problem because if I do – that's when it becomes too much and it gets on top of you and you just go under. No. I think

of it as situations that have just got to be dealt with. That's the way I look at it'
(Mrs Macrae, 63 year old carer)

The most widely used strategy of this type was 'taking things a day at a time'. Every carer (100 per cent) in the study said that they used this approach. Mrs Roberts for example, said:

'I could cope with anything but you have to be practical. I mean you can't live in airy fairy land. You have to deal with situations as they arise. Every day is different. Every day has a different problem. You have to take it a day at a time'

(Mrs Roberts, 65 year old carer)

This seemed to be a practical and pragmatic approach to caring but it was underpinned by worry about the future. Carers said they were afraid to look too far in the future. To consider what lay in store for them was a source of huge concern and worry and many carers said that they couldn't bear to think how long their caring responsibilities might continue for. The thought that caregiving might go on indefinitely threatened to overwhelm them and therefore they refused to consider the future. Mr Clark comments were similar to many other carers. He said that:

'I don't worry about it [future]. I don't think about it. I take each day as it comes. I don't like thinking that in ten years time she could still be here with me and I'll still be doing this and I'd still be... No, because then it would bring me down. I just take it as it comes'

(Mr Clark, 50 year old carer)

Taking a day at a time and refusing to consider the future were cognitive coping strategies. Although carers tended to use a variety of coping strategies, cognitive responses seemed to be more widely used than behavioural ones.

Behavioural responses

Behavioural responses were essentially efforts to deal with the results of stress. These strategies were activities that refocused the carer's mind even if only for a short time. They included listening to music, reading, painting, even fighting or crying and taking drugs or alcohol. The majority of carers (91 per cent) said that one way of dealing with the demands of caring was to take their mind off things by reading, watching TV. Many carers (62 per cent) said they tried to cheer themselves up by eating, drinking, smoking or the like. Just over half (52 per cent) said they coped by having a good cry. Others used music as an escape from the stress of caring. Listening to music was an effective strategy

because it involved either moving to another room or using headphones. Either way by concentrating on their music, carers were able to emotionally distance themselves from the care recipient if only for a short time. Mrs Yuill for example said that:

'When it's all getting on top of me I put my music on. I like music I can't do without my music. I just put it on when I get down. Well I do get a bit down but then I say well what's the use and I just go and put my music on or I have a wee cry. Sometimes I have a cry - in private. When there's no one about and when he's in bed and the family have all gone home'

(Mrs Yuill, 75 year old carer)

Some carers reported that they were concerned about their increasing use of prescribed drugs and alcohol. Mrs Kearns and Mrs Murphy in particular felt they were not coping well and were relying too heavily on alcohol. Mrs Murphy and her husband had previously enjoyed a very active social life and as members of a bowling club were out every weekend. Finding the loss of social activity very difficult to deal they had started drinking in the house while watching television in the evenings but it was not confined to weekends. They used to share a bottle of sherry but as her husband became frailer, he drank less. Mrs Murphy then found it difficult to stop herself drinking the entire bottle. In response to a question about she coped with the loss of social activity she said:

'I drink in the house. It's just a bottle of sherry. We used to drink spirits but he can't really handle it now. What happens now I don't really like. Before we'd drink, drink for drink, and he wouldn't go his bed till it [bottle] was finished. Now he'll only take about three and go to his bed. With the result I'm finishing it and I'm getting quite tipsy. He said why don't you just out the cork in it and I said it was easier said than done. I did say that I would never go out and bring it[alcohol] in but then I thought well why not, it's the only pleasure I get. I thought it would give me a bit of a lift but I find it doesn't, it makes you more depressed. So I didn't have one last night but I'm not saying I'll not have one on Wednesday or Thursday or Friday. It's not as though we can't afford it and it's the only pleasure I get even though I think it's a waste of money'

(Mrs Murphy, 65 year old carer)

Although Mrs Murphy realised that her alcohol consumption might endanger her own health, she found it difficult to either stop or reduce her consumption. By the final stage of the study however, Mrs Murphy had managed to stop drinking altogether. Mrs Kearns on the other hand had stopped drinking but was totally reliant on prescribed medication.

As we have seen the coping behaviour of carers in the present study was similar to that described by other research. Carers coping behaviour involved efforts to either change or alleviate a difficult situation, to alter or reduce perceived threats and to manage the symptoms of stress arising from the situation (Pearlin and Schooler 1978, 1990). Coping

efforts can be enhanced or hindered by carers' access to coping resources (Pearlin 1990). But what coping resources did carers in the present study have access to and in what way, if any, did they support carers attempts to cope?

Coping Resources

While coping strategies are concerned with *how* people manage, coping resources refer to the kinds of resources people might call upon to help manage situations (Pearlin and Schooler (1978). Analysis of qualitative data suggested that support networks and housing were the main resources utilised by carers in the present study.

Support networks

Support networks are a potential coping resource available to carers. The concept of social support focuses on both the informal and formal social resources available to individuals when faced with stressful situations. A support network is taken to mean a network that combines material, practical or emotional support from the extended family as well as friends. Although carers in the present study tended to have relatively small support networks, some attributed their ability to cope to the support of their family. The emotional and practical support provided by their families was valued highly by some carers. Mrs Roberts for example, explained how fortunate she was to have such good support from her family. She said that:

'Fortunately I've got a very supportive family – my children and their partners and my extended family are very supportive. Otherwise quite honestly, I don't think I could do it. My sons maintain the house, my daughters will come and help with the cleaning and the shopping. My sister takes me shopping on the days I can't walk awfully well. So I've got a lot of support from our family. We are very blessed that they want to do things, but I never ask them to do anything. I never need to ask. But I think to ask them to do things or expect them to do things is wrong for any parent, you really shouldn't expect things from your child'

(Mrs Roberts, 63 year old carer)

The support Mrs Roberts received from her support network was an important aid to her ability to cope with the stress of caring. However, for the majority of carers, caring was rarely shared with other family members or friends (Qureshi and Walker 1989, Parker 1993). Although most sons and daughters had other siblings, few were reported as supporting the carer to look after their parent. While some carers felt no resentment about this lack of support, it was a source of conflict for others. Family members not helping as much as they could was a source of stress for 52 per cent of carers (see Appendix V).

Some carers felt no resentment because they did not and would not entrust the care of their relative to others. They did not welcome support or practical help from other family members. This attitude stemmed from their belief that other members of the family were unable to meet the cared-for person's needs in the same way as the carer could. Fifty seven per cent of carers believed that because they knew the person they cared for in the way that they did, meant that they could give better care than anyone else. Some carers justified their actions by drawing on the history of their relationship and their intimate knowledge of the cared-for person's likes and dislikes. For example, Mrs Cranston, whose three siblings lived in the same street as her mother was highly critical of their ability to look after their mother. She claimed that:

'I enjoy it. Nobody else would do it right. I mean I know myself I can because I've done it for years. I know what my mum likes and doesn't like. I've been doing my mammy's shopping since I was four years old. I know all her wee ways. If I am looking after her, then I know she's eating, she's getting out and staying off the drink. I hate the thought that she's stuck in the house. Whereas if I am there she's getting looked after properly.'

(Mrs Cranston, 56 year old carer)

Carers such as Mrs Cranston preferred to have sole responsibility for caregiving. They felt that the less involved their siblings were the less likelihood of disagreements. In other cases though a lack of family support was a source of conflict and stress. For example, Mrs Ireland whilst appreciating the help she received from her younger brother resented the fact that her sister did not and would not help to care for their older sibling. Mrs Ireland said that she no longer spoke to her only sister as a major argument had occurred just before the first interview and as time went on, neither sister relented. By the third interview, the younger sister had started to visit her brother when he attended the day care centre. That way she did not have to run the risk of encountering her older sister at their brother's house. Mrs Ireland was quite bitter about the lack of support from her sister, she explained:

'I've got a sister and a brother that both stays nearby. The brother comes around but my other sister doesn't do anything. Couldn't depend on her. She let me down so many times. So I just don't bother with her. She goes and visits Alex at the day centre now. She stays quite near the day centre so occasionally she go up at lunchtime. Frankie [younger brother] takes him up to his house every second Saturday. You know he just comes round at lunchtime and takes him round to his house and brings him back at 9 o'clock at night. And then he'll maybe come down for a few hours on a Monday and see him. That gives me a Sat night off, well just a few hours. It does make a difference, aye it does. I feel as if I have worked all week and I can have a day off'

(Mrs Ireland, 63 year old carer)

Whilst a lack of support from family was resented by some carers, others had no expectations of support and indeed tried to justify why it was not forthcoming. The lack of support was often explained by the fact that the family had more important commitments. Mr Paul for example said that:

'They've either got full time jobs or they've got children to look after'
(Mr Paul, 63 year old carer)

The study of support networks has received increasing attention since their relevance to the supply and demand for care was recognised. Wenger (1989, 1990, 1995) whose work has focused on the composition and membership of support networks claims that variations result in different expectations and obligations in terms of provision of help and support. Her typology of support networks is based on three factors: the availability of local close kin, the level of involvement of family friends and neighbours, and the level of interaction with community and voluntary groups (Wenger 1990:23). Although Wenger's work has focused primarily on the support networks of elderly people living in the community, the current study is concerned with family carers' membership of these networks. It has been demonstrated that network type affects the supply of and support for caregiving (Wenger 1989, 1995, Grant and Wenger 1993).

The majority of carers in the present study seemed to belong to networks similar to those described by Wenger (1989, 1990, 1995). Wenger's typology is based on the availability of close local kin, the level of involvement of family, friends and neighbours and the amount of interaction with community and voluntary groups. The five support networks identified were (i) local family dependent, (ii) locally integrated, (iii) local self-contained, (iv) wider community-focused, (v) private restricted. A number of carers appeared to belong to local family dependent networks which were relatively small and where the care recipient depended on family either living with them or nearby, to meet their support needs. This network included very few friends or neighbours.

Other carers could be described as belonging to local integrated support networks. These networks were larger than the others and comprised family as well as friends. Moreover, having lived for many years in their present locality, as had the care recipient, these carers said they could rely on neighbours for help should it be required. These networks however, differed from Wenger's typology in that the care recipient had never been particularly active in their local community.

A few carers described networks that matched the private restricted support network. These carers were all looking after their spouses, apart from one who was caring for her mother. Their networks were particularly small, they had no relatives who lived in the same locality and they had only superficial contact with neighbours. None of them, either now or in the past were particularly involved with their local community.

Only one carer's description of their network matched the fourth one in Wenger's typology, the wider community focused support network. Having no relatives in their local area, Mrs Currie and her husband kept in close touch with distant relatives. Although their activities had recently been curtailed because of Mr Currie's mobility problems, they had been very active in the local community and as a result had a fairly large network comprising friends rather than relatives. However, they differed from Wenger's typology in that their circumstances were not as a result of retirement migration. They had in fact lived in the same house for over thirty years. No carers described themselves as belonging to a local self-contained support network.

The local family dependent and the local integrated type of networks have been associated with higher levels of both practical and emotional support, which makes it more possible for older people to remain in the community (Wenger 1990, 1995). This finding mirrors that of the present study, in that carers with these types of networks seemed to value high levels of support from other family members. However, according to Wenger (1995) those with private restricted networks are unlikely to have good long-term support because they have neither frequent contact with family nor relationships involving some expectation of practical help. Hence membership of private restricted networks may indicate a greater demand for support from formal service providers (Wenger 1995). While this group in Wenger's study, received very little informal support, formal provision was good. This finding contrasts with the present study, in which those with private restricted networks were not associated with higher levels of formal service provision. Rather, resistance to accepting help was found among all network types.

Accommodation

According to some authors particular aspects of accommodation may be a coping resource (Lazarus 1985, Pearlin et al 1990). But these studies of caregiver stress fail to detail the ways in which accommodation may be used. In the present study there were two ways in which accommodation was utilised as a coping resource. Firstly, the adequacy of accommodation could either facilitate or obstruct caregiving. Inappropriate

accommodation made the tasks of caring more difficult for the carer and deterred the independence of the care recipient. Mrs Black for example, looked after her mother who was incontinent. Their toilet was accessed by a short flight of stairs and because her mother had mobility problems she found it difficult to negotiate the stairs and was reluctant to attempt them herself. A friend had given her a commode but it was unsightly and embarrassing to use in the sitting room and it needed to be emptied. Other carers who lived in appropriate accommodation had made attempts to overcome problems with the use of aids and adaptations. Simple pieces of equipment such as strategically placed handrails, commodes and bathing aids made a considerable difference to the lives of both carers and care recipients by affording care recipients more independence and reducing the demands on carer's time.

Appropriate accommodation facilitated caregiving. Mrs Watson for example had been fortunate in that her local social work department had addressed the inadequacies of her accommodation by arranging the construction of an extension to her house. Where previously her father had occupied one small cramped room, the extension comprised a spacious bedroom and bathroom, fully equipped with lifting and bathing equipment. Mrs Watson was in little doubt that the space generated by the extension and the equipment greatly facilitated her caregiving.

The second way in which accommodation was used as a coping resource was in the creation of personal space. Carers used the physical arrangements of the house as a means of achieving space for themselves. For example, many carers had created bed-sitting rooms for care recipients who were subsequently confined to one room while the family ate and socialised in another. If space allowed, some carers had literally divided the house into two apartments with communal use of the kitchen and bathroom. For example Mrs Gordon and her father had their own sitting rooms and bedrooms but shared the kitchen, dining room and bathroom. Mrs Gordon valued having her own sitting room where she could entertain friends without being disturbed by her father. Another carer, Mrs Kearns and her partner, had financed the building of an extension to the care recipient's house in order to create a self contained flat. Despite the expense they did not regret the upheaval the construction had caused because in the end it reduced the frustration and feelings of claustrophobia they had experienced when sharing limited accommodation. Moreover, having a self-contained apartment for her mother made it easier for Mrs Kearns to accept support from service providers. It was less intrusive as the home carer could attend to Mrs Kearns's mother without disturbing the rest of the family. Other carers simply used their bedrooms as a retreat. It was a place of sanctuary that afforded them privacy and where

they were unlikely to be disturbed. Some carers found it difficult to distance themselves emotionally when they could not get away physically and said that it was more difficult to cope as time went on. Mrs Bennet in particular used the privacy of her bedroom to remove herself from her mother's presence. She explained that:

'I think it gets more difficult. You have your own coping methods and mine I'm afraid is taking to my bed. I mean Sheila [friend] will come in and I'll be in my room. She'll say are you resting or are you hiding? And most of the time I am hiding. Because it's the only way – and my mother can't understand it. I have to say that my back is sore today, I have to go to my bed. And I'm just hiding upstairs, because when I am in my bedroom I don't have to do anything for her. It's the only place where I don't do anything'

(Mrs Bennet, 67 year old carer)

Although Mrs Bennet said in her account that she didn't do anything in her bedroom she did in fact use her room for her favourite hobby of oil painting. Having discovered a talent for painting since her retirement she found that it gave her an emotional release. So when she shut herself in her room she was at times painting rather than sleeping.

In the cases outlined above co-resident carers had used their accommodation as a coping resource. Non-resident carers did not seem to experience the same feelings of frustrations and claustrophobia caused by inadequate accommodation that co-resident carers did. By maintaining their own homes rather than forming a combined household, non-resident carers were able to create a physical separation from their caregiving activities. This physical separation seemed to make it easier for them to maintain an emotional distance. Thus accommodation in that it either eased or obstructed carers' efforts, was an important coping resource. We have seen that in conjunction with coping strategies, resources were an essential component of coping. Whether caregiving was perceived as being positive or negative also seemed to play an important role in carers' ability to cope. In the current study, carers who perceived themselves to be coping well were more likely to report the existence of positive outcomes.

Outcomes of Caregiving

The findings discussed in this section emerged from analysis of qualitative data and the Carers Assessment of Satisfaction Index (CASI), a 30-item index developed by Grant and Nolan (1993) and described in chapter 4. The full results of this index are presented in Appendix VII.

Positive outcomes refer to the consequences of caregiving from which carers derived a reward or a sense of satisfaction. Positive outcomes arose from carers' ability to either protect the cared-for person from some negatively perceived event or to promote positive consequences. In other words, if caregiving was perceived as a satisfying experience, carers seemed to cope better. Whilst this suggests that there is a link between positive outcomes and carers' ability to cope the dynamics of this association are unclear.

Positive outcomes reported by carers included getting pleasure from seeing the care recipient happy (95 per cent), clean, comfortable, well turned out and being able to maintain their dignity (91 per cent). Other positive outcomes were an improvement in the care recipient's condition that had been contrary to medical opinion and the knowledge that they had done their best (86 per cent). Mrs Thompson for instance, explained that having done the best she could for her father, when he inevitably passed away, she would not be plagued by a guilty conscience. She said that:

'My dad was sent home from hospital on the understanding that he wouldn't last 6 weeks. That was four years ago. He used to be about 11½ stone and when I got him out of hospital he was 6st 4lbs and when I took him back for a check up he was 7st 5lbs. Of course he just got better and better and after six weeks they [hospital] said don't bring him back I know that he used to worry that he would end his days in an old folks home and I suppose I have kept him from that. When it comes to the crunch and it's time to farewell, I'll be able to put my head on the pillow that night and say I've done my best. Whereas the others –they'll be for months going oh I should have done my wee bit or I should have done this. They'll have the unrest whereas I'll be able to put my head on the pillow and say oh I done it'

(Mrs Thompson, 40 year old carer)

Mrs Thompson's account suggests that she derived satisfaction from knowing that her care had prevented her father's admission to a home. Indeed, for the majority of carers (91 per cent) in the present study, the fact that they were able to keep the person they cared about out of institutional care was a positive outcome. Carers tended to hold negative perceptions of both the quality of care and the standard of accommodation available. While some based their perceptions on personal experience, others tended to rely instead on anecdotal evidence and hearsay. For example, Mrs Smith's views were based on experience and knowing that she had prevented her mother-in-law going into residential or nursing home care was a positive reward for her efforts. She said that she derived a sense of satisfaction from:

'Just knowing that she's not sitting in some place, I mean I know if I put her in a home now, she won't survive...Some of these places are awful – I mean I've seen them, they're awful. I wouldn't want to go in. I've been up visiting people

and the first thing that hits you is the smell of urine. They can't give her the attention she gets here. No. I couldn't put mum in a home'

(Mrs Smith, 50 year old carer)

For others, a positive outcome was that caring provided a purpose in life that they had previously lacked (47 per cent) and also led to the development of new skills (38 per cent) and the chance to widen interests and contacts (33 per cent). These carers tended to be either unemployed or ones whose children had grown up and left home. Caring provided their day with a structure and a purpose that had been lacking as well as widening their interests. The development of new skills and interests was sometimes encouraged by attendance at painting, pottery and computing classes run by carers support groups. Some carers had become more involved in the running of these organisations. For Mrs Smith in particular, caring had led to widened interests, increased self-confidence and the opportunity to represent carers at policy meetings at the local council chambers. Having never been in paid employment since her marriage twenty-five years ago, Mrs Smith was for the first time in her life, developing interests outside her home. She enjoyed this new aspect of her life so much that she talked about staying in that line when her caring responsibilities ended. She was considering the possibility of paid employment when she said that:

'There'll maybe come a time when I will be able to do it as a job. I don't know. I suppose the clock is ticking and I'm thinking who would employ a 50 year old...I am now attached to the Princess Royal Trust for carers, so that's got me into a whole new field. I go to conferences, I've learned a lot about other people and aspects of training and caring. I'm part of a wee sub-committee so I have learned how a thing starts happening and how it carries on. I feel now that if I didn't have anybody to care for I could go into something like that. If something happened to my mother-in-law, I think I would want to use the knowledge I had for something'

(Mrs Smith, 50 year old carer)

In contrast to carers who felt they were coping, others whose perception was that they were not coping were more likely to experience negative outcomes. These outcomes tended to increase carers' feelings of stress and were accompanied by expressions of negative emotions. Two of the main negative outcomes were the restrictions imposed on carers' lives and the competing demands of caregiving and other family responsibilities.

The most consequential negative outcome was the restrictions that caring placed on carers' lives in general and social activities in particular. Restrictions on carers' lives often led to the loss of friends, social isolation and loneliness. Carers (67 per cent) tended to feel that they did not have enough time for themselves and 57 per cent felt that they couldn't see

their friends as often as they would like, have a break or take a holiday. Some expressed the view that caring had 'taken over' their lives and that looking after an older person was different to looking after children because few people were prepared to babysit for an adult. Mrs Teirney for example believed that the restrictions on her life, the loss of friends and the ensuing isolation and loneliness were an inevitable part of caring. Referring to it as 'the caring syndrome' she explained that:

'If you take over the care of another person, you take over their life and they in turn overtake your life because your life is now, you don't exist any more. You really don't exist. Your friends that used to be your friends don't come. The true friends that you have got get fed up asking you because you have to end up saying I can't go. I mean it differs from having kids and having an adult to look after. I remember when I was 18, I had my son and my friend phoned and asked me did I want to go out and my mum says away you go, I'll watch him. If my friend phones and says do you want to go out, nobody jumps and says they'll watch my daddy. That's it. That's the difference. Your life is overtaken, so friends do dwindle. The only thing I do miss is my friends. And I grudge losing a lot of my friends. You do find your true friends but they get fed up with you saying no you can't come out and then eventually the phone calls don't come. And it's not their fault and it's not your fault. It's just a fact. It's one of the things that happen. You're just a carer. It's just the 'caring syndrome'

(Mrs Teirney, 68 year old carer)

This account illustrates how some carers suffer from restrictions when the limits placed on the care recipient also affect their own lives. Restrictedness, according to Twigg and Atkin (1994), refers not only to the degree to which carers are unable to leave the cared-for person but it also encompasses the wider ways caring constrains and limits carers activities. They suggest that restrictedness is central to carers' lives and as such poses a problem for all carers (Twigg and Atkin 1994). This finding though is not consistent with those of the present study whereby restrictedness was a problem for some but certainly not for all carers.

Some carers, usually those who said they were coping, refused to allow their caring responsibilities to restrict their social life. For them it was not so much the practical aspects of caring that restricted them, as a general worry about what might happen in their absence. Although in many of these cases, there was no objective reason why the care recipient could not be left, carers tended to worry when they were left unsupervised. Rather than allowing caregiving to interfere with her social activities Mrs Currie for example, resolved the problem by ensuring that her husband accompanied her to the local pensioners club whenever she went. Although this entailed the extra expense of getting taxis to and from the club Mrs Currie preferred this solution to leaving her husband on his own or the alternative which was for her to miss the club. Mr Brown was also determined

that caring should place as few restrictions as possible on his life. He managed this by enlisting the help of friends if he wanted to go away for a weekend or overnight stay. Initially Mr Brown was uncertain how his father would react to being left on his own for an evening but he devised an unusual way of checking up on his father's activities. By installing video cameras in strategic positions in the house, Mr Brown was able to monitor his father's movements. He discovered that his father's habits were fairly predictable in that he would make a trip to the toilet every time a commercial break came on the television. By using these 'big brother' tactics he was able to leave his father alone in the house feeling certain that nothing untoward would happen in his absence. Mr Brown subsequently used this means of surveillance on a regular basis whether he was in or out of the house. Although this measure seems a bit extreme, it was utilised in an attempt to overcome any restrictions caring placed on Mr Brown's social life.

Another negative outcome described by carers was the competing demands of caregiving with other family responsibilities. Analysis of CADI found that 76 per cent of carers felt that caring put a strain on family relationship (see Appendix V). Further analysis of qualitative data shed further light on this issue and revealed that some carers felt that they were unable to devote enough time to other family members such as husbands and children and that caregiving was a threat to their marriage. This was a particular problem for younger married carers who were looking after a parent. The demands made on them by husbands and older parents were considerable, difficult to reconcile and at times generated a great deal of tension. Some found that their husbands complained about the amount of their time that was taken up with caregiving. In a few cases this seemed to cause conflict and jealousy between the carers' partner and their parent who seemed to compete for attention. For instance, Mrs Watson's father and husband vied for her attention and at times the atmosphere was so bad that she removed herself and her young daughter from the house. She explained that:

'My husband and father don't get on. I think my father resents him [husband] actually. And well, I know for a fact that my husband resents him [father]. I'm piggy in the middle. And if I do something for my dad, Robert will say to me, your daddy says something and you jump. I ask you for a cup of tea and you say can you not make it for yourself. And if your dad says can I have a cup of coffee you're up there like a shot. There's a lot of resentment ... My daddy says I should give him a divorce – so I can turn all my affection on to him. I told him - aye that will be right. There was a fight in here on Monday night and now I'm not talking to him. I'm not talking to my husband either'

(Mrs Watson, 38 year old carer)

Carers with young children were particularly resentful of the time spent with the care recipient, time which they believed should have been '*family time*'. The stress that Mrs Kearns experienced seem to increase as both her mother and her children grew older and her husband became more resentful of the amount of time she devoted to caring. She admitted that at times she felt like '*piggy in the middle*' and didn't seem able to please anybody. At the time of the second and third interviews Mrs Kearns was being treated for clinical depression which she attributed to the stress of caregiving. She explained that:

'Each year she gets frailer and frailer and she can do less for herself. You feel that life's passing you bye. The kids are getting bigger and there is so much you want to do with them and you don't get the chance. I think it [caring] affects all the family because sometimes the girls will say something and you have to say we can't because we've got to do this or that for Granny. Even on a day out, you've got to be back to make Granny's dinner. It's very difficult. My husband complains that I do too much for my mother. We've had a lot of rows and talked about splitting up. It's stressful because you have to try and split your time between so many people. I'm at everybody beck and call. I find that trying to get the time for the girls the less I give to her [mother]. One day, one hour, whenever I'm with the girls you're always getting interrupted or something'

(Mrs Kearns, 36 year old carer)

Balancing the demands of a family was very difficult for carers. The tension within their marriages added to their experiences of physical and mental stress. The findings of the present study, that the outcomes of caregiving seem to play an important role in carers ability to cope, are consistent with those of others such as Motenko (1989) and Nolan et al (1996). These studies have also noted that the temporal dimensions of carers' experiences have been overlooked by much of the caregiving literature. We turn now to consider the temporal aspects of stress and coping.

Temporal Aspects of Stress and Coping

Analysis of data from the present study revealed three concurrent and inextricably linked processes associated with the developments of stress and coping. One process was that carer's stress increased with the passage of time. The second was the development of expertise over time whereby carers became increasingly skilled in the tasks and management of caregiving. The third was the occurrence of crises in coping that sometimes marked a watershed in carers' careers. Whilst each of these processes will be

described separately it should be noted that they did not necessarily precede or follow each other in a deterministic way, but rather they seemed to occur simultaneously.

Increasing stress

The first discernible process was increasing levels of stress. We have seen that for the majority of carers in the present study caring was a stressful experience; a finding that is similar to those of other studies that focused on family caregiving (Gilhooley 1987, Boss 1993, Nolan et al 1990). Yet carers in the present study, appeared to perceive that the volume of stress increased with the passage of time. In other words, sources of stress seemed to multiply over time because one cause of stress gave rise to others. For example, apart from causing an unpleasant mess, incontinence also led to broken sleep and chronic tiredness. Similarly, demands for attention seemed to increase with frailty and intensified the restrictions on carers' lives. Therefore, as the length of time caring increased stress had an accumulative effect. Mrs Morrison for example, explained it by saying:

'I think it gets more stressful. I think it is resentment and because they are getting older and old folk keep expecting more of you. They are so set in their ways to begin with and because they have always got away with it. It's like you give them an inch and they take a mile. She could do a lot more for herself'
(Mrs Morrison, 58-year-old carer)

For some carers whose lives were increasingly restricted by the demands of caring, the cumulative effects of stress seemed to wear carers down and reduce their capacity to cope. This manifested itself in feelings of not only resentment but also irritation and intolerance towards the care recipient. Mrs Kearns for example, said that:

'It's very difficult being here with her all day. I am much less tolerant with her than I used to be. It's all the wee things that get you down'
(Mrs Kearns, 36 year old carer)

The most common pattern amongst carers was that caring was not perceived as being particularly stressful at the beginning, that it was only as the time spent caring lengthened that perceptions changed. The time taken for carers' perceptions to change varied and seemed to be unrelated to the pathway by which individuals became carers or to the nature of the caregiving relationship. This pattern, while best illustrated by the experiences of Mrs Duncan was common to the majority of carers. Mrs Duncan had made a positive decision to give up her job in London to care for her 74-year-old mother with whom she had a very close relationship. In response to a question about whether she perceived caring

to be stressful Mrs Duncan, caring for only six months compared it to the demands of her previous employment. She said:

'No, not at all. It's far less stressful than living and working in London. It's far less stressful. It's quite laid back actually'

(Mrs Duncan, 47 year old carer)

During the second interview six months later Mrs Duncan seemed less positive about caring and more anxious about life in general. A year later there were few traces of the optimistic and capable woman that had been interviewed previously. Mrs Duncan cried throughout the third interview and admitted candidly that caring was very stressful. She expressed regret about her decision to become a carer and about her loss of freedom. She also felt that she no longer had a purpose to her life and she missed her friends although she did manage to socialise occasionally with her cousins who lived nearby. She attributed the change in her to a number of factors. She explained that:

'I suppose the novelty of not working has worn off. I mean there's lot of things that I don't miss about London but I do miss my friends although they are always on the phone. I just feel that I have no goals in life. I'm just going from day to day. If I could do something, even just for half a day a week, something, anything it might give me an incentive. I'm becoming more emotional. I am often in floods of tears and my blood pressure was up. It's partly because I've got her twenty-four hours a day and I've got no life. I think you get to realise you have no freedom and you don't seem to have the time or the inclination to do things. I'm still the same person but you are living an entirely different way of life... My aunts were a bit annoyed that I contacted social work, that I wanted more help. They thought that we should be able to it ourselves but I wanted something on a stronger footing. She [aunt] knew I was really stressed out and she said I couldn't go out for a couple of weeks because they were doing things. And that was getting to me because she knows I go out on a Tuesday and for some unknown reason they had made arrangements to go out. That really annoyed me –she has the rest of the week to herself—she's retired. I only have one day. That's when I got to the stage that I thought I'm not going to depend on you any more''

(Mrs Duncan, 47 year old carer)

Mrs Duncan's account reveals that although her mother's condition had not deteriorated, she felt increasingly trapped and worn down by her caring responsibilities. A lack of support from her aunts who had previously cared for her mother added to her distress. It seemed their support had become increasingly unreliable and they had withdrawn it altogether since Mrs Duncan had approached service providers for help. Yet her level of stress had been increased further rather than alleviated by her contact with service providers who, despite promises of action, had provided no support within three months of her initial request. Many carers believed that their stress would only be relieved by their relative's

death or admission to either a nursing or residential home. However, believing that there was no real alternative to family care, carers tended to regard any type of institutional or long stay care as being totally unacceptable.

For other carers the length of time spent caring did not seem to have any relation to their perceptions of stress. Some, who had been caring for a number of years, did not perceive caring to be stressful. Mrs Currie for example, who had been a carer for twenty years said that caring was frustrating rather than stressful. Having had her social activities curtailed by the demands of caring, it was when she was confined to her home in the evenings that her husband's habits seemed to particularly irritate her. She described how in the evenings she would be sitting knitting while her husband watched television, when the peace and quiet would be broken by her husband's habit of rubbing his fingers together, thereby producing a rhythmic but irritating noise which upset her concentration. She said that:

'I don't find it [caring] stressful. Sometimes I get frustrated more than I would say stressed. Wee things he does irritate me – and I'll say keep your hands at peace Jimmy for goodness sake, but I would say that it's not stressful as much as frustration'
(Mrs Currie, 83 year old carer)

Carers such as Mrs Currie were unusual in that unlike the others they did not experience caring as becoming increasingly stressful, yet their circumstances were broadly similar. For most of these carers, their present role was not their first experience of caring. Whilst some had previously been employed as nurses or nursing assistants, others had looked after another relative. This prior experience seemed to provide them with a degree of expertise that other carers lacked.

Development of Expertise

The development of carer expertise was the second discernible process. During the course of the study, changes seemed to take place in carers' ability to cope. Carers appeared to develop a degree of expertise that led to an increase in confidence in their own abilities and by the time of the final interview reported that they were coping better than previously. Carers' accounts suggested that after a period of adjustment some adapted to and accepted their role. Mrs Ireland for instance, having cared for her brother for six years felt that although caregiving did not get any easier, she had now adapted to her role and to the routine that it instilled in her life. Her view was that:

'I think that it easier to cope as time goes on. It's just a case of saying, well this is it. I don't see it getting any better. You just get used to it I think. I don't

think it gets easier but I think you become accustomed to it. I think you have to adapt or sink. I'm so used to it now – it's just part of your life'

(Mrs Ireland, 63 year old carer)

Practical experience of caregiving seemed to encourage the use of an increasing number of coping strategies. Through a process of trial and error, carers were able to determine what worked best and what was a waste of time. For example some carers developed the ability to distance themselves emotionally from the situation. Mrs Kearns for example said that when her mother got annoyed or upset with her she treated her like a child and *'let it all go over my head now'*. Others reported that they were much more assertive and were now placing limits on their caregiving activities. Mrs Thompson for example, described her change in approach.

'I had got to the stage where I couldn't cope. I'd had enough. I have been at the stage where it was me that was going to go on antidepressants but I have gone the full circle. You see, now I don't stand for any nonsense. I suppose I have grown up. I am not his wee lassie any more. He might still be the daddy but I'm a granny now and I'm old enough to tell him to go take a walk. I don't stand for any of his nonsense now. And I think I cope great. It is easier now for me because I have stipulated the rules and I've stipulated the regulations. There has been a change in within me, there's been a change within the family and now there's a change within my dad.

(Mrs Thompson, 41 year old carer)

Evidence from the present study suggests that carers gain some degree of expertise similar to that described by Eraut (1994) in relation to professionals. Eraut's model sees the acquisition of expertise as a pathway from competence to proficiency and ultimately to expertise. He claims that normal or novice behaviour is characterised by an ability to carry out routine procedures. Competency is marked not only by an ability to carry out these procedures whilst under pressure but also to recognise and discriminate between the features of situations and plan accordingly. Proficiency marks the development of a different approach in that behaviour becomes semi-automatic rather than merely routine, situations are assessed and understood more comprehensively and any abnormalities are noted and attended to quickly. Eraut's pathway deems that expertise is acquired through practical experience rather than knowledge. He claims that there has been a shift away from the belief that professional practice is informed mainly by theoretical knowledge towards the realisation that in fact much of what happens emerges from experience. Family carers are similar to professionals in that they develop expertise through experience and their intimate knowledge of the situation. Although family carers do not have any formal training in which rules and practical skills are introduced, they are similar to professionals in that expertise can only begin to develop when skills are practised and

refined in real life situations. Carers developed their skills mainly by a process of trial and error but their intimate knowledge of the care recipient and their experience allowed them to select the most appropriate way of dealing with stressful incidents. In the present study carer expertise was acquired by experience, it tended to be intuitive and was based on a skilled management of the situation.

The two processes described above present an apparent paradox whereby the majority of carers who said that caring became increasingly stressful seemed to be the same people who perceived themselves as coping better. One possible explanation for this paradox may lie in the crises that carers experience.

Periodic crises

An experience common to the majority of carers was of a crisis in coping followed by a period of appraisal and sometimes a change in mind set. During the crisis carers were unable to maintain a reasonable emotional balance and negative feelings aroused by their situation were expressed. Crises were usually related directly to the caregiving situation although external events added to the tension and to carers' sense of helplessness. The typical pattern was of a period of stability followed by a series of minor problems each one dealt with in the way the carer thought most appropriate. Each problem irrespective of its magnitude increased the strain on the carer especially if it was not resolved satisfactorily. The cumulative effect of strain seemed to result in 'carer overload'. This occurred when carers felt they '*had had enough*' or were at '*breaking point*' and could not continue to look after the care recipient. Although this process is illustrated below by using Mrs Smith's account of her feelings, many other carers recounted similar experiences. Reflecting on her experiences of caring Mrs Smith recalled a period when she felt she could not cope. She explained that:

'I had a pretty bad time – when my aunt wasn't well and my mother-in-law was living with us and I had hurt my back. It was a pretty bad time and I just felt the world was caving in. I felt that I'd got older and I couldn't cope... suddenly you feel as if you can't sleep, your mind's in a turmoil and I was feeling absolutely miserable. I thought I was going to end up a nervous wreck on tablets and taken away to a psychiatrist or something. It was just one day I just suddenly felt that the world was – nothing was right. There was nothing bad about it. It was just like I had just reached a peak, all the years it had suddenly climbed up and I just remember saying to myself – I can't take much more of this. I'm off. I don't know what I was feeling, I can't even say. That was the only time I felt that I had had enough... I got through it by sheer determination and I just put everything down on paper. I found that I had to get it right in my head and I wrote like a journal. There's no dates, there's no actual stage, just

helping to get it out of my head. ...That was the only time I can honestly say I felt like that. I just said to myself, well all these years you've been on a treadmill and it's time to come off. And I must admit now I don't really get panicky. Nothing really bothers me now. I just get on with it. I don't see the point in getting angry or panicky'

(Mrs Smith, 50 year old carer)

The passage above illustrates how Mrs Smith experienced a 'crisis of coping' in her caring career. A period in which events were threatening to overwhelm her and she felt she could not cope with the situation. The catalyst for a crisis appeared to be the cumulative effect of a number of stressful events. Incidents such as deterioration in the carer or the care recipients' health, increasing anger or resentment and sometimes conflict with other members of the family contributed to carers perceived inability to cope. Some carers also perceived caregiving as posing a threat to their marriage or to their own health. When asked how they had coped with crises in their lives, carers' responses were broadly similar in that they all used verbal and written communication as a coping strategy. While some like Mrs Smith wrote in a diary, others talked to trusted confidantes and GP's about it. Vocalising or writing about how they felt helped carers to clarify their thoughts, feelings and the options available to them, and to release some tension.

Coping with a crisis usually entailed a process of appraisal. This appraisal was not initially a conscious act. Rather carers described a growing awareness of their own unhappiness, their own personal problems, the restrictions on their lives, their own needs and often feelings of guilt if they even dared to consider that they could not continue caring. Whilst the crisis forced carers to confront the realities of their situation, appraisal was a period during which, carers took '*a step back*' and reviewed their situation. This was a potentially crucial point in carers' careers. This was the point at which carers could have decided that they were not going to continue caring and alternative arrangements would have been made. In carers' eyes though the only alternative would have been institutional care and, as has been mentioned previously, this solution was totally unacceptable to them.

The appraisal process described by carers in the present study was similar to that contained within transactional models of stress and coping (Lazarus and Folkman 1984, Lazarus 1991, Pearlin 1991). These models explain how when a potentially stressful demand or event occurs a primary appraisal takes place. This essentially involves an individual determining whether or not there is a need to respond to the event or demand. If there is not a perceived need to respond then no action is taken. If there is a perceived need to respond then a secondary appraisal is made. In this secondary appraisal an individual takes account of what resources they have available to meet the demand. A coping response,

strategy or resource is then selected to deal with the event. If an individual feels that they can make an appropriate response this may lead to a new or fresh approach to coping. Following the appraisal process, some carers in the present study modified an existing routine or introduced a new one. Mrs Watson for example, introduced a new routine following her father's discharge from hospital where he had been admitted because of her coping crisis. When coping is successful a positive reappraisal of the self may also occur (Pearlin 1991). This is similar to the experiences of some carers whose fresh approach and positive self-appraisal were described above. On the other hand the model suggests that if individuals feel that they cannot make an appropriate response a reappraisal may lead to stress being manifest in the expression of negative feelings. In the present study, carers who believed that they were unable to cope with caregiving were more likely to express negative feelings than those who felt they were coping. This highlights the fact that carers' responses to crises varied.

Carers responses

The function of crises was to force carers to consciously think about and confront the realities of their situation. For some carers crises led to improved ways of coping. But this was not true of everyone. In accordance with this interpretation it is possible to describe three different responses to crises within the career of caregiving, the active, the passive and the expert.

Active response

Some carers whose caregiving career was characterised by increasing levels of stress and the development of carer expertise responded to crises in a pro-active way. The crises that they experienced were positive in that they were the catalysts for constructive change. Following a period of appraisal as described above, carers subsequently adopted a more pro-active approach to caregiving which included the setting of limits and being more assertive. Mrs Smith for example, became more assertive and adopted a positive 'can-do' approach to her caring responsibilities and most importantly of all, she accepted the situation. Carers who responded in this way, can be likened to the 'balanced and boundary setting' carers described by Twigg and Atkin (1994) in that following a crisis part of their positive reappraisal process was the adoption of a boundary setting approach. In some cases this boundary setting extended to practical tasks too. Mrs Morrison for example, steadfastly refused to take her mother-in-law out for a walk in her wheelchair. She claimed

that her mother-in-law liked to draw attention to herself when she was out and that she found this behaviour embarrassing.

Passive response

Other carers, whose caregiving career was characterised by increasing levels of stress, responded to crises in a more passive way. These carers differed to the active responders in two respects. Firstly, they appeared to develop little or no carer expertise. Secondly, their crises were not catalysts for positive change but rather were destructive in that they either caused carers to question their ability to cope, or they confirmed their belief that they could not. After a crisis they were unable to adopt a new approach but rather continued to be overwhelmed by caregiving. These carers were more likely to passively resign themselves to the situation rather than accept it and adopt a pro-active approach. Some had tried unsuccessfully to seek help from service providers because they felt that they could no longer cope but their failure to obtain help had lowered their self-esteem and confidence. Carers in this career were similar to the 'engulfed' carers in Twigg and Atkin's (1994) typology in that caregiving had become the focus of their lives and they found it difficult to distance themselves from it. Caregivers in this career differed from Twigg and Atkin's engulfed carers in one respect. In Twigg and Atkin's study engulfed carers tended to be wives or mothers of disabled children whereas in the current study carers in the passive career were more likely to be sons or daughters.

Expert response

One response stands outwith the other two. The caregiving career of these carers was marked by the absence of increasing levels of stress. This was the response of carers who said that they did not perceive caring as being stressful. They believed that they were coping well and were less likely to report having a crisis. These carers were more likely to already possess a degree of expertise than those in other careers. Many of them had been either trained or untrained nursing staff or had previously cared for other relatives. It seemed that having previous experience, the possession of caregiving skills and having confidence in their ability to cope with whatever came along protected them in some way from the stress that others experienced. This confidence and self-belief seemed to facilitate coping behaviours. These carers were similar to those described by Twigg and Atkins (1994) as being in the 'symbiotic' mode of caring in that they gained in a positive way from their role and would not wish the responsibility to be taken from them. However, carers in the present study who demonstrated an expert response differed to Twigg and Atkin's

carers in that were more likely to be spouses rather than parents. Thus we can see from the responses outlined above, that carers in the present study, who had broadly similar careers responded in different ways to caregiving processes.

The key issue in the processes described above is concerned with the nature of the appraisal process following a crisis. These were dynamic processes in that appraisal and coping influenced each other and were subject to change. When carers appraised a situation as potentially harmful, coping strategies were developed and pursued to reduce the perceived threat. Feedback from the coping process became part of a successive almost subconscious appraisal leading to modified coping, then further reappraisal and so on until a balance was reached. This process is what carers referred to as *'trial and error'*. A crisis though, by threatening to overwhelm carers' ability to cope, forced them to consciously reappraise their situation. A crisis could either be constructive or detrimental in that some carers subsequently modified their coping efforts by adopting a pro-active approach, while others took a more passive stance.

Conclusion

In this chapter we have seen how not only did the majority of carers experience caregiving as stressful but that stress increased over time. Stress was caused by both the direct and indirect activities of caregiving. Stress seemed to have a cumulative effect on carers and was related to the way in which problems evolved and developed. Over time one source of stress tended to generate others. For a few carers unremitting chronic stress seemed to lead to anxiety and depression.

The main coping strategies used by carers in the present study, were problem solving and practical solutions, and cognitive and behavioural responses. Their efficacy was enhanced by access to other coping resources such as social support and adequate living arrangements. Many carers in the present study tended to have small support networks and caring was rarely shared with other family members. Appropriate accommodation facilitated caregiving while inappropriate living arrangements made it more difficult and could deter the independence of the care recipient.

Carers who felt that they were coping were more likely to report a greater number of positive outcomes. In contrast, those who felt they were not coping tended to report

negative outcomes such as the restrictions that caring placed on carers' lives, which led to a loss of friends, loss of social activity, loneliness and the conflicting demands of caregiving with other family responsibilities.

Stress and coping are processes that must be understood in context and over time. Analysis of the data from the present study revealed three concurrent and linked processes with a temporal dimension. The time within which these processes took place varied enormously from a matter of months to years. Firstly, carers' stress seemed to increase as the length of time caring increased. Carers also seemed to develop a degree of expertise whereby they became increasingly skilled in the management and tasks associated with caregiving. The third discernible process was that of a crisis followed by a period of appraisal.

These processes represent an apparent paradox. Carers, who said that their stress increased with the passage of time, also seemed to be saying that they were coping better than previously. A possible explanation for this paradox focuses on the nature and the outcome of the crisis and appraisal process. Increasing levels of stress led to crises, which were followed by appraisal and the development of coping strategies and expertise. The crisis forced carers to face the realities of their situation and consciously reappraise them. For some carers the outcome was a positive reappraisal, an acceptance of the situation and a determined change in approach to caregiving and increasing confidence and self-esteem. For others, the crisis was less constructive. Their outcome was more likely to lead to passive resignation, confirmation of their failure to cope, a sense of hopelessness and lowered self-esteem. On the basis of this explanation a model of three career paths was proposed. The outcome of the crisis and appraisal process and the degree of developed expertise distinguished two of these careers. Pre-existing expertise and the absence of crisis distinguished one career standing outwith this paradigm. This explanation accounts for the way in which carers' experiences of stress, coping and crises differ.

This chapter has explored carers' experiences of stress and coping. The following chapter will discuss the transition to supported caregiving.

9. Transition to Supported Caring

The aim of this chapter is to explore how carers moved from unsupported to supported caregiving. It will begin by considering carers' reasons for not initially engaging with formal service providers. It will continue by exploring the triggers to service receipt and the pathways by which carers made contact with providers. It will conclude by discussing carers' experiences of services and whether it confirmed or contradicted their previous views.

A key theme running through this chapter is the issue of who formal services are for, carers or care recipients. Formal services refer to those that may be provided, funded and/or arranged by statutory and voluntary organisations. Traditionally, they include a range of health and social care services designed to meet the needs of care recipients. These services included domiciliary care such as home helps or home carers, community nurses, aids and adaptations, day care, residential and respite care. In the last decade however, carers' ambiguous position within the service system has been increasingly recognised (Twigg and Atkin 1994). They are neither clients nor patients but are rather the main provider of care given to frail older people (Wicks 1982, Allen and Perkins 1995, Walker 1995, Scottish Executive 2001). Carers only require support from formal services because of their relationship with another person.

Although policy has increasingly acknowledged the importance of support for carers, what is regarded as a service for carers is unclear. Service providers have the potential to assist carers by supplying either direct or indirect support. Direct practical support is when paid carers substitute for family care either to lighten the carers' workload or in order to give them space and/or time to relax. So for example, a paid carer would help the care recipient with bathing or dressing or provide a sitting service. Service providers can also provide support in an indirect way, for example, when decisions are made in relation to the care recipient because the carers' circumstances are taken into account. An example of this would be when a GP makes a referral for day care or when a day centre manager increases the care recipients' rate of attendance. As we shall see, in these cases, while the service recipient is the person being cared for, the beneficiary is primarily the carer. However, before exploring the move to supported caring further, it would be useful to determine how many carers experienced this transition.

Change in Status

The table below illustrates the changes in carers' status over the course of the study from unsupported to supported by formal services. Supported is defined as being assisted in either a direct or indirect way, to sustain existing caregiving activities.

Table 5: Status of Carers

	Unsupported	Supported	Total	Withdrawn
Stage 1	26	0	26	0
Stage 2	12	9	21	5
Stage 3	7	10	17	4

At the start of the present study, neither carers nor care recipients were receiving the support of formal services. For many carers this position changed over the course of the study. By stage two, 9 carers were receiving help from formal service providers and 12 continued to care without support. Only two carers reported using private services. One paid a private home help to clean her house while the other purchased bathing services from a private agency for a cost (at the time of interview) of £5.50p per hour. Once a week a carer from the agency would come in to bathe her mother.

By stage three of the study, seven carers continued to care without support from formal service providers. Ten were now using a wide range of services provided primarily by social services, which included day care, respite care, home care and the provision of aids and equipment. Of these ten, six also received a community nursing service. Two of the ten had comprehensive packages of care supplied by health and social care agencies, which included domicilliary care and community nursing. The two women who had used private services were no longer carers and had therefore cancelled these services.

Reasons for Non-use of Services

The main purpose of this chapter is to describe and explain carers' transition from unsupported to supported. However, in order to comprehend this transition it is important to understand why carers had not originally been involved with formal services. Carers put forward a variety of reasons for their reluctance to become involved with formal service

providers. While they differed in their knowledge and experiences of formal services, their reasons for not using them were remarkably similar. They fell into four main groups relating to; the nature of services, previous negative experiences, the wishes of care recipients, and a lack of knowledge about the availability of and access to services. Although each of these will be discussed individually, it is worth noting that carers frequently cited more than one reason for not using formal services.

Nature of services

The reason cited most often by carers was the perceived authoritarian and intrusive nature of services. In order to accept the support offered by services, carers had to be prepared to trust strangers and let them intrude into their homes and lives. But some carers believed that to allow strangers into their homes led to a loss of control over their own lives and the caregiving situation. So while some carers would have liked support, their dislike of strangers and mistrust of what they saw as authoritarian professionals far outweighed their desire for help. Mr Brown for example, described how he felt powerless during an encounter with service providers in his father's house. This experience made him determined not to accept their help when his father came to live with him. He explained that:

'I don't trust official people because I feel they are intruding. Sometimes, a social worker would come in or even his nursing staff would come in and start telling me how to run my house. I said, now just wait a minute. None of your bloody business was my attitude to it.. But there were times when people came in and you felt that you were losing control and they were telling you what to do...You can't treat people like that. Thinking that when you walk in a house you can take over. It's an intrusion, you feel the intrusion and it feels horrible. We keep to ourselves. We have never really had a lot of people just dropping in. It's still the same'

(Mr Brown, 40 year old carer)

Some carers believed that it would be easier to accept help if they did not live in the same house as the care recipient did. Then it would not be their lives, personal space or privacy that would be invaded by providers. Mrs Gordon for example, was adamant that she did not want homehelps or nurses coming into her home to help look after her father. She had previously received regular visits from community nursing staff but cancelled them because she felt that they were increasingly restraining her life. Out of concern for her health and because she had refused help from the community nurses, her GP wanted her to give up caring and agree to long term care for her father. But having refused help and knowing that the option of giving up was there made a tremendous difference to Mrs

Gordon's attitude. She perceived that control of her life and the caregiving situation was back in her hands. She felt empowered and was determined to continue caring without practical support from formal services. Mrs Gordon explained that:

'It is easier if you live in separate houses. It becomes easier to get someone in to help. Because I don't need a homehelp or a nurse. I just feel that why should I have somebody into my house going through my stuff when I don't need it...I think because I had the option now, I had the choice. That's what it was. Before I felt trapped and I felt I didn't have a choice, but now I feel I have got a choice. And that feels good because you seem to feel that you're not in control of your life any more. Someone else has taken control of it. So the control was back in my court and being a person who likes to control my own destiny, this having no control over anything was killing. I mean if I wanted to go out, I couldn't go out without having made sure the nurse had been. But sometimes you couldn't go out because the control was taken away from you and that was a killer. But now that I was in a position to say yes or no, the control is there and I basically can carry it through with it. Since then it's [caregiving] been quite good'

(Mrs Gordon, 63 year old carer)

Mrs Gordon's account raises the question of who is the focus of support, the carer or the care recipient. It also suggests that services provided to care recipients living in their own homes might be accepted more readily because they would not necessarily be seen as support for carers. While carers viewed the care recipients' need for support as legitimate, seeking help on their own behalf was tantamount to an admission of personal failure.

Safeguarding their privacy remained an important factor affecting carers' plans for the future. Some said they would only consider help if they were not physically able to continue caring. But even then preserving their privacy and control over events was important. Mrs Morrison for example, explained that:

'I never think about accepting help. For all the wee problems you just get on with it. If I am unable to look after her, she will go in a home. As long as I am here I don't mind looking after her. I mean I chose to do it so therefore I can't turn round and just say away you go I can't be bothered. And I'm kind of funny about having people coming in to my house. I like to be in charge and I like my own privacy too much. As I say the only reason I would put her into a home is if she got too much for me. If she got to the stage where she was incontinent or if she took a stroke'

(Mrs Morrison, 58 year old carer)

These accounts illustrate how some carers feared a loss of control and valued their privacy so much that they would rather put their relative into residential care than allow formal services into their home.

Previous negative experiences

Another reason for not using formal services was that previous unsatisfactory encounters with providers left carers with a enduring negative impression that made them very reluctant to become involved again. While some carers had encountered service providers when they had previously looked after another relative or when their parents lived alone. These services were subsequently discontinued when the carer and care recipient formed a combined household or at a later date. Although carers individual experiences varied, a number of themes were identified.

Difficulty in accessing services

Carers who had previous encounters with formal service providers talked about the difficulties they had experienced in accessing them. Service receipt is the product of negotiation with service providers (Twigg and Atkin 1994). Yet, rather than seeing it as a process of negotiation, carers in the present study tended to talk in terms of it being a 'battle' and that they had had to fight for what they wanted. Having experienced this once before they had little inclination to engage with providers again. They felt that they did not need help badly enough to want to fight what they saw as the bureaucracy of the system. Mrs Bennet's experience illustrates the difficulties carers faced when trying to access the service system. Having previously worked as a homehelp organiser she believed that she understood how the system operated and that she would have little difficulty in accessing support to look after her 94-year-old mother. Having encountered frustrating delays, cancelled appointments and feeling that she had been let down by the system, Mrs Bennet had eventually decided that she did not want help to care for her mother. She explained that:

'It's all the fighting you have to do. I don't mean fighting exactly, but it's all this telephoning you have to do. You're on the phone, you're down at the office and yet nothing gets done. I mean, what's the point of it, all that red tape, that's what it is. Why are they spending all this money on campaigns when they do nothing. That is what makes you so angry. I didn't ask for a lot but I didn't get anything so I'm not going to ask for help. What's the point, people don't do anything. I am an old age pensioner looking after a pensioner who could trip over anything and then what would they do. It would cost them thousands to look after my mother if I wasn't able. Carers don't know how to go about fighting for things. I mean I didn't know. I went about my normal life, never giving these kinds of things a thought. I thought help came easily but it doesn't it. I don't want to phone up and ask what's going on. I feel that I am able enough to do it but I shouldn't have to'

(Mrs Bennet, 67 year old carer)

Carers did not seem to understand the pattern of social work practice. They expected social workers to operate in a way similar to GPs in that they were assigned to a particular one whom they could contact when required. They failed to understand the case closure system that required a re-referral each time assistance was needed. This system was confusing to carers who expected to be able to contact the social worker they last dealt with. Carers' confusion about the system underpinned their comments about phoning up only to be told *'oh she's left, I'll get someone to contact you'* and they found themselves still waiting. This uncertainty over who was their social worker caused carers to experience the case closure system as bureaucratic inefficiency. Having experienced difficulties in bringing their situation to the attention of service providers, carers like Mrs Bennet simply gave up trying. Others though who had successfully negotiated the first hurdle of access then went on to experience difficulties with formal services.

Lack of understanding

Mrs Smith remembered how unsupportive formal services had been whilst she was caring for her ill father until his death a few years previously. She perceived that their lack of understanding had contributed to the difficulties of managing her father's care. As a non-resident carer with young children, not being able to drive and living a distance from her father's house, caring for her father was challenging. What she perceived as their unwillingness to acknowledge the conflicting demands on her, had made a harrowing situation even more stressful than it need have been. She felt that as a carer, the system had let her down at a time when she most needed support. As a result of this experience, although she had been offered help, she chose to care for her mother-in-law without support because she did not have faith in the ability of formal services to be supportive. She explained that:

'I've had bad experiences with social work departments, very bad experiences. My father was pretty ill and he was calling me down at all hours. It was getting pretty hairy and he asked me not to put him in a home and I said I wouldn't put him in a home. But I got no help from his doctor or social work. I was in a no win situation. But to do all that in your own home is not ideal because you have to be in when they [homehelps or nursing staff] come in and it's much easier for me to handle her on my own. I think you have to assert yourself very fast and access the services really quickly. And I think you have got to fight for what you want. They are not interested unless you push yourself forward and once you get on their books, unless you keep at them, they won't come to you...If I want it I'll use it but I don't. I feel there are other people who are more necessary, so I stand back and I just do things for myself. I can't fault the district nurses. It's just the social work I don't have faith in...

(Mrs Smith, 50 year old carer)

Mrs Smith's account illustrates how poor communication between providers and non-resident carers can be problematic. Nonetheless, she conceded that she could not have looked after her father in his own home if it were not for the help given by formal services. Now, however, as a co-resident carer she believed that she could cope without their help. .

Displacement of carer

Some carers had previously been in receipt of sitter services and cancelled them because it meant that they had to leave their own home. Crossroads Care schemes are one of the few services directly provided for carers. The service was originally designed to provide carers with short-term respite whereby a paid carer would sit with the care recipient whilst the carer relaxed or pursued their own interests for up to four hours at a time. Carers were expected to leave their own home whilst the sitter was present. However, some carers had nowhere they particularly wanted to go or no friends to meet up with. They preferred instead to remain in their own homes but felt that they could not because of the nature of the service. This ultimately led to them cancelling the service. Although changes have recently been made to the way this service operates, carers seemed to be unaware of them. Mrs Davidson for instance explained that:

'I had Crossroads for a wee while. And that was a killer because she would come in and throw you out. But I had nowhere to go and where do you go when you have no friends left. I mean once I actually walked from Castlemilk roundabout to Mount Florida just to give myself something to do. It was the middle of winter, nearly snowing that day and I met one of my old neighbours. I was near to tears by this time and she said oh come on. I went away back up to her house. I felt terrible, this was one of my old neighbours and I'm sitting there near to tears. But she taught me something that day. After speaking to her I came away that afternoon feeling a wee bit more confident. So I didn't suffer in silence after that, I stopped the Crossroads[service] coming in'
(Mrs Davidson, 68 year old carer)

This account shows that until she met her old neighbour Mrs Davidson felt unable to cancel a service that was clearly not meeting her needs. Her lack of confidence to cancel the service suggests that she experienced a sense of powerlessness when engaging with service providers.

Wishes of care recipient

In other cases the wishes of the care recipient determined the acceptance of support. Whilst some care recipients were relatively passive and went along with whatever the carer decided, others were more dominant characters. Care recipients could exert their influence

by refusing to accept certain forms of support such as home care or respite. Some refusals of help arose from the care recipients' belief that only their carer could or should look after them. Mrs Watson's father for example, believed that no one could look after him as well as his daughter could and he refused to accept help with personal hygiene from home care assistants. Other care recipients refused support from services on the grounds of privacy. They shared the views of some carers that formal service provision was intrusive. Carers responded to care recipient's wishes by either never raising the subject of service receipt or not exploring the possibility of other types of support.

Carers said that to override the wishes of the care recipient caused more problems for them and they tended to take the path of least resistance. It appeared that to accept a service without the agreement of the care recipient could lead to tension within the caregiving relationship whereby the cared-for person could make life difficult for the carer. Thus many carers preferred to continue without support if it meant that their relationship remained peaceful and harmonious. Mrs Thompson's situation illustrates clearly the conflict of interests between the carer and care recipient. Caring for her 78-year-old father, Mrs Thompson explained that:

'There's a limit to what I can do. I mean I can't turn round and say you've got to go there [day centre], it would be nice, if he would go out for a couple of hours and give me some time to myself during the day but it doesn't work that way. So you just get on with it yourself. I don't want help to look after him because it makes more problems for me. Because then I've got to sit and listen to him moaning about people coming in and invading his privacy and wanting to know everything... I don't need or want their[service providers] help. I always knew where the help was if I needed it - but my dad wouldn't accept it. It wasn't that I wouldn't accept it, it was my dad who wouldn't accept the help. My dad frowned on anybody coming through the door, definitely frowned upon it. Carers won't get help because it is the cared-for person who doesn't want help. It is better to be, it is easier - how can I put this - we have a helluva a time once that person goes, we have a worse time with the person. It is less hassle not having somebody here. Because if there is somebody here, well we used to have barneys [fights] about it. Aye there is more of a hassle for us to ask for help if the person doesn't want it. It's more oh well, keep the peace'
(Mrs Thompson, 41 year old carer)

The above account illustrates how service receipt may be influenced by the preferences of the older person being cared for. With other client groups the carer is sometimes able to exert greater control. For example, the physical dependency and the lack of mental competence in someone with dementia allows carers and service providers to overlook their reluctance to accept services (Twigg and Atkin 1993, Parker 1993). However, in the

present study care recipients had no cognitive impairment and therefore had a degree of autonomy in making choices and enforcing them.

Lack of knowledge

Lack of knowledge about 'the system' was another reason why carers were not in receipt of services. Some seemed to be completely unaware of what was available or what they were entitled to and this made it more difficult for them to identify what help they required. Carers who had little knowledge of services tended to have had no previous contact with providers although they had been caring for some time. Mrs Black, for example, a highly educated schoolteacher had been looking after her mother for three years, did not know what services were available in her locality nor was she sure of how to access them. Feeling certain that her local community centre or GP would be able to assist her if required, she explained that:

'I don't know what help there is in this area. But I'd probably ask at the Dixon Centre. They'd probably know and can supply the information if I needed it. Or maybe I would just go to the doctors I suppose. I don't know. No, I don't know anything really. I'm very naive. I don't know what would help'

(Mrs Black, 47 year old carer)

A number of carers recalled how it was only after many years of caregiving that they had discovered almost by chance some useful information about available services. Talking about her experiences, Mrs Kearns reflected on how carers can ask for help when they do not know what is available. It was some months after her first encounter with a social worker that she found out through a carers support group what it was she did not know. She was critical of service providers' failure to inform carers about the services to which they were entitled. She explained that:

'If you are a gibbering wreck and you ask for help when you are really down, when people come they don't tell you what you are entitled to. Nobody tells you until you know the system. And I found knowing what you can get makes a big difference because you can ask for it. When they come out and ask you 'well what can we do to help you?' well you just don't know. You want help of some sort and you don't have any idea really of what's available.'

(Mrs Kearns, 37 year old carer)

As we have seen, carers in the present study cited a number of reasons why they had no support from formal service providers. Despite these objections many carers did eventually accept help. We turn now to explore why and how this transition took place.

Reasons for the Transition

We have explored the reasons given by carers for not using formal services. However, some carers did eventually accept support from service providers. We need to ask why and under what circumstances did they change their minds? As we shall see, a variety of reasons underpinned carers' transitions from unsupported to supported. These categories are as interpreted by individuals. They illustrate that what may be one person's crisis may be another's critical incident.

Crises

In some instances, the transition was as a result of crises as described in the previous chapter, where carers expressed feelings of being unable to cope any longer and there was a sense of urgency about the whole experience. Mrs Watson for instance, found her mental health was deteriorating and attributed this directly to her caring responsibilities. Her father was a difficult man to look after and when he became incontinent she felt that she could no longer cope. Her GP clearly recognised that decisive action was required when she presented herself in his surgery in a very tearful state and refused the offer of antidepressants. He subsequently arranged for her father to be admitted to hospital for a few weeks. Whilst her father was in hospital the GP also made a referral to social work who arranged a placement at a local day centre for two days a week. Yet Mrs Watson had been told that there was a long waiting list for that particular centre. She explained that:

'I was crying all the time. If anyone spoke to me about him I was just crying. She prescribed the Prozac for me and I went no thanks. So the doctor put my dad in hospital for two weeks to give me a break because I was near breaking point and heading for a breakdown...He's now in Mayfield [day centre] because the social work stepped in and done a report. My father was out and in there within two weeks when I was already told there was 40 people in front of him on the waiting list'

(Mrs Watson, 38 year old carer)

In this instance incontinence was the trigger that led to Mrs Watson's decision to seek help from her GP and ultimately to engagement with service providers. It was as she said '*the final straw*'.

Critical incidents

In other cases, critical incidents rather than crises were the catalyst, which led to the acceptance or seeking support from formal services. Critical incidents differed in nature to

coping crises in that carers responded to them with less urgency. Neither did they make carers feel as though they could no longer cope. Rather these incidents added to the demands made on them and the decision to engage with service providers was not sudden but reached in a more gradual manner. Incidents of this nature included periods of ill health of the carer or other family member such as sons and daughters or close friends, or deterioration in the health of the care recipient. For Mrs Duncan it was the withdrawal of support from other family members that led to her accepting the need for service intervention. The level of support provided by her two aunts had been reduced as one had been unwell and the other's family took up more of her time. Mrs Duncan was never sure whether they would watch her mother who was too frail to be left on her own. Having recently had to cancel plans because her aunts let her down Mrs Duncan wanted a service that she could depend on. Although her account suggests that she took the initiative in contacting social work, a carers support group actually made the referral. She explained that:

'I finally came to the conclusion that I really needed some help so I got on to social work...Well my mum was getting worse basically and I just felt that I was going from day to day not knowing what was going to happen next. I felt that I needed something because I was not very much good to her either. My aunts weren't doing anything. One of them hasn't been well and the other one has a son and grandchildren here from New Zealand. But I've always got to ask them, they don't offer anymore. I want something on a firmer footing. She [aunt] knew that I was really stressed out and she said I couldn't go out for a couple of weeks because they were doing things and that was getting to me. The other one had made plans to go out when she knew I go out on a Tuesday. That annoys me – They have the rest of the week to themselves'

(Mrs Duncan, 47 year old carer)

Although Mrs Duncan did not express feelings of being unable to cope, her actions were designed to prevent her reaching that point. She had come to recognise that receiving regular support would enable her to achieve her ultimate aim, which was to continue caring for her mother and prevent her admission to a home.

Accumulative factors

For others the transition was caused by an accumulation of reasons and critical incidents, but again the decision to engage with service providers was not taken in haste. Rather carers came to a gradual acceptance that this was the only way to proceed. For example, in Mrs Kearns case not only was her mother becoming increasingly frail, but she refused to accept help from anyone other than her daughter. Mrs Kearns also felt guilty at not having enough time to spend with her husband who was off work with a slipped disc and awaiting

surgery. His complaints about how much his wife did for her mother led to arguments and Mrs Kearns felt that caring was threatening her marriage. Furthermore, her 8 year old daughter had just been diagnosed as having dyslexia and she needed her mother's help with exercises recommended by the psychologist. Matters came to a head when Mrs Kearns approached her GP for help but refused to comply with the treatment he prescribed for her depression because of the side effects of the medication. After further discussion, her GP made a social work referral and advised Mrs Kearns's mother that if she did not agree to accept help then the alternative would be institutional care. She explained that:

'I was treated for depression twice and the doctor said you should go back on the tablets. I said no because they are not going to deal with the problem, it is just masking the problem. So that's how he [GP] arranged the assessment and I got respite... It just felt at times as though it was never ending for us. Things had to change because at the time my husband was flat out on his back. He said you are doing everything for your mum. We were fighting a lot. We even talked about splitting up. It was just far too much. So that's when I started putting her in [respite] and I tried to keep it going because it was working and I don't see why I should change it and go back to the way things were... It was a case of mother wouldn't accept help. I think she was a bit nervous of it. But I think the fact that the doctor said to mum you might need to go into a nursing home, she thought it best to accept help'

(Mrs Kearns, 37 year old carer)

Service availability

Another reason for the transition was an increasing awareness of service availability and the realisation that aids and adaptations might improve the quality of their lives. Mrs Currie for instance, a volunteer helper at her local community centre, had heard tales of people getting help from service providers. Encouraged by her newly acquired knowledge that she was entitled to help with the cost of adapting her bathroom to suit her husband's limitations she approached service providers. Whilst she claimed to have no time for '*the social work*' she nonetheless decided to ask for handrails for the steps at her main door and an electric shower in place of the bath.

Mrs Morrison was unique in that she accepted services because she saw them as a means of increasing the activity and interests of the care recipient. It was her neighbour's suggestion that her mother-in-law might benefit by going to a nearby day centre. The neighbour's mother happened to work there and arranged matters. In response to a question about it Mrs Morrison explained that

'It was actually the wee girl up the stairs. Her mother didn't run the club but she looked after the people in it for the carers. She took to do with the finances. And Alison said to me, why don't you get your mum into the day centre. She said, I'll speak to my mother about it. And the next thing the van came down and picked her up and I just signed all the forms. It was the best thing that ever happened for her. It really is. All she does is watch the television but now she gets out, she meets people, she gets her hair done, she gets her dinner'

(Mrs Morrison, 58 year old carer)

This account suggests that Mrs Morrison perceived the day centre as providing a service for carers rather than care recipients. Yet her reason for accepting the offer of a place was because it would benefit her mother-in-law rather than herself. This preference for and acceptance of services directed at care recipients was widespread among carers in the present study.

How the Transition was Accomplished

We have so far explored the reasons given by carers for not using formal services and we have also considered why the transition from unsupported to supported occurred. Now we need to look at how this transition was accomplished? Analysis of the data revealed four main pathways by which carers accessed formal services. Access to these pathways was via GPs, self-referral, hospital discharge procedures and sometimes through other parties such as carers support groups, local clergy or even neighbours.

General Practitioners

The most common pathway to service providers was through General Practitioners. GPs played a key role in helping carers to access services by referring them to other medical and social services. The role of GPs as gatekeepers to welfare services has long been recognised (Foster 1983). Although helping carers is not a central aspect of their work, it was to GPs that the majority of carers in the present study said they would turn if they needed help and advice. Some reported that their GPs were very helpful and they felt well supported by them. They tended to praise their GPs for being sympathetic, for '*popping in*' from time to time to see how they were, or for visiting them at regular intervals. In such instances carers felt that their GPs were aware of the difficulties they faced and regarded their needs as important as the care recipients. Mrs Thompson for example, believed her GP was more concerned about her health than her father's and had indicated his support if she wanted to end her caregiving role. She said that:

'If I want support then I'll get a hold of Dr Lance. He changed my life in that he made me see sense and that's why I go to him when I need that kind of support. Because the day I went in and seen him and he wrote this prescription out and he says there it is, take the valium - but the problem is always going to be there. He says fix the problem and you've fixed yourself. I said how can I fix the problem, he says get rid of him. That was his attitude to it, get rid of him. I said it's all right you saying that and he says to me no it's not. If you want me to get rid of him, I'll get rid of him because I could hospitalise you tomorrow because you are ready for a nervous breakdown, he says, and where does he go, because your man and kids can't cope with him, so where does he go? So that does make you think. So aye, you have got to get your act together'

(Mrs Thompson, 41 year old carer)

By contrast, other carers said that their GPs were unsupportive of their caring role. Such GPs were less likely to refer carers on to other services and left them with the feeling that there was nothing that could be done for them. In these cases carers felt that their GP either trivialised or overlooked their concerns and they tended only to get help if it was directly related to the medical care of the care recipient, for example, if the care recipient's condition necessitated bathing aids or a stair lift. In Mrs Teirney's case, she had felt that she needed a break from caring but despite approaching her GP for help, he failed to refer her to other service providers, preferring instead to prescribe Prozac for her. It was only when her husband's condition deteriorated that the GP arranged for him to be admitted to hospital. Yet he explained it to Mrs Teirney in terms of having arranged a break for her.

This incident raises the question once again of who is the focus of service intervention. It also illustrates the way in which some GPs do not view family carers as a legitimate focus of their work. The patient or the care recipient whose health is compromised is their priority. It was sometimes only when the carers' health broke down that unsupportive GPs took cognisance of their caregiver role. In Mrs Teirney's case it was only when she collapsed at home and required an emergency admission to hospital that her GP acknowledged her caregiving responsibilities. Since his carer was unable to look after him, Mrs Teirney's husband was re-admitted to hospital until she had recovered. They were both discharged on the same day with the promise of support services. She explained that:

'I feel very bitter about it. When you come out of hospital, when you're looking after somebody and you are feeling terrible, you're really ill. I mean as you get older it takes you longer and longer to get over major surgery. Yet I'm still expected to look after him, I'm still responsible. I got a phone call saying that Mrs M. would be up to see me the next day. I thought Mrs M was a home help. Mrs M. never came. About 5 weeks after I was out of hospital Mrs M. came up and she was head of the home helps'

(Mrs Teirney, 68 year old carer)

In this instance, it was unclear who the main focus of service support was, Mrs Teirney's or her husband. Both needed help and could therefore be regarded as care recipients. Mrs Teirney however, believed that services were being provided to enable her, the carer, to continue caregiving. Her perception might have been accurate given that current policy aims to support carers wherever possible. According to recent Scottish legislation, the Community Care and Health Act 2001, services to carers should be provided as part of an overall package of care and carers are regarded as key partners in the provision of care. Whilst many carers might appreciate being accorded the status of partner, Mrs Teirney did not, she wanted someone else to take responsibility for her husband's care.

Planned discharge from hospital

The second most common pathway to service providers was through the planned discharge of the care recipient from hospital. For some carers their situation came to the attention of formal services because of either a planned or emergency admission to hospital. Carers however, were unsure of who within the hospital staff was responsible for their referral to social services but assumed that it was the hospital consultant. Through this pathway, two carers had a comprehensive package of health and social care arranged as part of the discharge planning procedure and others accessed aids, equipment, home and day care.

The trigger in these instances tended to be deterioration in the health of care recipients and carers concern about their ability to cope with this change. In these circumstances carers seemed to be reluctant or incapable of opposing the wishes of the hospital staff who made the referral for assessment. They preferred instead to adopt a 'wait and see' approach. If the services offered were perceived by carers as being beneficial, then they remained in place. If they proved troublesome or too intrusive carers were quick to cancel them.

However, some carers reported that support services were arranged without their knowledge. It was only through phone calls or visits from service providers once the care recipient was home from hospital that carers became aware that they had been referred. This seemed to happen because of the way hospital doctors practised. Carers were often absent when the care recipient's care and treatment were being considered by the consultant. As a consequence sometimes decisions were made without consultation with carers or they were left in ignorance of important facts that could affect their situation. For example, Mrs Kearn's mother had been admitted to hospital one evening after falling down the stairs. When she was discharged home Mrs Kearns was unaware that her mother had undergone an assessment by a social worker. It was not until her mother was re-admitted

within three days of discharge that Mrs Kearns was told about her mother's assessment and that no support had been arranged because her mother had insisted that no help was required. Yet re-admission had been arranged because Mrs Kearns was unable to cope with her mother after her fall reduced her mobility and caused some confusion. Mrs Kearns explained that:

'She had a fall, she broke her hip on the Friday night and was operated on the next day. They put her on morphine on the Sunday, gave her a blood transfusion on the Tuesday and sent her home on the Wednesday. By Friday I had to phone the doctor out because I wasn't coping and she was admitted again...The hospital said that they had done an assessment of her needs before she came out. But unfortunately, the social worker spoke to my mum and asked do you need a home help, do you need this, that or the other. And she said oh I don't need it, my daughter does all that for me. And that was that...So they did a re-assessment after she was home. She came home about the beginning of September and the home help started in October'

(Mrs Kearns 37 year old carer)

This case illustrates how service providers often overlook the needs of carers and how caregivers are unaware of their right to a community care assessment. It also highlights the potential conflict of interests between the needs of care recipients and carers. Recent legislation, the Community Care and Health Act 2001, does however, recognise the possible conflict of interests between carers and care recipients. It places a duty on local authorities in Scotland, to notify carers of their entitlement to an assessment in their own right. The assessment must consider carers' ability and willingness to provide care. Moreover, the results of carers' assessment must be taken into account when the needs of the care recipient are being assessed for community care services. This legislation aims to support carers by acknowledging their right to support while recognising the potential conflict of interests between them and care recipients. It is hoped that by placing a duty on local authorities to assess carers' needs in their own right, it will facilitate access to services. Had Mrs Kearns undergone a carer's assessment prior to her mother's discharge from hospital, it is possible that the stressful events she reported could have been prevented.

Self-referral

Self-referral was the least effective pathway to service providers. Although carers in the present study had expressed a reluctance to initiate contact with formal services some had managed to obtain help directly from providers. Their initial reluctance had stemmed from a lack of confidence and uncertainty about entitlement to and availability of services. As Mrs Kearns said:

' I'm not frightened now to ask. Knowing [what is available}] makes a difference. I know some of the stuff [services] is no use at all but there might be things that you think, hey that might make a difference. Like the respite care, I didn't realise I could get that. Things like that make a big difference...Now I'm not frightened to ask for something like an extra weeks respite or something like that. Before I wouldn't have thought about it. '

(Mrs Kearns, 37 year old carer)

Others who referred themselves to formal service providers were seeking help on a routine basis. Mrs Veitch for example, had been consistently let down by other family members and she hoped that formal services might be able to provide regular and dependable support. Having made the referral herself three months previously, she had accepted the offer of a place at a day care centre but had refused home care services. She explained that:

'I knew I needed to get help from somewhere. So I phoned everywhere and eventually I got put on to social work. He came out. I didn't really know though what they could do to help. I just knew I needed something'

(Mrs Veitch, 69 year old carer)

On the other hand, some carers who had succeeding in making contact with service providers were left feeling disappointed with their lack of progress. For example, while attempts at seeking help had resulted in a visit from a social worker, no services were forthcoming. Promises made were never kept and carers were left feeling bitter and disillusioned. Some carers tended to blame their lack of success on their unassertive nature and their reluctance to take a pro-active approach. Mrs Yuill for example had decided to seek help when arthritis in her hands made it extremely difficult for her to help her 78-year-old husband. She believed that because of their age they would surely be entitled to some help. She explained that:

'I phoned to see what help I could get. Then I got a letter back saying somebody was coming and they never turned up. But then eventually a man did come one day and sat there and talked but nothing ever happened. You see, I didn't know about anything. I've never had anything to do with anybody like that in my life. And then a nice person came from there[social work] and I was thinking I was going to get help. I'm still waiting... I think it's me. I don't push things. You know I just tend to sit back and let things happen. You know if someone suggests something, then I'll say oh yes that's fine, I'll try it. But I suppose really I don't know exactly what's there. But really, I'm not a pusher'

(Mrs Yuill, 75 year old carer)

Carers believed that a self-referral was treated with less urgency than if a professional such as a GP or community nurse had made it. Unassertive carers were easily deterred from pursuing the matter and they simply continued caring without support. By the time her

caregiving role ended with her husband's death, Mrs Yuill had received no support whatsoever from formal service providers despite her own frailty.

Carers Support Groups

The fourth pathway to providers was through carers support groups. Support groups, as one of the few forms of support directly provided for carers are sources of information about benefits and services, social and recreational facilities such as art and relaxation classes and advocacy services. Many carers lacked the knowledge and the confidence to make contact with service providers directly. Carers groups on the other hand possessed a great deal of information and experience in assisting carers to access a range of services and benefits. Moreover, their work in supporting carers seemed to be recognised and any referral they made to social services was acted upon quickly although the outcome may not have been the one desired by either carer or the support group. Mrs Davidson for example, described how a 'nice man from the social' came to visit her unexpectedly. When asked about who approached the social work department, Mrs Davidson said:

'The Carers Association did. I have had Maureen who runs it out, she came in and assessed my mum. I must admit after that they [social work] weren't long in coming out but nothing's happened since. So I'll wait and see what Maureen comes up with. She's to come out again to see my mum'

(Mrs Davidson, 68 year old carer)

Carers support groups were valued highly by those who made use of them. Mrs Beaton for instance had been looking after her 84-year-old mother for six years. She thought that becoming involved with the carers group was the best thing that had happened to her as a carer. She explained how her daughter put her in touch with them at a time in her caring career when she most needed help but didn't know where to turn to. She said that:

'As a carer you've no life. No social life. But the Carers [support group] is the best thing that has happened to people in our position. Because before that you'd nobody. I think back to two years ago, Saturday night, I'm no kidding I sat and broke my heart. I thought I need to get help from somewhere because if I don't I'm either going to murder her or I'm going to take an overdose. That was the only way I could see out of this. I'd to end up phoning my daughter and she got in touch with the Carers. She'd seen a poster in a shop window'

(Mrs Beaton, 51 year old carer)

Carers support groups also played a key role in enabling people to see themselves as carers and as such this identity sometimes became important in making them more assertive in seeking and accepting help. Moreover, hearing about the success of others was encouraging and once carers had an initial encounter with service providers that resulted in

a positive outcome, they were much more willing to instigate further contact. For instance, from having no contact at all at stage one of the present study, by stage three Mrs Beaton was keen to get whatever help she could.

One carer was exceptional in that his Church of Scotland minister had initiated contact with service providers. Whilst visiting Mr Downs and his wife, the minister explained to them about a day care centre that had been established in part of the local church hall. He felt that this service would benefit both of them and sought their agreement to arrange a place for Mr Down's wife. Since transport would be provided Mr Downs could think of no other excuse to refuse and he reluctantly accepted the offer of a place for his wife. However, he quickly came to appreciate the service and valued the support he received from the staff at the day centre.

Experience of Services

This chapter has traced carers' transition from being unsupported to supported by service providers. It has considered why they were unsupported in the first place, why they accepted help and how the transition was accomplished. Now it will explore how the realities of service receipt compared to carers' perceptions, did it overcome previous doubts or were their fears confirmed?

For a few carers who ultimately perceived their need for support as overwhelming, the actual experience of service receipt did not match their preconceived ideas. Although services such as home care, perceived by carers as being intrusive, were not widely used, those who did receive it valued it. The intrusive nature of the service became less important once its value to the carer was established. Mrs Kearns for example, having struggled to care for her mother on her own for six years could not imagine coping without support from the home care service. In this instance the home carer restricted her activities to the care recipient's bed-sitting room and the kitchen. The service allowed Mrs Kearns time to attend to her children and take them to school in the morning, knowing that her mother's needs were being taken care of. Mrs Kearns said:

'It is just amazing the difference it makes. You know just with that bit of help in the morning, it just makes things so much easier. Just having that space, the rest of it has fallen into place. The hospital said they would arrange things, they promised me help'

(Mrs Kearns, 37 year old carer)

Community nursing services were like home care in that they were regarded as intrusive but they were more acceptable to carers because the cared-for person was the direct recipient of the service. Carers perceived them to be supportive and responsive to calls for assistance. Mrs Watson for example, depended on community nurses for emotional support and advice rather than help with practical care. On the other hand, Mrs Macrae received visits from community nursing services three times a day, seven days a week. This service was part of a comprehensive package of care that was arranged prior to her mother's discharge from hospital. Rather than view this level of service as intrusive Mrs Macrae welcomed the visits because it alleviated the loneliness that she experienced as a result of caring. This was in marked contrast to her attitude some months before when she cancelled services because of their unsuitability. Thus for those who accepted services initially perceived as intrusive the reality of receipt did not match their preconceived ideas.

Other carers who perceived services to be authoritarian and intrusive in nature and expressed a dislike of having strangers in their home did not have the opportunity to have their fears either confirmed or overcome. When the need for support arose, these carers tended to accept the least intrusive forms of help such as aids and equipment, respite or day care. These services were not regarded as being intrusive and nor did they entail letting strangers in to their homes on a regular or routine basis.

A referral for aids and equipment was often carers' first contact with providers. Once the aids or equipment had been obtained there was no need to maintain contact with providers. Although this pattern suited some carers, for others a positive outcome tended to lead to further requests for help. Mrs Watson for example, caring for her rather obese and incontinent father had had a referral made on her behalf for bathing aids. The outcome of this referral was the provision of bath aids and lifting equipment that made her daily routine much easier. This successful encounter with service providers had given her the confidence to approach them herself for more help. She explained that:

'I phoned up and asked if I could apply again. I was told to go ahead and apply. Kay [social worker] said I should get a community care grant because of my dad being in hospital. I'm going to apply for trousers and things. I mean it's jogging trousers but he's going away and I've got to buy them for him. But I can't just go to any shop because of my daddy's size'

(Mrs Watson, 38 year old carer)

The provision of aids and equipment is important in supporting the caregiving role. A recent study highlighted how the use of aids and equipment enhanced carers' lives in a number of ways (Qureshi et al 2000). Not only did it help carers perform everyday tasks

with ease, it also helped relieve pain or discomfort for both carers and care recipients. Moreover, by increasing the self-sufficiency of the care recipient the use of aids and equipment reduced the demands on carers (Qureshi et al 2000). These findings are similar to those of the present study in that carers reported beneficial outcomes, particularly in relation to bathing or negotiating stairs.

The most widely used services were day and respite care. Like equipment, these services were not intrusive in nature and no invasion of carers space occurred because service provision took place outwith the home and only for a pre-determined period of time. Although carers had initially expressed concern over the possible standard of care the majority were pleased and particularly happy to accept respite again. Mrs Kearns for example, explained how important respite was to her:

'The respite is important because you can go so long and be fine and then. It's not that anything changes but suddenly you just need to have a break, just a family time. Time to be able to have a long lie in the morning if you want it you can have it because you don't have to worry about tablets and medicine and things like that, getting downstairs. You don't have to listen out for noise or bumps and things and you don't need to be on call. It just makes a difference having the respite. Even if it is only a week, just to please yourself. It is very, very important. Sometimes when she comes back it makes you feel disgruntled. It did at first because you never knew when you were getting it again. It used to be only two weeks of the year. It was a terrible thought to go back to that because you realised what you were missing out on and what normal life was like. But I think I have got used to it now because I know when my next break is coming up. Not that I count it down or anything but you think, that's fine you get back into the routine of it then you start looking forward to the next break. For me, knowing when the next break is coming up is very important.'

(Mrs Kearns, 37 year old carer)

When arranging respite or day care the care recipient's compliance was important and was gained by reframing the meaning of the service. For example, some carers found respite care more acceptable if it was thought of as a 'holiday' to which the care recipient was entitled. This seemed to give their requests for respite a legitimacy that did not generate feelings of guilt. Respite tends to be seen explicitly as a service for carers and they did not necessarily like admitting to a need for a break from caregiving.

Criticisms of services

While carers were generally pleased with the actual support they received, criticism was levelled at difficulties in accessing services. Access was constrained by complex administrative procedures and poor communication. Carers experienced the system of

referral and assessment for services as inefficient, unreliable and frustrating. For example, Mr Brown having received respite care for his father on more than one occasion found that each request was followed by an assessment. He felt that this was unnecessary since his father's condition remained unchanged. He found the delay between making the referral, assessment and confirmation of respite frustrating because his requests were never confirmed in time for him to book a holiday in advance. Although respite had never been denied he felt that the service was unreliable and had taken to making his own arrangements. Yet others living in the same area did not experience similar difficulties. Mrs Thompson for example, reported that she simply phoned up her social worker and told her when she wanted respite. She found access to respite straightforward and unproblematic. However, carers living in other parts of the city had experienced similar problems as Mr Brown and they too had taken to arranging their own respite care and informing their local social work office who would then provide financial assistance. Thus the availability of and access to respite services varied in that some carers found it relatively simple to arrange while others found it more difficult.

Only one carer was highly critical of the quality of the respite care her mother received and of the way the placement was dealt with. Mrs Smith explained that the social worker dealing with the request for respite was concerned to find a home that would cater for her mother's specific religious and dietary requirements. This was not of concern to the carer, the care recipient or her family who felt that the quality of care was more important. In the event, Mrs Smith's mother was found a place in a nearby home for a period of two weeks. However, within a week of the admission, staff at the home notified Mrs Smith that her mother had sustained an injury. On examination, Mrs Smith's mother had severe bruising and lacerations to her head, back, arms and legs. Yet no explanation was forthcoming. Care staff were apparently unable to account for these injuries. Moreover, when packing to take her mother home, Mrs Smith found that some clothes, underwear and personal belongings were missing. Despite making an official complaint the matter had never been resolved or explained to Mrs Smith's satisfaction. This disappointing experience led to withdrawal of contact with services and renewed determination not to seek their help again. It also confirmed Mrs Smith's belief that formal service providers were incompetent, unreliable and inefficient.

Access to day care seemed to be even more restricted than respite because carers were generally unable to make referrals themselves. Access was usually via a referral from either a GP, social worker or hospital consultant. Whilst in theory this service might be supplied for the benefit of the care recipient, in the present study it was usually arranged to

benefit carers who regarded it as short term respite. Once obtained, those who used it valued it highly because it was normally provided on a regular basis, with some care recipients attending on two, three or four days a week. Its function was supportive rather than therapeutic.

To carers the referral and assessment procedure seemed a lengthy and drawn out process which created unnecessary delays. Attempts to overcome these delays caused carers to experience the negotiation process with providers as a battle. In this respect their experiences confirmed the opinions of those who had compared negotiations with service providers to a fight. Experience taught carers that they had to be assertive and determined in order to access services. Delays, a seemingly inevitable feature of the journey to service receipt, increased their sense of helplessness and generated feelings of anger and frustration. Although some carers eventually succeeded in getting help they were critical about what they perceived as a lengthy fight to obtain it. Delays in obtaining aids and equipment were particularly lengthy. For example, Mrs Currie, caring for her 85 year old husband, explained that it took her about three years to get help:

'I am not awful keen on social services. I got what I wanted but it took a lot of hard work. You have to assert yourself very fast and access the services really quickly. And I think you have got to fight for what you want. They are not interested unless you push yourself forward. Unless you keep at them, they won't come to you. I felt they were pushing me back all the time and at one point I got really angry. I had been trying for three years. And one of the social workers said but your referral only went in last November. I said, I beg your pardon dear, I said, my referral didn't go in one year ago, not two years ago but three years ago. You may not have put it forward but I said, it did go in and I have proof of that. I said I'll be back and I'll be back every week because my husband can't get out and in the bath. So I went home and in about a fortnight the phone went. [The social worker said] 'Would it be all right if I came on Thursday to see about your shower?' Oh I said, by all means...The architect came, the head plumber came, the social worker came and the lady from the housing came and went into the bathroom. So that it was it, they decided. They said yes, they would put in a shower. I didn't like it, having to ask for help. I have never had to do it before'

(Mrs Currie, 83 year old carer)

It is recognised that the efficient and rapid provision of services is essential if older people are to avoid hospital admission and enjoy a good quality of life (SEHD 2001). Yet a recent survey confirmed the findings of the current study, that waiting times for the provision of equipment was problematic and unacceptable. Whilst this survey revealed that on average more than 5,000 people in Scotland were waiting for equipment, it did not detail the length of time people had to wait. The lengthiest delays seemed to occur in the stage between assessment and funding authorisation (SEHD 2001). A factor contributing to this was that

almost all assessments were undertaken by occupational therapists while team leaders and senior managers took funding decisions.

As we can see, once embarked upon the journey to service receipt, carers' experiences of services varied and their pattern of use was irregular. Davidson and Reed (1995) has likened the experiences of people embarking on a career as a client of services to stepping onto a moving escalator. It can be difficult to get on this escalator but once on board, the user is carried on towards increased dependency and reduced risk. The opposite process is refusing to accept or cancelling services thus moving to less dependency and greater risk taking. Davidson and Reed (1995) claims that once people are on the escalator, they are more likely to be offered other types of care that minimise risk but increase their dependency further.

However, the findings of the present study contradicted Davidson and Reed's views. In the current study it was younger rather than older people who once in receipt of services seemed reluctant to step off the moving escalator. In some cases, they remained on the care escalator in order to pre-empt future problems because they anticipated difficulty in regaining services, if required in the future. In contrast, older service users stepped on and off as it suited them. They were more likely to try out a service and then cancel if it proved unsuitable. A possible explanation for these differences might be that caregiving created more conflicting demands on younger carers than on older ones whose children had grown up. They perhaps remained on the care escalator because the receipt of formal services benefited not just the care recipient but the whole family unit. For younger carers whose caregiving role caused marital problems, increasing service use often reduced the tension within their personal relationships. Older service users did not experience the same conflicting demands on their time between caring and the needs of a young family. To them, service use was more intrusive and therefore less welcome.

Power of Service Providers

As has already been noted in a previous chapter, caring is a power relationship. Service provision also takes place in a context of power in which providers not only have control of allocations but also to some extent over the nature and the source of the problems that carers experience (Gubrium and Sankar 1990). As we have seen in chapter seven, Foucault's work has highlighted the complex ways in which power operates. Power for

Foucault, is fluid and flows in a capillary like manner. Operating in a covert way, it is all around, in and through society. According to this view, power is a strategy possessed by individuals and present in all social relationships. Examples of this are the relationship between a doctor and patient, carer and care recipient or user and service provider.

Concentrating particularly on 'bio-power' and 'disciplinary power' Foucault's (1979) work explains how new forms of power have emerged. These concepts explore the history of bodies and the effects of power on them. Power is exercised through a range of subtle controls and surveillance to define, order and control bodies. Foucault describes how constant surveillance of prisoners' bodies in penal institutions regulates inmates' behaviour without the use of force. Surveillance of patients in hospitals or in the community or children in schools also operates in this way. People must behave if surveillance is constant even if no one is actually observing at any given moment. These techniques were he claims, developed to control, manipulate and produce a

'body docile [that] may be subjected, used, transformed and improved'
(Foucault 1979:136)

Foucault argues that power, discourse and knowledge are inextricable connected and intertwined. Discourses and knowledge both inform practice and provide the authority for a group's claim to status and control. In his analysis of the development of health and welfare institutions, Foucault maintains that such systems provide the ideal setting for the exercise of power and domination because of the knowledge claims on which they are based. Within welfare systems providers are essentially professionals such as doctors, nurses and social workers. They exercise power through their practice and the discourses that relate to them. Not only do they provide help but also and more importantly, they define the object of their work in the form of a general concept of the client or patient. Their power can be seen in the general acceptance by patients or clients of decisions taken in relation to their care. Although located in the community rather than traditional institutions, even lower grade providers like home care assistants exercise power by managing clients care (Twigg 2000). Their role is similar to that of the prison wardens and nurses in asylums analysed by Foucault.

The power dynamics of caregiving whether in the formal or informal sector are inherently unequal. The service provider perceived as strong, capable and knowledgeable interacts with service recipients or in this case carers, who might be frail, vulnerable and unaware of their rights and forced to rely on their goodwill. In the current study, carers' accounts of their experiences illustrate the power dynamics that exist between service users and

providers. We have seen in this chapter how carers experienced access to services as conflict, how they perceived professionals as authoritarian and how some felt unable to exercise their power as a user to cancel services when they felt they were unsuitable. We also saw how the needs of carers tended to be overlooked when care recipients were being discharged from hospital or undergoing a community care assessment. These are all examples of interactions between carers and service providers where the balance of power was inherently unequal.

Service providers establish and maintain control through ownership of knowledge and resources. By exercising the authority vested in them by law, providers control carers access and receipt of services. The receipt of services hinges on assessment. According to Coulshed (1991 cited in McDonald 1999) an assessment is 'a perceptual, analytical process of selecting, categorising, organising and synthesising data' that relates to lives of carers and care recipients. In other words, an assessment is a process that evaluates carers' lives and determines their eligibility for services. Seeking or receiving help requires that carers offer themselves up as a client or an object for scrutiny and surveillance by professionals. The assessment process can be likened to the ritualistic admission practices in the institutions studied by Foucault whereby prisoners or inmates of asylums are stripped of their clothing and identity in order to reclassify them as objects. This according to Foucault is a process that objectifies silences, dominates and exposes people to public scrutiny.

In a community care assessment, carers and care recipients are similarly stripped of their right to privacy and are expected to divulge personal and intimate details of their lives, while the professional keeps theirs private. The assessment objectifies carers as clients and exposes them to the public gaze. Having their lives examined in this way, in the face of someone who is not in a similarly exposed position, creates a powerful dynamic in which the carer is vulnerable and dominated and forced to rely on the goodwill and knowledge of the professional in allocating services. This dynamic places the carer in a dependent and less powerful position.

However, where there is power there is also resistance (Foucault 1979). According to Foucault, resistance is an essential part of power. He claims that people are not simply victims of power, rather they continually seek to gain some control over their lives. Although few carers in the present study challenged the authority of service providers directly, some attempts were made to resist their power. Firstly, since control is related to decision-making (Lukess 1987) carers resisted service providers' power by challenging

their decisions. This usually took the form of refusals of offers of services or equipment that providers had decided would be beneficial. Mrs Duncan for example, despite admitting her need for help refused the offer of day care for her mother. Mrs Watson would not accept a standing frame for her father that the physiotherapist thought would be helpful.

Secondly, carers exercised power and maintained control by placing limits on the type of help they would accept. The majority accepted only the least intrusive forms of support such as respite and day care services that were provided outwith the carer or care recipient's home. Finally, the conflict that carers experienced in their interactions with service providers illustrated their attempts to redress the balance of power. Conflict was generated by both parties trying to pursue their own interests. Carers generally had an idea of what type of support they wanted and when. Professionals, on the other hand, were trying to assess and meet carers' needs within the restrictions of local budgets and service availability. Although few carers articulated their awareness of a power imbalance they were sensitive to it. This almost subconscious awareness of a power dynamic generated a sense of unease, which in some cases resulted in a continued reluctance by carers to engage with service providers.

Conclusion

The purpose of this chapter has been to describe and explain the transition from unsupported to supported carers. At the start of the study carers and care recipients were not in receipt of formal services. By the time the study was concluded, the majority were receiving some kind of help to continue caring. The most widely reported reason for non-use of services related to their authoritarian and intrusive nature. Carers' awareness of available services and how to access them varied.

Why then did carers eventually come to accept help formal support? For some carers the transition was as a result of a crisis in caring which left them feeling that they could no longer cope. In other cases, critical incidents, rather than crises were the catalyst. For some carers the transition was as a result of various difficulties and critical incidents accumulating over time. In these cases, non-resolution led to a particular incident becoming 'the last straw' that provoked the decision to seek or accept help. Increasing awareness of service availability and entitlement to support was another reason for the

transition. Once carers possessed the knowledge that they lacked, they were empowered to take decisive action.

Regardless of the reasons, service intervention was not necessarily quick. As we have seen, even in situations that carers perceived as a crisis, contact and receipt of support took time. From referral to receipt of services varied between two weeks to more than three years. The transition was accomplished via four main pathways by which carers accessed services; GP's, hospital discharge, self-referral and carer support groups. The pathway used most often by carers to access services was through their GP, followed by hospital discharge procedures. Self-referrals seemed to be the least productive pathway. Carers support groups were very influential in negotiating with service providers on behalf of carers and advising about benefit entitlements.

How did carers' experiences compare to their perceptions? Carers had expressed concern about the perceived intrusive nature of services. But in reality, they resolved this concern by accepting more readily the least intrusive services. In some instances carers' experiences of service receipt overcame their previous doubts. For example, those who accepted services perceived as intrusive such as home care, found that in reality the intrusion into their lives became less important once the benefits of receipt were demonstrated and helpers were no longer strangers. Complex administrative procedures and poor communication led to difficulties in accessing services. But having finally gained access to *'the system'* carers, were on the whole, happy with the services they received. It was only the journey to service receipt that was tortuous and beset with difficulties.

This chapter has focused on the barriers and drivers that might inhibit or encourage carers' access to services. A key theme throughout this chapter was the question of who is the focus of service intervention, the carer or care recipient. What is considered a service for carers is unclear. This uncertainty contributes to the difficulties carers' experience in accessing services. Carers' accounts suggest that they might find it easier to consider services that directly support the care recipient rather than themselves. Carers in the current study were deterred from seeking support because they felt it was the care recipient and not they that needed help. Seeking help was to them tantamount to an admission of failure. Carers accepted help from community nursing services more readily because there was no ambiguity over who this service was for.

Service receipt was a process of negotiation. It was also a power relationship. Service providers exercised power through their possession of knowledge and resources. This

allowed them to control carers' access to and receipt of services. Nonetheless, carers resisted service providers' control and domination in a variety of ways. It was the fear of service providers' authority and control over their lives that often discourage carers from seeking their support.

This chapter has discussed carers' transition to supported caregiving and how the reality of service receipt compared to their preconceptions. The following chapter will summarise the findings of the present study and present some recommendations for future policy and practice.

10. Discussion and Conclusion

Circumstantial Dimensions of Caregiving

This study sought to explore the question: why when caregiving is portrayed as being stressful do carers continue without support from formal service providers? In addressing this question, each of the previous chapters focused on a particular dimension of caregiving. By exploring the circumstantial dimensions of caregiving this study has shed light on carers' experiences and in particular, their interactions with service providers. Twin themes of choice and control underpinned carers' experiences. Thus analysis of the circumstantial dimensions of caregiving highlighted a number of processes such as becoming a carer and referral to services. Taken together these processes form a temporal model of caregiving, within which formal services are central. This chapter will summarise and discuss the findings of the present study before presenting this temporal model of caregiving.

Becoming a Carer: choice and control

This study began by highlighting the process by which individuals became carers. This process is marked by either the presence or absence of choice and control. The findings suggest that the way in which a caring role is adopted can have implications for the degree of choice that can be exercised. The majority of carers, whose ability and willingness to care were assumed, drifted into caring via the default pathway. They perceived themselves to have had little or no choice and no control over whether or not they became a carer. Adult children who lived some distance from their parents' homes tended to become carers via a positive pathway, where an element of choice was present and as a consequence, they experienced a degree of control over their situation. Adoption of the caring role by those who had a choice was underpinned by the view that there was no one else to provide care or that the alternative, institutionalised care, was unacceptable.

The majority of individuals in the present study became carers following the sudden or gradual deterioration of the person being cared for. This deterioration usually brought the care recipient to the attention of medical professionals. However, when people became ill

or were admitted to hospital, neither the patient nor family members understood the implications of the illness for their eventual role as carers. Hence, most carers took on their role in a state of 'initial innocence' (Taraborrelli 1994) with no real concept of the likely demands it would place on them. These findings are similar to those of other studies. Braithwaite (1990) for example, notes that particularly in crisis situations, the choice to care is frequently a passive one, based either on the belief that there is no one else or that there are no acceptable alternatives. She claims that the willingness of family members to care in such circumstances is usually taken for granted, without genuine assessment of their feelings or ability to care.

Nature of Caregiving: motivation and relationships

From the findings discussed in chapters five, six and seven it is evident that, irrespective of whether they made a positive choice to become one or not, the vast majority of carers had a powerful sense of duty and familial obligation. Most carers in the study were related to the person needing care and usually had feelings of affection towards them. This suggests that the motivation to provide care was strong because it was driven by emotional attachment. However, caregiving was provided even in situations marked by the absence of affection and reciprocity. In these cases, carers experienced such an overwhelming sense of obligation that they felt that they had no choice but to continue caring.

In the current study a sense of obligation directed carers' actions and helped them decide *what* they should do; should they provide care or not. On the other hand, the norm of reciprocity, which encompasses the notion of exchange, helped carers decide *whom* to assist. The care provided was often perceived as being in exchange for previous help and support from the care recipient.

The nature and quality of caregiving relationships were central to the experience of caring. Relationships based on affection and reciprocity were qualitatively different from those whose basis was obligation alone. Carers who had a strong and emotionally close relationship were more likely to perceive caring as unproblematic. In these positive relationships, there had usually been a long-standing close association where a good rapport had been established before the onset of caring. Affection in caregiving relationships that had developed over time was not easily diminished by the problems encountered in caring. However, carers who had a fragile and emotionally distant

relationship with the cared-for person tended to view caring as difficult and beset with problems. In these negative associations, the history tended to unveil an emotionally distant relationship that was problematic before the need for care arose. Problems in the relationship caused by personalities were long standing and not easily resolved.

Control within Caring: gaining and maintaining power

Problematic caregiving relationships were characterised by conflict and tension. Conflict within caregiving relationships was often related to issues of control. Gaining and maintaining control was an important issue for carers in the present study. Power and subsequently control, was related to ownership of and access to resources such as homes and money, irrespective of whether they belonged to the carer or the care recipient. By exercising power within their own home, carers who brought their parent to live with them were able to control the situation by establishing rules and boundaries and determining what was acceptable behaviour. However, carers who had moved into the home of the cared-for person were less likely to be in control of the situation and found it difficult not only to take control of caregiving but also to feel 'at home' in their parent's house. Feelings of being in control had important implications for carers' perceptions of coping and for their interactions with service providers. Carers who felt that they were in control of caregiving tended to perceive themselves as coping. If they felt they were coping, carers were less likely to want or seek support from service providers. On the other hand, carers who were not in control of caregiving perceived themselves as not coping and, as a result, tended to accept service support more readily.

Caregiving has been acknowledged by a number of authors as being a power relationship (Graham 1983, Orme 2001, Twigg 2000). References to power within caring imply that caregivers exercise power over care recipients (Twigg 2000) but this study has shown that in certain circumstances, care recipients are able to exercise their own power to achieve control. Few studies however, have explored in detail the ways in which power and ultimately control, is gained and maintained within the informal sector or how it relates to carers' experiences of stress and coping.

Coping with Caring: stress, expertise and crises

Stress was caused by the direct activities of caregiving such as the provision of personal and intimate care, the behaviour of care recipients, tiredness and having to deal with service providers. Equally stressful but less visible aspects of caregiving included feelings of constant responsibility, and the need for planning, supervision and monitoring of care recipients' activities.

Stress and coping are processes that must be understood in context and over time. As discussed in chapter eight, analysis of the data revealed the temporal and dynamic nature of stress and coping by highlighting three linked processes. Firstly, carers' stress seemed to increase as the length of time caring increased. Caring was not perceived as being particularly stressful at the beginning, and that it was only as the time went on that perceptions changed. Sources of stress seemed to multiply over time because one cause of stress gave rise to others. Therefore, as the length of time caring increased stress had an accumulative effect in that one source of stress gave rise to others. Carers who did not perceive caring to be stressful tended to have had previous experience of caregiving. This prior experience seemed to obviate the emergence of stress.

The second process was the development of expertise whereby carers became increasingly skilled in the management and tasks associated with caregiving. Practical experience of caregiving seemed to encourage the use of an increasing number of coping strategies. Through a process of trial and error, carers were able to determine what worked best and what was a waste of time. This process led to increasing confidence and ability to cope. These two processes present an apparent paradox whereby the majority of carers who said that caring became increasingly stressful seemed to be the same people who perceived themselves as coping better. The proposed explanation for this paradox related to the third process that carers experienced.

The third process was that of crises followed by a period of appraisal and sometimes a change in mind set. During the crisis carers were unable to maintain a reasonable emotional balance and expressed negative feelings about their situation. Crises were usually related directly to the caregiving situation although external events added to the tension and to carers' sense of helplessness. The pattern was for a period of stability to be followed by a series of minor problems. Each problem irrespective of its magnitude increased the strain on the carer particularly if it was not resolved to their satisfaction. The

cumulative effect of strain seemed to result in 'overload', which occurred when carers felt they had had enough and could not continue caring.

Coping with a crisis usually entailed an unconscious process of appraisal whereby carers described a growing awareness of their own unhappiness, and the problems and restrictions on their lives. A crisis forced carers to consciously think about and confront the realities of their situation, whilst appraisal was a period during which they reviewed their caregiving role. This was a potentially crucial point in carers' careers, when they could have decided not to continue caring.

Carers' responses to these crises varied and were described as being active, passive and expert. Carers who reacted to crises in a positive way made an 'active response'. The crises that they experienced were positive in that they were the catalysts for constructive change. Following a period of appraisal these carers subsequently adopted a more pro-active approach to caregiving which included the setting of limits and being more assertive.

The 'passive response' made by some carers differed to the active response in two respects. Firstly, carers who adopted a passive response appeared to develop little or no carer expertise. Secondly, their crises were not catalysts for positive change but rather were destructive in that they either caused carers to question their ability to cope, or they confirmed their belief that they could not. After a crisis these carers tended to passively resign themselves to the situation rather than accept it and adopt a pro-active approach. Some had tried unsuccessfully to seek help from service providers because they felt that they could no longer cope but their failure to obtain help had lowered their self-esteem and confidence.

The 'expert response' stood outwith the other two. These carers did not report having increasing levels of stress or a crisis. Rather they believed that they were coping well and were more likely to already possess a degree of expertise. Many of them had been either trained or untrained nursing staff or had previously cared for other relatives. It seemed that having previous experience, the possession of caregiving skills and confidence in their ability to cope with whatever came along protected them in some way from the stress that others experienced. These three differential responses illustrate how carers in the present study, who had broadly similar careers, responded in different ways to challenges of caregiving.

Transition to Supported Caring: negotiation and control

At the start of the study carers and care recipients were not in receipt of formal services. The most widely reported reasons given for not using formal services were related to the perceived authoritarian and intrusive nature of services and negative perceptions of service providers. It was often the fear of service providers' authority and control over their lives and the erosion of privacy that discouraged carers from seeking or accepting support. This finding is similar to that of Stalley (1991) who found that the desire for independence and control underpinned older people's refusal of the home help service. She concluded that maintaining a sense of control and independence was essential for the wellbeing of non-users.

By the time the present study was concluded almost two years later, the majority of carers were receiving some kind of help to continue caring. The pathway used most often by them to access services was through their GP. This was also the most effective pathway. The second most widely used pathway was hospital discharge procedures followed by self-referrals and carer support groups. The least effective pathway was self-referrals.

For some carers the transition to supported caring was as a result of a crisis in caring which left them feeling that they could no longer cope and forced them into a sudden decision to seek help immediately. In other cases, critical incidents were the catalyst. Critical incidents were important events such as a period of ill health, which added to the demands made on carers. Critical events differed from crises in that carers felt able to cope with them and as a result their response to them lacked a sense of urgency. For the majority of carers, seeking help was seen as an admission of their failure to cope with the demands of caring.

A key theme throughout negotiations with service providers was the issue of power and control. Service providers exercised power through their possession of knowledge and resources. This power allowed them to control carers' access to and receipt of services. Carers' experiences as discussed in chapter nine, suggest that they were aware of the power dynamic in their relationships with service providers. The power of service providers was apparent throughout carers' interactions with them. Carers experienced negotiations with service providers as a lengthy, drawn out, difficult and frustrating process characterised by delays and conflict, which they described as battles or fights. During this process carers felt helpless, disempowered and extremely frustrated. Some felt so disempowered that they were unable to cancel services deemed unsuitable.

The process of referral and assessment in particular, reflected service providers' power and control over carers' lives. The assessment process was central to service receipt. In order to access a service, a referral was followed by an assessment of need in order to determine eligibility. But in community care assessments carers' right to privacy is removed and they are expected to divulge personal and perhaps intimate details of their lives. Assessment places carers in a vulnerable position and susceptible to domination and control by service providers. Service providers' power was illustrated by carers' acceptance of their decisions.

However, where there is power there is frequently also resistance (Foucault 1977). Some carers resisted service providers' power and attempts to control the situation by refusing to accept their decisions in relation to the type of help that was appropriate. This conflict was resolved by carers exercising their own power to maintain control. They achieved this by either making their own arrangement for services from other providers or placing limits on the type of help they would chose to accept. For example, whenever carers tried to negotiate respite care, they found themselves very much at the mercy of social work services. In an effort to maintain control over what they perceived as a well earned holiday, some carers made their own arrangements for respite and contacted social work only to inform them about their need for financial assistance.

Carers who had originally expressed concern about the intrusive and authoritarian nature of service provision placed limits on the type of support they would accept. Service delivery in either the carer or the care recipient's home was seen by carers as having the potential to violate their privacy and as a result, reduce their control over the caregiving situation. Thus because they did not entail strangers coming into their homes on a regular basis, services such as aids or equipment and day care were considered to be less intrusive and usually chosen in preference to home care services. By accepting services such as day care that were delivered outwith the home, carers ensured that their need for support was met while at the same time their privacy and control over the situation was maintained.

However, having gained access to 'the system,' carers were generally happy with the services they received. The few who accepted services perceived as intrusive such as home care, found that in reality the intrusion into their lives and the lack of privacy became less important once the benefits of assistance were demonstrated and helpers were no longer strangers. Thus the reality of carers' experiences often compared favourably to their previous perceptions and helped to overcome their initial doubts.

Carers, who by the end of the study, continued without support from statutory providers were determined that they did not need or want service support. They wanted to maintain their sense of privacy and control of the situation. They continued to perceive service providers as authoritarian, intrusive and inappropriate. However, the experiences of other carers in the study allow us to speculate that, if visited again at a later date, many of these people might no longer be unsupported caregivers.

Temporal Model of Caring

The present study set out to extend our knowledge and understanding of the temporal and dynamic process of caregiving. Indeed, as discussed in chapter four, the research design for this study was chosen with the explicit purpose of exploring social processes. Grounded theory for example, was selected because it is a procedure whose purpose is to understand human behaviour by focusing on processes. Similarly, a longitudinal design was chosen because it allowed for an exploration of the temporal dimension of caregiving. It was noted also in chapter four, that there has been a failure to develop longitudinal models of caregiving (Opie 1994, Taraborrelli 1994).

Temporal models of care such as those developed by Bowers (1987, 1888), Wilson (1989), Willoughby and Keating (1991), Keady and Nolan (1993, 1995) have explored the process and meanings of care as defined by informal carers. However, as discussed in chapter one, these models have emerged from the literature on dementia, a degenerative condition with a recognised pathway. So while these models map carers' experiences in line with the progress of dementia, they fail to address the temporal and dynamic nature of caregiving for older people without any cognitive impairment and whose descent into frailty and increasing dependency is uncertain. Furthermore, these temporal models of care were based on the experiences of carers who were also service users. This focus on service users means firstly, that existing models tend to overlook the circumstances that lead to service provision. Secondly, it means that the experiences of non-users remain little understood.

Emerging from the analysis of the present study, the circumstantial dimensions of caregiving illustrate clearly how caring is a dynamic process with a temporal aspect. These dimensions encompass nine main processes, which taken together form a temporal model of caregiving. This model however, reflects the experiences of carers of frail older people

without any cognitive impairment, who were at the start of the study, non-service users. It illustrates the evolutionary process of family caregiving. The model comprises nine stages which each reflect a particular process. These nine stages are as follows:

- Dawning realisation
- Adopting the carer role
- Going it alone
- Gaining expertise
- Sinking or swimming
- Accessing services
- Carers as clients
- Continuation of caring
- New horizons

The time taken to reach a specific stage varies depending on individual circumstances. Similarly, the time spent in any one stage varies. Each stage will be elaborated on below.

Dawning realisation

Without exception, carers can recall the events, which led to them becoming a carer. Caregiving begins with this embryonic phase called ‘dawning realisation’. This stage is characterised by carers’ realisation that their relative needs to be looked after. The realisation that their relative needs to be cared for can happen either suddenly or gradually depending on the nature of events leading up to their ‘dawning realisation’. In situations where a sudden injury or illness is the catalyst for becoming a carer, the realisation is swift. On the other hand, where the older person experiences a gradual deterioration in their health, realisation is slow and gradual. The pace of this stage is not necessarily determined by residency, although many co-resident carers report a gradual awareness of how they are increasingly doing more for their relative.

Carers also realise that their relationship with the person needing care is undergoing a fundamental change, which entails a reversal of roles. No longer are they perhaps, parent and an adult child, rather they are becoming adult-child carer and cared-for parent. Similarly, the relationship between spouses becomes one of carer and cared-for rather than a partnership.

During this stage carers confront questions relating to their ability and duty. Rhetorical questions such as ‘why me?’, ‘can I do it?’, ‘should I do it?’, and ‘if I don’t – then what are

the consequences?’ These questions are not usually fully articulated or discussed with service providers or other family members. Nor are they answered, if at all, until the following stage.

For many carers, this stage is their first interaction with service providers, particularly if their relative has been hospitalised. Criticism of providers at this stage centres around their lack of concern about carers’ ability to undertake the required level of care, a lack of consultation and the assumption that individuals are willing to become the main carer for their relative.

Adopting the carer role

This stage is characterised by carers’ acceptance of their relative’s need for care and of their responsibility for providing it. This acceptance is often based on the belief that no one else is available or able to provide the care required. Carers subconsciously consider the alternatives, deem them unsuitable and accept that they should become the main carer. During this process carers answer the questions posed at the previous stage i.e. ‘can I do it?’, ‘should I do it?’, and ‘if I don’t – then what are the consequences?’ Only in very few cases are these questions discussed openly before the role is finally accepted.

In accepting the caregiving role, people tend to build on past relationships. Where caring represents the continuation of an established relationship then rarely are these questions raised and there is no decision to make. For example in the case of a spouse there is often little hesitation, but rather a strong desire to accept the caring role. In other cases, carers who have poor relationships with the person requiring care, accept the role with great reluctance. They are motivated by a sense of obligation rather than affection.

This is an important stage in the caregiving career. The most crucial aspect of it is the decision-making process. Yet carers can feel that they have not been offered the opportunity to make a fully informed decision. When carers have the choice of taking on the caring role then they have control over their decision. Where there is an absence of choice often no clear decision is made, rather their willingness to take on the caring role is assumed. Many carers feel they have little choice but to accept the role.

Going it alone

‘Going it alone’ represents the period after individuals have accepted their role and identified themselves as a carer. This, the third stage to emerge from the data, is the period

in which carers look after their relative without support from formal service providers. Some have limited support from their social networks but it tends to be short-lived. Carers report that family and friends soon leave them to 'get on with it' and express regret at the loss of friendships.

Many individuals become carers in a state of naivety in which they generally have no idea what caregiving will entail. Some might seek help from service providers once they encounter difficulties, but if their attempts are unsuccessful, carers are discouraged from trying again. Others might be offered a referral to health and social care agencies but refuse the opportunity. Thus for the majority, their caregiving activities go completely unacknowledged by formal service providers and their GP.

This is the phase in which the concept of control is most apparent. Carers who bring a care recipient to live with them tend to feel in control of the situation. This is in contrast to carers who move into the home of the care recipient who feel that they have little control. However, in cases where the care recipient is too frail or ill to exercise power, carers are able to maintain control.

Carers in the present study, were in this stage when contact was first made with them. They all described the stages of 'dawning realisation' and 'accepting the role'. At first interview, all carers had been 'going it alone' for periods of time, which varied from 6 months to 20 years, a period in which substantial amounts of personal and practical care was being provided. This stage can overlap with the following two, whereby carers 'gain expertise' and 'sink or swim' at the same time as 'going it alone'.

Gaining expertise

This stage is characterised by carers' ability to learn from their experience and eventually to carry out routine procedures that were once unfamiliar, in a competent and proficient manner. When they become carers, the majority of individuals have limited caregiving skills. Most take on the role without fully appreciating the nature or the extent of the care they are expected to provide. Many are ill prepared for their role and are given no training, and little information or advice even when caregiving follows a planned discharge from hospital. Those who have previous experience, either of caring or of having worked as a nurse, are more likely to adapt quickly to the practical aspects of the role. Others have to rely on their own initiative.

Carers gain experience and develop skills in caregiving through a process of trial and error. When faced with a problem they will consider the range of resources available and decide on a particular action. If that strategy is effective then it will be used again if and when required. If it is found to be ineffective, consideration will again be given to the problem and another possible solution identified. This process continues until effective strategies are identified and used routinely. Thus through a continuous process of trial and error, carers progress from being relative novices to being competent and proficient in the activities and management of caregiving.

Expertise is acquired through practical experience and entails an intuitive grasp of a situation based on an understanding of its important aspects. Thus carers developed expertise through experience and their intimate knowledge of the situation. This expertise allows them to notice and attend to any changes in the care recipient's condition quickly. However, carers develop expertise in varying degrees. Those who gain a great deal of expertise and feel competent are more likely to cope with caregiving. Many regard themselves as experts in the care of their relative.

Sinking or Swimming

The term 'sinking or swimming' is derived from carers' references to coping. Sinking refers to feeling overwhelmed and unable to cope, while swimming implies coping by being on top of things. Carers such as Mrs Thompson explained that:

'it [caring] either makes you sink or swim. Well I did sink but then I swam and now I am still standing here. I've come through it'

As caregiving progressed it becomes more stressful, even although carers become more competent and experienced. Stress has an accumulative effect in that one stressor like incontinence or demanding behaviour will beget another, such as tiredness. Although carers clearly develop a range of coping strategies, such as the use of routines, they take different approaches to problem solving.

When faced with crises or critical incident carers either sink or swim. Swimming is associated with an active response to crises, the presence of positive outcomes from which carers derive satisfaction, and caregiver control. Strategies such as seeking information and planning in advance are indicative of an active approach. In contrast, sinking is associated with a passive response, the presence of negative outcomes, which cause carers

to feel depressed and overwhelmed by caregiving, and a lack of control. Using music or alcohol to escape from the stress of caring are examples of a passive response.

Feeling that they are in control of their situation has important consequences for carers ability to cope. High levels of expertise in terms of having the necessary skills, knowledge and emotional support are also associated with an increasing ability to cope. The more competent and in control carers feel the less likely they are to be overwhelmed by the demands of caregiving.

Moving on from this stage to the next depends on the extent to which carers feel they are coping or not. If they feel they are coping and in control, then they are more likely to continue for longer without service intervention. On the other hand those who feel overwhelmed and unable to cope, are more likely to seek or accept support from service providers.

Accessing services

This stage is characterised by attempts to access services. These attempts are usually triggered by crises, which force carers to seek and accept help, although the process is not straightforward. A number of pathways are used to access services, the most effective of which is via GPs. The least effective is self-referral. Those who try but fail to seek help directly from providers are left feeling bitter and disillusioned with the system.

Sometimes the decision to accept service intervention is taken out of the carer's hands. If the care recipient is admitted to hospital, services can be arranged as part of a planned discharge procedure. In these cases, referral is sometimes made without consultation with carers. Yet this stage provides the ideal opportunity for service providers to view carers as 'partners in care' and in this way support their efforts to cope and continue caring.

Carers experience access as a lengthy protracted process fraught with difficulties, which they refer to as 'a fight' or 'a battle'. This process highlights the power of service providers, who control carers' access to services by exercising the authority vested in them by law. This confirms carers' perceptions of them as being authoritarian in nature.

Carers do not unquestionably accept service providers' recommendations for particular services. The least intrusive services such as day or respite care and aids and equipment, are the ones most acceptable to carers. Whilst home care services are not widely used, once the benefits are recognised, it is usually appreciated by carers who accept it.

This stage can also overlap with the previous one of 'sinking and swimming'. Although service intervention helps carers to cope, some still have difficulty in doing so. Service intervention can create problems as well as resolving them and so the cycle of sinking or swimming continues.

Carers as clients

This stage is characterised by carers' acceptance of service intervention in order to prevent the breakdown of care. This stage is closely linked to the previous one and refers to the status of carers, which changes to that of a client once contact is made with service providers. 'Carers as clients' is one of the ways in which carers are conceptualised by service providers (Twigg 1989).

Although many carers would like to continue without service support, for many there comes a point when they realise it is not in their best interests to continue without help. Acceptance of formal services is often associated with feelings of failure and relinquishing control of the caregiving situation. It is also in some cases, determined by the wishes of the care recipient and takes place only with their co-operation.

Carers are emphatic that it is not they that need help but rather the person they are looking after. They do not view themselves as clients and are aware that formal services are traditionally, designed to meet the needs of carer recipients. This is one reason why carers are reluctant to admit service providers into their homes. They do not want strangers coming into *their* home and intruding on *their* privacy when it is not they who are the clients in need of help. Nonetheless, a service such as respite care is frequently arranged because carers are regarded as clients in need of a break. By stage three of the current study 10 carers had reached the stage of being a client.

Continuation of caring

Service intervention marks a new stage in carers' careers. Caregiving continues but now with support from service providers. Carers have successfully negotiated the pathway to providers and for some there is a steady increase in the level of support they receive and accept. Thus carers have increasing levels of interaction with providers such as paid care workers who come into their homes or staff in day or respite care facilities.

This stage is also marked by the adoption of new routines, which are developed to take account of service intervention. For example, ensuring that the care recipient is up and

dressed in readiness for day care can require changes to existing routine. Similarly, ensuring that clean equipment and laundry is available should community nurses need it, requires a change to household routines.

But service receipt also creates tension. Carers report that interactions with service providers can be frustrating and stressful. Criticisms of service providers are based on their apparent disregard for carers' specialist knowledge about the needs of care recipients. Carers may be regarded as clients but certainly not as 'experts'.

New Horizons

New Horizons refers to the stage when, for what ever reasons, carers are no longer required to provide care. Interactions with service providers also tend to end at this stage because they believe that the problems are all over. The end of caregiving is due either to the death of the care recipient, an alternative caregiver taking over or admission to long term care.

Some carers may experience feelings of relief tinged with sadness and grief when caring comes to an end through death of the care recipient. For others, the end of caregiving may leave a huge void in their life especially if they have been providing a substantial amount of care over a number of years. Many carers are not quite sure what to do in this stage as it takes time to adjust to their changed circumstances. 'New horizons' therefore, represents new opportunities and challenges for carers as they come to terms not only with the loss of a loved one but also the loss of their role.

When contact was first made with them, all carers in the present study were in the stage 'going it alone', which overlaps with 'gaining expertise' and 'sinking and swimming'. Of the 17 carers who took part in the entire study, some progressed through each stage of the model while others remained in 'sinking or swimming'. By the end of the study, 2 carers, Mrs Veitch and Mrs Murphy, bypassed 'accessing services', 'carers as clients', and 'continuation of caring' by moving directly from 'sinking or swimming' to 'new horizons'. In Mrs Murphy case this was due to the death of her husband. In Mrs Veitch's case, caring came to end because her sister took over the caregiving role. Of the remaining carers, 5 were still in the 'going it alone' stage, and 10 were service users.

Some of the stages outlined above are similar to those described by Keady and Nolan's (1993) temporal model of caring although theirs is based on the experiences of carers who were already service-users. For example, taken together, the three stages, 'going it alone', 'gaining expertise', 'sinking or swimming', are comparable to Wilson's 'going through it' and Keady and Nolan's (1993) 'working through it' phases. Whilst the term 'working through it' suggests a more active approach than Wilson's term, they both nevertheless, conflate three stages into one. As a result of this conflation, certain aspects of caregiving such as gaining expertise and coping efforts are obscured.

Similarly, 'new horizons' can be compared to Keady and Nolan's (1993) 'reaching the end' but it has less negative connotations. 'Reaching the end' is the term used by Keady and Nolan to refer to the stage when an older person is admitted to a nursing home or another form of care is substituted. However, Keady and Nolan's terminology implies a bleak or non-existent life after caregiving. It also suggests that in the majority of cases, caregiving ends with the care recipient's admission to a care home. Yet, relatively few carers actively take steps to find a home and place their relative in it. Often the decision is taken in haste and in conjunction with service providers (Wright 2000). In the current study, only one care recipient was admitted to a home and that decision was taken without consultation with the main carer, who, had she known about it, would not have agreed to such action being taken.

The temporal model of caregiving presented here is based on the experiences of the carers in the present study, who were looking after frail older people. It can however, be applied to other caring situations and in that respect it should prove useful to service providers. Only at specific stages in their career do carers readily accept support. So providers need to be aware of and understand the various stages that carers go through in order to tailor service interventions to particular stages in the caregiving career.

Policy Implications

This study has highlighted the process by which individuals became carers. It has shown how the majority of respondents felt that they had no choice and as a result, no control over whether or not to become a carer. However, having accepted the role, carers found that through practical experience of caregiving they became experts in the care of their relative. Carers wanted to maintain their independence and control over their own lives and the

caregiving situation. They were initially reluctant to use services because they perceived them as being authoritarian and intrusive and believed that service intervention might lead to a potential loss of independence and control. Furthermore, carers did not perceive themselves as being the focus of service intervention. They felt that it was the care recipient and not they that needed help. In that respect they resented having to ask for help.

Carers reported that the stress associated with caregiving increased over time until they reached a crisis or a point where they felt that they could take no more. Crises were the most common catalyst for seeking help. Thus carers associated help seeking with a sense of failure and a loss of control. The most common and most effective pathway to services was via GPs. The least effective was self-referral. Access to services was determined by service providers and experienced by carers as a lengthy and frustrating process over which they had no control. Carers tried to re-establish control by either limiting the type of help they would accept, or by making their own arrangements for services. In some instances the actual experience of service receipt compared favourably to carers previously held perceptions. Once the benefits became apparent, carers were on the whole, happy with the services they received.

These findings from the present study highlight a number of issues that have important implications for policy. Whilst some of these issues are the focus of current policy others are overlooked. For example, we have seen in the present study that notions of choice and control were important to carers. They also seem to be important and emergent concepts in the field of caregiving policy. For sometime concern has been displayed over carers' lack of control and recent policy has attempted to empower them. The Carers Strategy (Department of Health 2000) in particular was intended to mark a 'decisive change' in policy and practice. It included proposals that should enable carers to choose to care or not, be adequately prepared to care, to receive relevant help at an appropriate stage and be enabled to care without it adversely affecting their health or inclusion in society. The strategy placed particular emphasis on providing support at key transition points, particularly at the beginning and end of care.

But most fundamental of all was the notion of choice, with the intention of policy, as stated in the Carers Strategy, to '*support people who choose to be carers*' (Department of Health 2000). This suggests that policy recognises that the transition into caregiving is a crucial phase and that when this occurs suddenly there is a need to exercise an informed choice about whether or not to become a carer. However, the findings from the present study

suggest that in reality, exercising such choice and having control over the situation is extremely difficult for many carers. The majority of them felt that they had no choice and little control over whether or not to become a carer.

Another issue highlighted by the present study and addressed by recent legislation is the question of who should be the focus of service intervention, the carer or care recipient? Traditionally, formal services were designed to meet the needs of care recipients. However, in recent years services have increasingly been designed to meet the needs of carers rather than the cared-for person, so professionals tend to view carers as clients. Yet, as we have seen from the present study, some do not see themselves as being in need of help. According to them it is the cared-for person who needs help and who should therefore, be the focus of intervention. Moreover, carers suggested that they would be more likely to accept services if they were not the ones being identified as being 'needy'.

This issue has been addressed by the Community Care and Health Act 2001 (Scotland) which introduces new rights for carers. By addressing the needs of carers as part of the overall package of care, and by placing a duty on local authorities to take account of carers' views when undertaking an assessment of a cared-for person, this legislation recognises carers as key partners in the provision of care. No longer are carers to be regarded as simply clients in need of support. This is an important measure because it clarifies the issue of who formal services are for. By providing services to support carers as part of the package designed to meet the needs of the care recipient, the Community Care and Health Act 2001 should encourage carers to accept support.

Moreover, by viewing carers as partners this legislation marks an important change in the way carers are to be treated in both individual caring situations and planning systems. This should ultimately change the balance of power between carers and service providers. This has important implications because carers in the present study were aware of service providers exercising their power and authority over them and determining their access to services. This was one reason why some carers were averse to seeking or accepting support from them. By changing the status of carers from client to partner, this legislation should empower carers and enable them to engage more readily with service providers. It should also encourage service providers to acknowledge their expertise.

This legislation is also of consequence because for the first time it places a statutory responsibility for carers on the NHS. Health Boards are to produce Carers Information Strategies, setting out how they will be making sure carers know their rights. As we have

seen, health care agencies and GPs in particular were the most effective pathway by which carers in the present study accessed services. Yet some reported that their GP was unsupportive and unaware of their caregiving role. In this respect the new legislation should increase awareness of carers amongst health care agencies including GPs.

Although this recent legislation seeks to empower carers and is a positive step towards acknowledging the contribution they make to the care of older people, there are areas it does not address. For example, this study has conceptualised caregiving as a series of nine stages. It suggests that carers are more likely to accept service interventions at particular stages of caregiving. Thus in order to meet the needs of carers more effectively, service providers should tailor interventions to specific stages in the caregiving trajectory. These stage specific interventions should aim to enhance the skills, competence and expertise of family carers thereby empowering them and facilitating the continuance of caregiving.

This study has also shown how difficult it is for carers to negotiate with service providers. It has shown how self-referral was the least effective way to access services. Some carers who sought and eventually succeeded in obtaining help experienced the process as a lengthy frustrating battle. Those who tried and failed to get help were left feeling bitter and disillusioned. These findings suggest that in order to improve support for *all* carers, policy needs to address more directly the complex issues surrounding caregiver interactions with service providers and their non-use or low take up of services. It needs to consider the most effective way to remove barriers and facilitate access to services. However, legislation alone may not be enough to change the mind set and attitudes of service providers. That will take time, training, and resources.

Appendix 1: Sample Access Letters Sent to Carers

7th July 1999

Dear

The Experiences of Carers

Further to our telephone conversation on Tuesday, I would like to thank you for agreeing to meet with me on Friday 23rd July at 10am.

As you know I am currently carrying out research on the experiences of family carers who do not receive services and it is important that I speak with people like yourself. The study is intended to provide information on how carers manage without help from formal services such as social work or district nursing. I hope to use the findings as part of my PhD research and to inform policymakers and planners of carers' views and experiences.

Our meeting should take approximately one hour. The information you give will be strictly confidential and you can end the meeting at any time.

I look forward to seeing you on the 23rd but should you have any questions about this study before then, please call me on 0141 339 8855 extension 0189.

Yours sincerely

Joyce Statham

Appendix II: Carers Assessment of Difficulties Index

CARERS' ASSESSMENT OF DIFFICULTIES INDEX (CADI)

CADI is a 30 item index that contains a series of statements which carers have made about the difficulties they have faced. Carefully read each statement and show if it applies to you by placing a $\sqrt{\quad}$ in the space available.

Caring can be difficult because:		This does NOT apply to me	This statement applies to me and I find it:		
			Not stressful	Stressful	Very stressful
1	I don't have enough private time for myself				
2	I can feel helpless/not in control of the situation				
3	I can't devote enough time to other family members				
4	It causes financial difficulties				
5	The person I care for can play me up				
6	The person I care for is immobile/has problems getting about				
7	Professional workers don't seem to appreciate the problems carers face				
8	It restricts my social life/outside interests				
9	It can put a strain on family relationships				
10	It is physically tiring				
11	The person I care for can demand too much of me				
12	I no longer have a meaningful relationship with the person I care for				
13	The person I care for needs a lot of help with personal care				
14	The person I care for doesn't always help as much as they could				
15	My sleep is affected				
16	Relatives don't keep in touch as much as they could				
17	I feel angry about the situation				
18	I can't see friends as often as I'd like				
19	My emotional wellbeing suffers				
20	I can't have a break or take a holiday				

[illegible]

Appendix III: Carers Assessment of Management Index

CARERS' ASSESSMENT OF MANAGEMENT INDEX (CAMI)

CAMI is a 38 item index that contains a series of statements which carers have made about the coping strategies they use. Carefully read each statement and show if it applies to you by placing a \sqrt in the space available.

One way of dealing with the demands of caring is by:		I do NOT use this	I use this and I find it:		
			Not really helpful	Quite helpful	Very helpful
1	Establishing a regular routine and sticking to it				
2	Letting off steam in some way eg. Shouting, yelling or the like				
3	Talking over my problems with someone I trust				
4	Keeping a little free time for myself				
5	Keeping one step ahead of things by planning in advance				
6	Seeing the funny side of the situation				
7	Realising there's always someone worse off than me				
8	Gritting my teeth and just getting on with it				
9	Remembering all the good times I used to have with the person I care for				
10	Finding out as much information as I can about the problem				
11	Realising the person I care for is not to blame for the way they are				
12	Taking life one day at a time				
13	Getting as much practical help as I can from my family				
14	Keeping the person I care for as active as possible				
15	Altering my home environment to make things as easy as possible				
16	Realising that things are better now than they used to be				
17	Getting as much help as I can from professionals and other service providers				
18	Thinking about the problem and finding a way to overcome it				
19	By having a good cry				
20	Accepting the situation as it is				
21	Taking my mind off things in some way, by reading, watching TV or the like				

[illegible]

Appendix 1V: Carers Assessment of Satisfaction Index

CARERS' ASSESSMENT OF SATISFACTIONS INDEX (CASI)

CASI is a 30 item index that contains a series of statements which carers have made about the satisfactions they have experienced. Carefully read each statement and show if it applies by placing a \sqrt in the space available.

Caring can be satisfying because:		This does NOT apply to me	This applies to me and provides me with:		
			No real satisfaction	Quite a lot of satisfaction	A great deal of satisfaction
1	Caring has allowed me to develop new skills				
2	The person I care for is appreciative of what I do				
3	Caring has brought me closer to person I care for				
4	It's good to see small improvements in their condition				
5	I am able to help the person I care for reach their full potential				
6	I am able to repay their past acts of kindness				
7	Caring provides a challenge				
8	Despite all their problems the person I care for does not grumble				
9	It is nice to see the person I care for clean. Comfortable and well turned out				
10	Caring enables me to fulfil my sense of duty				
11	I am the sort of person who enjoys helping people				
12	I get pleasure from seeing the person I care for happy				
13	It's good to help the person I care for overcome difficulties and problems				
14	It's nice when something I do gives the person I care for pleasure				
15	Knowing the person I care for the way I do, means I can give better care than anyone else				

16	Caring has helped me to grow and develop as a person				
17	It's nice to feel appreciated by those family and friends I value				
18	Caring has strengthened close family ties and relationships				
19	It helps to stop me feeling guilty				
20	I am able to keep the person I care for out of an institution				
21	I feel that if the situation were reversed, the person I care for would do the same for me				
22	I am able to ensure that the person I care for has their needs tended to				
23	Caring has given me the chance to widen my interests and contacts				
24	Maintaining the dignity of the person I care for is important to me				
25	I am able to test myself and overcome difficulties				
26	Caring is one way of showing my faith				
27	Caring has provided a purpose in my life that I did not have before				
28	At the end of the day I know I will have done the best I could				
29	Caring is one way of expressing my love for the person I care for				
30	Caring makes me feel needed and wanted				

Please add below any other aspects of caring that you find satisfactory and indicate how much satisfaction they give you

Caring can be satisfying because:		This applies to me and provides me with:		
		No real satisfaction	Quite a lot of satisfaction	A great deal of satisfaction

Appendix V: Carers Assessment of Difficulties

CARERS' ASSESSMENT OF DIFFICULTIES (n=21)			
Caring can be difficult because:	This does NOT apply to me	This statement applies to me and I find it:	
		Not Stressful %	Stressful or very stressful %
The behaviour of the person I care for is a problem	4	0	96
The person I care for can play me up	5	10	85
Professional workers don't seem to appreciate the problems carers face	9	7	84
I can feel helpless/not in control of the situation	14	5	81
The person I care for is immobile/has problems getting about	10	9	81
It is physically tiring	14	6	80
It can put a strain on family relationships	14	10	76
The person I care for can demand too much of me	18	6	76
The person I care for doesn't always appreciate what I do	19	5	76
My sleep is affected	21	4	75
The person I care for needs a lot of help with personal care	18	9	73
The person I care for is incontinent	13	19	68
It restricts my social life/outside interests	19	14	67
My emotional wellbeing suffers	10	23	67
Relatives don't keep in touch as much as they could	5	29	66
I don't have enough private time for myself	28	10	62
I can't see friends as often as I'd like	29	11	60
I can't have a break or take a holiday	29	14	57
I can't relax because of worry about caring	27	16	57
Watching over them all the time, keeping them from harm	32	12	56
Having to plan all my activities and not being able to do anything spontaneous	36	10	54
Some family members don't help as much as they could	34	15	52
I can't devote enough time to other family members	52	0	48
The person I care for doesn't always help as much as they could	47	5	48
I feel guilty about the situation	43	10	47
I don't get enough help from the health and social services	43	12	45
I no longer have a meaningful relationship with the person I care for	48	10	43
There is no satisfaction to be gained from caring	43	14	43
I feel angry about the situation	48	14	38
My standard of living has fallen	57	5	38
It causes financial difficulties	63	8	29
My physical health has suffered	62	10	29

Appendix VI: Carers Assessment of Management

CARERS' ASSESSMENT OF MANAGEMENT (n=21)			
One way of dealing with the demands of caring is by:	I do NOT use this	I use this and I find it:	
		Not really helpful %	Quite or very helpful %
Taking life one day at a time	0	0	100
Taking my mind off things in some way, by reading, watching TV or the like	0	9	91
Establishing priorities and concentrating on them	4	5	91
Relying on my own experience and the expertise I have built up	5	5	90
Looking for positive things in each situation	5	5	90
Realising there's always someone worse off than me	4	10	86
Gritting my teeth and just getting on with it	4	10	86
Talking over my problems with someone I trust	19	0	81
Altering my home environment to make things as easy as possible	9	10	81
Believing in myself and my ability to handle the situation	9	10	81
Keeping one step ahead of things by planning in advance	13	10	77
Seeing the funny side of the situation	18	5	77
Realising that no one is to blame for things	0	23	77
Keeping a little free time for myself	24	0	76
Realising the person I care for is not to blame	14	10	76
Keeping the person I care for as active as possible	24	0	76
Establishing a regular routine and sticking to it	14	14	72
Letting off steam in some way eg. shouting, yelling	18	10	72
Thinking about the problem and finding a way to overcome it	24	5	71
Accepting the situation as it is	15	14	71
Trying out a number of solutions until I find the one that works	19	10	71
Finding out as much information as I can about the problem	19	14	67
Remembering all the good times I used to have with the person I care for	24	14	62
Trying to cheer myself up by eating, drinking, smoking or the like	24	14	62
Keeping my emotions and feelings tightly under control	18	24	58
Being firm and pointing out to the person I care for what I expect of them	29	14	57
Maintaining interests outside caring	43	0	57
By having a good cry	19	29	52
Preventing problems before they happen	38	10	52
Getting rid of excess energy and feelings by walking, swimming or other exercise	52	0	48
Getting as much help as I can from my family	57	0	43
Drawing on strong personal or religious beliefs	47	10	43
Forgetting about my problems for a short while by daydreaming or the like	48	14	38
Attending a self-help group	61	5	34
Using relaxation techniques, meditation or the like	61	5	34
Realising that things are better than they used to be	66	5	29
Getting as much help as I can from professionals and other service providers	63	14	23
Ignoring the problem and hoping it will go away	66	19	15

Appendix VII: Carers Assessment of Satisfaction

CARERS' ASSESSMENT OF SATISFACTIONS (n=21)			
Caring can be satisfying because:	This does NOT apply to me	This applies to me and provides me with:	
		No real satisfaction %	Quite a lot or a great deal of satisfaction %
I get pleasure from seeing the person I care for happy	5	0	95
It is nice to see the person I care for clean, comfortable and well turned out	4	5	91
I am able to keep the person I care for out of an institution	4	5	91
Maintaining the dignity of the person I care for is important to me	4	10	86
At the end of the day I know I will have done the best I could	4	10	86
I am the sort of person who enjoys helping people	14	5	81
It's good to help the person I care for overcome difficulties and problems	14	10	76
I am able to ensure that the person I care for has their needs tended to	29	0	71
It's nice to feel appreciated by those family and friends I value	33	0	67
Caring is one way of expressing my love for the person I care for	9	24	67
It's nice when something I do gives the person I care for pleasure	24	10	66
Caring enables me to fulfil my sense of duty	23	19	58
Knowing the person I care for the way I do, means I can give better care than anyone else	29	14	57
I feel that if the situation were reversed, the person I care for would do the same for me	24	19	57
I am able to test myself and overcome difficulties	29	19	52
Caring provides a challenge	28	24	48
I am able to repay their past acts of kindness	34	19	47
The person I care for is appreciative of what I do	47	10	43
I am able to help the person I care for reach their full potential	43	14	43
Caring makes me feel needed and wanted	51	10	39
Caring has allowed me to develop new skills	57	5	38
It's good to see small improvements in their condition	43	19	38
Caring has helped me to grow and develop as a person	66	0	34
Caring has brought me closer to person I care for	43	24	33
Caring has given me the chance to widen my interests and contacts	48	19	33
Caring has strengthened close family ties and relationships	61	10	29
Caring has provided a purpose in my life that I did not have before	53	0	47
Caring helps to stop me feeling guilty	62	14	24
Caring is one way of showing my faith	62	14	24
Despite all their problems the person I care for does not grumble	71	15	14

Bibliography

- Abel, E. (1990) Daughters caring for elderly parents, in Gubrium, J. and Sankar, A. (eds) *The Home Care Experience*, London, Sage.
- Abbott, P. and Wallace, C. (1991) *Gender, Power and Sexuality*, Basingstoke, Macmillan.
- Abrams, M. (1978) *Beyond Three Score and Ten*, London, Age Concern.
- Abrams, P. (1977) Community care: some research problems and priorities, *Policy and Politics*, 6, p276-282.
- Age Concern Institute of Gerontology (1995) *The Hidden Carers: Developing A Methodology for Deriving Local Area Profiles of Informal Carers*, London, Princess Royal Trust for Carers.
- Allen, I., Hogg, D. and Peace, S. (1992) *Elderly People: Choice, Participation and Satisfaction*, London, Policy Studies Institute.
- Allen, I. and Perkins, E. (1995) *The Future of Family Care for Older People*, London, HMSO.
- Albert, M., Becker, T. and McCrone, P. (1998) Social networks and mental health service utilisation - a literature review, *International Journal of Social Psychiatry*, 44, p248-267.
- Antonovsky, A. (1979) *Health, Stress and Coping: New Perspectives on Mental and Physical Wellbeing*, San Francisco, Jossey Bass.
- Antonovsky, A. (1985) *Health, Stress and Coping*, London, Jossey Bass.
- Antonovsky, A. (1987) *Unraveling the Mystery of Health*, London, Jossey Bass.
- Antonovsky, A. (1993) The implications of salutogenesis: an outsiders view, in Turnbull, A., Patterson, J., Behr, S., Murphy, D., Marquis, J., and Blue-Banning, M., (eds.) *Cognitive Coping, Families and Disability*, Baltimore, Paul Brookes.
- Antonovsky, A. (1998) The sense of coherence: an historical and future perspective, in McCubbin, H., Thompson, E., Thompson, A., Fromer, J. (1998) *Stress, Coping, and Health in Families*, Thousand Oaks, CA. Sage.
- Antonucci and Jackson (1989) Successful ageing and life course reciprocity, in Warnes, A. *Human Ageing and Later Life: Multidisciplinary Perspectives*, London, Edward Arnold.
- Appley, M. and Trumbull, R. (1986) *Dynamics of Stress; Physiological, Psychological and Social Perspectives*, New York, Plenum Press
- Arber, S. and Gilbert, N. (1989) Men: the forgotten carers, *Sociology*, 23, p111-118.
- Arber, S. Gilbert, N. & Evandrou, M. (1989) Gender, household composition and receipt of domiciliary services by the elderly disabled, *Journal of Social Policy*, 17, p153-175.
- Arber, S. and Ginn, J. (1990) The meaning of informal care: gender and the contribution of elderly people, *Ageing and Society*, 10, p429-54.

- Arber, S. and Ginn, J. (1991) *Gender and Later Life: a sociological analysis of resources and constraints*, London, Sage.
- Arber, S., and Ginn, J. (1995) Gender differences in informal care, *Health and Social Care in the Community*, 3, p19-31.
- Arber, S., and Ginn, J. (1997) Informal care-givers for elderly people, in Ungerson, C. and Kember, M. (eds) *Women and Social Policy: a Reader*, Basingstoke, Macmillan.
- Archbold, P., Stewart, B., Greenlick, M., and Harvath, T. (1992) The clinical assessment of mutuality and preparedness in family caregivers of frail older people, in Funk, S., Tornquist, T., Champagne, M., and Wiese, R. (eds.) *Key Aspects of Elder Care: Managing Falls, Incontinence, and Cognitive Impairment*, New York, Springer.
- Aronson, J. (1990) Women's perspectives on informal care of the elderly: ideology and personal experience of giving and receiving care, in *Ageing and Society*, 10, p61- 84.
- Aronson, J. (1992) Women's sense of responsibility for the care of old people, *Gender and Society*, 6, p8-29.
- Ashworth, M., Nafisa, M., and Corkery, M. (1996) Respite care in an intermediate care centre: the views of patients and carers, *Health and Social Care in the Community*, 4, p234-245.
- Ashworth, M., and Baker, A. (2000) Time and space: carers views about respite care, *Health and Social Care in the Community*, 8, p50-56.
- Askham, J. (1995) Making sense of dementia: carers' perceptions, *Ageing and Society*, 15, p103-114.
- Askham, J., Tinker, A., and Grundy, K. (1992) *Caring: The Importance of Third Age Carers*, Research Paper 6, Dunfermline, Carnegie UK Trust.
- Askham, J. (1998) Supporting caregivers of older people: an overview of problems and priorities, *Australian Journal of Ageing*, 17, p5-7.
- Atkin, K. (1992) Similarities and differences between informal carers, in Twigg, J. (ed) *Carers Research and Practice*, London, HMSO.
- Baldwin, S, Godfrey, C. and Propper, C. (1990) *Quality of Life: Perspectives and Policies*, London, Routledge.
- Baldwin, S. and Twigg, J. (1991) Women and community care: reflections on a debate, in Maclean, M. and Groves, D. (eds.) *Women's Issues in Social Policy*, London, Routledge.
- Baldwin, S. (1985) *The Costs of Caring*, London, Routledge and Kegan Paul.
- Banks, P. (1999) *Carer Support: Time for a Change of Direction*, London, Kings Fund.
- Barker, J. and Mitteness, L. (1990) Invisible caregivers in the spotlight; non-kin caregivers of frail older adults, in Gubrium, J. and Sankar, A. (eds) *The Home Care Experience*, London, Sage.

- Bauld, L., Chesterman, J., Davies, B., Judge, K., and Mangalore, R. (2000) *Caring for Older People: an assessment of community care in the 1990s*, PSSRU, University of Kent, Aldershot, Ashgate.
- Bauld, L., Chesterman, J., Judge, K., (2000) Measuring satisfaction with social care amongst older service users: issues from the literature, *Health and Social Care in the Community*, 8, p316-324.
- Baum, A. (1993) Control and intrusive memories as possible determinants of chronic stress, *Psychosomatic Medicine* 55, p274-286.
- Bayley, M., Parker, P., Seyd, R. and Tennant, A. (1985) *Neighbourhood Services Project: Origins, Strategy and Proposed Evaluation*, University of Sheffield, Department of Sociological Studies.
- Beck, C., Heacock, P., Mercer, S., and Walton, C. (1992) Decreasing caregiver assistance with older adults with dementia, in Funk, S., Tornquist, T., Champagne, M., and Wiese, R. (eds) *Key Aspects of Elder Care: Managing Falls, Incontinence, and Cognitive Impairment*, New York, Springer.
- Behr, S., and Murphy, D. (1993) Research progress and promise; the role of perceptions in cognitive adaptation to disability, in Turnbull, A., Patterson, J., Behr, S., Murphy, D., Marquis, J., and Blue-Banning, M. (eds) *Cognitive Coping, Families and Disability*, Baltimore, Paul Brookes.
- Benner, P and Wrubel, J. (1989) *The Primacy of Coping: Stress and Coping in Health and Illness*, Menlo Park, California, Addison Wesley.
- Biggs, S., Phillipson, C. and Kingston, P. (1995) *Elder Abuse in Perspective*, Buckingham, Open University Press.
- Bland, R. and Hudson, H. (1994) *Providing Home Support to Frail Elderly People*, EPIC, Final Report, University of Stirling.
- Blakemore, K. and Bonham, M. (1993) *Age, Race and Ethnicity: A Comparative Approach*, Buckingham, Open University Press.
- Blaxter, L., Hughes, C. and Tight, M. (1996) *How To Research*, Buckingham, Open University Press.
- Bond, J. (1990) Informal care and social support, *Ageing and Society*, 10, p469-479.
- Bond, J. (1992) The politics of caregiving: the professionalisation of informal care, *Ageing and Society*, 12, p5-21.
- Bond, J., Coleman, P. and Peace, S. (1999) *Ageing in Society: An Introduction to Social Gerontology*, London, Sage, 2nd edition.
- Boneham, M., Williams, K., Copeland, J., McKibbin, P., Wilson, K., Scott, A., and Saunders, P. (1997) Elderly people from ethnic minorities in Liverpool: mental illness, unmet need and barriers to service use, *Health and Social Care in the Community*, 5, p162-172.

- Boniface, D., and Denham, M. (1997) Factors influencing the use of community health and social services by those aged 65 and over, in *Health and Social Care in the Community*, 5, 1, p48-54.
- Boss, P. (1993) Boundary ambiguity: a block to cognitive coping, in Turnbull, A., Patterson, J., Behr, S., Murphy, D., Marquis, J., and Blue-Banning, M. (eds) *Cognitive Coping, Families and Disability*, Baltimore, Paul Brookes.
- Bowers, B. (1987) Intergenerational caregiving; adult caregivers and their ageing parents, *Advances in Nursing Science*, 9, p20-31.
- Bowers, B. (1988) Family perceptions of care in a nursing home, *The Gerontologist*, 28, p361-7.
- Bowlby, J. (1973) *Attachment and Loss Volume 2, Separation, Anxiety and Anger*, London, Hogarth.
- Bowling, A and Brown, P. (1991) Social networks, health and emotional well-being among the oldest old in London, *Journal of Gerontology*, 46, p20-32.
- Braithwaite, V. (1990) *Bound to Care*, Sydney, Allen and Unwin.
- Bramson, R. (1985) Toward effective coping: the basic steps, in Monet, A. and Lazarus, R. (eds) *Stress and Coping: an Anthology*, New York, Columbia University Press.
- Brechin, A., Walmsley, J., Katx, J. and Peace, S. (1998) *Care Matters, Concepts, Practice and Research in Health and Social Care*, London, Sage.
- Brereton, L. and Nolan, M. (2000) You do know he's had a stroke don't you? Preparation for family caregiving, the neglected dimension, *Journal of Clinical Nursing*, 9, p498-506.
- British Medical Association (1995) *Taking Care of the Carers*, London, BMA.
- Brody, E. (1981) Women in the middle and family help to older people, *The Gerontologist*, 21, p471-479.
- Brody, E. (1995) Prospects for family caregiving: responses to change, continuity and diversity, in Kane, R. and Penrod, J. (eds) *Family Caregiving in an Ageing Society: Policy Perspectives*, Thousand Oaks, California, Sage.
- Brooks, J. (1998) Salutogenesis, successful ageing and the advancement of theory on family caregiving, in McCubbin, H., Thompson, E., Thompson, A., Fromer, J. (eds.) *Stress, Coping, and Health in Families*, Thousand Oaks, CA. Sage.
- Brown, G. and Harris, T. (1978) *The Social Origins of Depression, a Study of Psychiatric Disorder in Women*, London, Tavistock Publications.
- Brown, G. and Harris, T. (1989) *Life Events and Illness*, New York, Guilford Press.
- Bryman, A. (1988) *Quantity and Quality in Social Research*, London, Routledge.
- Bryman, A. (2001) *Social Research Methods*, Oxford, Oxford University Press.

- Bull, M. and Jervis, L. (1997) Strategies used by chronically ill older women and their caregiving daughters in managing posthospital care, *Journal of Advanced Nursing*, 25, p541-547.
- Bulmer, M. (1986) *Neighbours: the Work of Philip Abrams*, Cambridge, CUP.
- Burholt, V., Wenger, GC., and Scott, A. (1997) Dementia, disability and contact with formal services: a comparison of dementia sufferers and non-sufferers in rural and urban settings, *Health and Social Care in the Community*, 5, p384-397.
- Burr, W., and Klein, S. (1994) *Re-examining Family Stress: New Theory and Research*, Thousand Oaks, CA. Sage.
- Bytheway, B. and Johnson, J. (1998) The social construction of carers, in Symonds, A. and Kelly, A. (eds) *The Social Construction of Community Care*, Basingstoke, Macmillan.
- Cantor, M. (1983) Strain among caregivers: a study of experience in the United States, *The Gerontologist*, 23, 6, p597-64.
- Carers National Association (1995) *The Carers Recognition and Services Bill*, London.
- Carers UK (2002) *Without Us..? Calculating the value of carers support*, London, Carers UK.
- Carlson, K. and Robertson, S. (1993) Husbands and wives of dementia patients: burden and social support, *Canadian Journal of Rehabilitation*, 6, p163-173.
- Caro, F. (1986) Relieving Informal caregiver burden through organised services, in Pillemer, K. and Wolf, R. (eds) *Elder Abuse: Conflict in the Family*, Massachusetts, Auburn.
- Caserta, M., Lund, D., Wright, S. and Redbum, D. (1987) Caregivers to dementia patients: the utilisation of community services, in *Gerontologist*, 27, p209-214.
- Centre for Health and Social Research (1997) *The Carers (Recognition and Services) Act1995 and Crossroads Care Attendance Schemes: A Baseline Survey*, Glenrothes, Fife, CHSR
- Challis, D. and Davies, B. (1986) *Case Management in Community Care*, Aldershot, Gower.
- Challis, L. and Bartlett, H (1988) *Old and Ill: Private Nursing Homes for Elderly People*, London, Age Concern.
- Chapman, P. (1997) *Unmet Needs and The Delivery of Care*, Occasional papers on Social Administration No 61, Birkenhead, Social Administration Research Trust.
- Chappell, N. (1990) Ageing and social care, in Bibstock, R. and George, L. (eds) *Ageing and the Social Sciences*, New York, Academic Press.
- Chappell, N. (1994) Home care research: what does it tell us? *Gerontologist*, 34, p116-120.

- Charlesworth, A., Wilkin, D., and Durie, A. (1983) *Carers and Services; a Comparison of Men and Women Caring for Dependent Elderly People*, University of Manchester, Departments of Psychiatry and Community Medicine.
- Cicirelli, V. (1981) A companion of helping behaviour to elderly parents of adult children with contact and disrupted marriages, *The Gerontologist*, 23, p619-625.
- Cicerelli, V. (1986) The helping family relationship and family neglect in later life, in Pillemer, K. and Wolf, R. (eds) *Elder Abuse: Conflict in the Family*, Massachusetts, Auburn.
- Cicerelli, V. (1992) *Family Caregiving: Autonomous and Paternalistic Decision Making*, Newbury Park, CA. Sage.
- Clark, H., Dyer, S., and Horwood, J. (1998) *That Bit of Help: The High Value of Low Level Preventative Services for Older People*, Bristol, Policy Press.
- Clarke, C. (1994) Professional practice with people with dementia and their family carers: help or hindrance?, in Adams, T., and Clarke, C. (eds) *Dementia Care: Developing Partnerships in Practice*, London, Bailliere Tindall.
- Clarke, C. (1995) Care of elderly people suffering from dementia and their co-residents informal carers, in Heywood, B. (ed) *Researching User Perspectives on Community Health Care*, London, Chapman and Hall.
- Clarkson, P. and McCrone, P. (1998) Quality of life and service utilisation in South London: the PRISM of psychotic patients study, *Journal of Mental Health*, 7, p71-80.
- Cleary, B. (1992) Alzheimer's disease: stressors and strategies associated with caregiving, in Funk, S., Tornquist, T., Champagne, M., and Wiese, R. (eds.) *Key Aspects of Elder Care: Managing Falls, Incontinence, and Cognitive Impairment*, New York, Springer.
- Clifford, D (1990) *The Social Costs and Rewards of Caring*, Aldershot, Avebury.
- Clough, P. and Nutbrown, C. (2001) *A Student's Guide to Methodology*, London, Sage.
- Coates, D. (1995) The portrayal of family carers in dementia: some critical observations, *Social Care in the Community*, 3 (4) 261-270.
- Coe, R., Miller, D., and Flaherty, J. (1992) Sense of coherence and perception of caregiver burden, *Behaviour, Health and Ageing*, 2, p93-99.
- Coe, R., Romeis, J. and Hall, M. (1998) Sense of coherence and survival in the chronically ill elderly: a five year follow-up, in McCubbin, H., Thompson, E., Thompson, A., Fromer, J.(eds.) *Stress, Coping, and Health in Families*, Thousand Oaks, CA. Sage.
- Cohen, C., Gold, D., Shulman, K., and Zuccherro, C. (1994) Positive aspects in caregiving: an overlooked variable in research, *Canadian Journal on Ageing*, 13, 3, p378-391.
- Coleman, C., Piles, C., and Poggenpoel, M. (1994) Influence of caregiving on families of older adults, *Journal of Gerontological Nursing*, November, p 40-49.
- Command Paper 849 (1989) *Caring for People: Community Care in the Next Decade and Beyond*, London, HMSO.

- Corbin, J. and Strauss, A. (1988) *Unending Work and Care: Managing Chronic Illness at Home*, San Francisco, CA., Jossey Bass.
- Critcher, C., Waddington, D and Dickie, B. (1999) Qualitative methods and welfare research, in Williams, F., Popay, J., and Oakley, A. *Welfare Research: A Critical Review*, London, UCL Press.
- Crookston, E.M. (1989) *Informal Caring: The Carer's View*, Middlesborough, Cleveland County Council Research and Intelligence Unit.
- Curtice, L, Petch, A., Hallam, A., and Knapp, M. (2002) *Over the Threshold? An Exploration of Intensive Domiciliary Support for Older People*, Edinburgh, Scottish Executive Central Research Unit.
- Daatland, S.O. (1990) What are families for? On family solidarity and preference for help, *Ageing and Society*, 10, p1-15.
- Dalley, G. (1996) *Ideologies of Caring*, London, Macmillan.
- Davidson, N., and Reed, J. (1995) One foot on the escalator: elderly people in sheltered accommodation, in Heywood, B. (ed) *Researching User Perspectives on Community Health Care*, London, Chapman and Hall.
- Delbecq, A.L., Van de Ven, A. and Gustafson, D. (1975) *Group Techniques for Programme Planning: A Guide to Nominal Group and Delphi Processes*, Glenview, Illinois, Scott Foreman and Company.
- Delphy, C. and Leonard, D. (1992) *Familiar Exploitation; a New Analysis of Marriage in Contemporary Western Societies*, Cambridge, Polity Press.
- Department of Health (1999) *National Strategy for Carers*, London Stationary Office.
- Department of Social Security (1991) *Carers, Family Resources Survey Great Britain 1995*. London, HMSO.
- Dey, I. (1993) *Qualitative Data Analysis*, London, Routledge.
- Dick, B. (2002) *Grounded theory: A Thumbnail Sketch*, available on-line at: www.scu.edu.au/schools/gcm/arp/grounded.html
- Dohrenwend, BS. and Dohrenwend BP. (1978) *Stressful Life Events: Their Nature and Effects*, New York, Wiley.
- Dreyfuss, H.L. and Rabinow, P. (1982) *Michel Foucault: Beyond Structuralism and Hermeneutics*, Chicago, University of Chicago Press.
- Dunlop, M. J. (1986) Is a science of caring possible?, *Journal of Advanced Nursing*, 11, p661-670.
- Dunst, C., Trivette, C. and Deal, A. (1988) *Enabling and Empowering Parents*, Cambridge, MA, Brookline Books.

- Dunst, C., Trivett, C., Gordon, N., and Pletcher, L. (1989) Building and mobilising informal family support networks, in Singer, G., Irvin, L. (eds) *Support For Caregiving Families*, Baltimore, Paul Brookes.
- Eagles, J., Craig, A., Rawlinson, F., Restall, D., Beattie, J. and Besson, J. (1987) The psychological well-being of supporters of the demented elderly, *British Journal of Psychiatry*, 150, p293-8.
- Eastman, M. (1984) *Old Age Abuse: a New Perspective*, London, Chapman Hall.
- Eckenrode, J. (1991) *The Social Context of Coping*, New York, Plenum Press.
- Edwards, J. and Cooper, C (1988) Research in stress, coping and health: theoretical and methodological issues, *Psychological Medicine*, 18, p15-20.
- Edwards, J., Oakley, A. And Popay, J. (1999) Service users and providers perspectives on welfare needs, Williams, F., Popay, J., and Oakley, A. *Welfare Research: A Critical Review*, London, UCL Press.
- Equal Opportunities Commission (1980) *The Experience of Caring for Elderly Handicapped Dependents*, Manchester, Equal Opportunities Commission.
- Equal Opportunities Commission (1982) *Caring for the Elderly and Handicapped: community care policies and women's lives*, Manchester, Equal Opportunities Commission.
- Eraut, M. (1994) *Developing Professional Knowledge and Competence*, London, Falmer Press.
- Evandrou, M. (1990) *Challenging The Invisibility Of Carers: Mapping Informal Care Nationally*, London, London School of Economics, STICERD, Discussion Paper.
- Evandrou, M. (1995) Employment and care, paid and unpaid work: the socio-economic position of informal carers in Britain, in Phillips, J. (ed.) *Working Carers*, Avebury, Aldershot.
- Evandrou, M. (1996) Unpaid work, carers and health, in Blane, D., Brunner, E. and Wilkinson, R. (eds.) *Health and Social Organisation: Towards a Health Policy for the Twenty-First Century*, London, Routledge.
- Evandrou, M. (1997) *Baby Boomers: Ageing in the 21st Century*, London, Age Concern.
- Evandrou, M., Arber, S., Dale, A. and Gilbert, N. (1986) Who cares for the elderly?: Family care provision and receipt of statutory services, in Phillipson, C., Bernard, M. and Strang, P. (eds.) *Dependency and Interdependency in Old Age: Theoretical Perspectives and Policy Alternatives*, Kent, Croom Helm.
- Evers, A. (1995) The future of elderly care in Europe, in Scharf, F. and Wenger, C. (eds) *International Perspectives on Community Care for Older People*, Aldershot, Avebury.
- Fielding, N, and Thomas, H (2001) Qualitative interviewing in Gilbert, N. (ed) *Researching Social Life*, London, Sage.
- Finch, J. (1989) *Family Obligations and Social Change*, Cambridge, Polity Press.

- Finch, J. and Groves, D. (1983) *A Labour of Love: Women, Work and Caring*, London, Routledge and Kegan Paul.
- Finch, J. and Mason, J. (1990) Filial obligations and kin support for elderly people, *Ageing and Society*, 10, p151-175.
- Finch, J. and Mason, J. (1993) *Negotiating Family Responsibilities*, London, Routledge.
- Fisher, L.R. and Hoffman, C. (1984) Who cares for the elderly and the dilemma of family support, *Research in Social Problems and Public Policy*, 3, 169-215.
- Fisher, M. (1994) Man made care, community care and older male carers, *British Journal of Social Work*, 24, p 659-80.
- Fitzpatrick, B., and Taylor, R. (1994) A Comparative Study of Quality Criteria, *Nursing Standard*, 8, 37, p25-29.
- Folkman, S., Chesney, M., McKusick, L., Ironson, G., Johnson, D. and Coates, T. (1991) Translating coping theory into an intervention, in Eckenrode, J. (ed.) *The Social Context of Coping*, New York, Plenum Press.
- Foster, P. (1983) *Access to Welfare*, London, Macmillan Press.
- Foucault, M. (1979) *The History of Sexuality, Volume 1, An Introduction*, London, Allen Lane.
- Fox, N. (1995) Postmodern perspectives on care: the vigil and the gift, *Critical Social Policy*, 15, p107-125.
- Frey, J.H. and Fontana, A. (1987) The group interview in social research, *The Social Science Journal*, 28, p175-187.
- George, L. (1986) Caregiver burden: conflict between norms of reciprocity and solidarity, in Pillemer, K. and Wolf, R. (eds) *Elder Abuse: Conflict in the Family*, Massachusetts, Auburn.
- George, L. and Gwyther, L. (1986) Caregiver well-being: a multidimensional examination of family caregivers of demented adults', *Gerontologist*, 26, p253-9.
- Gilbert, N. (2001) *Researching Social Life*, London, Sage.
- Gilleard, C, Gilleard, E, Gledhill, A. and Whittick, J. (1984) Caring for the mentally infirm at home: a survey of the supporters, *Journal of Epidemiology and Community Health*, 38.
- Gilleard, C.J. (1987) Influence of emotional distress amongst supporters on the outcomes of psychogeriatric day care, *British Journal of Psychiatry* 150, p214-223.
- Gilles, B (2000) Acting up: role ambiguity and the legal recognition of carers, *Ageing and Society*, 20, p429-444.
- Gilhooly, M. (1986) Senile dementia: factors associated with caregivers' preference for institutional care', *British Journal of Medical Psychology*, 59, p165-171.
- Gilhooly, M. (1987) Senile dementia and the family, in Orford, J. (ed) *Coping with Disorder in the Family*, London, Croom Helm.

- Given, B, and Given, C. (1991) Family caregiving for the elderly, in Fitzpatrick, J., Taunton, R., and Jacox, A. (eds) *Annual Review of Nursing Research* 9, New York, Springer.
- Glaser, B. (1978) *Theoretical Sensitivity*, California, Mill Valley.
- Glaser, B. (1998) *Doing Grounded Theory: Issues and Discussions*, Mill Valley, California, Sociology Press.
- Glaser, B. and Strauss, A. (1967) *The Discovery of Grounded Theory*, Aldine, Chicago.
- Glendinning, C. (1983) *Unshared Care: Families with Disabled Children*, London, Routledge and Kegan Paul.
- Glendinning, C. (1992) *The Costs of Informal Care*, Social Policy Research Unit, London, HMSO.
- Goodman, C. (1986) Research on informal carers: a selected literature review, *Journal of Advanced Nursing*, 11, p705-712.
- Gottlieb, B. and Wagner, F. (1991) Stress and support processes in close relationships, in Eckenrode, J. (ed.) *The Social Context of Coping*, New York, Plenum Press.
- Gouldner, A. (1973) The norm of reciprocity, *American Sociological Review* 25, p161-178.
- Graham, H. (1983) Caring: a labour of love, in Finch, J. and Groves, D. (eds) *A Labour of Love: Women, Work and Caring*, London, Routledge and Kegan Paul.
- Graham, H. (1991) The concept of caring in feminist research: the case of domestic service, in *Sociology*, 125, p61-78.
- Graham, H. (1997) Feminist perspectives on caring, in Bornat, J., Johnson, J., Pereira, C., Pilgrim, D., & Williams, F. (eds) *Community Care: a Reader*, London, Macmillan in association with the Open University.
- Grant, G. (1986) Older carers, interdependence and the care of mentally handicapped adults, *Ageing and Society*, 6, p333-51.
- Grant, G. (2001) Older people with learning difficulties: health, community inclusion and family caregiving, in Nolan, M., Davies, S., and Grant, G. (eds.) *Working with Older People and their Families: Key Issues in Policy and Practice*, Buckingham, Open University Press.
- Grant, G., Nolan, M. and Ellis, J. (1990) A reappraisal of the Malaise Inventory, *Social Psychiatry and Psychiatric Epidemiology*, 25, p170-178.
- Grant, G and Nolan, M. (1993) Informal Carers: sources and concomitants of satisfaction, *Health and Social care*, 1, p147-159.
- Grant, G., McGrath, M., and Ramcharan, P. (1994) How family and informal supporters appraise service quality, *International Journal of Disability, Development and Education*, 41, p127-141.

- Grant, G., Ramcharan, P., McGrath, M., Nolan, M. and Keady, J. (1998) Rewards and gratifications among family caregivers: towards a refined model of caring and coping, *Journal of Intellectual Disability Research*, 42, p58-71
- Green, H. (1988) *Informal Carers: General Household Survey 1985*, OPCS. London, HMSO
- Griffin, A. (1983) A philosophical analysis of caring in nursing, *Journal of Advanced Nursing*, 8, p198-295.
- Gubruim, J. and Sankar, A. (1990) *The Home Care Experience*, London, Sage.
- Gunaratnam, Y. (1997) Breaking the silence: black and ethnic minority carers and service provision, in Bornat, J., Johnson, J., Pereira, C., Pilgrim, D., and Williams, F. (eds) *Community Care: a Reader*, London, Macmillan in association with the Open University.
- Guptta, R. (1999) The revised caregiver burden scale: a preliminary evaluation, *Research on Social Work Practice*, 9, p508-520.
- Gutting, G. (1994) *The Cambridge Companion to Foucault*, Cambridge, Cambridge University Press.
- Hakim, C. (1987) *Research Design: Strategies and Cohesion in the Design of Social Research*, London, Routledge.
- Hancock, R. and Jarvis, C. (1994) *The Long Term Effects of Being a Carer*, London, HMSO.
- Haralambos M. and Holburn, M (1995) *Sociology: Themes and Perspectives*, London, Collins Educational.
- Hardy, B., Young, R., and Wistow, G. (1999) Dimensions of choice in the assessment and care management process: the views of older people, carers and care managers, *Health and Social Care in the Community*, 7, p475-482.
- Harris, P. (1993) The misunderstood caregiver? A qualitative study of the male caregiver of Alzheimer's disease victims, *The Gerontologist*, 33, p551-6.
- Hart, C. (1998) *Doing a Literature Review*, London, Sage.
- Henderson, N (1995) A practical approach to analysing and reporting focus group studies: lessons from qualitative research, *Qualitative Health Research*, 5, p463-477.
- Heyman, B. (1995) *Researching User Perspectives on Community Health Care*, London, Chapman and Hall.
- Hirst, M. (1998) *The Health of Informal Carers: A Longitudinal Analysis*, University of York, Social Policy Research Unit, Working paper DH1563.
- Hirst, M. and Hutton, S. (2000) Informal care over time, *Benefits*, 28, p9-12.
- Hogg, C. (1999) *Patients, Power and Politics: from Patients to Citizens*, London, Sage.
- Holmes, TH. and Rahe, RH. (1967) The Sociological Re-adjustment Rating Scale, *Journal of Psychomatic Research*, 11, p213-218.

- Huang, C. (1995) Hardiness and stress: a critical review, *Maternal-Child Nursing Journal*, 23, p82-89.
- Hugman, R. (1991) *Power in Caring Professions*, Basingstoke, Macmillan.
- Hunter, D. and MacPherson, I. (1990) The influence of informal carers on service provision and allocation decisions, in Jamieson, A and Illsley, R. (eds) *Contrasting European Policies for the Care of Older People*, Gower, Aldershot.
- Hutton, S, and Hirst, M. (2001) *Caring Relationships Over Time*, University of York, Social Policy Research Unit.
- Jack, R. (1984) Dependence, power and violation: gender issues in abuse of elderly people by formal carers, in Eastman, M. (1984) *Old Age Abuse: a New Perspective*, London, Chapman Hall.
- Jack, R. (1995) *Empowerment in Community Care*, London, Chapman and Hall.
- Jarrett, N., Payne, S., and Wiles, R. (1999) Terminally ill patients and lay carers perceptions and experiences of community based services, *Journal of Advanced Nursing*, 29, p467-483.
- Jerrom, B., Mian, I. and Rukanyake, N. (1993) Stress on relative caregivers of dementia sufferers, and predictors of the breakdown of community care, *International Journal of Geriatric Psychiatry*, 8, p331-337.
- Jones, D.A. and Vetter, N. (1984) A survey of those who care for the elderly at home: their problems and their needs, *Social Science and Medicine*, 19, 5.
- Johnson (1981) *Structured Dependency of the Elderly: a research note*, London, Centre for Economic Policy research.
- Johnson, M. (1993) Dependency and interdependency, in Bond, J., Coleman, P. and Peace, S. *Ageing and Society: an introduction to social gerontology*, London, Sage.
- Joseph Rowntree Foundation (1996) *Meeting The Costs of Continuing Care*, York, JRF.
- Joshi, H. (1992) The cost of caring, in Glendinning, C and Millar, J (eds) *Women and Poverty in Britain in the 1990s*, London, Harvester Wheatsheaf.
- Jutras, S. and Veilleux, F. (1991) Informal caregiving: correlates of perceived burden in *Canadian Journal on Ageing*, 10, p40-55.
- Kahana, E. and Young, R. (1990) Clarifying the caregiver paradigm: challenges for the future, in Beigel, D, and Blum, A. (eds) *Ageing and Caregiving Theory: Research and Policy*, Newbury Park, CA, Sage.
- Kahana, E. and Kinney, J. (1991) Understanding caregiving interventions in the context of the stress model, in Young, R. and Olsen, E (eds) *Health, Illness and Disability in Later Life*, Newbury park, Sage.
- Kahana, E., Biegel, D., and Wykle, M. (1994) *Family Caregiving Across the Lifespan*, Thousand Oaks, CA. Sage.

- Kane, R. and Penrod, J. (1995) *Family Caregiving in an Ageing Society: Policy Perspectives*, Thousand Oaks, California, Sage.
- Keady, J. and Nolan, M.R. (1993) Younger Onset Dementia: developing a longitudinal model as the basis for a research agenda and as a guide to interventions with sufferers and carers, *Journal of Advanced Nursing*, 19, p659-669.
- Keady, J. and Nolan, M. (1994) The carer-led assessment process (CLASP): a framework for the assessment of need in dementia caregivers, *Journal of Clinical Nursing*, 3, p103-108.
- Keady, J. and Nolan, M.R. (1995) IMMEL: assessing coping responses in the early stages of dementia, *British Journal of Nursing*, 4, p377-380.
- Kobasa, S., Maddi, S. and Kahn, S. (1982) Hardiness and health: a prospective study, *Journal of Personality and Social Psychology*, 42, p168-177.
- Kobasa, S. (1985) Stressful life events: personality and health: an inquiry into hardiness, in Monet, A. and Lazarus, R. (eds) *Stress and Coping: an Anthology*, New York, Columbia University Press.
- Kosberg, J. and Cairl, R. (1986) The cost of care index: a case management tool for screening informal care providers, *The Gerontologist*, 26, p273-8.
- Krauss, K., and Seltzer, M. (1993) Coping strategies among older mothers of adults with retardation; a lifespan developmental perspective, in Turnbull, A., Patterson, J., Behr, S., Murphy, D., Marquis, J., and Blue-Banning, M., (eds) *Cognitive Coping, Families and Disability*, Baltimore, Paul Brookes
- Kyle, T. (1995) The concept of caring: a review of the literature, *Journal of Advanced Nursing*, 21, p506-514
- Land, H. and Rose, H (1985) Compulsory altruism for some or altruistic society for all? in McBean, P., Ferris, J., Whynes, D. (eds) *In Defence of Welfare*, London, Tavistock.
- Langan, J., Whitfield, M., and Russell, O. (1995) Paid and unpaid carers: their role in and satisfaction with primary health care for people with learning disabilities, *Health and Social Care*, 2, p357-365.
- Lazarus, R. (1976) *Psychological Stress and the Coping Process*, New York, McGraw Hill.
- Lazarus, R. (1985) The costs and benefits of denial, in Monet, A. and Lazarus, R. (eds) *Stress and Coping: an Anthology*, New York, Columbia University Press.
- Lazarus, R. (1991) Coping theory and research, past, recent and future, *Psychosomatic Medicine*, 55, p234-247.
- Lazarus, R.S. and Folkman, S. (1984) *Stress, Appraisal and Coping*, New York, Springer.
- Leininger, M. (1981) *Caring: an Essential Human Need*, New Jersey, Charles Slack.
- Leininger (1984) *Care: The Essence of Nursing And Health*, New Jersey, Charles Slack.

- Leontaridi, L., and Bell, D. (2002) *Informal Care of the Elderly in Scotland and the UK*, Health and Community Care Research Findings No 8, Edinburgh, Scottish Executive.
- Levin, E., Sinclair, I., Gorbach, P. (1984) *The Supporters of Confused at Home*, London, National Institute of Social Work.
- Levin, E., Sinclair, I. and Gorbach, P. (1989) *Families, Services and Confusion in Old Age*, Aldershot, Gower.
- Levin, E., Moriarty, J., Gorbach, P. (1994) *Better For the Break*, London, HMSO.
- Lewis, J., and Meredith, B. (1988) *Daughters Who Care*, London, Routledge.
- Lewis, J., and Meredith, B. (1989) Contested territory in informal care, Jeffreys, M (ed) *Growing Old in the Twentieth Century*, London, Routledge.
- Litwak, E. (1987) *Helping the Elderly: The Complimentary Roles of Informal Networks and Formal Systems*, New York, Guidford Press.
- Lloyd, L. (2000) Caring about carers: only half the picture? *Critical Social Policy*, 20, p136-150
- Lukess, S. (1974) *Power: A Radical View*, London, Macmillan.
- Lukess, S. (1987) *Power*, Oxford, Blackwell.
- McCubbin, H. and Patterson, J. (1983) Family stress adaptation to crises: a double ABCX model of family behaviour, McCubbin, HI. Sussman, M, and Patterson, J. (eds) *Social Stresses and the family: Advances and Developments in Family Stress Theory and Research*, New York, Haworth.
- McCubbin, H., Thompson, E., Thompson, A., and McCubbin, M. (1993) Family schema, paradigms and paradigm shifts, in Turnbull, A., Patterson, J., Behr, S., Murphy, D., Marquis, J., and Blue-Banning, M. (eds) *Cognitive Coping, Families and Disability*, Baltimore, Paul Brookes.
- McCubbin, H., Thompson, E., Thompson, A., Fromer, J. (1998) *Stress, Coping, and Health in Families*, Thousand Oaks, CA. Sage.
- McDonald, A. (1998) *Understanding Community Care*, Basingstoke, Macmillan.
- McDonald, C. (1999) *Support at Home: Views of Older People about their Needs and Access to Services*, Edinburgh, Scottish Executive Central Research Unit.
- McGlone, F. and Cronin, N. (1994) *A Crisis in Care: The Future of Family and State Care for Older People In The European Union*, Occasional Paper 19, London, Family Policy Studies Centre.
- McKee, K., Wittick, J., Gilhooly, M. Ballinger, B., Gordon, D., Mutch, W. and Philip, I. (1999) The willingness to continue caring in family supporters of older people, *Health and Social Care in the Community*, 7, p100-108.
- McLaughlin, E. (1994) Legacies of caring: the experiences and circumstances of ex-carers, *Health and Social Care*, 2, p241-253.

- Magnusson, D., Bergman, L. Rudinger, G. and Torestad, B. (1991) *Problems and Methods in Longitudinal Research: Stability and Change*, Cambridge, Cambridge University Press.
- Marshall, M. (1997) *State of the Art in Dementia Care*, London, Centre for Policy on Ageing.
- Matson, N. (1994) Coping, caring and stress, a study of stroke carers and carers of older confused people, *British Journal of Clinical Psychology*, 33, p333-334.
- Medalie, J. (1994) The caregiver as the hidden patient: challenges for medical practice, in Kahana, E., Biegel, D., and Wykle, M. (eds) *Family Caregiving Across the Lifespan*, Thousand Oaks, Sage.
- Merrell, S., Norris, F., and Grote, C. (1988) Life events in older adults, in Cohen, L. (ed) *Life Events and Psychological Functioning*, London, Sage.
- Monet, A. and Lazarus, RS. (1991) *Stress and Coping: An Anthology*, New York, Columbia University Press.
- Montgomery, R.(1989) Caregiving and the experience of subjective and objective burden, *Family Relations*, 3, p19-26.
- Moos, R.H. and Schafer, J.A. (eds) (1986) *Coping with Life Crises: an Integrated Approach*, New York, Plenum.
- Morgan, D. (1991) Designing focus group research, in Stewart, M., Tudiver, F., Boss, M., Dunn, E. and Norton, P. (eds) *Tools for Primary Care Research*, Thousand Oaks, Sage.
- Morgan, D. (1995) Piths, pearls and provocation: why things (sometimes) go wrong in focus groups, *Qualitative Health Research*, 5, p516-523.
- Moriarty. J. and Webb, S. (2000) *Part of Their Lives: Community Care for Older People with Dementia*, Bristol, The Policy Press.
- Morris, J. (1991) *Pride against Prejudice: Transforming Attitudes to Disability*, London, The Women's Press.
- Morris, J. (1993) *Independent Lives, Community Care and Disabled People*, Basingstoke, Macmillan.
- Morris, J. (1997) Feminist research and informal care, in Ungerson, C. and Kember, M. (eds.) *Women and Social Policy: a Reader*, Basingstoke, Macmillan.
- Morris, J. (1997) 'Us' and 'them'? Feminist research and community care, in Bornat, J., Johnson, J., Pereira, C., Pilgrim, D., & Williams, F. (eds) *Community Care: a Reader*, London, Macmillan in association with the Open University.
- Morse, J. (1990) Concepts of caring and caring as a concept, *Advances in Nursing Sciences*, 13, p1-14.
- Motenko A. (1989) The frustrations, gratifications and well-being of dementia caregivers, *The Gerontologist*, 29, p166-172.

- Mudge, K., and Ratcliffe, I., (1995) Considering the needs of carers: a survey of their views on services, *Journal of Advanced Nursing*, 9, p29-31.
- Muhr, T. (1993) *ATLAS Release 1.1e Users Manual*, Berlin, Technical University of Berlin.
- Muhr, T. (1996) *ATLAS: The Knowledge Workbench*, Berlin, Technical University of Berlin.
- Murphy, B., Schofield, H., Bloch, S., Herrman, H. and Singh, B. (1997) Women with multiple roles: the emotional impact of caring for ageing parents, *Ageing and Society*, 17, p277-291.
- Murray, J. and Livingston, G. (1998) A qualitative study of adjustment to caring for an older spouse with psychiatric illness, *Ageing and Society*, 18, p659-671.
- Myers, F. and McDonald, C. (1996) Power to the people? Involving users and carers in needs assessments and care planning, views from the practitioner, *Health and Social Care in the Community*, 4, p86-95.
- Nissel, M. and Bonnerjea, A. (1982) *Family Care of the Handicapped Elderly: Who Pays?* London, Policy Studies Institute.
- Nocon, A., and Qureshi, H. (1996) *Outcomes of Community Care for Users and Carers: A Social Service Perspective*, Buckingham, Open University Press.
- Nocon, A. and Pearson, M. (2000) The role of friends and neighbours in providing support for older people, *Ageing and Society*, 20, p341-367.
- Noddings, N. (1984) *Caring; a Feminist Approach to Ethics and Moral Education*, Berkley, University of California Press.
- Nolan, M. (2001) Acute and rehabilitative care for older people, in Nolan, M., Davies, S., and Grant, G. (eds) *Working with Older People and their Families: Key Issues in Policy and Practice*, Buckingham, Open University Press.
- Nolan, M., and Grant, G. (1989) Addressing the needs of informal carers: a neglected area of nursing practice, *Journal of Advanced Nursing*, 14, p950-961.
- Nolan, M., Grant, G., and Ellis, N. (1990) Stress is in the eye of the beholder: reconceptualising the measurement of carer burden, *Journal of Advanced Nursing*, 15, p544-555.
- Nolan, M., Keady, J., and Grant, G., (1994) Developing a typology of family care: implications for nurses and other service providers, *Journal of Advanced Nursing*, 21, p256-265.
- Nolan, M., Keady, J. and Grant, G. (1995) CAMI: a basis for assessment and support for family carers, *British Journal of Adult / Elderly Care Nursing*, 1, p822-826.
- Nolan, M., Grant, G., and Keady, J. (1996) *Understanding Family Care: A Multidimensional Model of Caring and Coping*, Buckingham, Open University Press.

- Nolan, M., Davies, S., and Grant, G. (2001) *Working with Older People and Their Families: Key Issues in Policy and Practice*, Buckingham, Open University Press.
- O'Connor, D. (1995) Supporting spousal caregivers: exploring the meaning of service use, *Journal of Contemporary Human Services*, 76, p296-305.
- Oliver, M. (1990) *The Politics of Disablement*, London, Macmillan.
- Olsen, R., Parker, J., Drewett, A. (1997) Carers and the missing link: changing professional attitudes, *Health and Social Care in the Community*, 5, p116-123.
- Opie, A. (1991) *Caring Alone: Looking After the Confused Elderly at Home*, Wellington, Daphne Brasell Association Press.
- Opie, A (1994) The instability of the caring body: gender and caregivers of older people, *Qualitative Health Research*, 4, p31-50.
- Orme, J. (2001) *Gender and Community Care*, Basingstoke, Palgrave.
- Orr, R., Cameron, S., Day, M. (1991) Coping with stress in children who have mental retardation: an evaluation of the double ABCX model, *American Journal on Mental Retardation*, 95, p444-450.
- Pahl, J. (1989) *Money and Marriage*, Basingstoke, Macmillan.
- Pandit, N. (1996) The creation of theory: a recent application of the grounded theory method, *The Qualitative Report*, 2, 4, available from: www.nova.edu/ssw/QR/QR2-4.pandit.html, retrieved on 22 April 2003.
- Parker, R. (1981) Tending and social policy, in Goldberg, E., and Hatch, S. (eds) *A New Look at the Personal Social Services*, London, Policy Studies Institute.
- Parker, G. (1990) Spouse carers: whose quality of life, in Baldwin, S, Godfrey, C. and Propper, C. (eds) *Quality of Life: Perspectives and Policies*, London, Routledge.
- Parker, G. (1990) Whose care? Whose costs? Whose benefit? A critical review of research on care management and informal care, *Ageing and Society* 10, p459-467.
- Parker, G. (1990) *With Due Care and Attention: a review of research on informal care*, London, Family Policy Studies Centre.
- Parker, G. (1992) Counting care: numbers and types of informal carers, in Twigg, J. (ed) *Carers: Research and Practice*, London, HMSO.
- Parker, G. (1993) *With This Body: Caring and Disability in Marriage*, Buckingham, Open University Press.
- Parker, G. (1994) *Where Next for Research on Carers?* Nuffield Community Care Studies Unit, University of Leicester.
- Parker, G. and Lawton, D. (1994) *Different Types of Care, Different Types of Carer*, London, HMSO.

- Parker, G. and Clarke, H. (2002) Making the ends meet: do carers and disabled people have a common agenda? *Policy and Politics*, 30, p347-359.
- Patterson, J. (1993) The role of family meanings in adaptation to chronic illness and disability, in Turnbull, A., Patterson, J., Behr, S., Murphy, D., Marquis, J., and Blue-Banning, M., (eds) *Cognitive Coping, Families and Disability*, Baltimore, Paul Brookes.
- Patterson, J. (1998) Theoretical linkages: family meanings and sense of coherence, in McCubbin, H., Thompson, E., Thompson, A., Fromer, J. (eds.) *Stress, Coping, and Health in Families*, Thousand Oaks, CA. Sage.
- Peace, S. (1998) Caring in place, in Brechin, A., Walmsley, J., Katx, J. and Peace, S. (eds) *Care Matters, Concepts, Practice and Research in Health and Social Care*, London, Sage.
- Pearlin, L. (1991) The study of coping: an overview of problems and directions, in Eckenrode, J. (ed.) *The Social Context of Coping*, New York, Plenum Press.
- Pearlin, L. and Schooler, C. (1978) The structure of coping, *Journal of Health and Social Behaviour*, 19, p2-21.
- Pearlin, L., Menaghan, E., Lieberman, M. and Mullan, J. (1981) The stress process, *Journal of Health and Social Behaviour*, 22, p337-356.
- Pearlin, L., Mullan, J., Semple, S. and Skaff, M. (1990) Caregiving and the stress process: an overview of concepts and their measures, *The Gerontologist*, 30, p583-594.
- Perring, C. and Twigg, J. and Atkin, K. (1990) *Families Caring for People Diagnosed as Mentally Ill: The Literature Re-examined*, London, HMSO.
- Phillips, L. (1986) Theoretical explanations of elder abuse: competing hypotheses and unresolved issues in Pillemer, K. and Wolf, R. (eds) *Elder Abuse: Conflict in the Family*, Massachusetts, Auburn.
- Phillips, P. (1993) A deconstruction of caring, *Journal of Advanced Nursing*, 18, p1554-1558.
- Phillips, J. (1994) The employment consequences of caring for older people, *Health and Social Care*, 2, p143-152.
- Phillips, J. (1995) *Working Carers: International Perspectives On Working and Caring For Older People*, Aldershot, Avebury.
- Phillipson, C. (1981) *Capitalism and the Construction of Old Age*, London, Macmillan.
- Phillipson, C. (1998) *Reconstructing Old Age*, London, Sage.
- Phillipson, C. and Walker, A. (1985) *Ageing and Social Policy*, Aldershot, Gower.
- Phillipson, C., Bernard, M., and Strang, R. (1986) *Dependency and Interdependency in Old Age: Theoretical Perspectives and Policy Alternatives*, London, Croom Helm.
- Pitkeathley, J. (1989) *It's My Duty, Isn't It? The Plight of Carers in Our Society*, London, Souvenir Press.

- Pitkeathley, J. (1994) Safeguarding the carers, in Davidson, R. and Hunter, S. (eds) *Community Care in Practice*, London, Batsford.
- Post-White, J. (1998) The role of sense of coherence in mediating the effects of mental imagery on immune function, cancer outcome and quality of life, in McCubbin, H., Thompson, E., Thompson, A., Fromer, J.(eds.) *Stress, Coping, and Health in Families*, Thousand Oaks, CA. Sage.
- Princess Royal Trust for Carers (1998) *Eight Hours a Day and Taken for Granted*, London, PRTC.
- Quine, L. and Pahl, J. (1985) Examining sources of stress in families with severely handicapped children, *British Journal of Social Work*, 15, p501-517.
- Quine, L. and Pahl, J. (1991) Stress and coping in mothers caring for a child with severe learning disabilities: a test of Lazarus's transactional model of coping, *Journal of Community and Applied Social Psychology*, 1, p57-70.
- Qureshi, H. (1990) A research note on the hierarchy of obligations among informal carers: a response to Finch and Mason, *Ageing and Society*, 10, p455-458.
- Qureshi, H. (1990) Boundaries between formal and informal caregiving work, in Ungerson, C (ed.) *Gender and Caring*, Hemel Hempstead, Harvester Wheatsheaf.
- Qureshi, H. (2000) *Surveying Outcomes of Equipment and Adaptations*, University of York, Social Policy Research Unit, Research Works 4.
- Qureshi, H. and Simons, A (1987) Resources within families: caring for elderly people, in Brannen, J. and Wilson, G. (eds) *Give and Take in Families: Studies in Resource Distribution*, London, Allen and Unwin.
- Qureshi, H. and Walker, A. (1989) *The Caring Relationship*, Basingstoke, Macmillan Educational.
- Raynes, N., Temple, B., Glenister, C., and Coulthard, L. (2001) *Quality at Home for Older People: Involving Service Users in Defining Home Care Specifications*, Bristol, Policy Press.
- Richards, E. (1996) *Paying for Long Term Care*, London, Institute Public Policy Research.
- Robinson, J. and Yee, L. (1991) *Focus on Carers*, London, Kings Fund.
- Rodgers, A., Karlsen, S., and Addington-Hall, J. (2000) All the services were excellent. It is when the human element comes in that things go wrong: dissatisfaction with hospital care in the last year of life, *Journal of Advanced Nursing* 31, p768-774.
- Rowlands, O. and Parker, G. (1998) *Informal Carers*, Office of National Statistics, London The Stationary Office.
- Royal Commission on Long Term Care (1999) *With Respect to Old Age: Long Term Care-Rights and Responsibilities*, London, The Stationary Office.
- Rutter, M., Graham, P., and Whitmore, K. (1970) *A Neuropsychiatric Study in Childhood*, London, Heinemann.

- Rutter, M (1983) Stress, coping and development; some issues and some questions, in Gramezy, N. and Rutter, M. (eds) *Stress, Coping and Development in Children*, New York, McGraw Hill
- Sarantakos, S. (1998) *Social Research*, Basingstoke, Macmillan Press.
- Schofield, H., Murphy, B., Herrman, H., Bloch, S. and Singh, B. (1998) Carers of people aged over 50 with physical impairment, memory loss and dementia: a comparative study, *Ageing and Society*, 18, p355-369.
- Schultz, R., Diegal, D., Morycz, R., and Visintairer, P. (1990) Psychological paradigms for understanding caregiving, in Light, E., and Lebowitz, B.D. (eds) *Alzheimer's Disease: Treatment and Family Stress*, New York, Hemisphere.
- Scott, S.D. (1983) Using the nominal group technique effectively, *National Productivity Review*, Spring, p173-184.
- Scott, P.A. (1995) Care, attention and imaginative identification in nursing practice, *Journal of Advanced Nursing*, 21, p1196-1200.
- Scottish Executive (2001) *Report of the Scottish Carers' Legislation Working Group*, Edinburgh.
- Scottish Executive (2001) *Fair Care for Older People: Report of the Care Development Group*, The Stationary Office, Edinburgh.
- Scottish Executive Health Department (2001) *Equipment and Adaptation Services in Scotland, A Survey of Waiting Times for Social Work Provision*, Health and Community Care Research Findings Number 17, Edinburgh, retrieved from: <http://www.scotland.gov.uk/cru/kd01/red/eass-02.asp> (15th Jan 2002)
- Scottish Parliament (2001) *Delivery of Community Care in Scotland, Research Note for the Health and Community Care Committee*, Edinburgh, Scottish Parliament Information Centre.
- Selig, S. (1991) Ethical dimensions of intergenerational reciprocity: implications for practice, *The Gerontologist*, 31, p624-630.
- Seyle, H. (1985) *The Stress of Life*, New York, McGraw Hill.
- Seymour, J. (1999) Using gendered discourses in negotiations; couples and the onset of disablement in marriage, in McKie, L, Bowlby, S., and Gregory, S. (eds.) *Gender, Power and the Household*, Basingstoke, Macmillan.
- Shakespeare, T. (2000) The social relations of care, in Lewis, C., Gerwitz, S. and Clarke, J. (eds) *Rethinking Social Policy*, Sage, London.
- Shanas (1979) Social myth ar hypothesis: the case of family relationships of old people, *Gerontology*, 19, p3-9.
- Simpson, R., Scotherm, G., and Mark, V. (1995) Survey of carers satisfaction with the quality of care delivered to in-patients suffering from dementia, *Journal of Advanced Nursing*, 22, p517-527.

- Sinclair, I. (1990) Carers: their contribution and quality of life, in Sinclair, I., Parker, R., Leat, D., and Williams, J. (eds) *A Kaleidoscope of Care: A Review of Research on Welfare Provision for Elderly People*, London, HMSO
- Sinclair, I., Parker, R., Leat, D., and Williams, J. (1990) *A Kaleidoscope of Care: A Review of Research on Welfare Provision for Elderly people*, London, HMSO
- Sinclair, I. (1994) On the receiving end, elderly consumers' perceptions of community care, Davidson, R. and Hunter, S. (eds) *Community Care in Practice*, London, Batsford.
- Social Services Inspectorate (1996) *Carers (Recognition and Services) Act: Policy Guidance*, London, HMSO.
- Stalker, K., Cadogan, L., Petrie, M., Jones, C., and Murray, J. (1999) *'If You Don't Ask You Don't Get': A Review of Services for People with Learning Difficulties: The Views of People who Use Services and Their Carers*, Edinburgh, Scottish Office Central Research Unit.
- Stalley, E. (1991) The Reluctant Client: a study of elderly people who decline the home help service, unpublished MSc thesis, University of Glasgow.
- Stearns, S. and Butterworth, S. (2001) Demand For and Utilisation of, Personal Care Services for the Elderly, Health and Community Care Research Findings No 7, Edinburgh, Scottish Executive Central Research Unit.
- Stone, A., Helder, L. and Schneider, M. (1988) Coping with stressful events, in Cohen, L. (ed) *Life Events and Psychological Functioning*, New York, Sage.
- Strauss, A. and Corbin, J. (1990) *Basics of Qualitative Research*, Newbury Park, CA. Sage.
- Strauss, A. and Corbin, J. (1997) *Grounded Theory in Practice*, London, Sage.
- Strauss, A. and Corbin, J. (1998) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, London, Sage.
- Straw, L., O'Bryant, S., and Meddaugh, D. (1991) Support system participation in spousal caregiving, *Journal of Applied Gerontology*, 10, p359-371.
- Summers, J., Behr, K. and Turnbull, A. (1989) Positive adaptation and coping strengths of families who have children with disabilities, in Singer, G., Irvin, L. (eds) *Support For Caregiving Families*, Baltimore, Paul Brookes.
- Tamborrelli, P. (1994) Exemplar A: Becoming a carer, in Gillbert, N. (ed) *Researching Social Life*, London, Sage.
- Taylor, R. and Ford, G. (1994) *Caring in the Community: a Study of Carers in the East End of Glasgow*, Glasgow, The Princess Royal Trust Glasgow East End Community Carers Centre.
- Taylor, R. and Ford, G. and Dunbar, M. (1995) The effects of caring on health: a community based longitudinal study, *Social Science Medicine*, 40, p1407-1415.

- Thoits, P.A. (1995) Stress, coping and social support processes, where were we, what next? *Journal of Health and Social Behaviour*, 35, p143-159.
- Thomas, C. (1993) Deconstructing concepts of care, *Sociology*, 27, p649-669
- Thompson, S. (1993) Individual and interpersonal influences on the use of cognitive coping, in Turnbull, A., Patterson, J., Behr, S., Murphy, D., Marquis, J., and Blue-Banning, M. (eds) *Cognitive Coping, Families and Disability*, Baltimore, Paul Brookes.
- Thompson, E., Futterman, A., Thompson, D., Rose, J., and Lovett, S. (1993) Social support and caregiving burden in family caregivers of frail elders, *Journal of Gerontology*, 48, p245-254.
- Tinker, A. (1997) *Older People in Modern Society*, London, Longman.
- Titterton, M. (1989) *The Management of Personal Welfare: a consultancy report for the ESRC*, Department of Social Policy and Social Work, University of Glasgow.
- Titterton, M. (1992) Managing threats to welfare: the search for a new paradigm of welfare, *Journal of Social Policy*, 21, p1-23.
- Townsend, P. (1957) *The Family Life of Old People*, London, Routledge and Kegan Paul.
- Townsend, P. (1997) The structured dependency of the elderly: a creation of social policy in the twentieth century, in Bornat, J., Johnson, J., Pereira, C., Pilgrim, D., and Williams, F. (eds) *Community Care: a Reader*, London, Macmillan in association with the Open University.
- Triantafyllou, J. and Mestheneos, E (1995) Professionalising the work of family carers of dependent older people, *Health and Social Care in the Community*, 3, p257-260.
- Tronto, J. (1993) *Moral Boundaries: A Political Argument for an Ethic of Care*, London, Routledge.
- Turnbull, A., Patterson, J., Behr, S., Murphy, D., Marquis, J., and Blue-Banning, M. (eds) (1993) *Cognitive Coping, Families and Disability*, Baltimore, Paul Brookes.
- Turner-Conway, K. and Karasik, R. (1993) Adult daughters anticipation of caregiving responsibilities, *Journal of Women and Ageing*, 5, p99-114.
- Twigg, J. (1989) Models of carers: how do social care agencies conceptualise their relationship with informal carers? *Journal of Social Policy*, 18, p53-66.
- Twigg, J. (1990) Carers of elderly people: models for analysis, in Jamieson, A. and Illsley, R. (eds) *Contrasting European Policies for the Care of Older People*, Aldershot, Gower.
- Twigg, J. (1992) *Carers: Research and Practice*, London, HMSO.
- Twigg, J. (1998) Informal care of older people, in Bernard, M. and Phillips, J. (eds) *The Social Policy of Old Age*, London, Centre for Policy on Ageing.
- Twigg, J. (2000) *Bathing: the Body and Community Care*, Routledge, London.
- Twigg, J., Atkin, K., Perring, C. (1990) *Carers and Services: a Review of Research*, London, HMSO.

- Twigg, J. and Atkin, K. (1993) Integrating carers into the service system: six strategic responses, *Ageing and Society*, 13, p141-170.
- Twigg, J. and Atkin, K. (1994) *Carers Perceived: policy and practice in informal care*, Buckingham, Open University Press.
- Twigg, J. and Atkin, K. (1995) Carers and services: factors mediating service provision, *Journal of Social Policy*, 24, p5-30.
- Tynan, C. and Drayton, J. (1988) Conducting focus groups: a guide for first time users, *Marketing, Intelligence and Planning*, 6, p56-63.
- Uehara, E (1995) Reciprocity reconsidered: Gouldner's moral norm of reciprocity and social support, *Journal of Social and Personal Relationships*, 12, p503-520.
- Ungerson, C. (1983) Why do women care, in Finch, J. and Groves, D, (eds.) *A Labour of Love: Women, Work and Caring*, London, Routledge and Kegan Paul.
- Ungerson, C. (1983) Women and caring: skills, tasks and taboos, Gamarnikow, E., Morgan, D., Purvis, J. and Tayorson, D. (eds.) *The Public and the Private*, London, Heineman.
- Ungerson, C. (1987) *Policy is Personal*, London, Tavistock.
- Ungerson, C. (1990) The language of care: crossing the boundaries, in Ungerson, C. (ed) *Gender and Care*, Hemel Hempstead, Harvester Wheatsheaf.
- Ungerson, C. (1990) *Gender and Care*, Hemel Hempstead, Harvester Wheatsheaf.
- Waerness, K. (1990) Informal and formal care in old age: what is wrong with the new ideology in Scandanavia today?, in Ungerson, C (ed) *Gender and Caring*, Hemel Hempstead, Harvester Wheatsheaf.
- Wagenfeld, M., Baro, F., Gallacher, T. and Haepers, K. (1998) The correlates of coherence in caregivers to demented and non-demented elderly in Belgium: an interim report, in McCubbin, H., Thompson, E., Thompson, A., Fromer, J. (eds) *Stress, Coping, and Health in Families*, Thousand Oaks, Sage.
- Walker, A. (1990) The economic burden of ageing and the prospect of intergenerational conflict, *Ageing and Society*, 10, p 377-396.
- Walker (1992) *Age and Attitudes: main results from a Eurobarometer survey*, Brussels, Commission of the European Communities.
- Walker, A. (1995) Integrating the family into a mixed economy of care, in Allen, I. and Perkins, E. (eds.) *The Future of Family Care for Older People*, London, HMSO.
- Walker, C., Ryan, T. and Walker, A. (1995) A step in the right direction: people with learning difficulties moving into the community, *Health and Social Care in the Community*, 3, p249-259.
- Warner, N. (1994) *Community Care: Just a Fairytale?* London, Carers National Association

- Warner, N. (1995) *Better Tomorrows*, London, Carers National Association.
- Warner, C. and Wexler, S (1999) *Eight Hours a Day and taken for Granted?*, London, Princess Royal Trust for Carers.
- Watson, J. and Taylor, R. (1995) *Addressing Carers' Needs: Current Practice And Recommendations For Change*, unpublished MSc thesis, University of Glasgow.
- Watson, S. (2000) Foucault and the study of social policy, in Lewis, G., Gewirtz, S., and Clarke, J. (eds.) *Rethinking Social Policy*, London, Open University in association with Sage Publications.
- Webb, C. (1996) Caring, curing and coping, in Heller, T., Muston, R., Sidell, M., and Lloyd, C (eds) *Working for Health*, London, Open University in association with Sage.
- Wenger, C.G. (1984) *The Supportive Network: Coping with Old Age*, London, Allen and Unwin.
- Wenger, C.G. (1989) Support networks in old age: constructing a typology, in Jefferys, M. (ed) *Ageing in the 20th Century*, London, Routledge.
- Wenger, C.G. (1990) Elderly carers: the need for appropriate intervention, *Ageing and Society*, 10, p197-219.
- Wenger, C.G. (1990) Personal care: variation in network type, style and capacity, in Gubrium, J. and Sankar, A. (eds) *The Home Care Experience*, London, Sage.
- Wenger, C.G. (1995) A comparison of urban and rural support networks: Liverpool and North Wales, *Ageing and Society*, 15, p59-81.
- Wicks, M. (1982) *Crisis or Challenge? Family Care, Social Policy and Elderly People*, London, Study Commission on the Family.
- Wilkin, D. (1990) Dependency, in Peace, S. *Researching Social Gerontology*, London, Sage.
- Williams, F., Popay, J., and Oakley, A. (1999) *Welfare Research: A Critical Review*, London, UCL Press.
- Williamson, G.M. and Schulz, R. (1993) Psychological and behavioural dimensions of physical frailty, *Journal of Gerontology*, 48, p39-43.
- Willoughby, J. and Keating, N. (1991) Being in control: the process of caring for a relative with Alzheimer's Disease, *Qualitative Health Research*, 1, p27-50.
- Willmott, P. (1987) *Friendship Networks and Social Support*, Policy Studies Institute Report No 666, London.
- Wilson, H.S. (1989) Family caregiving for a relative with Alzheimer's dementia: coping with negative choices, *Nursing Research*, 38, p94-98.
- Wilson, G (1995) *Community care: Asking the Users*, London, Chapman Hall.

Wister, A.V. (1992) Residential attitudes and knowledge: use and future use of home support agencies, *Journal of Applied Gerontology*, 11, p84-100.

Wood, P. (1991) Care of disabled people, in Dalley, G. (ed) *Disability and Social Policy*, London, Policy Studies Institute.

Wright, F. (1986) *Left to Care Alone*, Aldershot, Gower.

Wright, F. (2000) Continuing to pay; the consequences for family caregivers of an older person's admission to a care home, *Social Policy and Administration*, 34, p191-205.

Young and Wilmott (1964) *Family and Class in a London Suburb*, London, Routledge.

Zarit, S., Reever, K and Bach-Peterson, J. (1980) Relatives of the impaired elderly: correlates of feelings of burden, *The Gerontologist*, 20, p649-655.

Internet resources:

Carers and Disabled Children Act 2000

<http://www.hmsso.gov.uk/acts/acts2000/20000016.htm> (13th Dec 2001)

Community Care and Health (Scotland) Act 2001

<http://www.scotland.gov.uk/health/lrc/legislation.asp> (14th Feb 2002)

Equipment and Adaptation Services in Scotland, A Survey of Waiting Times for Social Work Provision, Health and Community care Research Findings No 17.

<http://www.scotland.gov.uk/cru/kd01/red/eass-02.asp> (15th Jan 2002)

Home Care Services in Scotland 2001

http://www.scotland.gov.uk/library3/health/hcs_infonote-00.asp (15th Jan 2002)

Public Views of Social Work Services in Scotland

<http://www.scotland.gov.uk/library3/social/pvss-01..asp> (17th Jan 2002)

