

**AN EXPLORATION OF THE
POST-CARING EXPERIENCES
OF FORMER CARERS**

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ABSTRACT

This thesis explores the subjective meaning of the post-caring experience for a range of former carers, and the conditions and consequences of such experiences, using a qualitative, interpretive approach. The research was based on grounded theory and, after a preparatory stage, data was gathered primarily through semi-structured in-depth interviews with thirty-seven theoretically sampled former carers. These interviews were carried out in the East Midlands between February 2000 and June 2001. Other sources of data were interviews with key informants and a research diary. Drawing on research and theoretical models within the disciplines of sociology, social policy, psychology, and politics, the thesis increases the understanding of many different aspects of former carers' lives. Examples of these are the implications of the cessation of caring, their health, the way they reconstructed their post-caring lives, and their experiences of different sources of support. The substantive theory that emerged from the analysis is developed into a theoretical representation of the post-caring experience. This highlights the extensive influence of both caring and its cessation on post-caring experiences, and introduces new concepts into the literature on post-caring life. It argues that former carers' lives are characterized by a post-caring trajectory that has three phases. These are the "post-caring void", "closing down 'the caring time'" and "constructing life post-caring". The concept of the "serial carer" is also developed to provide an understanding of the cyclical experience of caring in the lives of the participants. The thesis concludes with recommendations for the enhancement of policy and practice in supporting former carers, and for further research in this area.

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LIST OF ABBREVIATIONS

FC = Former Carer

GP = General Practitioner

ICA = Invalid Care Allowance

PCT = Primary Care Trust

SAE = Stamped Addressed Envelope

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INTRODUCTION TO THE STUDY

The decision to choose former carers as the topic for this research project was influenced by my personal and professional interest in the growing number of people who have relatively recently been identified as “carers”. There was a high proportion of older people in the neighbourhood in which I lived in the late 1980s and I co-ordinated a group of volunteers to support these people and those who cared for them in the community. During this time, I was particularly struck by the range of needs of these older residents in my community, and the extent to which those “caring” for them had to devote their lives to supporting them in order for them to remain in the community. Most noticeable were the effects of caring on their physical and mental health.

When I entered academia in the early 1990s, this personal involvement led to a professional interest in the 1990 NHS and Community Care Act, its development and some of its implications. The latter included the adoption of the concept of the “carer,” and the way in which more people would have to take on the role of “carer”. Indeed the number of carers has gradually increased; the 2001 Census showed that there were 5.2 million people providing informal care in England and Wales, which is one in ten of the population (<http://www.carers.gov.uk>). It has also been estimated that three in every five people will be a carer at some point in their lives (Brindle, 2001). Other implications of the 1990 NHS and Community Care Act were the pivotal role of carers in community care, and the way in which they provide the government with a cost-effective means of caring for those who would otherwise have required more expensive and /or residential care (Wicks, 1998).

The experience of my voluntary work stimulated an interest in the health of the growing number of carers. Some interesting findings were emerging in the literature at that time which supported my observations about the effects of caring on carers’ health. Studies also

explored the implications of carers' ill health. For instance, O'Reilly et al, (1996) estimated that if just one in ten carers were unable to continue, the cost of alternative provision would amount to two billion pounds a year. Although I originally intended to research carers' health, having reviewed relevant literature, I realised that it would be difficult to provide any new insights into this topic without carrying out a major survey which was obviously beyond the limits of a PhD thesis.

During my review of the wealth of studies on carers, my attention was drawn to the fact that the development of community care was not only linked to the emergence of carers but also to another group in society – those who *had been* carers. Even though there was evidence that the concept of a “former carer” did exist in different discourses, and formal recognition of them was just emerging in policy circles, the simultaneously increasing number of those in this group in society remained very much a “forgotten army” (Wicks, 1998:30). This was due to a lack of agreement over their definition and a relative dearth of research and knowledge about them. In particular, the experiences of former carers were under-explored in the limited literature concerning this group that existed.

I therefore devised this study to extend the knowledge that was beginning to emerge in the published literature about this new and expanding group in society who had “often alone and at serious personal cost” (Wicks, 1998:30) given so much to dependent people in our society and helped to conserve government resources. More specifically, it was anticipated that the study would lead to a better understanding of former carers' post-caring lives and experiences, which could also have implications for policy-making. Interest in the research had already been expressed by the Health Services Research Group of the British Geriatric Society and Carers UK.

It is a qualitative study that uses an approach based on grounded theory to inform the theoretical exploration of the ways that a range of former carers created their post-caring experience, and the subjective meaning of this experience for them. The conditions and

consequences of such experiences are also explored. The broad research question that guided the study was:

What are former carers' understandings of their post-caring experiences?

The thesis was started in 1998 and was funded through a De Montfort University Research Bursary for the first three years. However, due to my full-time working commitments from 2002, the analyses of the data and writing up was not completed until 2005. Whilst it is mainly sociological, several other disciplines such as social policy, psychology and politics are also drawn upon in the study. A broadly interpretive approach was adopted because interpretivism enabled the former carers' own perceptions and interpretations of the world to be investigated. However, as the research proceeded other approaches contributed in response to issues that arose (Noblitt and Engel, 1992; Layder 1993). The content of the thesis is organised in the following way.

Chapters 1 and 2 comprise the literature review for the study. The initial literature review was carried out between 1998 and 2000 and reflects the state of literature at that time. In addition, relevant sources were reviewed throughout the period of the study, and more recent literature is also referred to in these chapters and in Chapters 5 to 10 (*see below*). Whilst themes and issues that are pertinent to the study are highlighted in the literature review, the concepts of "community care" and the "carer" are also explored in depth because of their centrality not only to the concept of the "former carer", but to the lives and experiences of former carers. Therefore, **Chapter 1** specifically focuses on "community care" and its constituent concepts – "care" and "community" – before addressing the nature, development and explanations of "community care" itself. **Chapter 2** then discusses the literature on the associated concepts of the "carer" and the "former carer". It examines the nature of these concepts and shows how a working definition of a "former carer" was developed for the purposes of the study.

Chapters 3 and 4 address the research methodology used for the study. **Chapter 3** starts with an explanation of how the research question was developed and outlines the aims of the study. It then describes methodological issues in the research, locating them in the interpretive approach to the study. The reasons for using grounded theory as the main research methodology are explained. The way that the study was carried out, the research methods, data collection methods, theoretical sampling, and ethical issues are also described. **Chapter 4** provides details of the data analysis process, and discusses the important issues of the validity, reliability and generalisability of the study.

Chapters 5 to 8 present the findings from the data analysis. As the approach adopted was based on grounded theory, the findings are discussed in relation to the literature that was identified as part of the ongoing literature review. One of the main findings was that the respondents insisted on contextualising their post-caring lives by describing their caring experiences, often in great detail. Examining the context of the subject of study in order to give a broader understanding is in accordance with the interpretive approach used in this research (Brown and Stetz, 1999). Consequently, **Chapter 5** contextualises life post-caring by exploring the caring experiences of those interviewed. **Chapters 6 to 8** then address the former carers' understandings of different aspects of their post-caring experiences. The influence of caring is also discussed in these three chapters. **Chapter 6** discusses the issues that the former carers faced post-caring, such as the losses they faced upon the cessation of caring and their varying health experiences. The processes post-caring life involved for those interviewed, and the influences on these are the subjects of **Chapter 7**. **Chapter 8** discusses experiences of support post-caring. In addition, it outlines ideas put forward by the former carers about ways that post-caring support could be improved.

The main findings presented in Chapters 5 to 8 are reviewed in the light of existing literature in **Chapter 9**. This chapter also clarifies the original contribution to knowledge made by the thesis, presents, discusses and theoretically explains the formal theory developed about the post-caring experience and ends with an evaluation of the study.

Chapter 10 outlines recommendations for policy, practice and future research on the basis of the findings from the study before summarising the conclusions reached.

The terms carer, caring and former carer are used throughout, except when quoting from sources that use alternative nomenclature, such as caregiver, caregiving and ex-carer. As this study adopted an interpretive perspective, many of the definitions and classification systems were based around the information given by the interviewees, and therefore reflect their perceptions. Appendix 1 provides a list of the definitions and classification systems used, together with explanations and justifications for the approach taken to each one. Other concepts are defined within the main body of the thesis, and reference to Appendix 1 is made as appropriate.

CHAPTER 1: COMMUNITY CARE

This is the first chapter of the literature review. An in-depth analysis of the literature published since 1980 pertaining to carers, caring and former carers was conducted. This included reviewing textbooks, journal articles, research publications, theses and work in progress identified through a wide range of electronic and manual searches. Examples of electronic databases used were the Applied Social Science Index and Abstracts (ASSIA), Bath Information and Data Services Institute of Scientific Information (BIDSISI), Caredata, The Cochrane Library, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline (pubmed), and Social Science Information Gateway (SOSIG). Manual searches carried out included the Citation Index to Theses and National Research Register. Documentary evidence was also used to develop historical sensitivity to the research topic, and provide both background and specialist knowledge. Examples of such evidence included publications by charities such as Scope, Carers National Association, carers centres, official statistics, newspapers, magazines and policy documents produced by the government, social work departments, CCETSW and the NHS.

The chapter focuses on “community care” and its constituent concepts which are “community” and “care”. It starts by reviewing these two concepts and then moves onto the concept of “community care” itself. The discussions demonstrate the contested nature of these concepts and highlight the implications for any definition of a “former carer”. Other important conceptual issues relevant to the context of this study are simultaneously explored.

Concepts of “community” and “care”

“Community”

The concept of “community” is used in several disciplines. Sociologists have acknowledged its ambiguous nature for some time and emphasised the lack of clarity

caused by the absence of a single fixed meaning. Indeed, work done in this area draws attention to the variety of meanings of “community”; Bell and Newby (1975) discuss how ninety-four definitions have been identified. Furthermore, meaning varies over time, within different discourses and there is confusion over it in policy documents (Bell and Newby, 1975; Wilson, 1982; Finch and Groves, 1985; Mohan, 1995; Mayo, 1998; Symonds, 1998). Unsurprisingly, this has led to arguments that the concept of “community” is a constructed one; Symonds, (1998) maintains that it was only in the last century that

the phrase ‘community’ became a public discourse. The word itself became an organising principle for policies and practice, and gained a hold on everyday commonsense

Symonds, 1998:12

Many approaches to the constructed nature of the concept of “community” were identified in the literature. Two have been selected as examples of how these approaches vary; the first asserts that “community” has been constructed as an idealised way of living which is under threat. Such views tend to romanticise traditional communities, and portray them as close knit and mutually supportive (Tonnie, 1963; Abrams, 1977; Titmuss, 1979; Wilson, 1982; Bulmer, 1987; DoH, 1989; Mohan, 1995). An early proponent was Tonnie (1963) who was writing in the late nineteenth century when sociological thought was influenced by romanticism, and “community” was regarded as essentially beneficial to human needs and social interaction. He drew a distinction between “*gemeinschaft*” and “*gesellschaft*” to illustrate the changes to communities during industrialisation. He argued that the preindustrial world was based on *gemeinschaft* whereby community relationships were characterised by intimacy and durability, status was ascribed rather than achieved, kin relationships took place within a shared territory and were made meaningful by a shared culture. Industrialism and urbanism led to a replacement of *gemeinschaft* by *gesellschaft*. This gave rise to relationships which were impersonal, fleeting, contractual, competitive, rational and calculative rather than affective, and often characterised by anonymity and alienation. Status was based on merit, and was therefore achieved. Tonnie placed a high

value on *gemeinschaft* and was deeply pessimistic about the inevitable change from *gemeinschaft* to *gesellschaft* that industrialisation entailed because of his idealised view of the merits of traditional communities and the way that relationships would be destroyed. Such romanticised views of “community” can also be seen in post-war sociological research into urban communities which focused on working class neighbourhoods. An example is Young and Willmott's study (1957) of family life and kinship patterns in East London in the 1950s. They argued that “community” in the traditional sense, as referred to above, had survived in Bethnal Green despite rapid social change.

However, some maintain that such communities never existed (Abrams, 1977; Titmuss, 1979; Humphrey, 1989; Symonds, 1998; Chapman and Aiken, 2000). For instance, Titmuss (1979) warned that locally based communities who will help and provide services do not exist and compared the rhetoric of community to the illusion of the “everlasting cottage garden”.

Symonds (1998) offers an explanation of the existence of this construction of “community” as an idealised way of living despite the evidence to the contrary that most people encounter in their everyday lives. She argues that people can be aware of the latter whilst still holding onto the former because “the concept of community occupies two parallel realities” (Symonds, 1998:12). One of these is “social lived reality” and the other is the “dream” of community life. The first refers to the “community” in which we live and work. The second is based on an idealised view of communities as having shared values and culture based on “lost cosy worlds” (Symonds, 1998:13), as portrayed in the media and literature, rather than reflecting reality. Because of the duality of the nature of the concept of community, Symonds argues that it is perfectly possible to recognise that the first reality has negative aspects, such as conflict with neighbours and lack of social relationships with those within close proximity, whilst simultaneously holding onto the powerful reality of the “dream” world of community life.

Whether such “idealised” communities did or do exist, a contrasting approach in the literature is that adopted by those who have focused on the less than “dream-like” qualities of communities throughout history. Sennett (1993) uses the concept “destructive gemeinschaft” to explain how community feelings can be psychologically destructive. Abrams (1989) argues that the networks of traditional neighbourhoods developed as a response to adverse external conditions such as poverty and resourcelessness. He therefore concludes that such traditional communities are not necessarily desirable or ethical. In addition, the way that some groups in communities may have negative experiences of communities has been highlighted (DoH, 1989; Humphrey, 1989; Mayo, 1998; Means and Smith, 1998; Symonds, 1998). For instance, feminist writing in the 1980s emphasised how “community” can have negative connotations for women. Some of these arguments focus on the way that the different roles of men and women are ideologically constructed with the result that women are oppressed within communities because of their caring responsibilities (Wilson, 1982; Finch and Groves, 1985; Ungerson, 1985).

Irrespective of whether an idealised view of “community” is presented or not, ideas about ideological construction feature more strongly in several other approaches to this concept. These approaches see the concept of “community” as being politically constructed and therefore varying with political ideologies. Mohan (1995), for example, focuses on the New Right’s welfare anti-statism with its emphasis on an increased role for market forces, individualism, and individual freedoms to earn and spend money, rather than collective provision by the “nanny state” reliant upon excessive taxation. This anti-statism, he argues, means that the New Right sees the “community” as the “first port of call for those in need” (Mohan, 1995:102). Johnson (2000) shows how New Labour has adopted a different concept of “community” which is influenced by communitarian ideology. This ideology is opposed to purely individualistic conceptions of welfare and stresses common interest and common values arising from communal bonds. Within it, communities are seen as vital units of social organisation with shared moral values, and as a means for ensuring social cohesion (Powell, 2000; Johnson, 2000; Deacon, 2002). However, ambiguities in New Labour’s appeal to communitarianism have been identified; Chamberlyne and King

(2000) argue that there are conservative elements in New Labour's approach, thus suggesting that political constructions of the "community" may overlap to some extent.

This brief overview demonstrates how the concept of "community" is subject to different constructions, varies with political ideologies and has different meanings for different people. Thus it can be argued that this component of "community care" is contestable. The centrality of the concept of "community care" to that of the former carer has already been established. The conclusion about the contested nature of this first concept of "community" therefore not only has implications for the wider concept of "community care", but ultimately for any discussions about former carers. However, before these implications can be discussed further, it is necessary to examine the other concept integral to "community care" – that of "care".

"Care"

Although the reasons differ, it can also be argued that the concept of "care" is contestable. The first reason is that its definition and meaning varies within discourses and between contexts (Gaut, 1983; Swanson, 1991). Ideas about different dimensions of care have been put forward, particularly in the feminist literature. The distinction between "caring about" someone and "caring for" someone has been made (Ungerson, 1983; Dalley, 1996). The former involves affection and feelings for another person. The latter however concerns the tasks of tending for another person and has little to do with affective ties, referring more to a socially constructed sense of obligation, whether this is through payment or the exigencies of a social norm. Others have argued that giving "care" is a matter of both labour and love and that these two dimensions should not be separated as they provide the act of giving care its most distinctive and compelling qualities (Graham, 1983; Lewis and Meredith, 1988). However, there are cultural differences in the interpretation of care as meaning both to "care about" and "care for" someone; Norwegian sociologist Waerness distinguishes between "care" and "care-giving work" (Waerness. 1990:112) because of the association of "care" in Scandinavia with "work". She argues that the term "care-giving

work” refers to the activities of providing care for those who are unable to care for themselves such as the very young or very old. It is therefore “care-giving work” rather than “care” that involves both “caring about” and “caring for” a dependant (Leira, 1990).

These definitions can be criticised for presenting an inaccurate view of “care”; during caring the “caring about” component of care may change. There can be “resentment” (Lewis and Meredith, 1988:61) and “deterioration in a relationship” (Lewis and Meredith, 1988:68) with the result that “caring about” can become tense, fractured, distorted, abusive and can be transformed into a relationship that lacks genuine affection (Hasselkus, 1988; Lewis and Meredith, 1988). Nor are both “caring about” and “caring for” necessarily present in “care”; the “caring about” component may be absent when caring is taking place because of a feeling of obligation or resignation, and it is possible to “care about” someone but not “care for” them (Ungerson, 1983; Land and Rose, 1985; Leira, 1990; Dalley, 1996; Ackers and Abbott 1998; Biggs, 1998). An example of this argument can be found in the analysis of women’s caring relationships as “compulsory altruism” by Land and Rose (1985). They question whether such relationships are an expression of genuine affection because women “feel that they have no choice but to sacrifice themselves for another” (Land and Rose, 1985:93).

The second reason why the concept of “care” is contestable is that it is often used interchangeably and in conjunction with “informal care” and “formal care”. These both refer to the care of a sick or disabled person, and are very loosely constructed as informal unpaid care provided in the home and formal paid care provided either in the home or in an institution for such people respectively. However, there is much evidence to suggest that both “informal care” and “formal care” are ambiguous and subject to varying definitions (Abrams, 1984; DoH, 1989; Ungerson, 1990; Payne, 1991; James, 1992; Rose and Bruce, 1995; Chamberlyne and King, 2000). Indeed, as Rowlands (1998:1) has argued, there are no “widely accepted” definitions of either type of care.

With reference to “informal care” in particular, the literature highlights the way the constructed nature of this concept leads to problems of definition. Indeed, Ackers and Abbott (1998) maintain that it has only become visible and received acknowledgment over the past two decades because feminist research has highlighted how the operation of patriarchy meant that the work of women in providing “informal care” was unrecognised and unremunerated. Support for the view that “informal care” is constructed can be found in studies concerning the various types of informal care systems that exist and the way that these change with social, political and economic circumstances (Abrams, 1989; Snaith, 1989; James, 1992). An example of more recent work is that by Chamberlyne and King (2000) who argue that patterns of informal care networks are in many ways a response to “particular welfare regimes” (Chamberlyne and King, 2000:3).

One of the main difficulties when defining “informal care” and “formal care” is the fact that there are many similarities between them, and consequently they are not easily distinguishable. These similarities include the absence of mutual obligation (Swanson, 1991), the way that they encompass the same sort of activities (Stacey, 1988), involve caring *for* someone (Ackers and Abbott, 1998) and have common learning goals in terms of increasing understanding and skills (Payne, 1991). The predomination of women and lack of status and autonomy in both are further similarities (Walker, 1982; Abrams, 1989; Leira, 1990; Ungerson, 1990; James, 1992; Jones, 1994; Langan, 1997; Twigg, 1998; Cancian and Oliker, 2000).

Although other similarities identified in the literature highlight the way they both involve power, there are different reasons for this and the degree of their power is subject to varying influences (Bowling, 1984; Taylor, 1991; 1999). With regards to the reasons for power, in her comparison of family care and hospice care, James (1992) argues that those who provide “formal care” have power in terms of that conferred upon them as employees of their organisation. She gives the example of the way the aims, hierarchically-ordered division of labour and variations in status in the hospices she studied meant that members

of staff could “limit what was expected of them” (James,1992:499) in terms of the care they provided for a patient. The power of those providing “informal care” has been attributed to other factors, such as the absence of formal complaints procedures (Abrams, 1978) and the fact that they have considerable autonomy (Corbin and Strauss, 1988; Ungerson 1990). As Ungerson (1990:27) argues, they can decide “how best to organise the work”. This also gives them autonomy (Corbin and Strauss, 1988; Ungerson 1990).

However, recent work on “informal care” which has adopted a postmodernist approach has challenged more conventional sociological and political notions of power as involving one person’s ability to impose their will over another (May, 1992; Fisher, 1994; Dominelli and Gollins, 1997; Taylor, 1999). The asymmetrical view of power in informal caring relationships is rejected because caring relationships are

not simply a matter of the carer exercising ‘power over’ the cared-for. Rather power becomes a fluid entity which is constantly (re)created and (re)negotiated through interaction. ...power therefore is a fluid, complex, constantly shifting force

Dominelli and Gollins, 1997: 412-414

Thus, as power is constantly negotiated and recreated through the interaction between the informal carer and cared-for person, neither is “all powerful or all powerless” (Dominelli and Gollins, 1997:396).

Few clear differences between “informal care” and “formal care” emerge in the literature. An example is the work on the emotional labour of informal care. This has been defined in terms of managing and regulating feelings in order to fulfil a role, and respond to and produce an emotional state in another (Hochschild, 1983). It has been argued that “informal care” is more strongly associated with emotional labour whereas the focus in “formal care” is on the physical tasks of caring (James, 1992). Other points of distinction that have been made can be refuted. For instance, it has been argued that “formal care” is governed by workplace ideology and involves paid work for which people are trained, requiring specialist tools and buildings in which to use them (James, 1992; Taraborelli, 1993).

However, as training is available for those providing “informal care” (Payne, 1991, <http://www.carers.gov.uk>, 2002) this does not necessarily help to distinguish between those providing “informal care” who have undergone training of some kind from those providing “formal care”. Another distinction made in the literature focuses on the way that affection and warmth are more likely to feature in “informal care”; it takes place within an existing social relationship (Abrams, 1978; Hasselkus, 1988; Qureshi, 1990; Bibbings, 1998) and is an “expression of caring about” (Qureshi, 1990:61) with all the latter’s concomitant benefits, such as affection and warmth. However, Qureshi found that relationships between individuals in “formal care” do develop and transitions between the conceptual worlds of “formal care and “informal care” do occur.

In addition, there is much discussion in the literature about the unclear boundary between “formal care” itself and “informal care”. Ungerson, (1990) talks about the way in which this boundary varies culturally. For instance, in Scandinavia “informal care” is not always distinguished from “formal care” which is carried out by statutory social services and voluntary agencies within domiciliary and institutional settings. Some point to the confusion that exists between the division of responsibilities between “formal care” and “informal care”. Others have highlighted the variations in the position of the boundary between “informal” and “formal” systems of care in communities because of the many different relationships that exist between the two systems (Abrams et al, 1981; DoH, 1989; Langan, 1997).

Thus the meaning of “care” cannot be clearly defined and it is often confused with other ambiguous concepts. The way that “care” lacks distinguishing features is the third reason for arguing that it is a contestable concept. The literature on the tasks of “informal care” illustrates this well. Those identified are physical tasks (feeding and washing) some of which can be physically demanding as they involve lifting and hoisting, mental tasks (providing emotional support, empathy, and affection), the provision of services (administering medication and transporting dependants) and organising useful and

necessary services for the dependant in order to manage their illness (Walker, 1983; Corbin and Strauss, 1988; Leira, 1990; Parker and Lawton, 1994; Twigg and Atkin, 1994; Hooyman and Gonyea 1995; Cancian and Oliker, 2000).

However, these tasks are not always distinctive from those in other forms of “care”. Many of them overlap with tasks that are part of other familial roles involving the provision of unpaid care, such as caring for children, other dependants and partners. These include cooking special food and housework (Baldwin, and Glendinning, 1983; Walker, 1983; Corbin and Strauss, 1988; Popay and Jones, 1990). The tasks bear further similarities through being continuous and contributing to the quality of lives of the people receiving the care (Corbin and Strauss, 1988; Bond et al, 2003).

Other research shows that such tasks cannot be clearly identified because they also vary enormously (Lewis and Meredith, 1988; Twigg, 1992). There are many factors that contribute to this variation. One is the way that tasks change during “informal care” (Corbin and Strauss, 1988; Lewis and Meredith, 1988; Brown and Stetz, 1999). For instance, Lewis and Meredith (1988) found that tasks change over the time during which caring is provided; they identified a “caring sequence” which involved three stages and explain that

The caring period involved movement between these stages, usually from what have been identified as semi-care to either full care or part-time full care
Lewis and Meredith, 1988:32

The caring tasks were more onerous during “full care” than in the other two stages.

Other factors include the way the nature of the tasks can vary with the relationship to the dependant and the nature of the dependant’s illness; Ackers and Abbott (1998) report that wives, mothers and daughters are more likely to provide personal care whereas neighbours are more likely to provide surveillance. The care of those with a mental illness is far less likely to involve personal care tasks, and is more about responsibility and supervision than

the care of dependants with physical illnesses (Perring, Twigg and Atkin, 1990). The social context of “informal care” also leads to variation in its tasks; where “informal care” is being provided on a co-resident basis, caring involves personal care such as bathing, dressing and toileting. Where co-residency is not involved, there is less personal care but other tasks are involved such as supervising medicine-taking, keeping the dependant company, taking the dependant out and keeping an eye on him/her (Parker and Lawton, 1994). However, it would seem that co-residency in caring is subject to social patterning and some social groups are more likely to be co-resident than others; Arber and Ginn (1992) found that co-residency in caring is more common in working class than middle class families. Ahmad and Atkin (1996) cites studies which show that members of minority ethnic groups are also more likely to provide co-resident care. Whilst class and race can therefore influence the nature of the “informal care” tasks, other aspects of the social context are influential; it has been argued that the extent of “the provision of state services and resources” (Arber and Ginn, 1992:621) and “social change” (DoH, 1989:26) can also influence the nature, range and amount of “informal care” tasks.

The fourth reason why the concept of “care” can be contested concerns the difficulty in establishing precisely who provides and who receives “care”. This is because it is difficult to establish differences between those providing “care” of any sort and those who provide “informal care”. Similarly, there are few clear differences between those being cared for by others in some way and those who are receiving “informal care”.

With reference to the first difficulty, the feminist literature argues that both familial care and “informal care” are similar because they exploit women and are part of the way that the operation of patriarchy excludes women from power and authority in the public domain. Thus, the feminist view is that providing “informal care” for women is not distinctive from other caring roles they undertake. Examples of these arguments can be found in the feminist writing of the 1980s and 1990s. Some of this argues that “caring” and providing “informal care” for a family coalesce in women’s roles. Particular reference is made to

motherhood within this discourse, as it maintains that the conceptual distinction between the two is most problematic in the role of motherhood (Groves and Finch, 1983; Ungerson, 1983; 1990; Graham 1983; Dalley, 1996). Although such views can be challenged by those who maintain that motherhood is a socially and politically constructed concept (Borchorst, 1990; Siim, 1990) feminist work on the “caring cycle” supports these arguments about the coalescence of “caring” and “informal care” in women’s roles; women are seen as being caught in a “caring cycle” (Rimmer, 1983; Ungerson, 1987; Bartley et al. 1992) or “caring tricycle” as Doyal, (1995:41) refers to it, in which they first care for children, then for elderly relatives and then for aged spouses. As “care” and “informal care” are integral to women’s lives, such arguments indicate that it is very hard to identify when women are giving “informal care” and when they are not. Another argument in the feminist literature concerning the way informal caring cannot be differentiated from women’s other caring activities is that the relationships in which women carry out their caring activities (such as marriage, parenthood and kinship) are all “relationships of obligation” (Twigg and Atkin, 1994:10). However, a weakness of these feminist arguments is that their exclusive focus on concepts such as patriarchy, exploitation of women and motherhood limits their applicability to male carers.

Distinguishing between those being cared for by others and those receiving “informal care” is also problematic because the latter are not an identifiable and distinct group in society. This is evident from the literature as there are a number of definitions which use varied criteria. These include “inability to cope with tasks of daily living”, “manage at home without help”, “requiring social care” and “unable to manage without help”. Such criteria lack objectivity and are subject to interpretation. For instance, some of these criteria do not enable a distinction to be made between other groups in society who need care and those receiving informal care; Baldwin and Glendinning (1983) point out that a child without any disability is unable to manage without the help of a parent. In addition, the two most frequently used criteria in the definitions are disability and “dependency” of some sort (Twigg and Atkin, 1994; Brechin et al, 1998). Further exploration of these reveals that they do not help distinguish between those who receive informal care and those who do not.

Exploration of the use of criteria based on disability showed that it is well established that disability can be episodic rather than static, refers to a vast range of conditions and varies in severity, duration and degree of dependency (Means and Smith, 1998). Furthermore, the sociological literature highlights the competing constructions of disability within different discourses (Reynolds, 1996; Hughes, 1998; Oliver, 1998), and the way in which disability is socially constructed through the activities of powerful groups, historical and cultural developments, and ideology and language (Oliver, 1990; 1993; 1996; Campbell and Oliver, 1996). Campbell and Oliver describe the role of some of these influences on the changing construction of disability that occurred during the development of the social model of disability. During this time, there was a

challenge to dominant social perceptions of disability as personal tragedy and the affirmation of positive images of disability.....the origins of these fundamental changes..... can be found in the 1960s with the coming of the 'age of affluence' when disabled people began to organise around issues of income, employment, rights and community living rather than institutional care. It continued in the 1970s with the passage of the Chronically Sick and Disabled Person's Act (1970) [CSDPA] and the formation of the Union of the Physically Impaired Against Segregation [UPIAS]"

Campbell and Oliver, 1996:20-21

Similarly, there are arguments that society creates dependency (Walker, 1983; 1992; Oliver, 1990; 1993); Walker puts forward a Marxist interpretation and maintains that dependency in the elderly has been created by capitalist societies. This has arisen because of their "structurally enforced" (Walker, 1992:41) lack of participation in the production process due to capitalism's inherent drive for profit. As one of the consequences of the latter is that older workers are seen as being more expensive and less productive than younger workers, retirement policies have been subsequently developed to ensure the maximisation of profit. Walker argues that because work is a source of social and economic status, the move to a fixed age for retirement has "socially engineered" (Walker, 1992:41) a generally lower social status for older people, and simultaneously enforced their social and economic dependency on others and on the state (Walker, 1992). But, as Walker asserts,

this is a narrow construction of production because it ignores the role played by those who are deemed dependent in supporting the productive labour of others in capitalist societies. Furthermore, postmodernists argue that the focus on universal life stages and the categorisation of people into such stages is inappropriate in our postmodern society. The focus should be on the lifecourse of individuals and examine the way that our lives change and evolve as we experience different events (Chapman and Aiken, 2000; Holstein and Gubrium, 2000).

Thus, the many definitions of the recipients of “informal care” based on criteria of disability and “dependency” are essentially using concepts that do not help to clearly differentiate between those who receive “informal care” and those who do not. Some attempts have been made at distinguishing between dependency in informal caring relationships and other relationships where care is involved. However, these have limitations; Dalley (1996) defines dependency in informal caring situations in terms of involving the care of a child or non-child kinfolk in a condition of “extra-normal dependency”. A child is deemed to be in such a state when he or she is “chronically dependent beyond the constraints of dependency dictated by its age” (1996:15). However, the phrase “extra-normal dependency” raises questions about the nature of “normal dependency” and when dependency becomes “extra-normal.” For example if your partner/spouse has diabetes, does the extra attention you pay to their health and lifestyle amount to “informal care”? Also, there is no indication about the length of “extra-normal dependency”. As this is not specified, “a child or non-child kinfolk” with a short-term injury, such as a broken leg or a far longer-term condition such as Multiple Sclerosis or Alzheimer’s Disease could be receiving informal care. The two situations are very different in terms of the levels of dependency but both could be regarded as informal caring if Dalley’s ideas are applied. Therefore the concept of “extra-normal dependency” is not very helpful in distinguishing between dependency in informal caring and other types of situations.

To conclude, there are many debates about the concept of “care”. The debates identified have centred around the problems associated with establishing its meaning and definition, identifying its distinguishing features, and ascertaining who provides and receives it. The discussions so far in this chapter have therefore demonstrated the contested nature of both the concepts of “community” and “care”. Inevitably this affects the final concept to be addressed in this chapter – that of “community care”.

“Community care”

The concept of “community care” is generally used to describe care for those in need which is based on support and care in their homes provided through a mixed economy of care. This is based informally through the individual and collective efforts of those in the community on an unpaid basis, and formally by paid professionals employed by health and social care organisations and /or institutions (Finch and Groves, 1985; Higgins, 1989; Blakemore, 2001). However, close examination of the concept reveals a lack of coherence because it is the subject of varying perspectives and interpretations. These are discussed below.

The meaning of “community care”

Analysis of policy documents show that “community care” has had different meanings during its development. It can be traced back to the early 1900s when the 1904–08 Royal Commission on the Care of the Feeble Minded first signalled the shift in emphasis from hospital care to “community care” in policy initiatives (Finch and Groves, 1985; Means and Smith, 1998; Blakemore, 2001). From then, there was a growing emphasis on “community care” in policy documents (Parker, 1985; Brechin at al. 1998; Heaton, 1999).

Until the 1970s, policy documents, such as the Phillips Report (1954) and the Guillebaud Report (1956), talked about care *in* the community (Parker, 1985; Brechin at al. 1998;

Heaton, 1999). This meant care which is delivered within the locality, either in the home and /or in close proximity to those living in that locality. Consequently, various local authority based domiciliary services (such as home nurses, home helps and health visitors) and voluntary services (for example “meals on wheels”) were provided to support certain groups, such as “the elderly, the mentally ill and the mentally handicapped” (Baggott, 1998:228) in their homes within their community. Statutory care services were also provided in the community (for instance, hostels and sheltered housing) for such groups (Finch and Groves, 1985; Means and Smith, 1998; Baggott, 1998; Blakemore, 2001).

In the 1970s, there was a move away from the provision of services in the community by local authorities and statutory care services. Policy documents emphasised that family members, families and friends were now the main providers of “community care” with the support of statutory and voluntary services (Finch and Groves, 1985; Parker, 1985; Brechin at al. 1998). Throughout the 1980s, a variety of policy documents reiterated the theme that individuals in the community, and particularly the family, as opposed to the state had the main responsibility for care (Parker, 1985; Baggott, 1998; Brechin et al, 1998). The emphasis in policy documents gradually changed from care *in* the community to care *by* the community. The most explicit statement was made in the 1981 White Paper *Growing Older* which stated that

care in the community must increasingly become care *by* the community

Department of Health and Social Security (1981:3)

In the 1990s, these policy developments culminated in the National Health Service and Community Care Act 1990 which made it clear that care *in* the community was now care *by* the community (Finch and Groves, 1985; Blakemore, 2001). The implementation of this Act in 1993 meant that the “principal component” of care by the community was informal care supported by care management (Biggs, 1998:258).

Although the use of these terms *care in the community* and *care by the community* in policy documents seemed to imply different meanings, the distinction between the two is unclear. Similarities have been identified, such as the way they both involve sets of interagency relationships and interactions involved (Finch and Groves 1985; Snaith, 1989; Salter, 1998; Johnson, 2000) and both refer to “care within the home” (Symonds, 1998:4).

Explanations of the development of “community care”

There are also different explanations of the development of “community care”. Parker (1985) is amongst those who have written extensively about “community care”. She says the assumptions underpinning “community care” were that it was best for dependent people not to live in large-scale institutions, and to remain in their own homes or in the homes of close family members wherever possible. Indeed, Allen (2000) links these assumptions to an increase in the expectation that people look after dependent family members in other countries.

There are also broader explanations of “community care”. For instance, Symonds (1998) applies a sociological perspective and shows how shifts in discourses influenced the development and organisation of “community care”. Indeed community care policies in the 1980s were shaped by such discourses on social equality which were the outcome of the development of the disability movement (Campbell and Oliver, 1996), and the growing emphasis on user empowerment, promotion of user choice and independence (Means and Smith, 1998; Malin et al, 1999). Further evidence to support Symond’s view can be found in the literature on the criticisms of the National Health Service and Community Care Act 1990. These include the inflexibility and lack of integration of services, confusion over the roles of volunteers and professionals, the difficult relationships experienced with some professionals, the devaluing of physical care and the lack of focus on carers’ needs (Twigg, 1992; Macritchie, 1993; Nocon and Qureshi 1996; Bibbings, 1998; Walmsley, 1998; Nolan and Lundh, 1999). Such criticisms have led to accusations that service users have “limited rights” (Means and Smith, 1998:96) and the “rights-based and free system of

care” (Means and Smith, 1998:1) has been undermined. Data about the fact that only one in five carers had their needs assessed and only one in three had their identified needs addressed has been used to endorse such accusations (Bibbings, 1998; Miller, 2003). Thus, although enthusiasm for community care policies cut across political boundaries, the literature shows that some of these failures can be seen as a result of New Right ideology and its emphasis on privatisation, the finite public purse and the identification of low cost solutions (Balcock and Ungerson 1994; Finch and Groves, 1985; DoH, 1989; Mohan, 1995; Chamberlyne and King, 2000).

In contrast, Heaton (1999) proffers a Foucauldian analysis of “community care” based on the Foucauldian notion of the “gaze” which is about ways of seeing and understanding the world. Heaton uses the concept of the “medical gaze” which she defines as “ways in which objects of medical knowledge and practices have been viewed and understood” (Heaton, 1999:769). Therefore, the “medical gaze” directly affects health and social care provision. She attributes the development of “community care” to the discourses about “informal care” in the 1970s, late 1980s and 1990s, and argues that these discourses were influenced by the “medical gaze” becoming more multifarious and extending to the community and family. Consequently, the community and family were given the responsibility of overseeing and regulating the health of those around them. This was achieved by those providing “informal care” becoming “facilitators” (Heaton, 1999:771) because of their relationship with both those needing care and formal service providers.

However, Mohan warns against adopting one explanation of “community care”; in his words “policies are not amenable to such reductionism” (Mohan, 1995:41). He says whilst community care policies do show some consistent ideological themes, they do not represent a coherent approach. This is because, like all policies, they are politically mediated and are the product of a variety of factors. These include the interplay between central government, interest groups and external influences, the macro-political environment, technical

developments, the interaction between different ideologies (partnership and pluralism) and rationality.

The way that “community care” encompasses different meanings and is subject to different constructions has led to this concept being criticised as being both “meaningless” (Finch and Groves, 1985:39) “an unnecessary and complicating element on social policy analysis” (Higgins, 1989:15), having “confused boundaries” (Mohan, 1995:101) and no consistent meaning (Walker, 1982; Mohan, 1995; Ahmad and Atkin, 1996; Symonds, 1998). Indeed there are those who argue that the introduction of community care policies have not made any difference to the provision of “care” for dependent and vulnerable people. For instance, Walker (1983) says for most physically and mentally dependent older people, the alternative to institutional care over the post-war period has been “community care” anyhow. Rossiter and Wicks (1982, cited in Finch and Groves, 1985) argue that even in the absence of a political emphasis on “community care” and its desirability, much social care is and always has been undertaken by family and friends without recompense.

Conclusion

The examination of the concepts of “care”, “community” and “community care” in this chapter has been useful in a number of ways. It has not only introduced many other relevant concepts such as informal care, dependance and the tasks of care, but also different perspectives within the disciplines drawn upon in the study, relevant research, literature and policy documents have been discussed. In addition, it has contributed to the development of a list of substantive issues and themes about the post-caring experience that required exploration (discussed further in Chapter 2 and set out in Appendix 2). This all developed understandings and knowledge that were essential to the formulation of the research question and the rest of the study.

The discussions have also demonstrated that uncertainty surrounds the concept of “community care”. This is because of the complexities imposed by its constituent concepts

("care" and "community") and the nature of the concept itself. Given the centrality of this concept to the lives and experiences of former carers, this conclusion inevitably raises questions about the clarification of the main conceptual issues in this study. The next step in the exploration of these main conceptual issues is to examine the concepts of the "carer" and the "former carer". Both of these concepts are addressed in Chapter 2.

CHAPTER 2: CARERS AND FORMER CARERS

This chapter continues with the discussions of the conceptual issues that are central to the study and explores the concepts of the “carer” and “former carer”. The literature on the concept of the “carer” is explored and its essentially constructed nature demonstrated. A definition of “carer” is developed for the purposes of this research. Following the review of the literature on former carers, this is then refined to produce a working definition of a “former carer”.

The concept of the “carer”

Chapter 1 showed that the concept of “community care” has a range of meanings and that this concept is in turn based on the disputed concepts of “community” and “care”. Therefore, not surprisingly, the literature review also demonstrated that even though the term “carer” is now part of common parlance in this country, there is a lack of agreement about how it should be defined. Definitions differ in policy documents as well as research, many studies developing an operational definition, with the result that they vary across time and across discourses (Spackman 1989; Davey and Popay, 1993; Webster, 1993; Dean and Thompson 1996; Bytheway and Johnson, 1997; Rowlands 1998; Heaton, 1999). Indeed, it has even been argued that the concept of “carer” has limited meaning to many who themselves would be officially defined as “carers” (Hutton, 1998). This is because it is a role that “arises from mutual bonds of family, duty, and affection” (Hutton, 1998: 276). Thus “carers” often do not recognise or define themselves as such but simply see themselves as people providing love and comfort that comes naturally to them. Recent studies have highlighted some of the possible implications of this; one is that 300,000 people do not claim Carer’s Allowance, the main benefit for carers. There is also evidence that those formally identified as “carers” are only a small percentage of those who are providing informal caring services (Bibbings, 1998; Means and Smith, 1998; Heaton, 1999; Miller, 2003; Taylor, 2003).

In addition, there was evidence in the literature review of the socially constructed nature of the concept of a “carer”. This emerged from the way that a combination of different factors, such as policy, research, and pressure groups, has contributed to its construction. These are discussed below.

The role of policy

With regards to policy, although people have cared informally for family and friends for a long time, it is only since the 1980s that the term “carer” has been part of the English language (Snaith, 1989; Davey and Popay, 1993; Bytheway and Johnson, 1998). The change in emphasis in policy documents from care in the community to care *by* the community that occurred in the 1980s in the United Kingdom (see Chapter 1) was highly significant as it meant that “carers” became more central to the implementation of community care policies (Webster, 1993; Bytheway and Johnson, 1998; Heaton, 1999). In 1989, the term had been adopted in official policy documents such as the White Paper “Caring for People” (DoH, 1989). “Carers” also started to be officially recognised as an identifiable group (Heaton, 1999). The National Health Service and Community Care Act 1990 (implemented in April 1993) was highly significant as the term “carer” was finally brought into legislation and institutionalised in social policy. This Act declared that the main support for dependent people in the community should be provided by families and friends on an informal basis. It also asserted that those requiring care, as well as their relations and friends, felt this to be the best way of providing the care needed. Therefore it stipulated that statutory services were to be provided to “carers” in order to support them in caring informally for dependants in the community (Parker and Lawton, 1994; Dean and Thompson, 1996).

A further major consequence of the 1990 National Health Service and Community Care Act was that more people have had to take on the role of an unpaid carer because of the legislative enshrinement of this role and the limited sources of alternative support available to those who need care. As mentioned in the Introduction, the number of “carers” has increased and is likely to continue to increase (Brindle, 2001). This is largely due to the growth of some of the groups of people, such as the elderly, who are reliant on “carers”; long-term projections indicate that the numbers of people over 65

will rise to over 15 million in the 2030s, which will represent 20% of the population (Office for National Statistics, 1998). Indeed, Carers UK have commissioned research which suggests that there will be a need for another 3.4 million informal unpaid carers for those with long-term physical or mental ill health, disabilities or problems with old age over the next 35 years. These policy developments combined with changing demographics therefore suggest being a “carer” at some stage in life has, and will, become a reality for more and more people.

The literature on welfare regimes also highlighted the role of government policy on the social construction of the concept of the “carer”. Some studies in this area have identified the ways in which “carers” have been influenced by ideologically driven changes in welfare regimes (Qureshi and Walker, 1989; Webster, 1993; Dean and Thompson, 1996; Brechin et al, 1998; Symonds, 1998). The example of how New Right ideology has had a disempowering effect on community care service users in general was given in Chapter 1. Other studies have compared the experience of being a “carer” under different welfare regimes (Esping-Andersen, 1990; Chamberlyne and King, 2000). The study by Chamberlyne and King compares the experience of being a “carer” under the three different welfare regimes in Britain and East and West Germany. Whilst they did find that the experience of being a “carer” varied with the welfare regimes, there was not a direct link between the two. This was because those in the study developed their own responses to caring, created their own meanings, forged new identities and engaged in new activities. Therefore, an element of caution needs to be adopted in an analysis of the construction of the “carer” through welfare regimes as individual choice always affects the relationship between the experience of being a “carer” and the type of welfare regime.

The role of research

The studies mentioned in the previous paragraph are indicative of the research on “carers” and their experiences that has burgeoned since the emergence of the concept of the “carer” (Parker, 1985; 1993; Brechin et al, 1998). A wide range of issues has been researched and this has helped to raise the profile of carers and increase awareness of their needs. The tasks that “carers” undertake were discussed in Chapter 1. The many

other issues relevant to carers and their experiences that have been uncovered by the literature have been categorised into two groups - the influences on carers and their experiences of caring, and the effects of caring on carers.

Influences on carers and their experiences of caring

The adverse effects of *inadequate financial and material resources* on the meaning and experience of caring have been identified in the literature (DoH, 1989, Arber and Ginn, 1992, Cancian and Olicker, 2000). The study by Arber and Ginn (1992) (see Chapter 1) found that the working class experience the greatest burdens of informal care for a variety of reasons. As discussed they are more likely to provide co-resident care, which can lead to more stress than when care is not provided on a co-residency basis. Any stress may be exacerbated by the fact they have fewer resources to help them reduce the constraints and pressures of providing informal care, such as the purchase of aids and private domestic help. Finally, they are less able to negotiate for services with formal agencies which is crucial in obtaining “the most preferential set of services” to support them whilst caring (Arber and Ginn, 1992:623).

The influence of *gender* is addressed in both the early and later work on caring. Early writing focused on the way in which the role of carer has been traditionally associated with women (Cartwright, Hockey and Anderson, 1973; Kamerman, 1988; Arber and Gilbert, 1989a; Arber and Ginn, 1990; 1995; Graham, 1991; Rose and Bruce, 1995). Many explanations for this have been put forward, particularly in the feminist literature, which has again drawn attention to the exploitation of women as carers. However, since the late 1980s the contribution of men to informal caring has been increasingly recognised (Arber and Gilbert, 1989a; Arber and Ginn, 1990; 1995b; Fisher, 1994; OPCS, 1998). From the mid 1980s, central statistical gathering, such as the General Household Survey quantified the contribution of both male and female carers. This highlighted the fact that there was not a significant difference between the percentage of all males and percentage of all females that cared; between 1985 and 1995, this percentage difference was only been between 3% and 4%. The implications of more detailed

analysis of these figures need to be considered, for instance males are more likely to be involved in the care of certain groups of dependants, such as the care of elderly spouses (Arber and Ginn, 1990; Fisher, 1994), and there are still 16% more women caring than men (<http://www.carersuk.org>, 2006). Nonetheless, increased awareness of the numbers of male carers has been the stimulus for several studies into the way that men care. These have simultaneously raised the profile of male carers and highlighted the differences in the caring experience for men and women (Arber and Ginn, 1990; Fisher, 1994).

An example of such a difference highlighted in many sources is that men receive more support during caring, despite efforts throughout the 1990s to introduce anti-discriminatory practice (Horowitz, 1985; Arber and Ginn, 1992; Sayers, 1994; Twigg and Atkin, 1994; Dalley, 1996; Bywaters and Harris, 1998; Carers National Association, 1998a; Watson and Doyal, 2000). Another difference is that men's caring duties are less burdensome than women's; reasons for this are that women carry out a greater range of caring tasks when caring (James, 1992; Hooyman and Gonyea, 1995; Chesler and Parry, 2001) whilst men are more likely, particularly those who are of working age, to financially support and manage a dependant's care or provide the setting for care, rather than undertaking the "hands on" informal care themselves (Finch and Groves, 1985; Horowitz, 1985; Perring, Twigg and Atkin, 1990; Hancock et al, 1994; Parker and Lawton, 1994; Cancian and Oliker, 2000; Chesler and Parry, 2001). The final set of differences between the caring experience for males and females centre around the different meanings that being a carer holds for each, and how this leads to different approaches to providing it (Cancian and Oliker, 2000). For instance, Ungerson (1987) found that men conceptualise caring as a form of "work" and adopt occupational language that is used in the labour market. They also control their feelings, and value rationality. Similarly Hasselkus (1988) cites studies that show how men tend to be more task and project oriented when caring, whereas women focus on the way relationships change as a result of the dependant's illness and or disability. Men are also more likely to have chosen to go into caring than women and may well find it a welcome change and an opportunity to undertake a new role in their

retirement. (Fisher, 1994; Watson and Doyal, 1999). Nonetheless, more males than females providing informal care report that caring is isolating (Orme, 2001).

The nature of the dependant's illness has been found to influence carers' experiences (Corbin and Strauss, 1988; Lewis and Meredith, 1988; Bibbings, 1998; Carers National, 1998b; Parker and Lawton, 1994; Cancian and Oliker, 2000). An example of a study addressing this is that carried out by Corbin and Strauss (1988). They found that the physical and social limitations of some chronic illnesses require continual psychological adjustment and partial reshaping of daily life, lifestyle and identity by carers throughout the whole of informal care, from the diagnostic period to the end of informal care. Other studies have focused on the influence of specific types of illnesses, such as Alzheimer's Disease, which is associated with higher rates of carer depression (Mittleman, 1993; Newman, 1993; Bond et al 2003).

Other less well documented influences on carers include *the low social status of carers* (Jordan, 1990) *age* (Hancock et al, 1994), *past experiences* (Lewis and Meredith, 1988; Taraborelli, 1993; Davies, 1998), *culture* (Ungerson, 1990, Cancian and Oliker, 2000, Chamberlynnne and King, 2000), *social situation* (Cancian and Oliker, 2000), *co-residency with the dependant* (Carers National Association, 1998b), *variable and ineffective support* (Parker, 1985; Twigg, 1992; Parker and Lawton, 1994; Nocon and Qureshi, 1996) and *caring for more than one person at any one time* (Hirst, 1999). Furthermore, studies show how the *meaning and experience of being a carer is influenced by personal approaches to it*. Lewis and Meredith (1988) found three different approaches which they labelled the balancing act, immersion and integration. The first applied to those carers who balanced "caring for their mothers andother activities" (Lewis and Meredith, 1988:115). Immersion referred to those who immersed themselves in caring "to the exclusion of all outside interests" (Lewis and Meredith, 1988:115). Those who integrated caring into their lives were deemed to have adopted the integration approach. Immersion was more likely to lead to carers feeling restricted by their role and could also ultimately lead to breakdown. Taraborrelli (1993) uses a much

smaller sample in her study of those providing informal care for people suffering from Alzheimer's disease but also identifies three approaches. The approach of those who had "innocent conceptions about the caring role" (Taraborrelli, 1993:182) is referred to as "Pattern C" (Taraborrelli, 1993:182). As with Lewis and Meredith's immersion approach, this is characterised by a breakdown; carers who adopted this approach became "increasingly unable to cope with their situation until they suffer an emotional and physical breakdown" (Taraborrelli, 1993:182).

The way that this diverse range of influences on the caring experience give it a subjective, personal and individual nature is well-documented in the literature (Abrams, 1989; Graham, 1983; Lewis and Meredith, 1988; Taraborrelli, 1993; Ackers and Abbott, 1998).

Effects of caring on carers

Many studies emphasise the more negative effects of caring. With reference to *caring and health*, there was a lack of generalisable conclusions about the relationship between caring and health. This was because those studies reviewed only focused on specific groups of carers (Parker, 1985; O'Reilly, 1996), such as those caring for the elderly frail, and those with Alzheimer's Disease. The relationship between caring and health is also subject to many variables, such as the relationship to the dependent person (Coen, 1997; Robinson and Steele, 1995; Irving et al, 1995; Pimm, 1996), race (Tirrito and Nathanson, 1994), family adaptability (Smerglia and Deimling, 1997), gender (Sayers, 1994), class (Song et al, 1997), and the cared for person's type of illness (Hinchcliffe et al, 1995; Lieberman and Fisher, 1995).

However, there were two significant findings; there is evidence that caring can adversely affect both the physical and psychological health of carers. Many studies individually identified several physical and psychological health problems carers suffer from with the result that there is now an awareness of the wide range of such

problems that can be experienced during caring. These include depression, anxiety, emotional distress, stress, feeling tired, hernias, heart problems, arthritis, asthma, giddiness, backaches, and headaches (Walker, 1983; Quine and Pahl, 1985; Walton and Spackman, 1990; Mittleman, 1995; Newman, 1993; McLaughlin and Ritchie, 1994; Perring, Twigg and Atkin, 1994; Lamb and Layzell, 1995; Pruchno, 1995; Chappell and Penning, 1996; Evandrou, 1996; O'Reilly, 1996; Strawbridge et al, 1997; Buck et al, 1997; Carers National, 1998b; Hirst, 1999). Furthermore, the physical and psychological state of health of those providing care is often viewed both by themselves and health professionals as secondary to that of their dependent (Lewis and Meredith, 1988; Spackman, 1991). The literature showed that most carers "soldier on" with both minor and serious conditions because there is nobody else to provide the care their dependant requires (Lamb and Layzell, 1995). Thus studies carried out have increased awareness of the way that the experience of being a carer can potentially lead to health problems and how such problems may remain untreated.

Other studies highlighted *the restrictions of being a carer* and showed how carers can feel trapped, restricted and over-burdened (Lewis and Meredith, 1988; McLaughlin and Ritchie, 1994; Reviews in Clinical Gerontology, 1995). The intensity of these feelings varies with the different stages in caring (Corbin and Strauss, 1988; Lewis and Meredith, 1998; Kramer and Lambert, 1999; Seltzer and Wailing, 2000; Bond et al 2003). For instance, Bond et al (2003) found that caring was most restrictive at the end, often to the extent that household chores could not be done. Nonetheless, there was much evidence from many different studies that caring does restrict social lives and activities, and can lead to social isolation at *any* stage (Bowling and Cartwright, 1982; Walker 1983; Corbin and Strauss, 1988; Lewis and Meredith, 1988; Perring, Twigg and Atkin, 1990; Twigg and Atkin, 1994; Walmsley, 1998; Watson and Doyal, 1999; Clark and Bond, 2000; Bond et al 2003). For those of employable age, employment and career opportunities may also be restricted (Pitkeathly, 1996; Lewis and Meredith, 1988; McLaughlin and Ritchie, 1994; Reviews in Clinical Gerontology, 1995). The extent of the restrictions of caring on employment is however debatable. For

instance, Rowlands (1998) found that in 1995, 62% of female carers were in paid employment and 41% of informal carers aged 16-64 who spent 20 hours or more looking after a dependent were working (15% part-time and 26% full time). Yet even if a “carer” does not face restricted employment, they can experience heightened tension overall due to the fact that they are juggling two roles (Finch and Groves, 1985).

Meeting the needs of the cared-for person during caring can involve extra financial costs, such as increased expenditure on heating, food and bedding (Rimmer, 1983) which can lead to *financial difficulties during caring* (Walker, 1983; Lewis and Meredith, 1988; McLaughlin and Ritchie, 1994; Reviews in Clinical Gerontology, 1995; Hancock et al 1994). The lack of employment and career opportunities referred to above also have financial ramifications during caring in terms of saving money and building up a pension (Pitkeathly, 1996).

Some studies have raised awareness of the ways in which *caring can have negative psychological effects* in terms of loss of confidence, self-esteem and sense of identity (Lewis and Meredith 1988; McLaughlin and Ritchie, 1994; Reviews in Clinical Gerontology 1995). Many negative emotions, such as bitterness, and anxiety can also be experienced (Cartwright et al, 1973; Lewis and Meredith, 1988). Others, however, have highlighted more positive psychological effects, such as improved self-esteem (Spackman, 1989; Strawbridge, 1997).

Research has identified the *negative effects of caring on personal and family relationships*. With regards to personal relationships, research on spouse carers has demonstrated the adverse effects of the experience of disability and caring on marriage (Aneshensel et al. 1993; Parker, 1993; Robinson and Steele, 1995). There are difficult changes that have to be faced. For instance, social life can become restricted because of a dependant’s impairments (Parker, 1993; Twigg and Atkin, 1994). The psychological and practical adjustments to a dependant’s illness or disability and “its presentation to the world” can lead to tension and

“extra work or anxiety” for the carer (Parker, 1993:126). Parker also reflects upon the way certain aspects of the marital relationship itself may be challenged because providing intimate physical care for a disabled partner contradicts the “normal” expectations of intimacy in marriage. However, marriages during caring were subject to several influences and such adverse effects of caring did not necessarily lead to marital breakdown. Indeed many of the couples interviewed said it had “brought them closer together”, “strengthened their relationship” and increased their closeness “in terms of a deeper understanding and appreciation of their spouse” (Parker, 1993:91).

The effects on family relationships range from restrictions on family activities (Parker, 1993) to “considerable tension” and “interpersonal conflict” (Walker 1983:116). Some of the effects on relationships with children have been studied; Parker (1993) found that although spouses and carers who were parents worked hard to maintain a normal family life, younger children did experience more anxiety and worry. Studies of those caring for their older relatives found that relationships with their own children became strained because they had less time to devote to them (Walker 1983; Perring, Twigg and Atkin, 1990).

Despite these more negative aspects, some studies indicate that many carers feel *caring is a rewarding experience* that brings joys and is worthwhile and satisfying (Lewis and Meredith, 1988; Arber and Ginn, 1992; Askham et al, 1992; Fisher, 1994; Evandrou, 1996; Nolan et al 1996; Nolan and Lundh, 1999). For instance, Lewis and Meredith (1988) found that some carers felt it was one of the most worthwhile things they could do in their lives. Evandrou (1996) found the relationship between the “carer” and dependant improved during caring. Nolan and Lundh, (1999) found that caring in both UK and Sweden resulted in high levels of satisfaction for carers. The most frequent sources of satisfaction were

providing pleasure for the cared-for person, attending to his/her needs and maintaining his/her dignity...helping the cared-for person overcome difficulties and keeping him/her out of an institution

Nolan and Lundh, 1999:472.

It has also been shown that carers can combine high levels of stress with high levels of satisfaction (Evandrou, 1996). Indeed studies show that whatever the pressures of caring, many who provide informal care want to care and are motivated by love (Oliver, 1983; Levin et al, 1983 cited in Arber and Gilbert, 1989a; Hancock et al, 1994; Twigg and Atkin, 1994; Doyal, 1995).

The role of pressure groups for carers

The above discussions demonstrate how research has increased awareness of carers' needs and contributed to their growing recognition. The last factor to be considered in the construction of the carer is the interplay of these developments with the emergence of pressure groups for carers.

There has been a growth in the size and power of national and local organizations supporting and representing the interests of all "carers". Their advocacy role has also increased and this has simultaneously helped to raise the profile of carers (Twigg et al 1992; Brechin et al, 1998; Bytheway and Johnson, 1998; Rowlands, 1998). There is evidence that this trend will continue; at the beginning of this study the largest national and most active "carer-led organisation working for all carers" (<http://www.carers.gov.uk>, 2002) was the Carers National Association. In 2001, whilst this study was being carried out, it relaunched itself as Carers UK. It now has a stronger focus on campaigning for carers' needs and research (Brindle, 2001). This new approach should further increase the profile of "carers", for instance one of its aims was "to improve recognition and support for carers, through informing and creating dialogue with policy makers and professionals working with carers".

The role of pressure groups in the social construction of the "carer" can be explained in different ways. Pluralism sees pressure groups as being "at the heart of the policy process in representative democracies" (Baggott, 1995:33), having a strong influence over policy-making in such democracies and as a means of enabling those who wish to influence political decisions to do so (Baggott, 1995; Mohan, 1995). Thus, pluralists

would argue that such pressure groups play a key role in the policy making process and that the development of pressure groups for carers has contributed to the social construction of the carer. However, other political perspectives present a more circumscribed view of pressure groups. Neopluralism sees the influence of pressure groups on policy making as being more limited due to other often more powerful influences on the policy-making process. Corporatism also adopts a less positive view of the extent to which pressure groups can influence policy because it maintains that government shapes their interaction with the political system and devises the outcome of this interaction (Baggott, 1995).

Whatever perspective is adopted to the role of pressure groups in the social construction of the “carer”, the interplay between pressure groups, government policy and the rapid growth in the literature has been influential in the construction and increased recognition of the “carer”. The raft of legislation in the past twenty years that has aimed to help and support carers is evidence that this growth in recognition of carers and their needs has also had positive and tangible outcomes for carers (DoH, 1989; Brechin et al, 1998; Brindle, 2001); the 1986 Disabled Person’s (Services, Consultation and Representation) Act gave carers themselves many rights to assessment and support. The Carers Recognition and Services Act in 1995 was highly significant for carers as it gave those who are providing substantial and regular care the right to have a separate assessment of their own needs and for this to be taken into account when services for the person they care for are being planned (Carers National Association, 1998a). Although it has been argued that this was relatively ineffectual, recognition of its failings did prompt the Government to launch the first national strategy for carers - *Caring about Carers. A National Strategy for Carers* - in 1999. This contained extensive recommendations about information, support and care for carers (DoH, 1999; Nolan and Lundh, 1999). In the same year, the 1999 Employment Relations Act introduced carer-friendly employment practices (such as provisions for emergency leave) so that carers can stay in work whilst they are caring. The Carers and Disabled Children’s Bill (2000) built on the Carers Recognition and Services Act and aimed to support carers and safeguard their health and well-being while they carry out their caring responsibilities. This, plus other initiatives, should help address the health needs of former carers too. The Child Support,

Pensions and Social Security Act (2000) introduced a second state pension for carers enabling them to build up a second tier pension whilst they are caring. There is now a Minister of State for Community Care and a government website for carers has been set up to keep them informed of policy development (<http://www.carers.gov.uk>).

The researcher therefore concluded that not only is the concept of “carer” grounded in uncertain conceptual underpinnings, as demonstrated in Chapter 1, but that it is itself a contested concept which has been constructed in different ways. Consequently, it had been demonstrated that all the concepts central to the concept of a “former carer” were essentially contested. These findings were significant for two reasons. The absolute centrality of the concept of the “carer” to that of the “former carer” first of all raised definitional issues; a definition of a “carer” was required prior to establishing a working definition of a “former carer”. Since any definition of a “carer” had been shown to be arbitrary, the following definition of “carer” was therefore developed by the researcher from the literature review for the purposes of this study.

“A carer cares for a dependant who cannot care for themselves because of a disability /illness (not just because of immaturity) and for whom improvement/recovery is impossible. He/she feels a sense of obligation towards the dependant and carries the main responsibility for their care. The caring duties include both mental and physical support. These are not carried out on a paid professional basis and, excluding benefits, are unpaid. They impose more restrictions and complications on his/her daily life than when/if the dependant was ‘normally well’ or ‘not disabled’”

Secondly, the fact that it had been established that *all* the concepts underpinning the concept of a “former carer” were contestable led the researcher to the conclusion that it is inevitably a similarly contested concept. It is to a more detailed discussion of former carers that we now turn.

The concept of the “former carer”

The literature showed that in addition to its uncertain conceptual underpinnings, there was another reason why the concept of the “former carer” was problematic; despite the

fact that their public and political recognition had been slowly developing, there was still limited knowledge about this group of people and their experiences.

With reference to the gradual growth in their recognition, the concept of an identifiable group of people who have ceased caring has existed within official discourses since the mid 1980s. For instance, the 1985 General Household Survey had information about a group they defined as “ex-carers” for the first time. Information about “ex-carers” was provided again in the 1995 General Household Survey. From the late 1980s, various studies about people who had cared started to appear. However, several different terms were used when referring to this group of people. These included ex-carers (Lewis and Meredith, 1988; McLaughlin and Ritchie 1994; Evandrou, 1996), past carers (Reviews in Clinical Gerontology, 1995; Hancock et al, 1994) and “bereaved caregivers” (Mullan, 1992; Bodnar and Kiecolt-Glaser, 1994). Indeed some did not make a distinction between “carers” and “former carers”, an example being Brown and Stetz’s study (1999) of the “caregiving process” (Brown and Stetz, 1999:182) of those caring for a dependant with AIDs or advanced cancer. When discussing what they call “taking the next step” (Brown and Stetz 1999:192) after the death of a dependant, they continue to refer to them as “caregivers”. Other studies did not use any particular terminology but referred to issues relating to certain former carers, such as the effects on them of their dependant going into residential care (Aneshensel et al., 1993; Dellasega and Nolan, 1997).

In addition, from the late 1990s there was the beginnings of a political recognition of some of the possible after-effects of caring. The relevant policy documents and legalisation has already been mentioned in the previous section. One example is “*Caring for Carers. A National Carers Strategy*” (DoH, 1999). This contains commitments designed to help carers when they have finished caring. These include help with planning for the time when their caring duties cease and help with both staying in touch with the labour market or improving their employability throughout their period of caring responsibilities. Whilst some of the other initiatives were directed at those currently caring, they indirectly affect the post-caring period; the Employment Relations Act (1999) introduced carer-friendly employment practices (such as

provisions for emergency leave) so that carers can stay in work whilst they are caring. This will avoid carers having to give up work whilst caring and continue with their jobs/careers more easily post-caring. The Carers and Disabled Children's Bill (2000), which built on the Carers Recognition and Services Act, aimed to support carers and safeguard their health and well-being whilst they carry out their caring responsibilities. This, plus other initiatives, should also help address the health needs of former carers. The Child Support, Pensions and Social Security Act 2000, already mentioned, addresses some of the financial impacts of caring on post-caring lives through the opportunities it gives carers to build up their entitlement to a pension, other than the existing state pension, whilst they are caring.

Around the same time, carers' organisations were also making some provision for carers who had finished caring. For instance, although The Princess Royal Trust for Carers did not have a formal policy with regard to former carers, their 103 Carers Centres can allocate their resources for the support of former carers if they wish. By the late 1990s several had chosen to do this and were making provision for former carers, such as support groups. Many former carers were also involved in the management of Carers Centres. In addition, in 1993 the Carers National Association had co-produced (with CCETSW and Contact-a-Family) advice for Social Workers on helping carers when the caring role ceases. In 1997 they had also published a booklet for carers which contained advice about feelings and health post-caring, as well as discussing practical and legal matters (Carers National Association, 1997).

Although these developments show that the concept of a "former carer" existed in several discourses and there had been some growth in the recognition of those who had finished caring and their needs, the nature of the literature at the beginning of this study meant that there was limited knowledge about "former carers". This was because there was very little research into the lives of those who had finished caring in comparison with the wealth of literature about carers that has been described in this chapter (Bass and Bowman, 1990; Hancock et al, 1994; McLaughlin and Ritchie, 1994; Evandrou, 1996). Furthermore, that which existed only provided a few insights about the post-caring experience in general. This conclusion is justified below.

The main strength of the research was that studies focused on particular groups of former carers and therefore provided detailed knowledge about specific types of former carers. An example was the study by Lewis and Meredith (1988) who used a sample of daughters, most of whom were single, who had finished caring for their mothers on a co-resident basis within the last 10 years. McLaughlin and Ritchie (1994) used past and unsuccessful Invalid Care Allowance applicants to obtain their sample of former carers. This meant that their respondents had relatively substantial caring responsibilities as they had provided a minimum of 35 hours care a week for a severely disabled dependent. Other studies focussed on particular groups of former carers, such as those who cared for an impaired elderly relative, or AIDS patients (Aneshensel et al, 1993; Brown and Stetz, 1999). However there were the following significant weaknesses in the literature:

Inconsistency in the definition of a “former carer”

The definitions of a “former carer” used in the research varied. This was due to the fact that former carers are not a “uniform group” (Hancock et al, 1994:9) and there are three different situations which can lead to a “carer” becoming a “former carer”; it can occur when caring ceases because of the death, entry into residential care or recovery of the dependant. This means that some studies included former carers who had cared for a dependant who had died (Bass and Bowman, 1990; Mullan, 1992; McLaughlin and Ritchie, 1994) whilst others used those who had cared for a dependant who had entered residential care (Aneshensel et al., 1993; Dellasega and Nolan, 1997). The demarcation line between caring and post-caring is important because of the varying effects of the different causes of the end of caring. For instance, there is evidence that institutionalisation of a dependant is just another part of carers’ “ongoing role in providing social, emotional and financial support” (Quee, 1995:51) for their dependant. They “continue their caring role” (Quee, 1995:55) in terms of visiting regularly, giving emotional support, acting as advocate for their dependant and managing relationships with the staff in the residential home (Hasselkus, 1988; Lewis and Meredith, 1988; Perring, Twigg and Atkin, 1990; Arber and Ginn, 1992; Quee, 1995; White, 1994;

Nolan et al.,1996; Dellasega and Nolan, 1997). Indeed it has been argued that these are simply “new ways of caring” (Dellasega and Nolan, 1997:446). The concept of “quasi widowhood” has also been developed in relation to spouse carers of dependants who have been institutionalised to describe this “continuing involvement” (Rosenthal and Dawson, 1991:331) in their care.

Although there will inevitably be similarities between groups and types of former carers studied, this variation in definition limited comparisons between the studies of similar types and groups of former carers. It also restricted the extent to which the studies that had been carried out were representative of former carers in general.

Limited focus of existing studies

A further weakness of the existing studies was that they focussed on particular aspects of the post-caring experience, as opposed to the *whole* post-caring experience. This meant that the existing knowledge only provided some understandings about the early stages of post-caring life, and specific longer-term aspects of life after this.

With reference to the knowledge gained from studies of the *early stages of post-caring* life, negative and positive feelings when caring ceased had been identified, including the effects of bereavement on these stages (Worden, 1983; Hinds 1985; Kamerman, 1988; Lewis and Meredith, 1988; Vickio, 1990; Rowe, 1991; Askham et al, 1992; Bowling and Cartwright, 1982; Littlewood, 1993; Taraborelli, 1993; White, 1994; Quee, 1995; Nolan et al, 1996; Parkes, 1996; Schulz et al, 1997; Brown, and Stetz, 1999). Examples of negative feeling were “increased guilt” (Schulz et al, 1997:277). Positive feelings were “relief from overload and work strain and increased quality of life” (Schulz et al, 1997:279) and “an increased sense of personal mastery” (Schulz et al, 1997:277).

Other findings from these studies were the psychological and social changes that occurred when the person they cared for went into residential care (Quee, 1995; White, 1994; Nolan et al, 1996; Dellasega and Nolan, 1997). These included the “process of adjustment” (White, 1994:5), as well as social and financial difficulties. Lewis and

Meredith (1988) identified former carers' feelings at the end of caring, such as "fears and anxieties regarding their own ageing" (Lewis and Meredith, 1988:147) and "their own preferences for care" (Lewis and Meredith, 1988:148). Several studies had looked at bereaved former carers' patterns of depression but their findings were inconsistent. Bodnar and Kiecolt-Glaser, (1994) found that there was a likelihood that they were more depressed than those who had not cared, whereas Mullan, (1992) discovered that depression rates for bereaved former carers increases after the first year of post-caring. The lack of professional help available when caring ceases had been highlighted (Cartwright, et al, 1973; Hancock et al, 1994).

Some of the first changes in the lives of former carers had also been identified, such as the reduction in contact with formal services (Means and Smith, 1998) and the changes made to the home as a result of the cared-for person dying, such as the removal of adaptations and specialist equipment (Brown and Stetz, 1999). The continuities between caring and post-caring in this early stage are highlighted by Brown and Stetz (1999). They argue that the "labour" of caring continues in this stage because the tasks that are done "such as returning medical equipment, cancelling services, and notifying insurance agencies..... finish the physical tasks of caregiving" (Brown and Stetz, 1999:193).

The *longer-term aspects of the post-caring experience* identified included recognition that some former carers take on another caring role (Lewis and Meredith, 1988; Hirst, 1999). Indeed the term "vocation carer" had been used (Lewis and Meredith, 1988:143). Some gender influences had also been identified (Lewis and Meredith, 1988; Hirst, 1999). For instance, female former carers

under pension age are more likely than their male counterparts to take up or return to paid employment after care-giving ceases

Hirst, 1999:63

Other longer-term aspects of the post-caring experience identified in the literature concerned the way in which it can be linked to caring experiences (Bass and Bowman, 1990; Arber and Ginn, 1992; Hancock et al. 1994; Schulz et al, 1997). Some of these related to the relationship between caring and bereavement; Bass and Bowman's study

of the relationship between stress in caring and adjustment to the dependant's death found that those who found caring more stressful were more likely to report "greater bereavement strain" (Bass and Bowman, 1990:35) post-caring. On the basis of their findings, they hypothesise that "greater caregiving strain will predict greater bereavement strain" (Bass and Bowman, 1990:40). Others focussed on the links between caring and non-bereavement issues post-caring, such as the social, psychological and financial circumstances. An example of one of these links was the way in which caring could lead to a loss of social contact post-caring. This loss was

seen to be caused by the practical demands of caring, disengagement from employment, reduced income, loss of personal confidence, all of which had greatest effect at the time of caringsome people's social networks had been too fractured, or they had lost the habit of socialising

McLaughlin and Ritchie, 1994:245

Hirst (1999:46) also found that caring could lead to a loss of "role" and "status" post-caring. Connected with these points was the way that social isolation during caring can make adjustments to post-caring life harder (Lewis and Meredith, 1988; Taraborelli, 1993). Whilst caring had been shown to have negative effects on incomes, employment and pensions (Askham, et al 1992; McLaughlin and Ritchie 1994; Reviews in Gerontology, 1995), length of caring was found to be inversely related to household incomes (Hancock et al. 1994; McLaughlin and Ritchie 1994; Hutton, 1998; Brown and Stetz, 1999). Indeed, as Hancock et al. state in their study,

The clearest finding is that people who had cared for more than ten years were financially disadvantaged in almost all respects compared with non-carers and with people who had cared for shorter times. This was true of both retired and non-retired people and of both men and women

Hancock et al., 1994:4

Caring had also been shown to have negative physical and psychological health consequences in post-caring life (Evandrou, 1996; Lewis and Meredith, 1988; Askham, et al 1992; McLaughlin and Ritchie 1994). McLaughlin and Ritchie give the most comprehensive account of these when they describe how they found there were several former carers in their study who

said they suffered from physical health problems as a result of caring. The most frequently cited were back problems caused by regular lifting. Another commonly mentioned one was physical tiredness or exhaustion, the result of the constant physical and psychological demands arising from the caring

role. The removal of these demands meant that in the post-care period some ...found their health recovering ...others found their health problem continued or even started after caring ended ...it was clear that some of the health problems experienced in the post-care period were reactions to the strain that the carers had been under. Where nothing replaced that pressure, ex-carers' health, particularly their mental health, could be at risk

McLaughlin and Ritchie, 1994

Research methods used in existing studies

Another limitation of the existing studies was that the particular research methods used meant there was little understanding of the former carers' subjective experiences of post-caring. This was largely because most utilised quantitative methods, for example, questionnaires or known measures of health (such as those for depression and social health) during assessment interviews. Some were more speculative; White's (1994) study described the emotions that can occur when someone has cared for a dependant who can no longer be looked after at home, and made suggestions about practical ways in which staff in residential homes can help. Another type of study evaluated theoretical perspectives and research findings to explain caring and bereavement outcomes (Schulz, et al. 1997).

In fact there were only three studies which adopted a qualitative approach that would allow exploration of these experiences and their meaning. These all used in-depth interviews and were those by Lewis and Meredith (1988) McLaughlin and Ritchie (1994) and Brown and Stetz (1999). However, these qualitative studies of former carers' experiences were limited in the depth of the insights they provided because they were part of studies that focussed on other issues, and only small samples were used. For instance, McLaughlin and Ritchie's (1994) study of former carers was just a part of a larger national study of the effectiveness and targeting of social security help to carers; it only included in-depth interviews with ten former carers. Although the other two used in-depth interviews with larger samples, the findings did not focus on the post-caring experience; Brown and Stetz's study involved twenty-six in-depth interviews but most of the data was about the caring experience and only about a quarter of their article addressed the early stages of the post-caring experience. Lewis and Meredith's (1988) study used forty-one in-depth interviews to explore the legacies

of caring, but once again, much of the data related to the caring experience itself and not post-caring.

Thus the research methods employed meant there had been little exploration of the meaning of post-caring experiences for former carers. Although several of the findings of the three qualitative studies discussed above have already been referred to, the insights they provided into the subjective experience of caring are summarised below.

Lewis and Meredith (1988) highlighted the “profoundly ambivalent” feelings experienced by the single daughters who had cared for their mothers in their study post-caring. Whilst almost all of them said,

they were glad they had cared, they also often experienced loneliness and loss of purpose; difficulty ‘picking up the pieces’; residual bitterness about the behaviour of kin, lack of services, financial help and lost opportunities; and anxiety about their own old age

Lewis and Meredith, 1988: 138

In addition, they also experienced long term financial loss. Many had tried to fill “the gap” (Lewis and Meredith, 1988: 140) in their lives by undertaking new activities, such as voluntary work. Some were caring again. However, there were a few cases where the impact of these negative feelings was so extreme that they were “destructive of self and harmful to physical health and welfare” (Lewis and Meredith, 1988:154).

The study by McLaughlin and Ritchie (1994) supported Lewis and Meredith’s findings about the mixture of feelings post-caring. There were feelings of “considerable relief now that the dependant was no longer in pain” (McLaughlin and Ritchie (1994:245) but also “intense initial feeling of loss...considerable anxiety and stress...loss of confidence or self esteem” (McLaughlin and Ritchie (1994:245). Loneliness, loss of purpose and identity and a sense that they had lost skills and employment experience were also mentioned. Other issues that these former carers described were the negative impact of caring on their social lives, employment opportunities and financial situations. The respondents’ experiences of post-caring health are described above.

Brown and Stetz's (1999) study of those who cared for AIDS patients produced more findings about some of the mixed emotions of the early stages of the post-caring experience. These were a sense of relief, loss, and personal growth. The way they dealt with regrets was also described.

Some participants re-examined their entire caregiving experience from beginning to end as they tried to identify things they could have done differently, things that might have prevented death or lessened suffering. Many expressed some regret about the way they had interacted with their now-deceased loved one. Recalling criticism from others was particularly painful and accelerated self-doubt

Brown and Stetz, 1999:193

In addition, there were findings about their experiences of more practical issues, already discussed, such as sorting out financial matters and "tying up loose ends" (Brown and Stetz, 1999:193) from caring. They outlined how the experience of "positive feedback from others regarding their caregiving contribution" helped them with "moving ahead" (Brown and Stetz, 1999:194) and rebuilding their lives.

Therefore, at the outset of this study the inconsistencies and circumscribed nature of existing research meant there was a lack of knowledge of what has been termed the "legacies of caring" which in turn "limits our understanding" (Evandrou, 1996:227). In particular, few studies provided in-depth knowledge and insights into the post-caring experience. The discussions so far have also highlighted problems associated with developing a definition of a "former carer" for this study, notably the lack of any agreement over definitions, the contested nature of the concept itself and the limited knowledge about former carers and their experiences. Nonetheless, the overall review of the literature was productive in contributing to a *working definition* of a former carer. This was because it enabled the identification of some important characteristics of former carers which were used in conjunction with the definition of a carer that had already been developed. A key characteristic was that of having cared for a "deceased" dependant as opposed to a dependant who had gone into residential care. This was based on the evidence in literature (presented in the discussions on definitions used in studies on former carers) that the entry of a dependant into residential care is merely another

stage of caring as carers continue to provide informal care. The working definition of a former carer developed by the researcher following the literature review was therefore as follows:

“A former carer has cared for a deceased dependant who could not care for themselves because of a disability /illness (not just because of immaturity) and for whom improvement/recovery had been impossible. He/she felt a sense of obligation towards the dependant and carried the main responsibility for their care. The caring duties included both mental and physical support. They were not carried out on a paid professional basis and, excluding benefits, were unpaid. They imposed more restrictions and complications on his/her daily life than when/if the dependant had been ‘normally well’ or ‘not disabled’”

The way in which this working definition contributed to the development of the definition of a former carer used in the study will be discussed further in Chapter 3.

Conclusion

The literature review undertaken in this chapter has presented further evidence of the fragility of the concepts that are central to the lives and experiences of former carers. It has also explored the existing literature about these people and their lives. More generally, the review of the literature in Chapters 1 and 2 has not only produced definitions and contextual understandings essential to the study of former carers and their experiences, but has helped to develop a list of substantive issues and themes about the post-caring experience for exploration (see Appendix 2).

CHAPTER 3: METHODOLOGICAL ISSUES

The methodological context of the research is addressed in this chapter. It begins by explaining how the research question was formulated from the literature review and describes the aims of the study. This is followed by outlines of the theoretical perspective underpinning the study, the research methodology and methods used, giving a rationale for the choice of each. Finally, the way in which the study was carried out is explained. This includes the different stages of the project, the theoretical sampling and how ethical issues were addressed. The process of data analysis and the issues of validity, reliability and generalisability are discussed in Chapter 4.

The research aims

In addition to establishing that the existing research on former carers was limited in amount and depth, the discussions in Chapter 2 showed that there were “gaps” in the current understanding of the post-caring experiences of most former carers. More specifically, as explained, there was an absence of substantial qualitative studies that focused exclusively on the post-caring experience in general. Therefore, the researcher felt that research on former carers offered very few insights *into the meaning of the whole post-caring experience for a range of former carers*. Furthermore, the literature reviews discussed in Chapters 1 and 2 had suggested substantive issues and themes in the post-caring experience that had not yet been explored (see Appendix 2). These were both general themes (such as the ways in which gender can influence the post-caring experience and how post-caring experiences are linked to caring experiences) and particular aspects of the post-caring experience (such as mental and physical health, and the effects of the loss of restrictions and complications that caring imposed on their lives). Thus, the researcher had identified a group of people in society who potentially had many needs, about which there was

relatively little public and political recognition, research and understanding. Indeed, although the number of former carers was growing, at the time this study was conceived they received little attention as carers were still at the forefront in policy initiatives.

These reviews of existing research guided the formulation of the research question and direction of the study. The research project was devised with the following main aim:

“to uncover the subjective meaning of several aspects of the post-caring experience for a range of former carers and to explore theoretically the conditions and consequences of such experiences”

In doing this, it was hoped that the study would:

- provide an in-depth qualitative analysis of the post-caring experience
- accurately represent respondents’ subjective conceptions of their experiences
- build up knowledge from the analysis with a view to increasing understanding of former carers’ experiences
- extend and make an original contribution to the knowledge that is emerging about former carers
- consider the potential implications of the findings for the development of policy that will meet the needs of this group
- highlight areas for further research

Theoretical approach

As explained in the Introduction to the thesis, a broadly interpretivist perspective was adopted in this study of former carers’ experiences. Interpretivism has emerged over the last four decades. It is an amalgam of several schools of thought and epistemologies, including symbolic interactionism, ethnomethodology, phenomenology, hermeneutics and Weber’s ideas on verstehen. As a result, interpretivism has a unique view of social reality as being “created” (Browne, 2000:10) in human beings’ minds through the meanings they

assign to events, and reinforced by “meaningful social interaction” (Clarke and Layder, 1994:6). The subjectivism inherent in this view of social reality means that the natural world is seen as being fundamentally different from the social world. Therefore, unlike more positivistic approaches which view the social world as being a single objective reality with its own existence in the same way as the natural world, the social world does not have “tangible, material qualities that allow it to be measured, touched or observed” (Denscombe, 2002:18). Interpretivism’s view of social reality also means that it sees human beings as occupying a central position in the social world. Thus it asserts that the study of social life should aim “to understand people’s own” (Clarke and Layder, 1994:6) meanings, motives, definitions and interpretations as they engage in social life and how these direct social action. Social reality is also seen as having patterns, which are the result of social conventions, established through interaction (Pawson, 1989; Clarke and Layder, 1994; Sarantakos, 1998; Schwandt, 1999; Browne, 2000; Denscombe, 2002).

Interpretivism therefore researches the social world by “attempting to understand people’s own perceptions and interpretations of the world fashioned through interactions with others” (Clarke and Layder, 1994:6). It also explores the way humans construct their lives and the meanings they attach to them, as well as the social context of social action (Clarke and Layder, 1994; Silverman, 1995; Hughes and Sharrock, 1997; Browne, 2000). Hence, it eschews more positivist approaches which aim to produce factual and observable evidence that can be used to establish causal laws; for interpretivists, such approaches distort the “fundamental nature of human existence” (Hughes, 1976, cited in Bilton, 1997:109) and carve up the very reality of which an understanding is being sought (Pawson, 1989; Schofield 1993; Porter, 1998; Sarantankos, 1998). Instead, interpretivists use specific approaches which allow them to fulfil their aims of understanding individuals’ subjective perceptions and interpretations of the world that are unique to their situation, and hence the meaning and motives of social action. These approaches let those who are the subjects of the research “speak for themselves”. Consequently, such approaches focus on small-scale interaction, are inductive, proceed from the specific to the general, and from the concrete to

the abstract (Burgess, 1991; Baker et al, 1992; Clarke and Layder, 1994; Silverman, 1995; Bilton et al. 1997; Hughes and Sharrock, 1997; Sarantakos, 1998; Browne, 2000).

Critics of interpretive sociology have accused it of disregarding “anything which cannot be readily observed and described” (Clarke and Layder, 1994:8) and being unable to establish the extent to which “our actions are really causally determined or whether they are really all free” (Hughes and Sharrock, 1997:119). However, such criticisms did not lessen its relevance to this study or weaken the arguments for its choice. This was because it enabled the researcher to achieve understandings of the world from the point of view of the people being studied. It also suited several different aspects of the research. One was the emphasis on the ways that post-caring social reality was created and shaped by those who were directly experiencing it. Another was the centrality to the study of understanding former carers’ subjective perceptions of their situations, and the meanings they create and give to their lives. A third was the importance of the social context of post-caring experiences that had been highlighted in the literature review.

Other approaches were also drawn upon during the research. For instance, social constructionist perspectives were useful in addressing issues around the contextualisation of the research and the findings about the way life was reconstructed post-caring. These perspectives fall within postmodernism which argues that social order is socially produced and that “there are a number of alternative versions of reality and truth, and “there is no logical ground for seeing any one version of reality as superior to others” (Denscombe, 2002:20). Thus, whilst social order may appear “natural”, for social constructionists there are multiple, changing and often competing realities, which are primarily subject to historical, economic, and socio-cultural influences. However, they argue that although social order is socially constructed, it does not make it any less real for individuals. Nor does the provisional character of social life mean that social constructions are all fluid. Indeed as “all human activity is subject to habitualization” (Berger and Luckmann, 1967:71) many social constructions have become deeply embedded or solidified as ways of

thinking and acting which do not change even when they are challenged by competing constructions. For instance, despite competing constructions such as feminism, social constructions about men and women have resisted change (Berger and Luckmann, 1967; Freund and McGuire, 1991; Guba, and Lincoln, 1994; Lippa, 1994; Saiki-Craighill, 2002; Hockey and James, 2003).

Another approach used was symbolic interactionism. This was helpful in this study because of the way it could explain the role of individuals in creating the meaning of some of the issues that were identified; it argues that social life is expressed through symbols and that language is crucial as it is the most important symbolic system. People create and maintain meaningful worlds via social interaction during which they make reflexive use of these symbols and interpret and elicit meanings in situations. Thus, individuals “respond to and create meanings in situations” (Morse, 1992:257). These meanings are “shared..... in processes of negotiation and renegotiation” which then produce norms and patterns of action (Morse, 1992:257). Although acknowledgement of the context of such social interaction gives it rationality, there is no obdurate single reality as meanings are modified during this process (Goffman, 1968; Blumer, 1969; Silverman, 1995; Thoits and Virshup, 1996; Miller and Glassner, cited in Silverman, 1997; Cuff et al, 1998).

As mentioned above, the adoption of interpretivism had implications for the methodology and research methods used in the study. Another more general implication of the interpretive perspective for the research was the *approach* to the research question. The interpretive view is that the social construction of reality, and understanding of the world can only be gained by searching for the systems of meanings that actors use to make sense of their world. This can be seen in the way the study aimed to gain in-depth and detailed understandings of the meaning of the post-caring experience for a range of former carers, and how they construct and make sense of their experiences. This approach to the research is also evident in the way that it aimed to explore the conditions and consequences of these experiences, and to identify any shared meanings and patterns that existed. By adopting this

particular standpoint, it was intended that the study would extend the knowledge that was emerging about former carers by producing detailed and rich qualitative data that would lead to a better understanding of how former carers construct their post-caring lives. The more specific implications of the interpretive perspective for the methodology and research methods are discussed below.

Research methodology

The research methodology used in the study was informed by grounded theory. The rationale for the choice of grounded theory and the decision to use a research methodology that was informed by this approach is outlined below.

Grounded theory is rooted in symbolic interactionism. It was originally developed by Glaser and Strauss in 1967 as part of the post-positivistic tradition, which challenged positivistic assumptions that qualitative research could not be adequately verified (Baker et al, 1992; Strauss and Corbin, 1994; 1998; Glaser, 1999; Hall and Callery, 2001). Although there were different strands to grounded theory when it was introduced, and there is still some controversy over what it is and what it entails, it has evolved by default and is now accepted as an inductive qualitative method, which operates within the interpretive tradition. It has also become established as accepted practice across a broad spectrum of disciplines. It has been used on many different types of research projects that have studied a range of phenomena and culturally diverse environments (Layder, 1982; 1998; Baker et al, 1992; Morse, 1992; Denzin, 1994 and Lincoln; Strauss and Corbin, 1994; Donovan, 1995; Smith and Biley, 1997; Denscombe, 1998; Glaser, 1999; Bryman, 2001; Hall and Callery, 2001).

Grounded theory is committed to discovery. One of the consequences of this is that, unlike other qualitative approaches, it involves the use of a “total methodological package”

(Glaser, 1999:836) to develop a particular type of theory. The process of theory development in grounded theory involves starting with a research topic without any preconceived theory in mind, and allowing the theory to emerge from the data through a continuous process of systematic data collection and rigorous analysis, using a range of guidelines and procedures (Denzin and Lincoln, 1994; Strauss and Corbin, 1997; 1998).

The data collection that occurs throughout this process of theory development involves searching for, establishing access to and collecting a range of sources of information, such as observations, other studies, documents, interviews, diaries, newspapers and other media materials. Analysis of the data involves microanalysis of words, sentences, lines or paragraphs. This is necessary for the identification of indicators and establishment of concepts. Indicators are concrete data which the researcher observes or finds in the various sources of information used and include social events, and behaviour patterns in individuals and groups. Examples of indicators from this study are “disposing of the equipment” and “now undertaking informal care”. These sets of concrete data are seen as indicators for the concepts that the researcher develops. Such concepts are central to grounded theory. Use of the various procedures for interpreting and organising the data means that it is theoretically coded during analysis and that new ideas, hypotheses, and concepts are worked out from the data. Any new findings are constantly checked out against the existing findings. During this constant comparison and verification there is continual development and refinement of the theory and concepts generated during the research. (Denscombe, 1998; Strauss and Corbin, 1997; Sarantakos, 1998).

The theoretical concepts are developed through careful use of three different types of coding of the data. Open coding refers to the way that the data is first broken down into discrete parts and concepts are identified. In this study concepts such as “closure tasks associated with the end of caring” and “serial caring” were developed. These concepts are then compared and examined for similarities and /or the same meanings and then grouped

into categories which are then developed further, for instance, into subcategories. Two subcategories in this study were “closing down ‘the caring time’” and “constructing life post-caring”. Axial coding involves seeing how the categories and subcategories are related. Open coding and axial coding are not necessarily sequential acts and often occur concurrently. The third type of coding is selective coding. This involves the integration of the major categories to form a larger theoretical scheme and marks the point in the research when the findings take the form of a theory. The central category (an example in this research is “life post-caring”) that has evolved out of the existing categories is identified and the other categories are organised around it in order to explain the social processes which are being studied (Strauss and Corbin, 1998).

Certain analytic tools facilitate coding; examples are questioning and comparative analysis. Questioning aims to unblock the analyst’s thinking and help when he or she “cannot seem to see nothing but the standard ways of explaining phenomena” (Strauss and Corbin, 1998:90). Questions can include who, what, when, why, where, what, how, how much? Comparative analysis means comparing indicators, concepts and categories with those that are similar or different in order to draw out hidden or overlooked properties and dimensions. An example of this is the flip-flop technique (Strauss and Corbin, 1998). This helps to obtain a different perspective on the data during comparative analysis. It involves looking at “opposite or extremes” of an “event, object, or action/interaction” in order to bring out “significant properties” (Strauss and Corbin, 1998:94). The indicators, concepts, subcategories and categories identified during the analysis are given codes or labels by the researcher. These are devised by the researcher and can be derived from the literature, and /or other labels used. They may also include “in vivo codes’ which use the words of the research participants themselves (Glaser and Strauss, 1967; Strauss and Corbin, 1998).

The concept of saturation in grounded theory is important as it controls the extent to which a process of analysis and comparison goes on (Strauss and Corbin, 1997); “saturation is considered to have been reached, and the process is complete” (Sarantakos, 1998:205)

when collecting more data seems counterproductive because no new information (such as new properties, dimensions, conditions, actions) about categories emerges.

Several techniques are available to help with the integration of categories that occurs throughout the whole process of the research. These include theoretical memos which are “the researcher’s record of analysis, thoughts, interpretations, questions, and directions for further data analysis” (Strauss and Corbin, 1998:110). They are written during all the stages of the research and can take many forms, such as orientation memos, inspiration memos, memos about categories or discoveries, comparison memos, and summary memos (Strauss, 1990).

There are also mini-frameworks/conceptual diagrams. These are essentially grids which help the researcher to identify any patterns that are emerging, if there are any similarities and differences, and common themes in the concepts and categories. Another technique is a “conditional matrix” which is used to help locate phenomenon in their context. It does this by integrating the macro and micro, identifying the intricate interactions between these and how they “thereby, in direct and indirect ways, become part of the situational context” (Strauss and Corbin, 1998:182) so that they can be woven into the analysis (Coffey and Atkinson, 1996; Strauss and Corbin, 1998).

Another key procedure in grounded theory is theoretical sampling. This means that the sampling is not predetermined before the research begins but is driven by theoretically relevant concepts identified during the ongoing analysis of the data in order to explore such concepts further (Strauss and Corbin, 1998). Hence analysis and sampling are sequential. This is referred to as sequential analysis and can include sampling of incidents, events, activities, populations, and key informants (Strauss, 1990) that are relevant to the evolving theory (Baker et al, 1992).

The particular type of theory produced through the use of the guidelines is therefore not only conceptually dense but it is substantive theory, grounded in data that is systematically gathered and analysed during the research (Miller and Fredericks, 1999; Strauss and Corbin, 1998). It is argued that such substantive theory is grounded in “empirical reality” (de la Cuesta, 1993; Glaser, 1999) and represents people’s “understandings and social experiences faithfully” (Layder, 1998:18).

There were many reasons for adopting grounded theory. As it is a qualitative, interpretive approach it met an essential prerequisite of the study. It also met other prerequisites that were integral to the aims of the study; it would enable the accurate representation of former carers’ understandings of their experiences and allow the subjective meaning of experiences and realities of everyday situations for individuals to be elicited (Baker et al, 1992; Morse, 1992; Smith and Biley, 1997; Layder, 1998). Use of grounded theory would facilitate the building up of knowledge from the understandings gained from those who are the subjects of the research, which in turn could increase understanding and extend the existing body of knowledge. Another argument for its use was that it could produce findings that are relevant to both academic and non-academic audiences, and that could be used to guide future action (Burgess, 1991; Baker et al, 1992; Strauss and Corbin, 1994; Donovan, 1995; Strauss and Corbin, 1998; Durham, 1999; Glaser, 1999; Sayre, 2000; Martyn and Hutchinson, 2001). In addition, careful application of grounded theory and its procedures meant that the development of detailed, in-depth understandings of former carers’ experiences and the production of original findings, could be realised (Morse, 1992; de la Cuesta, 1993; Blaxter et al, 1997; Layder, 1998; Glaser, 1999; Marshall and Rossman, 1999; Silverman, 2000).

Further reasons for the adoption of an approach informed by grounded theory centred around the way such an approach would help to address potentially important issues in the study that had been highlighted in the literature review. Some of these were related to broader issues whilst others were more specific. An example of the former was the general

nature of the research, such as the way that it was a small-scale study about a relatively unresearched area. There was evidence that grounded theory would match the parameters within which the study was operating. For instance, Denscombe (1998) maintains that grounded theory is “geared to modest localized explanations based on immediate evidence rather than efforts to produce or prove grand theories” (Denscombe, 1998:217). Expectations of equal modesty were held about the explanations that this study would be able to provide. It was also clear that it would be useful for the sociologically-based study of former carers where the research is in its infancy, little is known (Baker, 1992; Smith and Biley, 1997) and the researcher wants to gain “new and theoretically expressed understandings” (Strauss and Corbin, 1998:8).

The more specific issues highlighted in the literature review included the role of the social context; a consequence of the evolution of grounded theory is that its procedures allow the possibility of an analysis of the contextual environment of those who are the subject of the research and its incorporation into the developing theory. The “conditional/consequential matrix” ensures that conditions at all levels (micro and macro) of the social world that may have relevance to the phenomenon being studied are analysed and built into the theories generated in a grounded theory study. In fact, it has been used in studies *because* of the way it builds theory in relation to social contexts and social processes (Durham, 1999; Glaser, 1999).

It was therefore clear that use of grounded theory and its procedures would meet the main aims of the research and address issues relevant to the research. There was also evidence that it could be used to resolve some of the particular problems of this research. One of these was the large amount of unorganised qualitative data that was likely to be produced. Grounded theory’s “total methodological package” (Glaser, 1999:836) which provides “a set of clearly defined steps” (Denzin and Lincoln, 1994:508) could deal with this problem; not only can “any researcher... follow” (Denzin and Lincoln, 1994:508) these guidelines but because they are *guidelines and not rules*, they can be used flexibly and creatively to

cope with any ambiguity (Glaser and Strauss, 1967; Patton, 1990; Denzin and Lincoln, 1994; Strauss and Corbin, 1994; 1998). Simultaneously, these guidelines and procedures would add rigour and some standardisation to the analysis of the quantity of unorganised qualitative data that was likely to emerge. Moreover, it was clear that they would provide a method of analysing the data which would prevent the study from merely being descriptive (Strauss and Corbin, 1998).

Another potential problem was the fact that the study was dependent on respondents' powers of recall and self-expression; there was no guarantee as to the reliability of respondents' memory and language skills. Use of grounded theory procedures meant that this problem could be addressed. For instance, these procedures ensure that findings are continually checked throughout the research and therefore act as corrective techniques for erroneous information (Glaser and Strauss, 1967; Strauss and Corbin, 1994). Furthermore, whilst respondents' conceptions are inclusive to theory building, it is only those that are significantly relevant to the evolving theory that *have* to be included (Strauss and Corbin, 1994). The fact that every actor's perspective does not need to be discovered may compensate in some, albeit minor, way for the weaker memory and language skills of some respondents.

In the above discussions of the arguments for the use of grounded theory in this study, there have been a few references to some problematic aspects of this approach. Indeed, grounded theory is not without its critics; there have been adverse comments about its failure to acknowledge researchers' implicit theories in the research process. Criticisms have focused on the argument originally put forward by Glaser and Strauss (1967) that substantive theory should only be built up using the actor's accounts of "what is going on" (Layder, 1982:117) and the way their empiricist approach meant that they excluded extant theories (Strauss and Corbin, 1994). These features of grounded theory have been criticised for erroneously conceptualising human beings as the "single, most important locus of action" (Layder, 1982:119) and producing sterile research (Strauss and Corbin, 1994). Other criticisms have

been made about grounded theory's emphasis on theory generation rather than theory testing, its lack of objectivity and the way it ignores the interactions between interviewer and interviewee and hence the way that the data is socially constructed (Burgess, 1991; Silverman, 1995; Smith and Biley, 1997; Hall and Callery, 2001). Concerns have also been expressed about the use of grounded theory's guidelines; it has been argued that unintelligent use of them can mean that grounded theory research can degenerate into "a fairly empty building of categoriesor into a mere smokescreen to legitimize purely empiricist work" (Silverman, 1995:470).

However, not all these criticisms are justified; with reference to the lack of acknowledgment of the role of the researchers' implicit theories, the evolution of grounded theory means that it now has a more positive view of researchers' values than most other approaches. Recent versions of grounded theory maintain that such criticisms were based on a misunderstanding about what was being advocated in the original work. The result is that researchers' theoretical sensitivities, professional knowledge as well as their personal and research experience and extant theories are currently viewed as "data" (Baker, 1992; Strauss and Corbin, 1998). As such, they can be beneficial to the research if systematically applied to the gathered data and the theories that emerge from their analysis (Layder, 1982). Indeed, it has been argued that this "interplay between researchers and data" (Strauss and Corbin, 1998:13) contribute to the distinctive and unique analysis that takes place in grounded theory studies (Morse, 1992; Strauss and Corbin, 1998).

In addition, procedures in grounded theory, such as constant comparison, theoretical questioning, and theoretical sampling, ensure that the application of the researcher's theoretical sensitivities is constructive and truly systematic at every stage of the research. There is also an emphasis on researchers taking an active responsibility for their interpretive roles and putting into practice those procedures that constantly force them to question their own values and interpretations. Use of these procedures consequently ensures that any assumptions and hypotheses are provisional, and that they are endlessly tested and

reformulated throughout the entire research project as part of the process of representing reality as created by those who are the subjects of the research (Strauss and Corbin, 1990; 1994; 1998).

Criticisms about the use of prior theories and theoretical models can also be counterbalanced by arguments that value freedom in research is neither necessary nor possible (Hindess, 1973; Pawson, 1989; Taylor, 1992; Denzin, cited in Silverman, 1995; May, 1997; Sarantakos, 1998; Mason, 2002). Furthermore, as demonstrated above, use of grounded theory's guidelines can address criticisms about its focus on theory generation; although grounded theory "is not primarily a theory testing approach" (Layder, 1998:18), careful use of its guidelines include elements of testing as emergent hypotheses and ideas are constantly checked against existing and incoming data. In relation to some of the other criticisms mentioned, there are now additional corrective techniques to improve the rigour of grounded theory studies (Hall and Callery 2001). These are discussed in more detail in Chapter 4.

There was much evidence that it is perfectly acceptable to "adopt and adapt" (Glaser, 1999:837) grounded theory and that it has been "easily adapted" (Strauss and Corbin, 1994) for use in a range of different types of studies (Strauss and Corbin, 1994; 1997; Glaser, 1999; Miller and Fredericks, 1999). Examples of adaptations made were studies which had combined qualitative and quantitative techniques of analysis (Strauss and Corbin, 1994; Glaser, 1999) and had used it with other approaches (Morse, 1992; Denzin and Lincoln, 1994; Smith and Biley, 1997; Strauss and Corbin, 1994; Denscombe, 1998; Glaser, 1999). Indeed, Layder (1993) argues that it *should* draw on "other approaches to research as well as forms of general theory" to maximise its strengths (Layder 1993:51). However, when grounded theory is used in conjunction with other approaches, care must be taken not to abandon the central features of grounded theory, otherwise poor grounded theory is produced (Baker, 1992; Smith and Biley, 1997; Glaser, 1999; Hall and Callery, 2001).

In order to avoid some of the other criticisms described above, and to capitalise on the strengths of grounded theory in relation to this study, the decision was therefore taken to use an approach that was *informed* by grounded theory. This would also allow the guidelines to be used in response to particular requirements of the study identified as it was being conducted. Details of the way grounded theory was adapted in this study are given later in this chapter and in Chapter 4.

In summary, the systematic review of the evidence from the literature on grounded theory clearly demonstrated that use of an approach informed by grounded theory would be appropriate for the research. This widely-accepted, adaptable, qualitative methodology was congruent with the interpretive underpinnings of the research and the research question. It met the aims and expectations of the research, and could address potential issues and problems that had been identified. Careful and informed application of its guidelines and procedures would also ensure that a rigorous qualitative study could be carried out. However, it would be necessary to test out its procedures before the study was carried out.

Research methods

The adoption of an interpretive perspective in this study excluded the use of some research methods because they cannot be used to gain the understandings that were required in this study. For instance, field observations, videotapes, and participant observation do not produce data on the subjective meaning of social actions and of how individuals create reality in interaction with others (Strauss and Corbin 1994; Sarantakos, 1998; Browne, 2000). The main research methods chosen were focus groups and in-depth interviews. These are discussed below, together with the reasons for their choice.

Focus groups

As discussed in Chapter 2, the contested concept of a carer is central to a definition of a former carer. Whilst the literature review had contributed to the development of a *working definition* of a former carer through the insights it had provided into the concept of the carer, it could not provide the necessary *experiential* element to this concept. Therefore, as an *operational definition* of a former carer was required, the ideas developed about the concept of a carer required further refinement through the exploration of its experiential dimensions, before the main part of the study took place.

The use of focus groups added this experiential element. This qualitative data gathering technique comes largely from marketing research but has been adapted for use within applied social science research (Krueger, 1994; Kitzinger, 1994; Arksey and Knight, 1999:77; Marshall and Rossman, 1999; Bloor, 2001). Disadvantages of using focus groups are the complexities of assembling them and problems that can arise during their facilitation, such as the discussion of irrelevant issues or sensitive topics and the emergence of a group culture which interferes with individual expression (Denzin and Lincoln, 1994; May, 1997; Marshall and Rossman, 1999). However, the arguments for their use in this study were far more persuasive than those against. These included their compatibility with the use of grounded theory and the fact that they have been used in similar studies (May, 1997; Layder, 1998). In addition, focus groups can offer another perspective on the research problem not available through individual interviews, and are especially useful for checking out initial ideas and focusing sampling (Denzin and Lincoln, 1994; Marshall and Rossman, 1999). They also allow the researcher to focus on group norms around issues under investigation to gain an understanding of the meanings that people hold for their everyday activities and experiences as well as providing the flexibility to explore unanticipated issues as they arise in the discussion (Denzin and Lincoln, 1994; Kitzinger, 1994; May, 1997; Arksey and Knight, 1999; Marshall and Rossman, 1999).

Semi-structured in-depth interviews

In-depth interviews are one of the data gathering methods strongly advocated for research adopting a grounded theory approach and were therefore linked epistemologically to the study (Morse, 1992; Smith and Biley, 1997; Layder, 1998). The identification of the list of substantive issues and themes to explore (referred to above and set out in Appendix 2) indicated that the in-depth interviews in the study needed some structure. However, any form of structure imposed needed to ensure that these important areas of the post-caring experience were covered and there was flexibility in the phrasing and sequence of questions. It was therefore decided to use semi-structured in-depth interviews (Bryman, 2001).

Silverman (1998) criticises what he regards as the current overuse of in-depth interviews in qualitative research. He blames this on their “unthinking adoption” (Silverman, 1998:105) and the lack of “careful weighing of the alternatives” (Silverman, 1998:105) by qualitative researchers. However, as indicated above, alternatives were considered. There was also much evidence that in-depth semi-structured interviews would allow an exploration of former carers’ experiences, emotions and feelings from their own perspectives, and would produce “rich” data (Burgess, 1991; Blaxter et al, 1997; Morse, 2000; Denscombe, 1998; Arksey and Knight, 1999; Marshall and Rossman, 1999; Silverman, 1998; 2000). Such interviews had proved to be good strategies in research where the emphasis was on discovery and exploration of a topic about which little is known, where the subject matter is sensitive and where the sample was relatively small (Burgess, 1991; Fielding, 1993; Silverman, 1995). Indeed, additional support for the use of semi-structured in-depth interviews in this type of research was found in similar studies; Oakley (1990) argues that they are useful when interviewing women as they facilitate the establishment of a non-hierarchical relationship, which encourages greater responsiveness in female interviewees. As there are still more female than male carers (see Chapter 2), it was anticipated that there would be a higher proportion females amongst the former carers interviewed. This strength of semi-structured in-depth interviews would therefore be advantageous to this study. These

interviews have also been used successfully in research on carers and caring; Lewis and Meredith (1988) in their study of daughters who had cared for their mothers used in-depth semi-structured interviews to encourage respondents to “tell their stories” about their experiences of caring. They said that such interviews avoided the danger of “prepared” responses, and allowed the interviewer to probe and return to the same topic several times over to ensure a full exploration was carried out.

Difficulties identified with regards to in-depth semi-structured interviews related to the way that the interviewees themselves can affect the validity of the findings if they do not cooperate fully, are dishonest or their powers of recall are limited. They may also become confused about what is relevant in in-depth semi-structured interviews where the interviewer only asks a few questions (Burgess, 1991; Marshall and Rossman, 1999). However, there are a number of techniques that can increase the validity of in-depth semi-structured interviews. Examples of these include probing interviewees’ responses, introducing other research methods to supplement and triangulate the data, and cross-checking accounts (Hasselkus, 1988; Burgess, 1991; May, 1997; Arksey and Knight, 1999; Silverman, 2000).

The use of other research methods and the way that interviews were cross-checked are dealt with later in this chapter and in Chapter 4. The interview technique comprised suitable techniques identified in the literature as well as those advocated to overcome the above problems. These included the use of open questions, reflecting interviewees’ responses back to them as appropriate in order to probe their feelings further, watching for non-verbal behaviour, establishing rapport and empathy through allowing time for an initial “chat” at the beginning of the interview, emphasising that the interview is a two-way process, dressing neutrally in order to create a non-hierarchical relationship between the interviewer and interviewee, tolerating pauses and silences, and avoiding speaking too soon, too often and for too long (Burgess, 1991; Arber, 1993; Davis et al., 1997; May, 1997; Denscombe, 1998; Silverman, 1997; 1999; Sarantakos, 1998; Marshall and Rossman, 1999). Although it

was not intended that the role of counsellor would be adopted, some of the generic listening and responding skills (Jacobs, 1994) the researcher learnt on the Certificate in Counselling Studies course at Leicester University (completed April 1999) were used too.

Preparatory phase

In order to develop and refine outstanding key issues in the research, the main study was preceded by a preparatory phase. The first of these issues was the *definition of a former carer*; as mentioned in the discussion of focus groups above, an understanding of the experiential dimensions of the concept of a carer was required before the main part of the study could take place. In addition, although the *use of a research methodology informed by grounded theory* had been confirmed as being suitable, its precise use still needed to be tested out. The final issue was *the use of qualitative research methods*; the use of in-depth interviews and the interview technique needed to be piloted prior to carrying out the main study. As other grounded theory studies had benefited from using a number of research methods, the use of other supplementary data collection methods also required exploration (Morse, 1992; Taraborelli, 1993; Strauss and Corbin, 1994). The preparatory phase comprised two focus groups and four pilot interviews and the way that it allowed the development and refinement of these key issues is described below.

The two *focus groups* were conducted to explore everyday understandings of the experience of caring and being a "carer". One group comprised five "carers" and the other comprised five "non-carers". The "carers" group were unpaid, informal carers and members of a Carers Forum who volunteered to take part. It was held at a local community centre. The "non-carers" group was held five days after the "carers" focus group in the researcher's home. All participants in this group were contacted in advance and were known personally to the researcher.

The planning, organisation, conduct and analysis of the focus groups were carried out in accordance with the guidelines in the focus group literature. The questions were planned and sequenced; after an introduction, opening, introductory, transition, key and then ending questions were used (see Appendix 3 for the Focus group schedule used for both groups). Care was taken to phrase the questions appropriately. A conversational style was adopted. Simple open-ended phrasing of questions was used to encourage participants to reveal what was in their minds, plus “think back questions” to encourage them to ground their responses in their experiences. Both focus groups were within the recommended size range of four to twelve, and the participants had characteristics that were relevant to the study. As the length of each was just over an hour, they also fell within the suggested time limit for focus groups. The exploratory nature of the focus groups meant that the researcher adopted the role of facilitator, as opposed to controller. She created a supportive environment and promoted a semi-structured discussion of the topic. Techniques used were pauses and weaving comments made by the group into the researcher’s questions. Ethical considerations were addressed; the researcher carried official identity, the aims of the focus groups and the research were discussed at length with each participant before they took part and their consent obtained, and the nature of agreement that had been entered into between researcher and participants was made clear. The researcher emphasized that there was no obligation for participants to respond to questions if they did not wish to do so. The focus groups were tape-recorded and then transcribed by the researcher. The transcription was thorough and aimed to reproduce the group discussions as accurately as possible. The transcripts therefore included all speakers and all speech. Speakers were identified and notation was used to indicate aspects of speech such as pauses, interruption and non-verbal behavior. The data was analysed using a systematic and rigorous process of analytic induction. In order to understand and identify substantive themes in the data, the data was indexed starting with codes that were quite broad and inclusive of all possible relevant data. These codes then became more narrow and focused as the analysis continued. The context of speech extracts, changes in individuals and the group’s arguments over the course of the

focus group were also studied. Interpretation of the data involved developing initial hypotheses to which other data were compared in order to ascertain whether they confirmed or refuted it. Hypotheses were then revised as appropriate. Storage and retrieval was done manually using an organised electronic filing system (Kingry et al, 1990; Stewart and Shamdasani, 1990 cited in May, 1997; Fielding, cited in Gilbert, 1993; Denzin and Lincoln, 1994; Krueger, 1994; 1998a; 1998b; 1998c; Kitzinger, 1994b; Flores and Alonso, 1995; May, 1997; Denscombe, 1998; Morgan, 1998; Arksey and Knight, 1999; Marshall and Rossman, 1999).

Despite the efforts made to use the guidelines in the focus group literature, it transpired that some of these were not adhered to. For instance, during the course of the focus group sessions, the researcher discovered that several of the participants in both groups (particularly the first) were familiar with each other. The suggested selection criteria about ensuring the participants are not familiar with each other (Marshall and Rossman, 1999) was therefore transgressed. Furthermore, the two groups differed in that the participants in the first one were volunteers, whilst those in the second were selected by the researcher. The latter also had at least 24 hours notice of the group's meeting and in general were more articulate and educated as they were chosen because of their abilities to contribute to the focus group. But, as Blumer (1969, cited in Denzin and Lincoln, 1994) argues, a small number of participants who are acute observers and well-informed, brought together as a discussion and resource group, is much more valuable than any representative sample. In addition, the fact that they were held at different venues could have impacted on the data (Green and Hart, 1999). However, when questioned, none of the participants had concerns about the focus group being held in the researcher's house and the way that they expressed their views and feelings was a further indicator that they did not feel inhibited by the location. Consequently, it can be argued that the focus groups were carried out appropriately and that the findings that emerged from them were both reliable and valid.

The focus groups provided experiential confirmation of the conclusions drawn from the literature review that a “carer” is a socially contested concept in that they showed there is a lack of conceptual clarity in distinguishing a “carer” from a “non-carer”, there is no general agreement about the definition of a carer and that it is defined differently across different discourses and contexts. This therefore provided further confirmation of the socially contested nature of the concept of the former carer. Additionally, the focus groups contributed to the continued refinement of a definition of a former carer in other ways as they confirmed some of the characteristics of former carers that had been identified during the literature review.

The findings from the focus groups also helped to develop the research in other ways; new themes about the post-caring experience emerged from the analysis of focus groups transcripts. Consequently the substantive issues and themes listed in Appendix 2 were refined to produce an “Initial interview schedule”. This is shown in Appendix 4.

Whilst the focus groups helped with some of the issues identified earlier, several still needed to be addressed. These included testing out the working definition of a former carer that had been developed, the use of grounded theory, the use of in-depth semi-structured interviews, the interview technique and the exploration of other supplementary data collection methods. A pilot study was carried out to resolve these remaining issues (Cartwright and Seale, 1990; Blaxter, 1997; Sarantakos, 1998).

A pilot study is normally a “small-scale replica and a rehearsal of the main study” (Sarantakos, 1998:292). They are more commonly used in quantitative research. One of the consequences of this is that apart from the suggestion that they should use the same principles of social research that are employed in the main study, there is no set format advocated for pilot studies in qualitative research. Their design, structure and purpose vary with the nature of the study and methodology used (Blaxter, 1997; Sarantakos, 1998).

Given the flexibility afforded in the conduct of pilot studies in qualitative research to meet the needs of a specific study, *pilot interviews* with four former carers were therefore carried out. These former carers were selected through professional and personal contacts, using the definition of a former carer developed after the focus groups. The interviews were carried out during the first two weeks of November 1999. They not only provided an opportunity to test out the use of in-depth semi-structured interviews and the interview technique, but also the way in which interviewees were prepared for the interview, place of interview, recording, use of interview schedule, time limit, additional notes taken, follow-up activities such as letters of thanks, and the analysis of transcripts.

The pilot study showed that the working definition of a former carer that had been developed could not be operationalised. However, the findings highlighted new, and confirmed already established key characteristics of former carers. These were that even though some of those who were interviewed did not define themselves as former carers, they had experienced at least one episode of unpaid caring (excluding benefits) in the past that had ended with the death of their dependant. As a result, it was decided not to adopt the working definition that had been developed but to adopt the following less prescriptive definition of a former carer in the main part of the study:

“A former carer is someone who does not necessarily identify themselves as a former carer but who has experienced an episode of caring in the past that ended with the death of their dependant. This caring was not carried out on a professional basis, and excluding benefits, was unpaid”

Moreover, the pilot study provided further support for the use of grounded theory. It was clear that working within a grounded theory approach would provide a framework for achieving the aims of the study. For instance, use of its procedures would facilitate in-depth and sensitive theoretical exploration of former carers' experiences. Adaptations of some of these procedures, such as microanalysis, (for a detailed discussion of these adaptations, see Chapter 4) had been developed to ensure that the subjective meaning of the post-caring

experience emerged from the particular type of data that the study produced. In addition, a grounded theory approach would provide a framework for addressing new issues that had arisen. One of these was that an understanding of former carers' experiences requires not only the eliciting of subjective meanings but also the exploration of the conditions and techniques of certain experiences and strategies for coping (Strauss and Corbin, 1998).

The pilot study also confirmed the use of interviews as the main method of collecting data, and the suitability of key informants and the researcher's research diary as supplementary methods (Sarantakos, 1998). The way that they contributed to the research at this stage informed their use in the main part of the study. This is discussed later in this chapter.

Therefore, during the preparatory stage, the outstanding issues about the way the study should be carried out were resolved. An operational definition of a former carer was finalised, and an approach informed by grounded theory was confirmed as being both congruent with the interpretive epistemology and relevant to the research question. The suitability of the interview technique was also established and the ways that semi-structured in-depth interviews were used as the main data collection method and other data collection techniques confirmed. Finally, a theoretically sensitive way of carrying out these interviews was derived inductively from the findings and conclusions drawn from this preparatory stage. As a result, the main part of the study was able to proceed.

The main study

Data collection

All the data that was gathered was formally documented. The data collection methods used are described below. Data from the semi-structured in-depth interviews was cross-checked using that which was gathered from the other data collection methods.

Semi-structured in-depth interviews

Interviews were held between February 2000 and June 2001. Although only one interview was conducted on any one day, a time limit was not set for the interviews, and the approach to the length of the interviews was flexible. This enabled the researcher to facilitate interviews that were productive and to discreetly end interviews that had ceased to be productive. The recording equipment was tested out in advance to avoid missing part(s) of the interviews and therefore compromising the data. At the beginning of each interview, the purposes of the research were restated, the written informed consent of the participants (see Appendix 5) was obtained and the official identity of the researcher was demonstrated.

In accordance with the use of grounded theory, amendments were regularly made to the interview schedule that had been developed during the earlier literature review, and the preparatory phase (Glaser and Strauss, 1967; Smith and Biley, 1997). Issues and themes were incorporated and questions amended in the light of the ongoing review of the literature and other relevant sources of data, and the simultaneous primary and secondary data analysis. A total of eighteen amendments were made to ensure that concepts and ideas that seemed to be relevant to the evolving substantive theory were explored, compared, validated, revised and saturated as appropriate (Strauss and Corbin, 1998). A summary, the dates and brief explanation (in italics) of the changes is set out in Appendix 6. A copy of the interview schedule was used unobtrusively as an “aide memoire” during each interview. The emphasis was not on using it prescriptively, but on eliciting meaning from the interviewees’ perspective, as opposed to that of the researcher.

As a result of the sequential analysis of the findings and concurrent reflection on relevant literature and the researcher’s diary, the interview technique was continually refined and extended. Certain strategies, such as posing open questions, tolerating pauses and silences, allowing time for an initial “chat” at the beginning of the

interview to establish rapport and empathy, and avoiding speaking too soon, too often and for too long were still used. However, there was a more considered use of non-verbal signals and greater use of direct questioning and summarising of interviewees' responses as probes and prompts to seek further information and clarification as required. More efforts were also made to develop rapport and empathy such as appropriate use of self-disclosure. Attention was paid to achieving balance in the extent of the rapport developed. This was to avoid the problem of the interviewee answering questions in a "way that is designed to please the interviewer" (Bryman, 2001:155) that can result from an over-friendly relationship (Bryman, 2001).

As well as emphasising that the interview was a two-way process and paying attention to personal presentation, the researcher made additional attempts to establish a non-hierarchical and egalitarian relationship between the interviewer and interviewee. These included stressing that the interviewer wanted to learn from the interviewees, being neutral to interviewees' views, sharing of experiences and validating interviewees' subjective experiences, avoiding the use of academic language and using informants' vocabulary and expressions as far as practicable.

Additional strategies were those for maintaining a balance between objectivity and sympathy for the interviewee's distress, such as allowing time to deal with distress in the interviews, turning off the tape for a while, and reassurance that it was perfectly normal to feel upset. Paraphrasing was used to check the accuracy of the interviewer's interpretations. Techniques were also developed to encourage interviewees to focus on key issues and triangulate the interview data. These included telling them what other former carers had said to prompt them to talk about their own experiences, similar or otherwise. This simultaneously helped to validate data from previous interviews. More attention was paid to achieving positive closure (Hasselkus, 1988; Cartwright and Seale, 1990; Oakley, 1990; Lee, 1993; Taraborelli, 1993; Strauss and

Corbin, 1994; Smith, 1995; Sarantakos, 1998; Arksey and Knight, 1999; Morse, 2000; Eaves, 2001).

An official letter was sent to each interviewee afterwards, thanking them for their time and the insights they had provided. The interviews were then transcribed using the guidance available about ensuring the validity of the transcriptions. This involved using a set format and transcribing each interview very soon after it had taken place. Although the pilot study demonstrated that transcription by the researcher increased familiarity with, and closeness to, the data, pressures of time meant that a professional transcriber transcribed ten of the tapes. The transcriber was advised about the transcription conventions that were being used. All the transcripts were checked carefully for errors. Pauses, intonation, nuances, non-verbal behavior, implied meanings and the context in which they were said were also recorded (Arksey and Knight, 1999; Silverman, 1999; Easton et al 2000).

Field notes were made in a notebook prior to and after each interview. These field notes included points made by the researcher about interviewees informally before and after the interviews, potentially sensitive issues to be aware of during the interview, information given about possible key informants or other sources of information, non-verbal behaviour during the interview, direct observations of behaviour, evidence of support from friends and neighbours, type of housing, personality and significant reactions to the interview.

Key informants

Key informants who had specialised knowledge on particular topics were interviewed during the study. In keeping with theoretical sampling, they were interviewed selectively in the light of the ongoing data analysis and as other issues emerged. There were three types of key informants; there were those who the researcher contacted directly because of their known specialism about issues arising from the ongoing

analysis. Some of these proved to have additional specialist knowledge and the researcher was able to explore other relevant findings with them. There were also those who the researcher met during the course of the study, who unexpectedly volunteered specialist knowledge about pertinent issues that had arisen in the study at that particular time. Notes of any discussions or interviews with key informants were made. These proved a useful source of additional data that would have been difficult or time consuming to unearth through other data gathering techniques, and such data added to the total understandings of the topic being researched (Cartwright and Seale, 1990; Burgess, 1991).

Examples of those interviewed as part of the research process were research staff at Carers UK, members of carers support groups, senior academics, carers centre research workers, District Nurses, co-coordinators of carers' organisations (such as Crossroads), and bereavement counsellors. These are listed in Appendix 7, together with the reasons for contacting them and issues discussed with them. In order to ensure validity and reduce the potential for error, a number of key informants were interviewed about the same issues and the data was cross-checked from these interviews (Bryman, 1995). For instance, support available for former carers was discussed with District Nurses, and several co-coordinators of carers' organisations and carers' support groups. If information proved to be unsupported, it was not used.

Research diary

The researcher kept a word-processed research diary throughout the course of the study. This included factual data, such as a log of what happened, conferences and training sessions attended, decisions made, contacts established, details of literature searches undertaken, suggestions made by colleagues, informal conversations, significant incidents and observations. It also contained personal reflection and interpretations of events and ideas that were developed during the research. The entries were organised chronologically. Although this diary was not viewed as an

objective statement of fact, it did *increase* objectivity. This was because it contextualised the research, and helped to keep personal biases in perspective. This enabled the researcher to be more open-minded to ideas that were emerging from the interviews and from other data. It also provided a rich source of data, which was used during the ongoing analysis in the study (Blaxter et al, 1997; Denscombe, 1998; Eaves, 2001).

Theoretical sampling

Strictly speaking, theoretical sampling in grounded theory is used for the “refinement of ideas rather than boosting sample size” (Bryman, 2001:302). However, it was adapted in the early stages of the main part of this study in order to identify and develop a theoretically sensitive sample, and simultaneously refine ideas. Therefore, the fundamental objectives of this procedure were not compromised. The way it was used in these early stages is described below.

A sampling strategy was devised which reflected the working definition of a former carer and could be used to generate further data. This strategy involved establishing direct or indirect contact through intermediaries with both former carers who defined themselves as former carers and those who did not define themselves as such. Those who acted as contacts included Community Nurses (known to the researcher in a professional capacity), co-coordinators of carers’ organizations such as Crossroads, carers and former carers group co-ordinators, carers forums and staff at carers centres. Some former carers made themselves known to the researcher when they heard of the research, for instance, following presentations the researcher made about the research at De Montfort University and at conferences.

The range and number of contacts increased during the study as the researcher continually followed up suggestions about possible contacts. For instance, one of the Community

Nurses who was contacted at the beginning of the research suggested that the researcher attend the weekly meetings held for Community Nurses in each Primary Care Group to see if anyone would be willing to act as contacts. During one of these meetings, it was suggested that the researcher speak to the co-ordinator of the local branch of Crossroads, a carers organisation. Through this visit, contact was established with other Crossroads co-ordinators. Staff at carers centres also arranged visits to carers forums and carers groups.

Whether meetings with contacts were on an individual or group basis, the aims of the research, its accountability and relevance were explained. The definition of a former carer and the sampling techniques were also outlined. Integral to the latter was a questionnaire based on the findings from the study to date (see Appendix 8). Whilst it aimed primarily to distinguish between different types of former carers for sampling purposes, and to invite former carers to give their contact details if they wished to be interviewed, it also unobtrusively gathered more information about the post-caring experience. This, together with a letter explaining the research on De Montfort University-headed notepaper (see Appendix 9) was made available for inspection and comment. Depending on the extent to which those present at the meetings had direct contact with former carers, some were then asked to give copies of the questionnaire and the letter explaining the research to any one who might fit the definition of a former carer being used and to invite them to complete it. A SAE was attached to the questionnaire and letter so that the respondents could return it to the researcher. At the meetings where those present had a more detached role, (such as coordinators) they were invited to give their names if they thought they could help so that a further meeting could be arranged. During these “second round” meetings, the researcher went through the same process with those who were likely to have productive contact with former carers. The ethical issues involved in the above are addressed in more detail at the end of the chapter.

Thirty visits were made to various contacts and groups in the Midlands. Three hundred and fifty-three questionnaires were given out to former carers or to people who had contact with

former carers. Sixty-five completed questionnaires were returned, and fifty four former carers offered to be interviewed. There were two possible reasons for this low return rate. Those questionnaires that the researcher gave personally to former carers had a 100% return rate. Thus, the low return rate could have been partly due to the use of the intermediaries who perhaps did not promote the research with the same enthusiasm as the researcher herself. Another reason for the low return rate could have been that there were anxieties about being interviewed and the optional nature of the interviews in the research was misunderstood. This hypothesis was supported by the fact that four of those who had completed questionnaires withdrew when contacted by the researcher to make arrangements for their interviews because they were very anxious about being interviewed. Once again, where contacts distributed the questionnaires as opposed to the researcher, reassurances about the optional nature of the interviews could not be guaranteed.

When the completed questionnaires were received, the data in them was entered on a database and used to develop a theoretically sensitive sample which contained respondents who had “expert knowledge of the phenomenon under scrutiny” (Smith and Biley, 1997:21) and who could bring about the greatest “theoretical return” (Strauss and Corbin, 1998:202). Initially respondents were selected because they met the criteria for the definition of a former carer being used in this study, and they had offered to be interviewed on their questionnaire. Those in this “pool” of respondents were then telephoned for a preliminary discussion about the research, its aims and purpose, the format and recording of the interview, and practicalities to reduce environmental hazards such as the need for a quiet room where the interview could be conducted without interruptions (Krueger, 1998; Easton et al, 2000). As a result of this initial telephone contact, it transpired that four of those who had offered to be interviewed did not meet the criteria, one was uncontactable, four no longer wanted to be interviewed and one had such severe hearing problems that an interview would have been unproductive.

Thus the sample size was eventually forty-four. Before each interview, participants were telephoned once more to check the arrangements that had been made during the previous telephone conversation. The interviews started with the first six former carers who had offered to be interviewed. The interviewees were then divided into “batches”. Further details of those interviewed, the batches and how the theoretical sampling was informed by the analysis are provided in Chapter 4.

Ethical issues

The study was scrutinised by De Montfort University Higher Degrees Research Committee. In order to ensure that the study was ethically rigorous, Diener and Crandall’s (1978) four main ethical principles were used (discussed below). Decisions taken about each principle were based on reflection on the aims of the research, consideration of relevant legislation (such as the 1998 Data Protection Act), professional guidelines and literature, and discussions with supervisors and colleagues. The approach adopted was therefore not deontological, but ethical issues were seen as being integral to the research and the emphasis was on maintaining the integrity of the study in its search for understandings of former carers’ experiences (Burgess, 1991; Lawson, 1991; Blaxter et al. 1997; May, 1997; Boman and Jevne, 2000; Silverman 2000; Bryman, 2001; Davies and Dodd 2002; Denscombe, 1998; 2002; Arksey and Knight, 1999; Easton et al 2000; Chesler and Parry, 2001; Mason, 2002).

The way that each of Diener and Crandall’s (1978) ethical principles was addressed in the study is outlined below:

Informed consent

This refers to the way participants should be fully informed verbally and in writing, of the nature of the research so that consent can be freely given or withdrawn at any point.

Efforts were made to ensure that the research was transparent and voluntary. Participants were fully informed of the nature of the research through detailed written and verbal explanations about the research and its accountability. All potential interviewees received the questionnaire referred to above (see Appendix 8), which invited them to give their details and to be interviewed if they so wished. Thus interviewees were given the choice of volunteering to be interviewed or not. When those who had volunteered were telephoned to discuss the aims and purpose of the research and the nature of the interview, they were also assured of their rights to confidentiality and to withdraw at any time. As explained earlier the purposes of the research were restated, the written informed consent of the participants was obtained and the official identity of the researcher was demonstrated at the beginning of every interview.

Therefore on several occasions, the interviewees were provided with information about the study and given opportunities to decline to be interviewed. Although feedback on overall findings was offered, only one accepted and this was for professional reasons. There was one anomaly in this area of ethical concern. This was the lack of informed consent about the field notes that were made and is one of those areas of “uncertainty” about the “limits to consent” (Denscombe, 2002:190). Only information from the field notes that was pertinent to the aims of the research was used to reduce the loss of ethical rigour.

Harm to participants

This includes physical or psychological harm. Obviously physical harm was not applicable to this study, and throughout the whole study, efforts were made to avoid causing participants psychological “harm” in the broadest sense of the word. The researcher was sensitive to the potential power the role of interviewer conferred upon her. The attempts to establish an egalitarian relationship between the interviewer and

interviewees have already been described. Equal opportunities issues were paramount and participants were treated with respect at all times. The value of their “stories” was also reinforced during the interviews, and afterwards when each one was sent a personal letter of thanks.

As explained in the Introduction, with the exception of one, all those interviewed had suffered bereavement and the average length of time since their bereavement was only two and a half years. Thus psychological distress was anticipated, and, indeed, five cried during their interviews. However, it has been argued that *distress* is not necessarily equivalent to harm (Faulkner, 2004) in situations where interviewees want to talk about their experiences. As most of the former carers in this study wanted to talk (see Chapter 5), any distress they did experience did not necessarily cause them any harm. Nevertheless, several strategies were used to address interviewee distress before, during, and after the interviews; the possibility of interviewee distress was acknowledged in the individual discussions with participants held prior to the interviews (referred to above). Those who felt an interview would be too distressing were therefore able to withdraw at this stage. Strategies used to deal with interviewee distress during the interview were described above. After the interview had finished, the interviewer used further strategies, such as talking to them until they were calmer and ensuring that they had someone to contact if required (Faulkner, 2004).

Protection of privacy

Although there is some overlap with informed consent, this focuses specifically on participants’ right to privacy. Steps were taken to protect participants’ privacy at each stage of the study, such as offering interviewees a choice in date, time and place of interview. All of them chose to be interviewed in their own homes at their convenience, and they were also telephoned a few days in advance to check the arrangements made. During the interviews, the researcher took care not to abuse any trust placed in her and emphasised that there was no compulsion to answer questions

or discuss issues that were uncomfortable for them. The steps taken to ensure there was parity between the interviewer and interviewee in terms of power were outlined in the discussion above about the strategies used to establish non-hierarchical relationships during the interviews.

Procedures used during the analysis and writing up ensured that data could not be traced back to participants. For instance, numbers were given to the interview tapes and transcripts, pseudonyms were adopted for participants and anybody else they mentioned, quotations were mainly short which helped to anonymise them and fictitious place names were also used. Organisations were only named if the analysis would have been compromised otherwise. In such situations, generic nomenclature (for instance, social services) was used and the identities of individual employees could not be traced. None of the interviewees' personal details were disclosed to anybody else. All the data was securely stored, only used for the purpose of the research and will not be kept for any longer than necessary.

Deception

This is “when researchers represent their research as something other than what it is” (Bryman, 2001:483). The conduct of the research as described under the previous three principles is proof that participants were not deceived about the research at any point during the course of the study.

Conclusion

The theoretical and methodological approaches to the study, and the way it was conducted have been addressed in this chapter. Reference has already been made to the sequential nature of the analysis and sampling that occurred because of the use of grounded theory. It is to a more detailed account of the analysis that took place in the study that we now turn.

CHAPTER 4: ANALYSIS

Chapter 3 described the principles of theoretical sampling that took place. This chapter provides details of the sample, data analysis and how this informed the subsequent chapters that address the findings. It ends with an assessment of the validity, reliability and generalisability of the study, drawing on the discussions in both Chapters 3 and 4.

Sample characteristics

As explained later in this chapter, thirty-seven former carers were interviewed. Appendix 10 gives a pen-picture of each interviewee. Although these brief descriptions include information from the questionnaires used for sampling, other details are not completely uniform as they are based on information that was gathered as theoretical sensitivity increased throughout the interview process.

The sample was analysed in relation to gender, age, average length of time spent caring average time since caring had ceased and for whom they had cared. A potential weakness of the study (discussed further in Chapter 9) was that an analysis in terms of their socio-economic status was not possible; establishing a valid indicator of the socio-economic status of those in the sample proved problematic. This was partly due to inconsistencies in the information about the occupations of those interviewed; whilst the occupations of all the male former carers were obtained, only some of the occupations of the females' husbands (where applicable) who had worked were ascertained. This problem was exacerbated by the fact that two thirds of the sample was female. Another reason was the age structure of the sample; two thirds were over retirement age and using criteria, such as housing tenure, and access to cars did not accurately reflect socioeconomic status (Arber et al; 2003).

Eleven of the sample were male and twenty-six were female. There was a much higher proportion of older former carers than younger ones; only twelve were under sixty years of age whereas twenty-five were over sixty (see Appendix 11). Their age groups ranged

from 30-39 to 80+ with the modal being those in the 60-69 age group. The average length of time spent caring was nine years (see Appendix 12). The average time since caring had ceased for the whole group was two and half years. This is shown in Appendix 13 which also shows that at the time of their interviews, significantly more had ceased caring less than three years ago compared to those who had ceased more than three years prior to the interview. With reference to the characteristics of their dependants, many were their partner; twenty-four had cared for a partner (twenty-three of these had been a spouse), compared to ten who had cared for a parent, two had cared for in-laws (a sister-in-law and a father-in-law) and one for a neighbour. These characteristics of the sample will be referred to again in the discussions about the findings that emerged.

The data analysis process

Throughout the whole of the data analysis process, the researcher became immersed in the data, systematically analysing and theoretically coding interview transcripts and other data gathered in accordance with the principles of grounded theory. Some of the guidelines were adapted to meet the aims of the study and to suit the interpretive approach adopted. The emphasis in this informed use of grounded theory guidelines was therefore on gaining deeper understandings of the former carers' descriptions of their interpretations and constructions of the post-caring experiences, and the social context of these experiences (Strauss and Corbin, 1990; 1994; 1998; Silverman, 1995; Baker, 1997; Glaser, 1999). These adaptations are described in the discussions about the data analysis process that follows.

During the analysis, the researcher attempted to be objective in terms of the influence of her own values on the study. She aimed to be detached, questioning, receptive to new findings, open-minded, consider alternatives and remain open to being wrong. Constant reflection and use of a research diary helped with the achievement of these aims. However, limitations to objectivity are always unconsciously imposed because of a researcher's own social and cultural background. Nonetheless the overriding influence

on the researcher was her commitment to discovering more about former carers' experiences and the wish to execute a rigorous study that would produce new knowledge which could be used to help this group (Blaxter, et al, 1997; Bryman, 2001; Denscombe, 2002).

The use of qualitative computer aided data analysis packages was explored. It was evident that these packages had some advantages, such as the ease with which data can be stored and retrieved. However, in terms of their applicability to this study, the disadvantages outweighed the advantages. For instance, they did not allow the sensitivity to the data that was required and implied meanings could not be analysed. Many of the interviews produced masses of what seemed to be irrelevant data but taken in its entirety was very significant. Using such programmes would have run the risk of breaking it up and losing the significance of this data. In addition, it is difficult to contextualise what interviewees say using these programmes. As contextualising interviewee's responses is vital to gaining an understanding of meanings, this was yet another disadvantage. Furthermore, critics argue that such packages are of limited value for small-scale projects because of their high set-up costs (Buston, 1997; Wyse, 1997; Denscombe, 1998).

The data analysis process started with grouping the sample into "batches" for interviewing purposes. This was done by subjecting each transcript to a preliminary analysis using symbols in order to identify key themes. Although such an analysis is not characteristic of grounded theory, this initial identification of key themes helped to theoretically structure the sample by establishing a broad classification system. This was then used to allocate individual transcripts to a "batch".

As discussed in Chapter 3, the interviewing process began with interviews with the first six former carers who had offered to be interviewed. Three key themes emerged from the preliminary analysis of these transcripts. Two of these were that length of caring and gender both had an influence on post-caring experiences. For instance, where former carers had only cared for a short time, post-caring there were fewer effects on social and

family relationships, less effects on health, less feelings of being “out of things”, and changes they made to their lives whilst caring were more easily reversed. The theme about gender was that male former carers could rebuild their social lives more easily because they find it easier to go out on their own. Serial caring was the third theme. Thus, four batches were initially created. The first comprised those former carers who had cared for the shortest lengths of time (between 7 and 14 months). The second batch had cared for a longer period of time (between 2½ years and 38 years). The third and fourth batches consisted of males only and those who had cared at least twice respectively.

The findings from these initial batches were subjected to a preliminary analysis. This was used to develop the next three batches to explore further emergent themes. A theme that had emerged from the interviews with those who had cared for a long time was that the post-caring experience is different for those who worked and those who did not work whilst caring. Although work gave carers an identity, they seemed to suffer from more stress because they had less opportunities to relax and socialise during caring. They organised less help than their non-working counterparts. In addition, any help they did receive, such as respite care, provided them with less freedom and rest because of their work commitments. This made them more tired post-caring and they also felt less positive about the caring experience. Therefore, the next two batches were those who had undertaken paid work whilst caring and those who had not.

The final batch was developed to explore a theme that had emerged from the preliminary analyses of batches two to seven. This was that having cared for a parent may have different consequences post-caring than having cared for a spouse. An example of this theme was the post-caring changes in the relationship between the former carer and his/her own children that occurred as a result of caring. Consequently, this last batch contained those who had cared for a parent.

The information on the questionnaires used during sampling (as discussed in Chapter 3 and see Appendix 8) was used to allocate interviewees to the batches. The

questionnaires were also used to match the batches as far as possible, so that each batch following the first one contained at least one former carer who had characteristics that had already been shown to influence the post-caring experience, and that variables other than those which had already been explored were not introduced. Each batch contained between three and six former carers. Batch size was determined by the number of interviews it took to reach the point where new information about each “type” of former carer was no longer emerging, and thus saturation had been achieved. It transpired that seven of those in the sample did not need to be interviewed as saturation was reached for their “type” through interviews with other former carers. As a result, a total of thirty-seven former carers were interviewed.

Thus the sample was structured theoretically as the preliminary analysis proceeded. An overview of the sample structure is set out in Table 1.

TABLE 1: SAMPLE STRUCTURE

BATCH 1 6 who had been the first to offer to be interviewed	BATCH 5 6 who had cared at least twice
BATCH 2 4 who had been short-term carers	BATCH 6 5 who had undertaken paid work whilst caring
BATCH 3 4 who had been long-term carers	BATCH 7 4 who had not undertaken paid work whilst caring
BATCH 4 5 males who cared for varying lengths of time	BATCH 8 3 who had cared for a parent

Figure 1 on page 89 summarises the whole of the theoretical coding process that took place in the study. This shows that the concurrent preliminary analysis and theoretical structuring of the sample described above was then followed by the other stages in the grounded theory theoretical coding process. Thus, they were additions to the grounded theory procedures. Furthermore, their use in conjunction with the other stages in theoretical coding processes increased the depth and rigour of the analysis, and in turn, contributed to meeting the aims of the study.

In terms of the details of the theoretical coding process illustrated in Figure 1, after preliminary analysis and theoretical structuring of the sample, all the interviews in each batch were microanalysed and theoretically coded. Each batch not only provided more data about its particular “theme” and other themes but also produced vast amounts of data that contributed to the emerging theory. All the interview transcripts were then revisited many times for further microanalysis and theoretical coding as dictated by the ongoing analysis. As a result, constant comparison, verification and integration of indicators, concepts, sub-categories and core categories took place throughout the whole process of the research. These stages were not sequential and were frequently carried out simultaneously. As they proceeded, the researcher became increasingly theoretically sensitised. This included scrutinizing the literature for existing theories that might be relevant to the emerging theory (Strauss and Corbin, 1994) and examining the data generated through the other research methods used.

Although this process began with microanalysis of the data, microanalysis was used throughout in order to substantiate and verify indicators, concepts and categories. It involved the examination of single words, phrases, sentences, units and pages. The emphasis was on allowing the raw data to “speak for itself” and exploring a range of potential meanings of the specifics of the data. Attention was paid to both *what* the interviewees said, and *how* it was said in order to ascertain their interpretations of events and situations, and any variations in these interpretations. Explanations of inferences and hypotheses made were noted in theoretical memos and used to support any conclusions drawn, both during the analysis and in the data chapters (Strauss and Corbin, 1998).

During microanalysis similarities in the raw data were labelled with indicators to denote their shared characteristics. The names of these indicators were constantly refined during the whole process of constant comparison and verification that took place during the analysis. “In vivo codes” were used where they provided accurate representations. Other codes were devised by the researcher to provide further objectification through the application of theoretical knowledge so, whilst the length and nature of the labels varied considerably this was necessary in order to code accurately and effectively

(Layder, 1982; Dey, 1993; Fielding, 1993; Coffey and Atkinson, 1996; Blaxter et al, 1997; Cavanagh, 1997; Strauss and Corbin, 1990; 1994; 1998; Marshall and Rossman, 1999; Silverman, 2000).

The final versions of the indicators are set out in the tables in each data chapter (Chapters 5 to 8). As the lists of indicators demonstrate, their shared characteristics were far more wide-ranging than suggested in the outline of grounded theory in Chapter 3. Examples of features of the raw data that they are based on were timing, number, frequency, length, detail provided, nature of activity involved, losses and gains, positive and negative aspects, physical and psychological effects, feelings expressed, evoked same images, local and national, range, limitations, extent to which they represented decreases and /or increases, degrees of permanence, difficulty, formality, change, continuity, involvement, consciousness, limitation, extent, and influence of gender, age and socioeconomic group, caring and bereavement. The length and nature of the labels also varied considerably. However, the researcher felt this adaptation of the grounded theory guidelines was necessary in order to capture the meaning of the data and accurately reflect former carers' interpretations of their experiences and the social context in which these took place.

The identification of indicators was followed by theoretical coding. Open, axial and selective coding were used, often at the same time to produce concepts, sub-categories and core categories. Details of the development of each core category are represented diagrammatically in the tables (referred to above) and discussed in detail in Appendix 14. Questioning, mini-frameworks and comparative analysis techniques, such as the flip-flop technique, were used during open, axial and selective coding, in addition to the techniques used during microanalysis. Theoretical memos were also made about any indicators, concepts and subcategories that did not "fit" and explanations sought. For example, Clive's experience did not "fit" the indicator "restricted opportunities to pursue interests and activities when caring". This is because he not only continued to pursue some of his existing interests but also pursued new interests, such as undertaking an Honours degree. The theoretical memo made reminded the researcher to establish *why* his experiences did not match those of the other former carers.

During *open coding*, the researcher carefully examined the indicators that had been identified and looked for similarities and differences in order to identify concepts. This involved many stages. Initially the indicators were loosely classified into four groups; those that related to the caring experience, the cessation of caring, the post-caring experience and links between caring and post-caring experience. Some appeared in more than one group. Many concepts were then established within and across these broad groups of indicators.

Axial coding involved integrating these concepts into sub-categories. The core categories evolved out of the sub-categories in various combinations during the *selective coding* that took place. Some of the core categories therefore shared certain sub-categories, concepts and indicators. More generally, axial and selective coding were used to refine and develop a larger, conceptually dense theoretical scheme. This involved saturating and establishing relationships between concepts and categories, identifying new dimensions that emerged during saturation, exploring poorly developed categories further, considering frequencies of particular indicators, concepts and sub-categories in order to assess the weighting they should be given, tabulating data and undertaking additional microanalysis. New indicators, concepts and categories and extra dimensions to existing ones were identified throughout this process. The numbers of indicators and concepts that were used to develop each sub-category were not necessarily evenly balanced. Findings that emerged from the analysis that seemed to be relevant to the substantive theory that evolved simultaneously were used to sample theoretically and directed further data collection (Glaser and Strauss, 1967; Smith and Biley, 1997; Strauss and Corbin, 1990; 1994; 1998, Groger et al 1999; Morse, 2000).

Consequently, all the data were also reanalysed several times. Increasing theoretical sensitization meant that the data from individual interviews were cross-checked with interviews within their own and other "batches". The findings from batches were also cross-checked with other "batches", and with individual interview data within them. When these analyses of the batches had been completed, they were *all* reanalysed to

explore emergent issues. Some of these were generated by the quantification of the data. An example was the way it emerged that 70% of those interviewed were serial carers. A retrospective analysis was therefore undertaken to establish what conditions lead to serial caring. All the batches were also reanalysed for the effects of gender and age on the post-caring experience. Other retrospective analyses were undertaken to account for deviant cases and variation within categories; it was important to develop explanations of these and build these into the evolving theory to extend its explanatory power.

During the analyses and reanalyses, relevant literature, and data produced through the use of the other data collection techniques (such as the key informants and research diary) were scrutinised and compared to the findings that were emerging. Emergent fit with existing and new research was ensured so that the emerging theory was not isolated and contributed to knowledge about former carers. The macro and micro were integrated with the resulting theory. A “conditional matrix” was used to do this (Strauss and Corbin, 1998; Wuest, 2000).

Other compatible approaches were used to ensure the rigour of the study and holism of the analysis. Sociolinguistics helped in the reanalysis of transcripts to explore, for example, any violations of turn-taking in interviews and repetition of phrases and words by interviewees (Coates, 1993; 1996; Spolsky, 1998; Trudgill and Cheshire, 1998). Such sociolinguistic analysis helped to develop deeper understandings of the former carers’ perceptions and experiences. As this adaptation to grounded theory enhanced, rather than directed the analysis already produced, the central features of grounded theory were therefore, once again, not abandoned.

The core categories that emerged as the result of the re-analyses and integration of the concepts and categories related to both caring and post-caring experiences and were:

- the caring time
- issues in the post-caring experience
- life post-caring

- support post-caring

They are used as headings for, and discussed in, Chapters 5 to 8. As indicated above, the development of the core category being addressed, together with its concepts and indicators, is represented diagrammatically in each of these chapters and outlined in detail in Appendix 14. The chapters make reference to the specific concepts associated with the category that is being explored, and the indicators are integrated into these discussions. In accordance with grounded theory, literature that was identified as part of the ongoing review is also integrated into the explorations of the core concepts. Quotations from the interview transcripts and the results of any quantitative analysis of the findings are used to support and illustrate the findings, and to help convey the meaning of the former carers' experiences to the reader. The substantive theory that was generated inductively throughout the analysis from the many conceptual relationships was then integrated into formal theory. (Handler et al 1996; Strauss and Corbin, 1998; Bryman, 2001; Mason, 2002). This is discussed in Chapter 9.

Data analysis issues

Before the results of the data analysis are discussed in the next chapters, there are a few outstanding matters that arose during the analysis that require explanation. One is the approach taken to the exploration of emotions. Although grounded theory is particularly useful for the exploration of emotions because of the constant interplay between the findings, data collection and reflection, this was the most problematic aspect of the interviewees' experiences to explore. Over a quarter (ten) neither wanted to discuss their emotions or feelings in much detail nor dwell on them for any length of time. They seemed happier to describe events. Joyce provided an example of this. When asked about how she felt when all the additional equipment was returned to the Red Cross, she merely replied "It were a bit upsetting". She then proceeded to describe the *process* involved in the return of the equipment. Consequently, as some emotions remained unverballed, identifying emotions depended on inference from the former carers' stories. In addition, as emotions were intertwined with all aspects of their lives, it was

impossible to disentangle them in order to present a separate chapter on them. As a result, emotions are addressed within the discussions in each chapter as appropriate.

The multifaceted and multidimensional nature of emotions means that different approaches have been taken to them across several disciplines. For instance, within sociology, there are divergent theoretical perspectives which all raise deeper epistemological and ontological questions. These can be placed on a continuum with those that are “organismic” at one end, interactionist in the middle and social constructionist at the other end (Rosenburg and Turner, 1990; Williams and Bendelow, 1996; Williams, 2003). However, as an interpretive perspective was adopted in this study, emotions were viewed as being essentially based on the subjective meanings that the former carers ascribed to their thoughts, sentiments and feelings as expressed verbally and non-verbally. A classification system for the different groups of emotions was devised. Although there are many ways in which emotions can be classified (examples include animal, rational, socially distinguished, collective or primary emotions) the categories of negative and positive were used to classify the emotions expressed by those in the study. The former involved the expression of unpleasant feelings, such as fear, tension and anger. The latter involved the expressions of feelings such as happiness and satisfaction (Harre, 1986; Crossley, 2000; Barbalet, 2002).

In addition, it is necessary to clarify the approach taken to the influence of bereavement on the post-caring experience. This is important as the definition of a former carer developed for this study meant that the end of caring and the death of the most recently cared-for dependant should have occurred simultaneously. Therefore each former carer would also have been bereaved. The adoption of this definition was successfully translated into practice, because, with the exception of one, all of those interviewed had been bereaved when the last episode of caring ceased. The one deviant case was Lucy, whose most recent caring experience had involved her son who had subsequently recovered from his mental illness. However she had previously cared for her father and caring had ceased when he died. Consequently, she had experienced the death of a dependant for whom she had cared, even though this was not her most recently cared-for dependant.

It could be argued that the relationship between bereavement and the end of caring is complex and co-terminous and therefore could lead to confusion between the feelings associated with each occurrence. Any confusion could also have been exacerbated by the fact that the average length of time since their bereavement for the sample was only two and a half years. Such a short length of time could have reduced the ability of those interviewed to distinguish between the influence of bereavement and the influence of the end of caring. In the following extract, Claude illustrates this confusion. The contrast between the way that he struggles, hesitates and presents a convoluted argument with the eloquent way he expresses his ideas in the rest of his transcript illustrates the intricacies of the relationship.

“it’s a lot more than a repercussion of a death. Maybe the caring as well, it’s very difficult to unscramble the two er it lasts a lot longer than you would think, I would think that the length is due to the death though, I think you would get this er if you had a death without the caring. If somebody suddenly dies I think you would have exactly the same feeling and it must be quite difficult to unscramble the two because they’re so intimately linked”

However, the analysis showed that in some areas of post-caring life, influences that were exclusive to the post-caring experience because of their links with *caring* and its cessation could be distinguished from the influence of bereavement. Where such a distinction could not be made, this is acknowledged and the significance of the lack of distinction in relation to the findings assessed. Therefore, it can be argued that in addition to establishing some of the experiences of bereaved former carers, it was also possible to identify many influences on the post-caring experience of all former carers. Consequently, the relevance of the findings was increased in that they were extended to both bereaved and non-bereaved former carers.

Validity, reliability and generalisability

There are a variety of definitions of validity and reliability (Oyster et al. 1987); conventional approaches to validity refer to the extent to which the conclusions are based on accurate data and analysis (Bryman, 2001; Denscombe, 2002) whilst reliability is defined in terms of whether the results of the study can be repeated (Denscombe,

1998; 2002; Bryman, 2001). The concepts of validity and reliability are contentious issues in qualitative research and the disagreements about their relevance qualitative research are well documented in the literature (Angen, 2000). Some argue that validity and reliability are unnecessary in qualitative research whilst others argue that they are fundamental in order to maintain its credibility as rigorous research (Strauss and Corbin, 1990; Silverman, 1995; 1998; Seale and Silverman, 1997; Smith and Biley, 1997, Morse, 1999). Another faction is critical of such conventional ideas of reliability and has developed alternative means of assessing the reliability of qualitative research. One of these is Mason (2002) who argues that a qualitative study is reliable if the data generation and analysis have been appropriate to the research questions, and are both thorough and accurate. Nonetheless, some grounded theory studies have been accused of failing to address questions of reliability and validity (Silverman, 1998; Easton et al, 2000) and the way that these were approached in this study needs to be clearly justified.

With reference to *validity*, this study was valid in a generic sense because it aimed to accurately represent the subjective meaning of the post-caring experience (Oyster, 1987; Silverman, 1995; Denscombe, 1998; Morse, 1999; Angen, 2000). It can be argued that this interpretation of validity immediately implies the very nature of a grounded theory study should be valid. As already explained, this is because any theory produced will be faithful to participants' reality as it will be grounded in, and derived, from data (Strauss and Corbin, 1994; Smith and Biley, 1997). Moreover, there are those that argue that theory derived from data as in grounded theory, is more likely to resemble participants' reality than is theory derived from other methods, such as putting together a series of concepts based on experience or through speculation (Layder, 1982, Strauss and Corbin, 1998). Despite such arguments, grounded theory studies, particularly those that use interviews and participant observation, have been criticised for the way they assume that data are reproductions of participants' reality. This assumption is said to compromise the validity of grounded theory studies (Silverman, 1997; 1998; Hall and Callery, 2001).

The researcher ensured that the validity of this study could not be questioned in this way; the appropriate use of the full range of grounded theory's guidelines and

procedures (such as theoretical coding, comparative analysis, and the use of conditional matrices) has been demonstrated in this chapter. The adaptations made to grounded theory guidelines for the theoretical sampling, theoretical coding and analyses were justified in terms of the needs of the study, its aims and approach. Nor did they compromise the central features of grounded theory.

The specific techniques that researchers using grounded theory can employ as additional safeguards for the validity of their work were also used (Glaser and Strauss, 1967; Baker, 1992; Blaxter et al, 1997; Layder, 1998; Silverman, 1998; Easton et al, 2000; Hall and Callery, 2001). For instance, the findings in grounded theory study can be validated by presenting them to the participants to see if they are recognisable to them (Glaser and Strauss, 1967, Layder, 1982, Strauss and Corbin, 1998). Therefore the validity of the findings from the ongoing analysis was regularly assessed by seeing if they were understandable to interviewees in subsequent interviews. Other techniques used in grounded theory as additional safeguards for validity are the corrective techniques of reflexivity and relationality. Reflexivity is defined as “critically examining one’s effect as a researcher on the research process” (Hall and Callery, 2001:263) to address the effects of the interaction between the researcher and interviewee on the construction of the data. The researcher therefore reflected on each interview, assessing the extent to which factors such as her own and the interviewee’s background and values, and the order in which the questions asked shaped the knowledge that emerged. Adjustments to the way the interviews were carried out were made accordingly. During the analysis, use of reflexivity meant that the researcher critically reflected on her interpretive role. Such reflection on the researcher’s values throughout the research helped to ensure that reality as constructed by the subjects of the research was represented and that data was not ignored (Denscombe, 2002).

Relationality emphasises the importance of a shared power relationship between the researcher and the interviewee in producing valid findings about what is significant to interviewees. Thus, strategies were used to develop the rapport and sense of trust necessary for the interviewees to speak as openly and honestly as possible about their experiences. These included the development of rapport and empathy, and the

establishment of a nonhierarchical relationship between the interviewer and interviewee. These are described in the discussions of ways in which the interviews were carried out (Glaser and Strauss, 1967; Strauss and Corbin, 1990; 1994; 1998; Hall and Callery, 2001) (see Chapter 3). In addition to advocating relatively unstructured interviews as a means to establishing the non-hierarchical relationship necessary for encouraging greater responsiveness in participants, Oakley (1990) also argues that the aforementioned strategies increase the objectivity of the data. This is because they further increase the responsiveness of participants and help to explore “their own accounts of their lives” (Oakley, 1990:48).

Other aspects of the research methodology (described earlier in this chapter) that also contributed to the validity of the study included use of relevant literature to devise appropriate interview, recording and transcribing techniques, and triangulation of the data both in the interviews and through the introduction of other methods of data collection.

As this study looked at meanings and understandings, and therefore could not be replicated, conventional concepts of *reliability*, such as replication over time and across contexts, were not applicable (Burrows and Kendal, 1997, Silverman, 1995, Smith and Biley, 1997, Denscombe, 1998, Browne, 2000, Davies and Dodd, 2002). Some aspects lent themselves to such interpretations of reliability more than others. For instance, to ensure reliability during the analysis and theoretical coding, a record of all codes was kept so that early concepts could be revisited and re-analyzed (Silverman, 1995, 1998, Strauss and Corbin, 1998).

Nonetheless, it was more appropriate in this study to adopt a broader approach and concentrate on reliability in terms of authenticity. Reliability could be operationalised in this sense to meet the requirements for rigour in qualitative enquiry by informed, consistent and careful use of the many techniques suggested in the literature to ensure reliability in qualitative studies. Examples of such techniques were pre-testing interview schedules, taping interviews, using detailed transcription techniques, using guidelines

properly, engaging the trust of interviewees and ensuring the published findings are assessed by other researchers (Seale and Silverman, 1997; Morse, 1999; Browne, 2000; Davies and Dodds, 2002). Once again, with the exception of the last technique, the way that these were used have been described in this chapter. The findings were regularly assessed by the researcher's supervisors, and discussed with other academic staff with relevant expertise and interested professionals. It is intended that the comments of other researchers will be invited upon the completion of the thesis.

Thus, informed use of the guidelines for grounded theory and those for rigorous qualitative research ensured the validity and reliability of the analysis. The final issue to be discussed is the *generalisability* of the study. The generalisability of qualitative research is subject to much controversy. It usually refers to being able to draw conclusions from a set of data about a particular set of examples that can then be applied to the whole group from which those examples come, in order to build theory (Silverman, 2000; Denscombe, 2002). Yet, there are those who maintain that generalisability is more appropriate to quantitative research and that which adopts a positivistic approach. Moreover, there are arguments that generalisations are unnecessary in qualitative research, and particularly in interpretive research (Silverman, 2000; Bryman, 2001; Denscombe, 2002). Nonetheless, generalisability continues to be an important aspect of most qualitative research, albeit in a more limited way than other types of research.

The generalisability of a study can be obtained through a variety of means (Silverman, 2000; Bryman, 2001; Denscombe, 2002). These include use of the comparative method and theoretical sampling. The adoption of a method informed by grounded theory automatically involves a comparative method (through the use of the constant comparison and verification procedures) and theoretical sampling. Thus it can be argued that the use of grounded theory contributed to the generalisability of the findings. In addition, as explained earlier in this chapter, the findings are relevant to both bereaved and non-bereaved former carers. However other features of the study could have reduced its generalisability. An example was the use of in-depth interviews; these have been criticised for their lack of generalisability (Sarantakos, 1998) and their adoption as

a main data collection technique could therefore have counteracted some of the contributions of aforementioned procedures to the generalisability of the study.

There are other approaches to generalisability that are used in qualitative interpretive research which provide a more accurate assessment of the nature of the generalisability of this study. The related concept of transferability is more frequently associated with interpretive research and the use of qualitative data. Transferability involves the researcher providing "thick description"; this means a rich and detailed account of the many facets of the phenomenon under investigation in order to capture its complexity. This "thick description" also requires interpretation and evaluation by the researcher. Those who read the findings are not viewed as passive recipients of this information; they are expected to use it as a database and transfer the knowledge to other situations themselves, using their own knowledge and skills (Geertz, 1973; Guba and Lincoln, 1994). During the writing up process of this study, those who read the in-depth descriptions of former carers' experiences given in Chapters 5 to 8 were able to "transfer" the findings reported to other situations. Thus the study is generalisable in terms of the transferability of its findings.

Another way in which the generalisability of qualitative research can be defended is in terms of the extent to which it can generate possible theories and theoretical concepts which can be explored further in other studies (Denscombe, 2002). As demonstrated in Chapter 9, this study produced a theoretical schema of the post-caring experience and introduced several new concepts. The further exploration of this theory and its concepts was strongly advocated. Indeed a more detailed study into the concept of the serial carer is planned. Thus it can be argued that the study is generalisable in terms of its ability to generate theory.

Conclusion

Chapters 3 and 4 have provided a thorough outline of the rigorous conduct of the study and the analysis of the data it produced. The next chapters discuss the main findings and start with "The caring time".

CHAPTER 5: THE CARING TIME

This chapter explores the core category of “The caring time” and addresses the caring experiences of those interviewed. The indicators, concepts, and sub-categories identified during the development of this core category are set out in Table 2 on page 103 and details of the analysis are discussed in Appendix 14. Table 2 shows that this core category has five sub-categories - “caring and daily life”, “caring and health”, “caring and support”, “caring and the role of the carer” and “caring and the cared-for person”. The last of these sub-categories is about dependants’ perspectives on caring. As the focus of the interviews was on the former carers’ own experiences, and over a quarter of those cared-for (ten) had a considerably reduced ability to communicate because of their illness or disability, there was very little data on this sub-category. Therefore it is woven into the discussions of the other four sub-categories in the rest of this chapter.

Caring and daily life

The former carers expressed both positive and negative views about the effects of caring on their lives. Twenty-eight said they felt positive and made comments about the “good times”, having “had some fun,” the “special times” and “times when we had plenty of laughter”. Peggy smiled when she said it was “wonderful.” Indeed, over half of the sample (twenty) felt that their caring experience had been enjoyable overall and saw it as a valued part of their lives. It was described as “giving you a purpose,” “rewarding” as well as an “honour” and a “privilege” to have cared for their dependants.

The more negative views that were expressed focused on the restrictive nature of caring and the way in which this impacted on their lives. Just over three quarters (twenty-nine) said caring had restricted their lives to a greater or lesser extent. Some found the restrictions less binding than others. Amongst those who did not see caring as being overly restrictive were Lydia and Penny. Lydia compared the restrictions of caring to

TABLE 3: DEVELOPMENT OF THE CORE CATEGORY "THE CARING TIME"

"THE CARING TIME"					
CORE CATEGORY (Selective coding)	caring and daily life	caring and health	caring and support	caring and the role of carer	caring and the cared-for person
<p>concepts (open coding)</p> <p>positive experiences restricted time interests and activities social life personal and family relationships employment financial resources</p>	<p>emotional stress physical strain social contacts inattention to own health reduction in health</p>	<p>multiple sources of support used subtypes of support provided satisfaction rates</p>	<p>clear sense of having fulfilled the role of carer distinct set of experiences and tasks associated with caring significance of the role</p>	<p>appreciation of carers' efforts recognition of the restrictive nature of caring for the carer dissatisfaction with statutory services</p>	<p>indicators (microanalysis)</p> <p>good times, fun, rewarding, caring gives a purpose, privilege, honour, responsibilities of main carers, tasks, restrictions on time, time-consuming nature of caring, time and energy required to obtain services, rigid routines, routines took up most of day, gave up interests and hobbies, limited opportunities to pursue interests in activities outside caring, activities, accommodated within the constraints of the caring role, activities linked to the caring role, varied over time, relatively unrestricted routines, lost social life, limited social life, lost friends, friendships changed, restricted by nature of dependant's illness, advancing age affected number of friends, positive experiences of friendships, negative impacts on personal relationships with dependant, negative impact on relationships with spouse, relationships with family members suffered during caring, impact on other family members, tension in family, friction over the responsibility of caring and misunderstandings, improvements in family relationships, loss of paid and unpaid employment, loss of income, loss of financial resources, change of employment</p>
	<p>behaviour of the dependant, time-consuming nature of caring, rigid routines, lack of control over daily life, conflict with services and service providers, emotional labour of caring, guilt, anger, friction with the dependant, fear, psychological strain of caring, heavy physical tasks of caring, restricted opportunities to pursue interests and be involved in activities outside caring, social life restricted by illness, social life restricted by nature of illness, impact on other family members, loss of employment, no time to think about their health, forgot about health whilst caring, did not think about their health whilst caring, ignored own health during caring</p>	<p>emotional, instrumental, informational and appraisal support, statutory organization General Practitioners, Social Workers, Hospitals, District Nurses, Social Services carers, Occupational Therapists and chiropodists, benefits, grants for building alterations, respite care, use of privately run carers agencies, use of private care homes, carers groups, carers centres, voluntary groups, hospices, support from family and friends, local community support, satisfaction expressed, dissatisfaction expressed, level of support for their dependant was inadequate, the level of support for carers was inadequate, services were unsuitable, staff were unsympathetic, quality of support</p>	<p>caring for their dependant was integral to their relationship with him/her, did not define themselves as carers, attendance at carers groups or centres, wanted to tell the interviewer about their caring experiences before and during interview, returned to the story of caring experiences when interviewer tried to end the interview, longest responses to comments or questions by the interviewer were about the caring experience, details about the personal nursing care that they had provided for their dependant, continued presence of equipment and accessories required for caring in their homes</p>	<p>verbal expressions of gratitude, non-verbal expression of gratitude, sensed encouraged to pursue interests, encouraged new activities, created opportunities for leisure activities, acknowledged need for carer to have a break from caring, verbal expression of dissatisfaction with statutory services, non-verbal expression of dissatisfaction with statutory services</p>	

those of having a baby when she said “well it’s exactly the same situation as having a baby. You just have to organise someone to replace you”. Consequently, she maintained some aspects of what she called a “normal life” such as doing “basic shopping for the whole time” but she “never went shopping for clothes or for pleasure”. Similarly Penny, who had two children and cared for her father, found that although they did less as a family and could not go so far as they did pre-caring, they still did things. They were just restricted because they “couldn’t go far” and “always had to be within a certain distance”. This group also comprised those who found the degree to which their lives were restricted varied during caring. Some said the restrictions increased over time. For instance, Joan gradually reduced her working hours as the demands of caring for her husband increased. Others, such as Betty, felt the extent to which her daily life was restricted varied throughout caring. She found she could go out sometimes but there were times when she “wasn’t getting out, only up to the village”.

Nonetheless, half *felt* that their lives were restricted to the extent that they could not live their own lives whilst caring. Of these, sixteen were females and ten were males. Given that only eleven males were interviewed, this meant that the men were more likely to express this view. There was a general feeling that they were not participating in mainstream society during caring because they were completing a “sentence” or were “trapped” on “a desert island”. Life during caring was described as “frozen time” or as being on a “state of hold”. Explanations of this included the way that caring means you spend “your whole life concentrating on one thing” and therefore have to “give up your own life” or “shut down your life”. Claude went as far as to say that he felt he had lost part of his identity during this time as there was a “submersion of self”.

Therefore, whatever the extent of the restrictions, the nature of caring meant that the majority of those interviewed felt that their lives were restricted and half felt they could not live their own lives whilst caring. Upon saturation, concepts emerged which demonstrated some of the more specific reasons why caring produced these feelings. These were associated with the way that caring impacted on their time, opportunities to pursue interests and activities, personal and family relationships, employment and finances.

Time

All but two of the former carers had borne the full responsibility for the care of their dependant. Indeed eight cared without any other form of help or support at all. Each former carer described the extent of the responsibilities they had shouldered; these included being totally responsible for the health and welfare of their dependant, acting as their dependant's advocate, negotiating for services, managing a home and family around the needs and routines of the dependant single-handedly, working outside the home (eighteen worked at some point during caring), and addressing the needs of other members of their families such as spouses and children.

The extent of these responsibilities meant that nearly three quarters (twenty-six) talked about the way caring imposed restrictions on their time. Several commented on how it was so time-consuming that it could also occupy most of their day, or take up most of the time they had available in the day. Ted provided a good illustration of the former when he said his wife "needed practically everything doing for her so you had a full day's work". Penny illustrated the latter when she talked about all the tasks she had to undertake associated with caring for her father and how she had to fit these in with "everything else" she had to do as a wife and mother, even when he went for respite care:

"...the doctor's appointments to go to - and I had been incredibly busy with all this - I didn't really need a job! Arranging care, getting special food, cooking extra meals, taking him to the doctors and the hospitals and visiting him in hospital. It was really exhausting visiting in hospital, because you had to go for a certain length of time - you have to fit it into everything else - the idea of respite was to give me a break - but he wanted me to visit him everyday so I would just go"

Similarly Ethel, who worked for some of the time she cared for her mother described how her caring tasks took up all the time she had outside her working hours.

"Getting up at four, Mum woke at half past five, getting home at half past two and then doing everything. She was incontinent most days. Also, looked after her twenty four hours a day, lay on the floor boards with her at night I was putting her on her commode seventeen eighteen times a day"

In addition to the daily care of dependants, obtaining the services required for a dependant was also time-consuming. Indeed, *nine* described how they had devoted much time and energy into obtaining such services. One of these was Sue who described the time and energy she had to devote to sorting out suitable care at home for the neighbour for whom she cared. She explained how the GP...

“...came to see me on various occasions, really when John came out of hospital. Um I tried to contact him to support John in this new rehousing and I told him everything about the situation. And when I couldn't get past these receptionists. 'Well what is it about?' I said 'I need to speak to Dr Bell.' 'No'. 'Could you ask him to ring me back then?' 'Oh we don't do that sort of thing' (*imitates receptionist*).... in the end he did ring me back and I was so pleased I got hold of him.... it was exhausting with all the various things”

Not only was caring time-consuming, the nature of some dependants' illnesses meant that time had to be very closely “structured” around the needs of the dependant. Indeed twenty-one felt their daily lives had, in Paula's words, “revolved” around the person for whom they cared. Many described the daily routines they had followed when providing co-resident care. Derek provided a good example of how structured his daily life became during the last the two or three years of caring for his wife who had ME.

“She would er stay in bed until lunchtime. She would get up and go to the bathroom..... and um then I would cook lunch and she would, she would, we never shared..... she had a meal sitting in this room and I would be having my meal either in the dining room or in the kitchen....., I er had fourty winks er after lunch....I very rarely left the house except to er er do the shopping and I would leave her safely tucked up in bed in the knowledge that she'd got the 'phone and I would go, my nearest shop was in Runford, which is 4 miles away, and I would ring her when I got there and she'd say 'I'm all right”

Such routines could also be very rigid; Ted found that he “had to do things to the minute almost” and Ethel said “you have to get the medicines at a certain time and all that”. Some described these rigid daily routines. For instance, Lydia explained how she had to keep to a tight schedule day and night. This was because her mother's toileting needs involved hoisting her “every hour” during the day, and she also “used to get up twice” during the night. Even those who did not provide co-resident care found their daily lives followed a set pattern and their time had been structured; Una's mother lived on the

other side of the same housing estate that she lived on. She “used to go down every night” to see her. There were also rigid weekly routines. Claude provided an insight into his weekly routine when he explained how he used to think “ if it’s Thursday I do this, if its Friday I do that type of thing or on Saturday we’ve got so and so calling”.

Thus caring was both time-consuming and could lead to inflexible routines which clearly had implications for other aspects of the interviewees’ caring experiences. These are discussed below, together with the other impacts of caring.

Interests and activities

One of the impacts of restricted time when caring was on the opportunities to pursue interests and activities. Many said they had to give up interests and hobbies. This was due to both the time-consuming and demanding nature of caring and the restrictions imposed by the dependant’s illness. Doris provided an illustration of the former when she explained that she “didn’t get out” except for doing “shopping”. Greg talked about how his wife’s arthritis meant that they had given up their hobby of “caravanning,” which they had done each year for “three months of the year, not in one stretch but we would go away for a fortnight”.

Although nearly half (seventeen) said they managed to pursue any interests and activities during caring, these were often connected with their caring role. Twelve joined carers groups, participating in the activities offered. Six undertook voluntary work of some sort for those with an illness or disability. This could take up a significant amount of time. For instance, Frieda set up and ran a group for disabled people that she referred to as a “Disabled Group”. As she was secretary she was kept busy with all the organising and it also “used to get George and I out.....into town or wherever we wanted to go, you know shopping and that”. Others became involved in support groups for their dependant's impairment (such as an “Amputee Club” and “Alzheimer’s Group”) or helping out neighbours locally. Bob took “people shopping in the vicinity, that sort of thing and get their pensions, that type of thing”. In some cases, such as Betty, their new activities were not only associated with their caring role but also a

direct consequence of it. Betty helped out at the Day Centre her husband attended because

“.....he wouldn't go there unless I took him, he wouldn't go on buses, I had to take him, which in a way was a very good thing because although I got him there, I didn't have to rush him.....then shortly after that he decided he would go on condition that I stayed with him – so I became a carer at the Age Concern, a volunteer.....there was three of us apart from the organiser and we just looked after them but I was still with Ted and instead of him calling the others he would call me, so really, although we went out for four or five hours I was still looking after him”

Other activities described were only undertaken if they could be accommodated within the constraints of the caring role. Ethel, who cared for her very disabled mother continued her interest in gardening because it was something she could do whilst caring. It also provided entertainment for her mother.

“I used to put her in a wheelchair on a day like this (*very sunny and warm*) and I'd put a belt round her so she wouldn't fall forward and I took her out the garden with me. She liked it in the garden”

Similarly Terry continued to pursue his interests in repairing clocks and gardening because he could do this when his wife was sleeping. He explained that this was because he “had time on my own in the house to do these things”. A deviant case was Clive who continued with some of his existing interests as well as developing interests that were unconnected with his caring role: “I went to college, trained as a teacher in FE and er I got a BA Honours in Business Studies”. However, the extent to which he did pursue such interests could have been a product of the very slow progression of his wife's Multiple Sclerosis and the fact that he cared for her for so long (thirty-two years).

Overall, the opportunities to pursue interests and be involved in activities outside caring were constrained by the demands of the caring role.

Social life

There was much evidence that caring also impacted negatively on socializing and friendships. Just under three quarters (twenty-six) said they had either lost their social life or that it was limited. For instance, Doreen said, "I didn't have any social life at all". Half (eighteen) reported that they had lost some or all of their friends whilst they were caring. At one extreme Ethel said that she had "lost all my friends" whereas Ted said that he had "lost about three sets of friends." For those in this half of the sample, even if friendships were not lost, friendships changed because of the limitations imposed by caring. This usually involved seeing and socialising with friends less frequently; Penny said that her friends did not come "to the house so much" and Clive said the "opportunities" to meet friends "were limited".

Various reasons for this emerged. Some felt socialising was difficult because their dependant was ill *per se*, whilst others thought their dependant's particular illness was responsible for their limited social life. Examples of the former were provided by Joan, Julie and Clive. Joan felt that illness itself was a deterrent to friends and socializing and said "people don't necessarily want to come where there is illness". Julie and Clive talked about how the demands of caring for a person with an illness meant that they could not keep arrangements made with friends. Julie explained:

"You might have friends that you'll perhaps see every month and you can never tell when you're looking after somebody, you can't tell from one day to the next whether you can still make these arrangements. So you can't keep up, you can't say 'Oh well I'll see you next Tuesday.' And then something crops up 'Oh I can't come' you know, and you keep having to let people down"

Clive described the restrictions on his social life imposed by caring for his wife who had Multiple Sclerosis in the following excerpt from his transcript:

"Well um firstly one had the problem of not being able to travel distances for instance to go to a football match – I used to go to Birmingham quite often to see the Blues (*laughs*) but I used not to be able to stay out late, I had to be home at a certain time because otherwise she would worry so therefore the time to socialize, stop off and meet friends and so on and so forth was greatly diminished in that sense of the word. The other thing of course was that one couldn't easily leave the house with my wife in it, not unguarded but unsupervised because she might want to do all sorts of things and would have been unable to do so and to arrange a sitter at short notice was quite impossible so that er was one of the chief problems because, the curtailment of the social side....."

With reference to those who felt the nature of their dependant's illness had impacted on their socialising, some found that friends were unable to cope with the particular illness. For instance, Ted's wife suffered from Picks Dementia and he said that their friends "couldn't bear to see Hilda, it was so horrifying..... they couldn't stand the (*pauses*) seeing her. One in particular was horrified". Others, such as Lucy and Derek, found friends did not "know how to handle" or "*just* could not understand" their dependant's illness. The nature of the dependant's illness could also hinder some aspects of socialising. Doreen's husband suffered from Alzheimer's disease which meant that he "objected to people being here, he didn't like other people being here". She therefore could not invite friends to the house. Joan found that caring for a wheelchair user made socialising with friends in their homes problematic. As she explained:

"It's not always easy with somebody in a wheelchair to get in their house you know. Um we've got some friends at Farborough and the house they lived in I couldn't get him in the house. I could if we had struggled but it took the paint off the doors, you know!"

A few (six) reported more positive experiences in terms of their friendships. Sandy felt "just as close" to her friends when she was caring. Some had made new friendships during caring. However, these were mainly those who had joined carer or voluntary groups whilst caring and simultaneously developed other friends who were also caring. Others found that some existing friendships developed as a consequence of the caring experience because they found friends were more supportive than they had anticipated. An example was given by Beth who cared for her son whilst he was mentally ill when she said:

"Some friendships develop some people would take him out for a walk just in the daytime and just say "Oh lets go for a walk" and some of our friends would do that and that was a tremendous help to know that"

There was a deviant case. Lydia felt that her social life whilst caring for her mother was not affected because of the nature of her pre-caring social life. As she explained ...

“ ...we don't go out.....our socialising involves um seeing close friends that we've known for years and years and years, based on the home as it were, we just have supper together or whatever”

Nonetheless, the evidence pointed to the fact that the demands of caring in terms of its time-consuming nature and unpredictability, the dependant's illness and its nature limited the opportunities to have a social life when caring.

Personal and family relationships

Caring could also impact on personal and family relationships. With respect to personal relationships, nearly a quarter (eight) felt that their marital relationship, if not lost, was adversely affected by caring. Where the marital relationship was between the carer and dependant, the nature of the dependant's illness could affect the spousal relationship in different ways. For instance, Ted, whose wife suffered from Picks Dementia felt that he had “lost” her whilst caring because she had “died at least five years before she stopped breathing”. With regards to intimate relationships between carers and dependants who were marital partners, three referred to the fact that they had “separate bedrooms”. Another two said they “had single beds”. Doris was also explicit about the implications this had for their physical relationship when she said “in the bedroom.... I wasn't a woman at all, I was the fellow that slept in the next bed to him”. Bob commented on the “damage and consequences” caused to his relationship with his wife because of “a lack of personal contact with the person you love”.

It could be argued that a degree of “disengagement” (Hislop and Arber, 2003:189) from intimacy in the couple relationship is a natural feature of ageing. Given the age distribution of those interviewed, such findings were inevitable. However, Hislop and Arber (2003) found there were more impediments to intimacy between couples where one was the carer and the other was the dependant. Despite the fact that they focused on women only, their findings are useful in explaining the way the role of carer structures the marital relationship. They argue that in any marital relationship sleep patterns become more disturbed with age and this leads to pressure for separate sleeping arrangements. In marital relationships between carer and dependant additional factors

intervene. Not only can illness change the relationship, but sleeping with a dependant also involves physical and emotional labour such as “worry work” (Hislop and Arber, 2003:196), listening out for the dependant, administering medication, and being woken for toileting. Hislop and Arber (2003) therefore concluded that these factors increase the chances of separate sleeping arrangements and the ending of the sexual partnership in such couple relationships.

Some of those who were not caring for a marital partner specifically attributed problems in their own marital relationship to caring for their dependant, even when they were not providing co-residential care. Sue, who cared for a next door neighbour for ten years, three of which involved intensive care, described the tension it caused between her and her husband (David) several times at different stages during the interview:

“My husband said ‘it’s none of your business’ ...it caused problems in the family because David thought I shouldn’t be doing this, it was none of my business....I thought he was very cruel, I thought he was really horrible and cruel at the timeI think the worst bit was the tension between me and my husband. Um that was the worst bit and made me feel ill”

Another example was given by Una. Even though her mother did not live with her and her family whilst she cared for her for twenty-two years, she said her relationship with her husband suffered so much during caring that their physical relationship ceased. She explained:

“.....in fact the stresses and strains could have divorced us, it affected my marriage (*whispers*). We live in the same house but we don’t share a bed..... we’re ships that pass in the night”

Nearly two thirds (twenty-three) talked about the ways in which other family relationships were adversely affected by caring. In fact, seven of these reported that their relationships with family members suffered during caring. For instance, Paula explained that whilst she was caring for her terminally ill mother “Mum came first” and her five-year-old son, Ryan, came “second”. She felt that she had neglected him and she “hadn’t had time to spend with him.....time to take him for walks to the park “ and “he couldn’t have friends in the house, so he didn’t socialise”. She felt that as a result of

her inattention, his behavior towards her deteriorated to the extent that it was “appalling” and she could not “control him sometimes”.

Some commented on friction with family members over the responsibility of caring. An example was Joseph who felt angry with his sister because she “didn’t want to have to do it” and did not visit their mother for whom he was caring “very often”. Tension also arose because family members could not face or understand the illness. Derek said that there had been tension in the relationship with his wife’s sister because she was “offended” that his wife’s illness meant that at times his wife “just couldn’t tolerate seeing anybody and I literally had to turn them away on the doorstep”. Terry became disappointed with the relationship with his daughter-in-law when caring for his wife because.....

“.....she doesn't like being with ill people and she found it very hard to come here, which was a disappointment, but if that's the way she feels then I don't think it was because she didn't want to come - when my wife went into hospital, she was very reluctant to bring the children to see her, which would pass her feelings on to the children. It was a bit upsetting”

Although personal and family problems were attributed to caring in general and more specifically to issues associated with the dependant’s illness itself, its demands, friction over the responsibility of caring and misunderstandings, there were exceptions. Three experienced improvements in some of their family relationships; Beryl’s pre-caring experience of her daughter-in-law was that she had a “cold or something wrong with her” if asked for any help. However, “the minute” Beryl started to care for her husband she was “very good” to her. Lydia found the relationship with her son (Hugh) improved because she was caring for her mother. She discovered “another side” to the personality of this “determined-to-have-his-own-way type of adolescent, very forceful in his views, not thoughtful for other people”. She went onto describe how he came home from University and saw that she.....

“...was completely exhausted nursing my mother, and to my surprise, my initial reaction um, or that my anticipation would be that he would take one look at her and say ‘Well I don’t want anything to do with her’ you know. ‘I know she’s my grandmother and I love her, but I can’t cope with this’. She was physically quite different”

Instead, to her surprise

“...that was quite the reverse of the reaction. He was horrified that she should be suffering so much and if I got up in the night he’d say ‘Now you will wake me won’t you? I’ll come and help you’. And he was more than happy to help with her. I mean she couldn’t feed herself and he would do things like that which I never in my wildest dreams thought he would do. So as a result of that, it changed my whole perception of him. It was *very* good that it happened because we would have probably for the rest of our lives together I would have thought ‘Well it’s only Hugh’ (*laughs*) being difficult again you know!”

Employment

Over three quarters of the former carers who worked pre-caring (twenty out of twenty-six) had to give up their paid or unpaid employment in order to cope with their caring duties. Although this illustrates another impact of caring, this figure has to be considered in the light of some of the different circumstances in which this occurred. In some cases, this was a gradual process and working hours were reduced as the demands of caring increased. Seven reported that they took early retirement. One went from a full-time job to a part-time job and three took extended leave. This was extended sick leave for two of the latter. One of the respondents gave up a voluntary as opposed to a paid job but she said she had “never wanted to go back since”.

Nonetheless, the importance of paid work in relation to income is well-documented (Townsend, 1979; Oliver, 1990; Jones, 1994; DiPrete and McManus, 2000; Gough, 2001; Ferrie et al, 2003). It was therefore not surprising to find that this group of twenty respondents (just over half of the sample) had also experienced a loss of income during caring because of the change in their employment status. For instance Penny had to take a lower paid job at what she described as a “really low level” for some of the time whilst caring for her father to accommodate his needs. As Bob said “I went from getting ten thousand a year to £45 a week... it is a terrible drop and it does affect you”. Giving up a job or taking early retirement also affected pension rights. Greg pointed out “you see I retired when I was 62, largely to look after Ena, for various reasons I lost some of my pension”.

Such changes in employment status for these twenty respondents could have had other implications for their daily lives. Whatever the reasons or circumstances, loss of social status and social identity occur when both paid and unpaid work ends (Argyle, 1974; Hockey and James, 2003). It is possible that the sense of loss of status would be compounded by the fact that caring has a low social status (Twigg, 1998).

Financial resources

Five reported that their financial resources had been depleted by the additional expenses incurred during caring. For instance, Greg said that when caring for his wife, he “spent our savings” to buy equipment and carry out building alterations to ease the burden of caring. Clive felt that this sort of expenditure was necessary because the benefits available were “hopelessly inadequate”. Derek and his wife had to use their own resources to pay for her treatment because:

“We spent a great deal of money, I can’t say exactly, we spent a great deal of money trying to get the right sort of treatment and I do know of instances where people have mortgaged their homes in order to get private treatment. Where, in the first year we were covered by BPP but then we tried to switch schemes they wouldn’t accept my wife. (*Pauses*) so we had to, from then on we were on our ‘Jack Jones’ as the saying goes and were paying for it out of our own pocket”

Thus the time-consuming nature of caring meant that the opportunities to pursue interests and activities outside of caring were limited. Social and working lives, as well as personal and family relationships, suffered. In some cases, financial resources were depleted. There was evidence that those who were being cared-for did acknowledge these restrictions on their carer’s lives; three dependants expressed their gratitude. For instance, Sandy described how “every night for five and half years before we went to sleep” her husband said

“‘Thank you for the lovely day’. Even if I hadn’t done anything, if I’d been at work in the morning and the garden in the afternoon and we hadn’t done anything he’d say “Thank you for the day” you know and he’d write in his diary and um say you know that he’d had a lovely day”

Another five described how their dependants wanted them to retain some freedom and have a life of their own. An example was Clive's wife who

“was very careful not to let me abandon my Saturdays out at the football or the cricket or what have you, so it did..... No she recognized the fact that I needed some time on my own and she just sort of sat there and said ‘I’m going to read a book for the afternoon’”

Another example was given by Beryl whose husband paid for her to go on holidays during caring and always told her to “go and enjoy yourself”.

Caring and health

There was much evidence in the study that caring could adversely affect health. This came from the four sets of influences on health during caring identified from the concepts developed. These are discussed below; as the influence that was talked about most by the former carers was the emotional stress of caring, this is discussed before the others. The approach to the definition of health in this study is outlined in Appendix 1.

The emotional stress of caring

Two-thirds (twenty-five) spontaneously described in their stories how emotionally demanding and stressful they found their caring role. One of the greatest sources of stress given was the behaviour of some of the dependants. This was particularly noticeable amongst those caring for people with Alzheimer’s. The stress of coping with the behaviour of a dependant who had got Alzheimer’s is a constant theme throughout the whole interview with Julie. Her husband suffered from Alzheimer’s and she described how he became destructive in the home and “was wrecking everywhere, he’d got ornaments, chairs tipped up side down, the ornaments over.” She described how he “knocked me out one day”. Physical abuse by dependants is well documented (Rose and Bruce, 1995). He also pestered her at work, ringing her “up at work every 5 minutes, ‘What time is it? When are you coming home?’ I’d put the ‘phone down. Two minutes later ‘It’s me again. What time is it?’” It was also emotionally exhausting dealing with his massive mood changes as she would “never know from one hour to the next what he was going to be....whether it was going to be the nastiness, or the very nice, then he used to break down, he used to sit and sob”. She had to be constantly

vigilant and her “mind was like on the move all the while”. The situation deteriorated to the extent that she felt “We just can’t carry on like this”. Doris’s husband also suffered from Alzheimer’s and although his behaviour was not so erratic or dramatic as Julie’s husband, some of his Alzheimer-induced behaviour caused her much stress. She paid carers to help as his Alzheimer’s progressed, but he refused their help and “wouldn’t let them do anything for him, so it was all left to me. Doris will do that, Doris will do this, Doris knows what I need”. As she said “it was a big demand on me”.

The second source of stress was the daily pressure of caring. The way that caring impacted on daily lives was discussed earlier in this chapter. The evidence presented showed that it was very time-consuming and could lead to inflexible routines. As a result, daily life could become very stressful emotionally. Some also felt that the source of this daily stress was the pressures they were under every day. Phrases such as “the battle” were used to convey how it felt to deal with all these daily pressures of caring. Penny confessed that as result of coping with all the pressures, “I was very snappy and not as even-tempered as I usually am”.

Others felt that the lack of control they had over their daily lives, because it was dictated by the needs of their dependant, was stressful. Having little control over your life as a source of stress has been established for some time (Berkman, 1995). Paula illustrated how difficult this could be when she described her daily life whilst caring for her terminally ill mother:

“I couldn’t do anything..... I couldn’t plan - sometimes beyond lunchtime because I didn’t know what was going to happen.... I didn’t know when the phone would ring - so I couldn’t go too far away - I had to make sure that my mobile was always on - even if I was driving I had to make sure that I could easily stop and pick up the mobileI couldn’t plan”

Other stressful situations described included conflict with services and service providers. With reference to the former, Ethel described how her “big barney” with “social services” over getting a “stair lift fitted” had made her very angry. Frieda became red in the face as she described how she “got ever so cross” was “livid” and “were fuming” about errors in her husband’s medical care at times. There was one incident she described where her

husband's medical notes were not updated to say that he had bowel cancer. She was told by a hospital doctor that "there's nothing been recorded, nobody's been in touch with your Doctor". She had to inform him herself in order to get her husband treated properly.

Ethel also had problems with "Social Services carers" (see Appendix 1). She used expressions such as "done my head in" and "done my brain in" to describe how stressful she found her dealings with these paid carers. She recounted an incident which very clearly illustrates the stress she experienced with the way that they treated her mother

"...and then I mean she'd lost the use of her legs after her tenth stroke and then we had Social Services come. They said to keep four carers for her and I had forty-six carers pass through for her and one night me Mum just lay there crying and she couldn't talk because she'd lost all conversation. And I said 'What's wrong?' and she went (*shook her head*) I said 'Its the carers' so one nightI crept up and all they were doing was effing and blinding at her in the bathroom. 'I'd put er in a nursing home they said'. I said (*raises voice*) 'Excuse me ladies, leave me mother there, the front door you come in, go out of it !' I rang the office..."

A further cause of emotional stress was the way that unpaid carers managed and manipulated their own emotions in order to produce a particular emotional state in their dependant. This is known as the emotional labour of caring (see Chapter 1). Whilst the former carers did not explicitly mention it as a source of stress it was implicit in some of their stories. Madge was an example of one of those who indirectly referred to the emotional labour of caring. She said she could accurately interpret her husband's actions and manage her own reactions in order to keep him happy because she had "read up" about Alzheimer's when her husband was diagnosed to find out "what might happen". She described how she did this in response to his changeable perceptions of her ...

"...sometimes he would look at me and laugh because I was the person out in the kitchen you see, I would always be getting his meals you see and I was that lady out in the kitchen. But then I was another person that would give him a kiss, I was sort of his little bit on the side"

Other sources of stress mentioned were guilt, anger, friction with the dependant and fear. Four said they often felt guilty during caring. Reasons given were mainly concerned with their feelings about the adequacy of the level of care they were

providing for the dependant. Una looked chastened when she said she used to feel guilty that she did not “invite her mother out all the time” and Brenda felt guilty about using respite care even though she “couldn’t have done it without the respite.” She describes her feeling in the following extract:

“Oh yes.. I did feel guilty about it because you do. I used to take him in there and I can remember feeling guilty and feeling awful, thinking ‘I wouldn’t like it if I was I here for a fortnight’ (*laughs*). And they used to say you don’t have to come and visit but I did!”

Some reported experiencing anger about the injustice of the suffering that their dependant had to endure. For instance Joyce said that she used to think “why should it happen to him because he’s always been a likeable chap and always been hardworking.” An example of friction with the dependant was given by Greg who described how he and his wife “lost our tempers with each other sometimeswe got cross with each other”. Lydia illustrated how fear could feature during caring when she talked about being “frightened” by aspects of her mother’s illness at times.

Therefore, the former carers’ stories showed that there were many reasons why caring could be a stressful experience. In fact, twenty-four (nearly two thirds) specifically commented on the strain they were under when caring. Examples of such comments included the way that former carers were “stressed”, “stressed and strained”, “tired “ or “exhausted” during caring, and that caring was “a lot of stress”. Furthermore, nearly all of these (nineteen) commented on the psychological strain of caring. Brenda illustrates this well when she said:

“I felt it was almost mental, because he was so awkward because, there was no other word for it but it was such a strain..... I can remember saying to the District Nurse, that I felt nearly suicidal and asked her if there was anyone I could talk to about it. Thinking that a one-to-one social or psychological, you know that I could talk to. Nobody told me, it was like having a baby again. I mean you’re just landed with them aren’t you?”

Some felt that caring had been a greater strain psychologically rather than physically. Julie, talked about the “mental strain not so much physical. I mean I could deal with the toileting, the dressing, the washing, the feeding, that. It was the mental

strain...more mental than anything” . Similarly, Sylvia felt “the mental strain is there and that is probably more what I felt than physical”.

One of the consequences of the challenges to the mind-body dualism that is embodied in the medical model of health has meant the adoption of such concepts as “the expressive body” and a more general acknowledgment of the connectedness of emotional stress and health (Herzlich, 1973; Jewson, 1976; Radley, 1994; Stainton Rogers, 1994; Petrie and Weinman, 1997). As a result, there has been much research into the influence of emotional stress on health (Selye, 1975; Hochchild, 1983; Freund and McGuire, 1995; McDade, 2001; Schilling, 2003). Despite the difference in approaches, the overarching conclusion from all the research carried out is that there is a clear link between emotional stress and illness in general. It can therefore be argued that the emotional stresses and strains of caring identified, particularly if long-term caring was involved, predisposed carers to more ill health than non-carers.

The physical strain of caring.

Another influence on health was the physical strain of caring. Some of the heavy physical tasks of caring were referred to during the interviews. These were mainly associated with “lifting” the dependant “for the toilet” and /or “the wheelchair”. In some cases lifting the dependant was an extremely strenuous task; Bob described how his wife’s size meant that lifting her involved taking “double my weight”. The way that carrying out such tasks without training can lead to physical injuries, joint and back problems is also well established in the literature (Walton and Spackman, 1990; Lamb and Layzell, 1995; Carers National, 1998).

The effects of caring on social contact

The third set of influences on health during caring was associated with the effects of caring on social contact. In the first part of this chapter, we saw that caring had a negative effect on socialising, friendships and personal and family relationships. The importance of social contact with family and friends is a known influence on health and well-being (Oakley, 1992; Berkman, 1995; 2000; Arber et al, 2003). Despite the fact

that there was an absence of comments in this study on the effects of such social losses on health, the evidence from the literature and the existence of these losses make it not unreasonable to surmise that they could also have a potentially negative influence on health during caring.

Inattention to health needs

The final influence on physical and psychological health during caring that was identified came from the way that just under a third (fourteen) of the interviewees showed that they did not put their own health first when caring. Betty provided a good illustration of this when she said:

“In all the time I looked after Ted I really had never been ill. I've been to bed and laid down for an hour because I've not felt well but then got up to see to Ted”

A variety of reasons why carers did not pay much attention to their own health needs emerged from the study. Some, such as Joyce said, “you hadn't got time to think of yourself”. Others talked about how they forgot about or just did not think about their own health whilst caring. For instance, Jane said, “You forget yourself, you know you are not feeling very well but you must get an inner strength because you keep going” and Terry described how “you just don't think about it yourself”. Bob went as far as saying that he was “oblivious” to his own health whilst caring. An alternative view was put forward by Penny who felt that her contact with the Health Service during caring had dissuaded her from going to the doctors herself. As she explained, “I would have to spend hours sitting in the doctors or hospitals for Dad so it was the last thing that I wanted to do, so I didn't go to the doctors at all really!”

The study also showed that some former carers did just “get on”, as Michael described it, with caring, in spite of their own health problems. Six of the fourteen that were in this group put their own health needs “on hold”. Brenda described how she delayed having the hysterectomy that she badly needed because she was caring: “I left it you

could say to the last minute really (*laughs*) but if I hadn't been caring I would have had it done earlier".

Although the study showed that there were many reasons as to why there should be a reduction in physical and psychological health during caring, under half (sixteen) actually reported that their health had worsened or that they had developed health problems during caring. However, this study did produce evidence that it was *caring itself* that led to the reduction in the health of those interviewed during caring; twelve specifically attributed their health problems to their caring role. Some of these referred to the psychological strains and stresses of caring as the cause of these problems. For instance, Paddy thought the deterioration in his heart problem during caring "was due to the stress I was under with Betty my wife" and Clive said he developed "high blood pressure, due to stress" whilst caring. Jo blamed the exhaustion of caring for her worsening asthma and said, "I'm quite sure the actual tiredness, the exhaustion aggravated the breathing problems". Others blamed their new or worsening health problems on the heavy physical tasks of caring; Greg felt the "back trouble" he developed during caring was "associated with the care" and Joan blamed the exacerbation of her back problems when caring on "lifting the wheelchair into the boot" of the car when caring. Furthermore, all but two of these twelve also described how emotionally and physically demanding caring was for them, which is indicative that caring could have contributed to their health problems.

Caring and support

Part of the experience of caring involved the use of support. Table 2 shows that the three concepts in this sub-category were multiple sources of support, subtypes of the support provided and satisfaction rates. These were developed from the indicators which showed that all of those interviewed had received help whilst caring from more than one source, and identified multiple sources of support about which they expressed varying levels of satisfaction. These sources had also provided different types of support. Thus, the sources of support, the number of those in the sample that used them, the subtypes

of the support provided and the level of satisfaction expressed about each source are discussed below. The classification system used in the study for the sources and subtypes of support is outlined in Appendix 1.

Statutory organisations

Almost three-quarters (twenty-six) of those in the sample had received support from statutory organisations. This was wide-ranging and included all four subtypes of support. Informational and appraisal support was provided by General Practitioners, Social Workers, Hospitals, District Nurses and Social Services carers. For instance Lydia's District Nurse gave her information about "what would happen" during her mother's illness and the type of support available, and then helped her decide on the best course of action. Instrumental support came in the form of practical help with the care of their dependant as provided by Social Services carers, District Nurses, Occupational Therapists, chiropodists, benefits, grants for building alterations and respite care. Whilst emotional support was provided as a matter of course by some professionals from statutory organisations to those carers with whom they had contact, two of the former carers (Pat and Madge) were also offered and provided with counselling.

Only ten of these former carers were satisfied with the support they had received from statutory organisations. In addition, any satisfaction they expressed seemed to ensue from the efforts made by specific individuals (such as GPs, District Nurses, consultants and Social Workers) within the statutory services to meet their needs, rather than the quality of the services themselves. Paula, Brenda and Julie were amongst those who were satisfied with their support from particular District Nurses, consultants and Social Workers; Paula was so pleased with her District Nurse that she "wrote a thank you letter to her...because she was brilliant". Brenda also used the word "brilliant" to describe the support a hospital specialist arranged for her husband. Julie said that she had a "very good Social Worker" who had arranged "home care" which helped her enormously because they "came in, sort of like if I was on morning shift, they'd come in and get Dennis up and stop with him until I came home, on and off. They'd keep popping back".

In some cases, the support received seemed to be influenced by the nature of the relationship between the interviewee and the member of the statutory services concerned. For instance, Frieda had been going to the same GP for many years. Her relationship with him was on a more personal level and he visited her to see if she was coping; she used phrases such as “he sat talking to me”. He had been particularly instrumental in the provision of her support.

Indeed, over two thirds (twenty) said they were dissatisfied with the overall level and quality of the support they received from statutory organisations. Four main reasons were given. One was that the level of support for their dependant was inadequate. Greg gave an example of this. He said that “the Council..... couldn’t find the cash” for the ramp they needed to get his wife’s “wheelchair out”. As he explained, “we had to pay for that ourselves because otherwise we wouldn’t have got it done”. The adequacy of support for the dependant could also have adverse effects on carers. Jenny found that Social Services could not keep up with the “rapid deterioration” in her mother’s health with the result that she had to do “more and more” herself and became exhausted.

The second reason was that the level of support for carers was inadequate. Peggy said the inadequate support for carers meant that she “never got a break from me Mum.” June gave another example of this when she said, “there was not enough counselling or information” for carers. Beryl was critical of the lack of information about benefits; she struggled financially for several years whilst caring, and it was only when her husband was finally admitted to hospital that the social worker there told her she could have “all these benefits and she got all these benefits for me” which she “could have had before”.

The third reason was that services were unsuitable. For instance, Pat explained how her husband felt that the counselling they had at the hospital was “a complete waste of time” with the result that “we never did have any more counselling and we coped with the whole scenario ourselves and with friends”. Nonetheless, she did have a “very understanding Doctor” who was sympathetic to her needs as a carer. The final reason for the dissatisfaction with the support received from statutory organisations was that

some found staff were unsympathetic. An example was given by Paddy whose District Nurse “blew up” at him when he had changed his wife’s dressings because he felt “she required it” and thought he was doing the best for her. As the discussion about the experience of health during caring showed, Ethel found the totally unsympathetic attitude of her Social Services carers made her mother so upset that she “just lay there crying”.

Commercial organisations

Under half (fifteen) had received support from commercial organizations. Fourteen had used carers in the home from privately run carers agencies, and three of these had also used private care homes. The remaining one, Doreen, had used a private care home only.

Although the support was mainly instrumental in that the dependant was cared for, there was evidence that some emotional support was provided. For instance, when Peggy’s mother was resistant to respite care, the carer was sympathetic to Peggy’s need for a break and said to her mother, “Mrs Higgins don’t you think your daughter needs a rest?” She obviously understood the strain that Peggy was under and tried to emotionally support her by encouraging her mother to accept the respite care that was on offer. Julie received emotional and appraisal support from the private care home her husband stayed in from time to time, in that she received “some counselling” there.

Thirteen of this group of fifteen had been satisfied with the quality of the support provided by such commercial organisations. Expressions used were “very good” and favourable comparisons were made with statutory services. Ethel was amongst those who explained why they were satisfied. She was impressed by the flexibility of the support provided by Min, the carer she had employed through a private care agency for her mother because she “could ring Min any time of the day or night and she’d come”.

The other two were less than satisfied with the support they had received. Frieda was “disgusted” at the quality of the care provided by the carers she employed temporarily

whilst she had to go into hospital. Doreen felt the staff at her husband's private nursing home had "no heart" and she lost faith in their ability to care for her husband when they "started telling a few lies".

The voluntary sector

Two thirds (twenty-five) of those interviewed received support from the voluntary sector. Sources of support were carers groups, carers centres, voluntary groups and hospices. Twenty of this group had received support from carers groups, carers centres and voluntary groups. Eighteen of these found them to be a useful form of support. Some found them useful for informational, appraisal and emotional support. Madge found it "helpful" to listen to the "different approaches that others used" and to be able to "talk and laugh about it". Penny felt that her carers group had helped her to get things in perspective because she saw "other people who were in a far worse position than me." Others had received instrumental support, such as advice about claiming benefits, help from advocacy workers when fighting for suitable medical care for their dependants and practical support with caring. Doreen gave an example of advice about claiming benefits when she recalled the "wonderful, wonderful" lady at the carers centre who "got me extra money and then she got me income support". Paddy gave an example of practical support with caring; the "group leader" of his carers group managed to resolve the problems he was experiencing in making arrangements for his wife while he had an operation in hospital. He relayed the story of how this happened.....

"he (*the group leader*) said, 'Don't worry about it. Can you get round here Wednesday, you know, about 2 o'clock and I'll get an Occupational Therapist from the hospital to talk to you'..... when I explained the situation she (*the Occupational Therapist*) started getting the ball rolling and she got er Betty into Cedar House, a residential home for five weeks so it was a big relief"

The two remaining former carers in this group of twenty who had received support from carers groups, carers centres and voluntary groups felt that such groups and organisations were of limited value when caring. Such views need to be considered in context. For instance, one of these was Sandy who said, "I did go, I did go once and ask them something but I think, I don't think anybody could tell me anything I don't already

know". Her experience could be due to the fact that she was a District Nurse herself and therefore her background meant that she was less in need of the type of support on offer than the typical carer.

Five of them had experienced support from hospices. Fewer details were given about the actual type of support available but it appeared to be mainly instrumental in that there was obviously help and advice with physical care of the dependants. Joyce "had a visitor" from the hospice who ensured that she had the right practical help to deal with her husband's care. She described how

"....she used to come about once every five weeks but I could still contact her, you know, if I wanted anything, and then if there was any problems at all, which we did hit on a couple of times"

There was also evidence of some informational and emotional support in terms of the provision of information about the dependant's condition and such services as listening and counselling by individual members of staff. For instance Jane talked about the information she had received about her husband's condition and said "they don't tell you lies, they tell you the truth but somehow they have an exact way of telling you – you expect it". In addition, she was offered and attended group counselling sessions for "people who had got husbands that were dying as well" and clearly felt emotionally supported by the staff because she felt "you knowthat they are there when the time comes".

The view of the services provided by hospices was again mainly positive. Four used expressions such as "superb" and "cannot recommend them highly enough" to describe the support they had received. However, Paula "had problems with the hospice" and gave several examples of her experiences that made her unhappy with the support provided. She said:

"I got the feeling that they were a bit fed up with me. I got told off by the cook for demanding a meal one day - my aunt offered to pay for it - but the cook said that it wasn't an hotel - and I said that I was perfectly aware that it wasn't an hotel and that it was a hospice as my mother was upstairs dying..... they came to take away the mattress before she died - which was totally inappropriate"

Family and friends

As Pat indicated above in the discussions about dissatisfaction with statutory services, friends helped when caring for her terminally-ill husband. Indeed, nearly three quarters (twenty-seven) talked about how family and friends helped them when caring. Thirteen of these found that both family and friends helped them, three talked about friends only and nine mentioned family only.

All four types of support were provided by family and friends. Instrumental support was in the form of minor house repairs, financial assistance and visiting and sitting with the dependant. Examples of each of these were given by Sandy, Paula and Ted respectively. Sandy talked about when her husband initially became ill and “we had to carry him upstairs to bed”. Her son-in-law then “put another handrail up so we had a handle each side” which helped. Paula’s aunt wrote her “a cheque” to help her meet some bills during caring and said “cash this and don’t bother to pay me back”. Ted described how his friend “came and sat when I went out in the evenings”.

Emotional and appraisal support comprised listening and talking problems over; Doreen had a friend in whom she could confide as she “understood because she is a carer herself”. Some family members also provided informational support; Christopher’s son had found out about a more suitable house and then “persuaded me to take this house” because “he could see what she (*his wife’s condition*) was like”.

Twenty-one of those in this group made positive comments about the support provided by family and friends. Clive captured the feelings expressed about the role of the family when he said:

“I don’t know what it is like without the family there because I’ve had it that way but I would have hated to have done this on my own, you know, I don’t know quite how you do that”

Similarly, Paula conveyed the value she placed on the support from friends when she referred to them as her “extended family”. This was because the level of support they provided her with was comparable to that of family members.

Whilst ten said they had no support from family at all, this lack of support could be accounted for. Reasons included that they did not have any family “around,” regular contact with family members had ceased pre-caring or family members were unable to help because of their own ill health.

The local community

Another important aspect of the context of post-caring support is the extent to which carers were integrated into their communities whilst caring. Just over two thirds (twenty-five) responded to questions about their participation in their local communities by giving examples of their involvement with local schools, churches, voluntary groups, parish councils, and local clubs such as golf clubs. These were all viewed positively and were mainly a source of emotional support whilst caring, as illustrated by Lucy when she said, “my church fellowship was supportive”. Terry provided another example. His “golfing friends” from the golf club seemed to have made efforts to support him and “used to come” to visit him. Whenever they played golf he described how “any of my friends would drop me off”.

Further analysis showed that there were gender differences in the support received during caring. Overall, the male former carers had more support than the females. Other findings about the experiences of support during caring also emerged from this further analysis. These are summarized in Table 3 on page 130.

TABLE 3: SUPPORT DURING CARING

Source of support	% provided with support	% satisfied	type of support provided
statutory organisations	70 (males 82 females 65)	38	emotional instrumental informational, appraisal
commercial organisations	40 (males 27 females 38)	87	emotional instrumental
voluntary sector	66 (males 64 females 64)	88	emotional instrumental informational appraisal
family and friends	73 (males 91 females 69)	77	emotional, instrumental informational appraisal
community	66 (males 67 females 53)	100	emotional

This table shows that several different sources of help were used. Although many received help from statutory agencies, considerable support was also provided by other sources such as commercial organisations, the voluntary sector, family and friends and the local community. These provided a range of emotional, instrumental, informational, and appraisal support with statutory organisations, the voluntary sector and family and friends providing the widest range of support. From highest to lowest, the satisfaction rates for these were the local community, voluntary sector, commercial organisations, family and friends and finally statutory services. Factors that influenced satisfaction rates were the extent to which the different sources of support met their own and their dependant's needs for support, the staff, their quality, suitability, and reliability. Even though statutory services provided the four different types of support, the level of satisfaction with these services was on average nearly half that for the other sources of support.

Caring and the role of carer

The extent to which caring impacted on daily life, health and experience of support during caring meant that the role of carer and its associated duties had featured prominently in the lives of those interviewed. As mentioned previously, twelve of those interviewed attended carers groups or centres whilst caring which indicated that they had *identified* with the role of carer. However, it should be noted that this figure could be inflated because interviewees were recruited by visiting carers forums and carers groups. Indeed, many did not seem to have defined themselves as carers during their caring experience as they had accepted that caring for their dependant was integral to their relationship with him/her. There were comments from over half (twenty) that it was nothing more than what they “should have done” and it was “the right thing to do.” Pat, who cared for her husband for fourteen months whilst he was dying of lung cancer said “I did what most wives would do I’m sure”.

Nonetheless, irrespective of whether the interviewees formally identified with the role of carer or not, the concepts that emerged showed that the way caring had affected their lives resulted in them having a clear sense of having fulfilled this role with its associated tasks and experiences. Furthermore, the role of carer had significance for them.

The way that *all* of the interviewees, whatever their age, gender, who they had cared for or length of caring and so on, described their caring experiences (as discussed in this chapter) demonstrated that they recognised that these experiences were distinctive and involved role-specific tasks. They also demonstrated the significance they attached to these experiences in various ways. The most obvious indication was that three quarters (twenty-eight) *wanted* to tell the interviewer all about their caring experiences, despite having been told by the interviewer that the research was about their experiences since caring had ended. This occurred at various stages in the interviewer’s contact with the interviewees. It occurred before the interview when the interviewer telephoned them to arrange an interview. It also occurred during the interview; some would automatically

start to tell the interviewer the story of their caring experience at the beginning of the interview. Once the interviewer tried to focus them on the research topic, frequently they would briefly address the interviewer's question and then spontaneously return to their caring experiences. Sylvia did this when asked about the impact of the cessation of visits from professionals post-caring. She said:

“It didn't really impact that much. I don't think there was any other than I suppose (*pauses and then returns to caring*), because the nurse would come between 11 and 12 and I would give dad his breakfast before she came and he would get dressed and try and be ready for when she came. The day was much more structured and then of course everybody was here for dinner so I used to start cooking quite early. It was like with my father”

Moreover, interviewees returned to the story of their caring experiences when the interviewer tried to end the interview. Lucy illustrates this point well. When told that the interviewer had covered all her points and invited her to reflect on any other ways that the caring experience had affected her post-caring, she simply reverted to talking about how she coped with caring and said:

“I suppose I had to be proactive and find solutions when caring. I never had to use the carer agency but I know that some people do need that kind of support to get through those things but we could get through those things. Nobody ever rang up and offered help. My sister kind of went off”

Another indication that these experiences were significant for them was that the longest responses to comments or questions by the interviewer were about the caring experience. Often very detailed descriptions of caring experiences were given, which could take up to a third of the interview. Even the least forthcoming interviewees became far more responsive when talking about their caring experiences. For instance, Ted provided one-sentence answers to questions about the post-caring experiences and sounded quite uninterested. In contrast, when he talked about his caring experiences, his responses were four times longer and delivered with much more enthusiasm.

Despite the fact that the interviewer was a complete stranger, some gave many details about the personal nursing care that they had provided for their dependant. Doris was amongst these former carers and told the story of...

“.....when we went to Blackpool one day and I had to carry a wee bottle with me, and he could use the disabled things and wee, but we were in the gardens in Blackpool and I had to put a blanket round him while he weed in the bottle and carry it in a plastic bag and take it myself which was embarrassing”

The final indicator of the significance of the caring experience for those interviewed was the continued presence of equipment and accessories required for caring in their homes. Whilst six had made a conscious effort to get rid of all such equipment when caring ceased (see Chapter 7), eight still had the handrails, ramps, toilet seats and electric stairlifts that had been installed during caring. However, there are mitigating factors that need to be considered when assessing the significance of this indicator. One was the length of time since the end of caring. In all these cases, this was less than two years, which was less than the average for the group as a whole. Therefore, some of these former carers may simply have not got around to disposing of these adjuncts to caring. Another factor was the cost of removing fixed equipment. As Penny pointed out, it would be expensive to remove the electric stair lift in her home. Furthermore her children still liked playing on it!

Conclusion

Although “the caring time” was viewed positively by many of those interviewed, it had considerable impacts on many different aspects of their lives and experiences, which clearly had implications for their post-caring lives. This chapter has therefore demonstrated that post-caring life occurred at a point in the lives of those interviewed where they had been through particular sets of experiences. Furthermore, it has contextualised the post-caring experience by highlighting some of its potential influences on life post-caring.

CHAPTER 6: ISSUES IN THE POST-CARING EXPERIENCE

The analysis showed that those interviewed shared the experience of certain key substantive issues in their post-caring lives. These were “the cessation of caring”, “the post-caring void”, and “post-caring health”. These areas of post-caring life are the three sub-categories that were integrated to develop the core category of “Issues in the post-caring experience”. These are shown in Table 4 on page 135 and discussed in detail in Appendix 14. This chapter focuses on these three sub-categories and their associated concepts.

The cessation of caring

The concepts identified in this sub-category showed that several losses were experienced following the cessation of caring. Some were of a *personal* nature. As explained earlier, the cessation of the most recent episode of caring had coincided with the death of their dependant for all but one of the interviewees. This study supported the findings in the literature on caring that the most significant personal loss for those interviewed was that of their dependant who, in most cases, was a loved one for whom they wanted to care, despite the effects this had upon their lives (Bibbings, 1998; Hutton, 1998; Heaton, 1999). Bob had cared for his wife for nineteen years and had never been able to develop a career because of his caring duties. He felt strongly that “when you love somebody you do it for better or worse”. Similarly, Doreen explained “it was for my husband and I loved him to bits”.

The loss of the dependant also meant there were other personal losses, such as the loss of friendship and companionship. Comments were made about the way the interviewees felt they had lost a “friend”, “someone to talk to” and someone who was there “in times of trouble”. Even though some dependants were seriously ill, sixteen of the respondents said that they missed the companionship of the dependant. Terry’s wife had been incapacitated by a severe stroke and was unable to communicate but he still said “I haven’t got the companyI still talk to her about the house now”.

TABLE 4: DEVELOPMENT OF THE CORE CATEGORY "ISSUES IN THE POST CARING EXPERIENCE"

ISSUES IN THE POST CARING EXPERIENCE			
CORE CATEGORY (<i>Selective coding</i>)	cessation of caring	the post-caring "void"	post-caring health
sub-categories (<i>axial coding</i>)			
concepts (<i>open coding</i>)	<ul style="list-style-type: none"> -personal losses -social losses -financial losses 	<ul style="list-style-type: none"> - void - sense of a void - experiences of a void 	<ul style="list-style-type: none"> - absence of illhealth - improvements in health - new temporary physical health problems - new temporary psychological health problems - new temporary psychological/ physical health problems - permanent physical health problems - permanent physical and psychological health problems - influences on post-caring health
indicators (<i>microanalysis</i>)	<p>death of dependant, loss of friendship and companionship of the dependant, loss of social network of caring, improvement in financial situation, lost benefits, lack of adequate life assurance, financial hardships whilst finances were sorted out, loss of social role, loss of daily routine, limited recognition of concepts of former carer and post-caring experience, general lack of differentiation between carers and former carers, role of the former carer was far less significant for those interviewed than the role of carer, unable to engage with the concepts of the post-caring experience and former carer, ignored questions about the post-caring experience, cursory responses to questions about the post-caring experience, needed constant refocusing on question about the post-caring experience</p>	<p>use of word "void", use of word to convey a "void", loss of purpose, feelings of loss, disequilibrium, loneliness and emptiness</p>	<p>angina, panic attacks, insomnia, back problems, arthritis, sciatica, depression, diabetes, high blood pressure heart disease and kidney problems, development of health problems during caring but these had remained stable post-caring, new permanent health problems post-caring, health had deteriorated since caring finished but general health had started to deteriorate before or during caring, tiredness, depression, sleeping problems, skin disorders, infection, no health problems, no after effects of caring, resolution of health problems, felt better, looked better, acknowledgement health had been affected by bereavement, influence of health in caring, influence of carers' inattention to their own health needs during caring, influence of stress of caring, physical and mental impacts of caring experience, influence of caring experience on bereavement emotions, negative post caring emotions, positive post caring emotions, increased health consciousness, increased willingness to use health services, reduced expectations of personal health, former carers over sixty less likely to have health problems than those under sixty, females and males with health problems, female and males who reported an absence of health problems</p>

Other losses were *financial* and *social*. Although three found that they were financially more comfortable after caring ceased, nearly half (seventeen) said they had experienced *financial loss* upon the death of their dependant. Eleven talked about the way they had unexpectedly lost benefits, such as Mobility Allowance and Attendance Allowance, as soon as caring ceased because these were directly linked to the care of the dependant. An example was Joan who described the way that the “benefits just stopped ” and how this was a “shock” to her. The loss of such benefits meant loss of income. Julie’s husband had Mobility Allowance and she noticed a “big drop”. Joan found that the loss of benefits left her in a precarious financial situation; she described this when she said “Well if my husband hadn’t got some money in, some cash, I mean, I’d got some money probably but not cash. If he hadn’t have had some cash in his wallet I would have been stuck”.

The financial losses experienced because of the sudden cessation of such benefits were compounded in some cases by other factors beyond their control. Joyce illustrated this point well when she explained the financial situation she found herself in when caring ended.

“Oh I lost money yes yes, plus I’d got no insurance because they wouldn’t insure him because of his heart valve so I did find it a struggle. I mean with him, it wasn’t as though he worked until he was 65 and retired, I mean we’d lost 5 years previous, just on Invalidity money before he was 65. So consequently when it did happen it was a real strain on me to get the money together, and that, and losing, as I say you lost your Attendance Allowance and that.....And that, that had to go. I lost about £100 a week. ‘Cos me rent, being a council house, I got property tax 25% off that and they said there wouldn’t be any rent to pay. The first 3 months I was really in a state and I filled all the forms in and they said no there wouldn’t be any rent to be paid. So I thought right, I myself didn’t get a full pension because I hadn’t paid enough stamps. But then I’d got some to come from John’s like when it was all sorted out. And then I didn’t have a penny come in, not even my own pension for seven weeks”

This example shows how a combination of her gender and the nature of her dependant’s illness led to severe financial problems post-caring. As a woman, she had broken her employment to have and raise children and then worked on a part-time basis. Therefore, gender inequalities in pension accumulation meant that she did not qualify for a full

pension (Price et al, 2003). Furthermore her husband's chronic health problems had meant that he was uninsurable prior to his final illness, and she also suffered financially because he fell ill with cancer prior to his sixty-fifth birthday.

A further five suffered financial hardships because of the time it took to sort out legal problems over finances after the death of the dependant. For instance, Claude found himself in a situation where he could not access money to which he was entitled.

“With Angela and myself it was the nature of our arrangements. I had retired and at the time of the retirement because I retired early, we had the option of taking the pension or reducing the pension and have a lump sum as well so, there was a case for the lump sum and I stored that away in a long-term account. We were both very careful with our money but it turned out when Angela became terminally ill that we didn't realise that we should have given our accounts to each other rather than store our money separately, which perhaps advisors should tell you. So it turned out that whilst we have a joint accounts and some joint money which we could get hold of, Angela had most of the middle-term money in her name and I had a lot of the long term money in my name. But I couldn't get at the middle-term money because it was in her name. I couldn't get at my money unless I paid the equivalent of 6 months penalty fees, not just interest. So Angela's money which came to a fair few thousand pounds worth made up of the allowances..... At that period I was very very short of cash, it was touch and go financially. All right I could go to the bank and get a loan and relatives said they would help out who I could then pay back and the arrangements were made. Luckily I never had to have them but I sailed very very close. So there were difficulties”

This sort of situation could have arisen if Claude had not been a carer. Nonetheless, he still had to contend with short-term financial loss and difficulties when he ceased caring because of rules and regulations about accessing vital sources of income.

The *social losses* were loss of social role and loss of social network. Social role refers to the interviewees' role in life as the carer of their dependant, as discussed in Chapter 5. It was clear from the evidence presented in Chapter 5 that, even if interviewees had not defined themselves as a “carer” when caring, they did have a real sense of the meaning and significance of this role. Consequently, the death of their dependant also meant the loss of this role. As Clive explained “it becomes part of your identity”. He and others found themselves thinking and behaving as if they were still “in role”. For instance,

Clive went on to talk about how he repeatedly thought he was “in charge”. Julie described how a friend drew her attention to the fact that she was still thinking and behaving as if she was a carer.

“I couldn’t explain that to anybody. I went round to a friend’s once and, about 2 o’clock, lunchtime. At about half four, I said, ‘I must make a move’. ‘Why?’ ‘Well I’ve got to get home’. ‘Why have you got to go home?’ ‘Well, there might be some ‘phonecalls’. ‘Who’s going to ring you? The hospital’s not going to ring you now, the nursing home’s not going to ring you’”

Eight of the interviewees talked about the loss of the daily routines that they had followed associated with their role of carer. As Paula said, she had “no routine because my routine had revolved around Mum”. Jo found that “suddenly life presented itself without any sort of structure”.

The average length of caring was nine years and over half (twenty-one) of those in this study had cared for over five years during their most recent episode of caring (see Appendix 12). As the sense of loss of a role is more acute the longer the role incumbent has spent in a role (Goffman, 1971; Quee, 1995), the loss of the role of carer might have been particularly acute for over half the sample. The sense of loss of social role could have been compounded by the fact there is a lack of recognition of the concepts of “former carer” and the “post-caring experience”. As discussed in Chapter 2, although the concept of a “former carer” does exist and there has been some growth in the recognition of those who have finished caring and their needs, the recognition afforded to this group of people is limited.

There was also evidence in this study that former carers are not generally recognised as a group in their own right. One set of evidence emerged from the findings about the general lack of differentiation between carers and former carers. For instance, Peggy described how both carers and former carers were invited to the same Lord Mayor’s event without any distinction being made between the two groups. The members of the carers group and carers forums visited during the research were composed of carers and former carers. The other evidence was the way that the concepts of “former carer” and

“post-caring experience” had very little meaning for most of those being interviewed. Only six showed that they had any understanding of the research topic when it was introduced. This was because most of these had some kind of more formal involvement with caring and caring issues. As in Cartwright and Seale's study (1990) one or two said they wanted to take part in the research to benefit others who were in the same situation as themselves.

Furthermore, there was evidence that the role of the former carer was far less significant for those interviewed than the role of carer. This came from the analysis of the way they responded to questions about the post-caring experience. A third (thirteen) were simply unable to engage with the concepts of the “post-caring experience” and “former carer”. They responded to questions about the post-caring experience by consistently ignoring them or giving them cursory responses and then talking about other issues. This occurred even when the interviewer actively tried to discourage them from doing so. The following extract from Frieda's interview provides a good example:

Interviewer: “A lot of former carers I talk to say that when they finish caring, everybody stops coming to the house, like the paid carers the Doctor doesn't come and the nurses don't come and there's nothing. And they say there ought perhaps to be some form of support for.....”

Frieda: “(Interrupting) You see, I, let me put it this way, David will tell you the same if you talk to him I'm a very forceful person. If I want something done, I make sure it's done.”

Interviewer: And do you think that's helped you

Frieda: (Interrupting) If I

Interviewer: (Continuing) helped you cope ? Because

Frieda: (Interrupting) Tell you what, I can't do with people who've got to rely on somebody else. I mean I've gone out my way to help an awful lot of people and I get annoyed then if I find they give in, but if you give in you'll go downhill.”

This is indicative of how Frieda did not respond to any attempts by the interviewer to encourage her to talk about the post-caring experience. At the end of the extract she simply moved onto another topic altogether. In addition she ignored conventional turn-

taking in conversation by not waiting for the interviewer to finish and repeatedly interrupting her (Coates, 1993). Sociolinguistic analysis of this indicated that she “was not supporting” the interviewer in her “choice of topic” (Coates, 1993:109). This can be taken as further evidence that she did not engage with the concepts of the “post-caring experience” and “former carer”. Similarly, analysis of Michael’s transcript showed that the interviewer had to try seven times at one point in the interview to encourage him to focus on a question about his post-caring experiences.

The rest of those interviewed *could* focus on the post-caring experience and responded to questions about being a former carer. Nonetheless, after answering a question, they tended to drift off the topic, usually onto caring, as mentioned in Chapter 5. They constantly needed to be refocused on the research topic. Indeed, the interviewer’s overall impression was that she was almost imposing a false identity on the interviewees by using such concepts such as “former carer” and “post-caring” because these concepts simply seemed to have no public or private meaning for them.

Therefore, it is possible that the cessation of caring also meant that those interviewed were moving from a situation where they had a recognisable role (even if they did not define themselves as carers) to a situation where there they had no clearly defined or recognised role that had meaning for them. This could have increased the sense of loss of role upon the cessation of caring.

Roles, such as that of a carer, are inevitably part of a social network (Gottlieb, 1981; Sankar, 1991, Degenne, 1999). The analysis showed that the loss of the role of carer meant the additional loss of contact with a social network. This network included a variety of health and welfare professionals with whom there had been contact during caring, both in the public and private domain. The nature of this network was illustrated by Julie when she said “when you’re caring, you’re in touch with doctors, social workers, hospitals, appointments”. As over three quarters (thirty-one) of the sample also had nurses, paid carers and cleaners come into their homes at some stage during caring

to help them care for their dependant, these sources of help were yet another part of the social network associated with the role of carer.

When caring ceased, this social network was lost. Evidence of this came from the fourteen former carers who talked about the way they experienced a loss of the social network that they had been involved in as a carer. Those who had cared for over the average of nine years were more likely to miss the caring network (ten compared to three). The female former carers in particular commented that they missed the caring network (two thirds of the females compared to one third of the males). Julie described this loss; she said “suddenly when the caring has gone, you’ve lost it all…… there’s nothing now. I’m not even going to see a Social Worker, there’s not going to be a hospital visit”. Two commented specifically on the way they were instantly excluded from the health professionals network of which they had been a part. One of these was Sandy who explained, “once Ed died that seemed it as far as the medical profession were concerned, you know that it was over. Nobody ever asked me if I was alright”.

Others, such as Penny and Claude commented on the loss of those coming into their homes. Penny noted that “all of a sudden all the people disappear” and Claude commented on how “the flow of people in and out of the house immediately stops”. Most welcomed it, but four said they missed the contact, particularly contact with the carers that came into their homes. Terry remarked that the carers coming in the morning was “one of the things I miss”. Indeed Penny had become friendly with the carers and commented that when caring ceased “the carer didn’t come anymore – we had got quite friendly – she was lovely”.

It has therefore been demonstrated that in addition to personal losses associated with the death of their dependant, the former carers experienced other losses at the end of caring itself. They faced financial losses because of the cessation of benefits and problems with access to finances following the death of their dependant. There were also social losses, such as their role as “carer” of their dependant and the related social networks. It was

therefore not surprising to find that those interviewed experienced some sort of transitional reaction following the cessation of caring.

The “post-caring void”

The majority (thirty-two out of the thirty seven) spontaneously talked about their experience of a “post-caring void” of some sort in their lives after caring ceased. Table 4 shows the different concepts within this sub-category. Over half of these (seventeen) specifically referred to a “void” of some description when caring ceased. For instance, Una used the word “void” itself when she said “you have a great big void left”. Others used words to convey the sense of a void, such as “big hole”, “blank”, “ghastly space”, “vacuum” and “there is nothing”. All of those who cared for the longest time were in this group. There was one deviant case who did not experience a “void”; Sue felt that “there wasn’t a void or anything because I still had lots of other things to do”. This could have been because she was the only one who cared for a neighbour and also led a very busy life whilst caring.

Despite such exceptions, this “post-caring void” was clearly a major feature of life post-caring because of the frequency to which it was referred. Moreover, many (twenty-one) described their experiences of the different aspects of this void. Upon saturation it emerged there were several dimensions to this experience. A main theme was the way that the void made them feel “lost” and “at a loss”. For instance Doreen said, “I was at a loss, I was at a loss”. This was not solely attributable to the loss of the person who was their dependant but was also because some felt they had lost their purpose in life. Bob and Ted gave examples of this. Bob felt that caring for his wife had given him a “purpose” which was now gone. Ted went one step further and said he felt that “all the reason for living had gone.”

Others experienced disequilibrium. Claude conveyed the feeling in what was probably the most poetical description when he said:

“The sudden cessation (of caring) leaves you like an astronaut who has suddenly lost gravity. Now you are really sort of all at sea..... all at sea”

Thus his experience of the void was feeling completely off balance and without control over his life. Doreen expressed similar feelings when she said she “fell apart” when caring ceased and came to a “standstill”. Although several said they experienced loneliness during the post-caring “void,” their loneliness had different causes. Madge evoked a powerful image of this experience, remembering how “it was as if somebody had shut the door and nobody knew I was there, it was as if somebody had shut the door”. The repetition of “as if somebody had shut the door” reinforces her point about the acuteness of her sense of loneliness when her social network as a carer disappeared (Coates, 1993; 1996). Elizabeth gave another reason for loneliness when she described the time when caring ceased as being “very lonely” because she was trying to “pick up the threads” of her life. The final set of feelings that were experienced during the void was that of emptiness. Christopher and Jenny mentioned these feelings. Christopher said he had a “feeling of emptiness” and Jenny explained how she “felt very empty”.

Thus, when caring ceased a “void” was experienced by the majority of those interviewed. This involved a sense of loss, and feelings of disequilibrium, loss of purpose, loneliness and emptiness.

Post-caring health

The final issue is the experience of health post-caring. As Table 4 shows, there were many concepts which emerged and these are addressed below. They have been combined for discussion purposes into two groups – the nature and pattern of health problems and influences on post-caring health. These are addressed below.

The nature and pattern of health problems

Overall, the findings showed that the sample was divided more or less equally into those who did not and those who did report post-caring health problems (nineteen and eighteen respectively). Of those eighteen who did experience post-caring health

problems, with the exception of one, they all developed new but temporary problems in the first year of post-caring. All but four of these former carers went on to experience more permanent psychological and /physical health problems post-caring.

Greg provided a response typical of one of the nineteen who claimed that they did not experience ill health post-caring when he commented that “health wise there’s not been a thing”. Similarly, when asked about her health post-caring Lydia replied, “No, I had nothing, no ill effects afterwards”. Five of this group described improvements in their health, irrespective of whether they had reported that they experienced health problems whilst caring. Molly and Ted had experienced health problems during caring which improved post-caring; Molly found that within a year of the end of caring she did not have to take the antidepressants that she had been prescribed whilst caring. Ted had been drinking “a bottle and a half of scotch a week” whilst caring and said, “I don’t drink now”. Although the other three in this group did not identify any health problems during caring, they talked about the way they were “better” post-caring. This was based on their own or others assessment; Penny said herself that she was “better really.” The other two recounted how people told them they looked “better” post-caring; one of these was Julie who said, “Well people said I looked a lot better”.

As mentioned above, the remainder of the sample (eighteen) reported that they had experienced or were experiencing temporary and permanent health problems. Temporary health issues were defined as those that were only present during the first post-caring year. Permanent health issues were defined as those that were present both during the first and subsequent years of their post-caring lives.

Just under half (seventeen) of those in the whole sample developed a variety of new temporary physical and psychological health problems. Whilst these are discussed below, together with an example of each type of illness suffered, their relationship to bereavement is addressed later in the chapter. One former carer, Christopher, had suffered from more than one complaint as he had experienced both tiredness and a skin rash.

Eight suffered from tiredness. Some, such as Elizabeth, merely referred to being “tired”. As she explained, “I didn’t realise how tired I wasthree months afterwards, (after caring ceased) I suddenly realised how totally tired I was”. There were also those who referred to just being “physically” tired. However, others used the words such as “exhausted” and “drained” to describe the extent of their tiredness. Another four experienced various symptoms of depression. For instance, Paula talked about how she was “not coping” and “was probably suffering with mild-depression”. In contrast, Bob admitted that during “the first few weeks I took too much alcoholic comfort and was smoking myself stupid”. Three developed skin disorders; Joyce said she had “come out in eczema” and Derek “came out in a rash”. Two got infections; Betty gave a good illustration of this when she described how she developed a “very bad chest infection” soon after caring ceased. Finally, one had sleeping problems. This was Doris who said she “couldn’t sleep at night”. Although some of these are psychological, such as depression and sleeping problems, the others are harder to categorise. This is because the physical health problems such as skin disorders and infections could easily have been responses to psychological stress (Seyle, 1975; Williams, 2003; Ogden, 2004).

More permanent, and often serious, physical and psychological health problems were experienced by fourteen of the sample. There was no pattern to these and they included a range of health problems such as angina, panic attacks, insomnia, back problems, arthritis, sciatica, depression, diabetes, high blood pressure, heart disease and kidney problems. Using the definitions of physical and psychological health developed for this study (see Appendix 1), eight of these had physical conditions that were clearly physical health problems. One of these was Beryl who had severe arthritis. No one had psychological health problems that were due to mental/emotional distress or disturbance alone, but six had permanent physical and psychological health problems. For instance, Sandy had coeliac disease and still suffered from being unable to relax and disrupted sleeping patterns even though she ceased caring seven years ago. She explained, “I’m just permanently on the go and now I can’t stop. I mean seven years later, I still don’t sleep, you know, and I still can’t stop and I can’t relax..... I mean I often don’t sleep

four hours now. I only sleep for two hours. Sometimes I don't sleep at all". Ethel suffered from arthritis and depression.

However, such arbitrary distinctions between physical and psychological health problems may be unrealistic given the interrelationship between the two. Although they did not all demonstrate the influence of the caring experience, more clearly identifiable were the three patterns in these post-caring health problems. These patterns were the development of new permanent health problems, the continuation of health problems that had developed during caring, and the development of health problems in addition to those experienced during caring. Nine experienced the first pattern; Sandy's experience of psychological problems described above is an example of these former carers. Two continued to suffer from the health problems they had developed during caring; Clive was in this group as he had developed diabetes and high blood pressure whilst caring and these health problems had remained stable post-caring. Another four followed the third pattern; Doreen provided a good illustration of this pattern when talking about her physical health since her husband Jim died.

" I did have a heart attack before Jim took poorly but it's since Jim's gone that I've had this very bad arthritis, its osteoarthritis, and with the heart attack the angina is pretty bad now you know.....it's become worse since Jim passed away"

Another example was Paddy, who, in addition to the heart problems he suffered from when caring said that he had now also

".....got a condition where me heart misses a beat and that come on last September. I think it were the tablets I'd been put on, they didn't agree with me and when I went down to see the Doctor about it, she said 'Oh we'll stop them and put you on something else'. But me heart hasn't gone back to normal beat"

Influences on post-caring health

The key influences on post-caring health that emerged were bereavement, the caring experience, emotions, and attitudes to health post-caring. Although there was some evidence about the influence of age and gender, much of this was unclear as it conflicted with existing knowledge for no apparent reason. For instance, with reference to age, those over sixty normally experience more health problems than those who are

under sixty (Busfield, 2000; Hockey and James, 2003). However, there was very little difference between those over and under sixty years of age who had post-caring health problems. Despite the fact that morbidity rates for females are higher than those for males (Acheson, 1998; Busfield, 2000), over three-quarters (twenty-nine) of those in the sample who reported an absence of health problems post-caring were female. Other evidence about age and gender was in relation to their effects on the key influences identified and is therefore incorporated into the discussions below.

Bereavement

There were many similarities between the types of ill health experienced by the former carers interviewed and those illnesses identified in the literature as being the outcome of bereavement and the grieving process. These included depression, sleeping problems and lowered immunity (Parkes, 1970; Bowling and Cartwright, 1982; Worden, 1983; Murrell et al, 1988; Ferraro, 1989; Rosenthal and Dawson, 1991; Rowe, 1991; Dickenson and Johnson, 1993; Murray-Parkes, 1993; Schulz et al 1997; Walter, 1999; Bond et al 2003; Hislop and Arber, 2003). For instance, Michael's depression was typical of a bereaved person. He explained how he "got into a bit of a deep hole" and once he had taken his prescribed "antidepressants and some valium for a week" he felt he had "come out of it all right".

Such similarities showed that where the end of caring involves a bereavement, the bereavement could influence post-caring health. Indeed, seven openly acknowledged that their health had been affected by their bereavement. An example was Bob who described some of his post-caring health problems as "post bereavement" health problems. Some, such as Terry, did not explicitly make the connection but seemed to have some awareness of the way that bereavement had influenced their health. He explained how his wife had "... died in October and then I got the flu at Christmas, which was the first time I had had that, then I had a funny spell of when all my muscles went funny".

The caring experience

The caring experience itself also affected the post-caring health of those interviewed. This came from the analysis of the impact of caring on health (discussed in Chapter 5) and the connections the former carers made themselves between their caring experiences and their post-caring health. Nine of the sixteen whose health suffered whilst caring continued to experience the same health problems post-caring. The illnesses were both psychological and physical. An example of the former was given by Ethel whose depression which she developed during caring (see Chapter 5) continued into her post-caring life; she was “still on antidepressants”. Frieda illustrated the latter when she talked about the fact that she had to carry on taking “tablets” for the arthritis that she had developed during caring.

However, inattention to their own health needs during caring and the stress of caring were found to be more significant influences on the interviewees’ post-caring health. With reference to the former, twelve out of the fourteen who showed that they did not put their own health first when caring had either temporary or permanent post-caring health problems. An example was Michael who developed a back problem during caring. He did not seek medical help at the time and now it meant that he could not “sit comfortably” anymore and he was “waiting now for an MRI scan”. In relation to the stress of caring, two thirds of those who said they found the caring experience stressful went on to develop post-caring health problems. This suggests the emotional stress of caring was influential on health during caring but that there was a delayed immunosuppressive reaction (Radley, 1994; Freund and McGuire, 1995; Petrie and Weinman, 1997; Williams, 2003). Conversely, four of the five who said they had experienced improvements in their post-caring health had experienced stress during caring. They made comments about having “lost the stress” and not feeling “any stress” post-caring which indicates that the improvements in health were due to the absence of stress experienced whilst caring. The loss of stress post-caring

could also partly explain why the remaining third of those who thought they were stressed during caring did not develop post-caring health problems.

As mentioned above, some former carers *felt* that their experiences of caring were influential on their post-caring health. Fourteen of the eighteen of those who experienced temporary and permanent post-caring psychological and physical health problems explicitly linked these to their caring experience themselves.

With reference to temporary health problems, the effects of the caring experience on these differed in the explanations proffered. The discussions above about post-caring experiences of health showed that the most common short-term health problem was tiredness. All those who suffered from this blamed caring for tiring them mentally and physically (the ways in which it did so are described in Chapter 5). Ted said he had needed “some sleep” when caring ceased because caring had “exhausted” him. Caring had made Madge “very very tired” with the result that she was still “drained and tired “ a year after caring ceased. Four of these said this post-caring tiredness was serious enough to necessitate recovery time, for instance, Jenny said her doctor told her she had to spend time “recovering as it were and getting myself on an equal level”. Other temporary post-caring health problems were attributed to specific aspects of the caring experience; Bob focussed on the way the length of caring and being a co-resident carer were the cause of the temporary psychological problems he had experienced since caring ceased. He said:

“I think the longer you are a carer the longer the time, then the longer the healing process it takes a lot longer time, when you are at home twenty-four hours a day, weeks at a time with one person, it causes a strain on your disposition which doesn’t seem to clear up for a long time”

Some of the more permanent physical health problems were mainly attributed to the physical demands of the caring experience. For instance, Ethel’s doctor told her that the arthritis she developed after she ceased caring for her mother was due to the lifting she had to do whilst caring:

“I’d no aches and pains while I were lifting her probably twenty, thirty times a day and as soon as she were gone it were ache, ache ache and the doctor says ‘It’s wear and tear on your bones. There’s nothing we can do, arthritis has set in through lifting your Mum’”

Madge said she now had.....

“.....back problems with the lifting.....it came on afterwards, I had an operation years ago for a trapped nerve so whether that was a weakness there or not I don’t know and by lifting himI used to have to lift him and for the toilet and thing’s like..... so I think the strain of that is just beginning to show itself now”

There were also those who referred to their permanent state of ill-health as being the outcome of the effects of the strain of caring. For instance, Frieda was still “not sleeping properly”. She felt this was caused by the way that her sleep had been so disrupted during caring because she “used to turn” her husband “as much as nine times a night”.

Some of the above examples suggest that the caring tasks required for dependants’ different types of illnesses led to particular post-caring health problems. Indeed studies have shown that the nature of the dependant’s illness can influence post-caring health problems. Bodnar and Kiecolt-Glaser (1994) found that carers of those with progressive dementia are likely to remain depressed for longer after caring ceases when compared to carers of dependants with other illnesses. Unfortunately, the sample size and the diverse range of illnesses of the interviewees’ dependants did not allow any further analysis of this aspect of the caring experience.

Post-caring emotions

As emotions influence health (see Chapter 5), post-caring emotions were yet another influence on post-caring health that was explored.

As explained at the beginning of this discussion, bereavement was an influence on the post-caring lives of those former carers in this study and its effects on the types of the post-caring illnesses experienced have already been discussed. There was

also evidence that *bereavement influenced the post-caring emotions* of the interviewees as they all expressed a variety of emotions associated with bereavement itself. These emotions were identified using the literature on bereavement; they included anger and bitterness about the loss of their loved one, loneliness, jealousy of other couples and tearfulness (Murrell et al, 1988; Rowe, 1991; Mullan, 1992; Murray-Parkes 1993; Ridley, 1993; Schulz et al 1997; Walter, 1999; Bond et al 2003; Hislop and Arber, 2003). As mentioned in Chapter 3, five cried when talking about their loved one during their interview. Only one was more positive. This was Lydia who said that she was “relaxed about death”. This could be attributed to her background and the circumstances under which she was caring. She had been “brought up in a family of clergy and death was ordinary, sort of, death was a natural part of life, so there’s nothing to worry about”. Furthermore she felt strongly that there comes a point when we all have to die and laughingly said “when a body is tired its time to die!”

However, despite the fact that bereavement led to the aforementioned emotions, *the caring experience* also influenced post-caring emotions. The influence of the caring experience manifested itself in two ways. These were clear from the way that it shaped the former carers’ bereavement emotions and the more general post-caring emotions that were expressed. Whilst the first set of emotions are exclusive to bereaved former carers, it can be argued that the second form part of a more universal post-caring experience. Both of the ways that the caring experience influenced post-caring emotions are discussed below.

With reference to the way the caring experience shaped the former carers’ bereavement emotions, some found that the caring experience had eased post-caring bereavement, whereas others felt having been carer made the experience of bereavement worse; four of those interviewed focused on the fact that the grieving process was “not so bad” as when “someone dies suddenly” because you are “prepared for it ” by the caring experience. The often long period during which carers have to adapt to the idea that their dependant is dying has been referred to as “anticipatory grieving”. The extent to which death was anticipated has been

identified as attenuating the relationship between bereavement and ill health. Work done in this area suggests that “anticipatory grieving” may lead to a less intense grief reaction when death ultimately occurs (Murrell et al, 1988; Rosenthal and Dawson, 1991; Bond et al, 2003). Although this work is limited as it only refers to spouse carers, all those mentioned above, and indeed two thirds of the sample (twenty-four) had been the carer of a spouse or a partner. Moreover, it is quite possible that non-spouse carers experience “anticipatory grieving” for the same reasons as the spouse carers in the research about this concept. Therefore, the concept of “anticipatory grieving ” could contribute towards an explanation of these differences in post-caring and post-bereavement emotions.

Another factor to consider when discussing factors which lessened the impact of death of the dependant in the post-caring grieving process was the way that others felt the nature of some illnesses, such as Alzheimer’s, meant that the dependant was “lost” before caring ended. Ted, whose wife suffered from Picks Dementia said that she “died at least five years before she stopped breathing”. Consequently these former carers felt that the type of illness or disability the dependant suffered from could lead to a softening of the impact of their actual loss.

Furthermore, the emotional adjustment required during bereavement for the former carers was eased by the way that certain aspects of the caring experience could be a form of preparation for life post-caring. Fourteen (a third) commented on the skills they had developed as a result of caring. Brenda “took over” aspects of their lives which had always been her husband’s responsibility, such as “driving the car” and the “money situation”. Claude learnt to iron and clean the house, Greg learnt to do the cooking because his wife used to “sit in the kitchen....in the wheelchair” and taught him to “basically cook”. Brenda summed up the overall feeling this induced when she said, “I got used to coping. I cared for him for so long that I used to do everything myself.” The acquisition of these sort of skills and the fact that they had become acclimatised to coping independently with life meant they were prepared for life post-caring. As Greg said “while you’re caring

in a sense you're being prepared for it". In addition, their post-caring lives were an extension of many of the roles and activities associated with running their lives, their home, and their family that they had undertaken whilst caring. This meant that, in Brenda's words, the death of the dependant "wasn't such a big shock as when people die suddenly". Thus, the explanations offered by these former carers show that the impact of the loss of their dependant was lessened because of the preparation for life post-caring that caring had provided. The fourteen former carers in this group had cared on average three years more than the average for the rest of the group. This indicates that length of caring may also influence the extent to which this phenomenon occurs post-caring.

Nonetheless, another six found their loss *harder* to bear because they had cared. Three said this was because they had not anticipated the death. As Doreen said "I never, I thought that Jim would get over it. I never thought that he would pass away". Joan felt that rather than being prepared for her husband's death by long-term caring, she had been almost lulled into a false sense of security about his continued existence. She said "you almost don't expect death with long-term caring because he'd been ill for so long, I think you sort of take it for granted. ...he's still here sort of thing".

A further reason put forward about why the loss was worse for some former carers was the fact that caring had increased the amount of time they had spent with their dependant; three former carers said that they missed their dependant more because they spent so much time together as a result of caring for them. As Joan said, "you spend a lot of time together. I think that's it, you spend an awful lot of time the two of you together".

Although as Joyce said "it's a big loss whoever it is," another influence on bereavement emotions was the type of relationship with the dependant. Sue, who had cared for a neighbour, said she was "fond" of him. In contrast, there was evidence that those who had cared for a spouse did experience a greater sense of

loss than those who cared for a non-spousal dependant. Joan conveys her sense of loss upon the death of her husband when she says “I mean that person is yer other half, you can tell them anything you know! I mean you could shout and row but I mean you could tell them things that you wouldn't tell another soul in the world”.

In addition to shaping bereavement emotions, the caring experience also had both positive and negative effects on post-caring emotions in general. These included a sense of freedom, sense of relief, a sense of personal satisfaction, personal change, guilt and anger. Each one is addressed in turn below.

It was reported in Chapter 5 that three-quarters of those interviewed had found caring restricted their lives and half felt that it had been restrictive to the extent that they could not live their own lives. A third (thirteen) said they had a sense of freedom after the initial post-caring period. Common sentiments amongst these were of being able to do “whatever you like” and being able to be more “spontaneous” now that caring was over. Some described their feelings as analogous to the sense of freedom that release from any form of captivity or enforced isolation brings. Derek described the end of caring as “like being collected from a desert island”. They felt they now had the freedom in which to start their own lives again, and recalled feeling that “my life can start again” and “I've got my life back”. There was one deviant case; Joan felt the sense of freedom was unwelcome because “you are free but it's not a freedom by choice is it?” As her husband had been her dependant and his death was relatively recent, her feelings could have reflected the effects of recent bereavement more than the others interviewed.

It was the male former carers who were more likely to express a sense of freedom; twice as many males said they had sense of freedom post-caring (a third of the males compared to one sixth of the females). A possible explanation for this is the social construction of traditional gender roles. The sexual division of labour in traditional cultural gender roles means that women's lives are more home-based,

as they have responsibility for childcare and domestic tasks (Titmuss, 1979; Qureshi and Walker, 1989; Baldcock, and Ungerson, 1996; Symonds, 1998; Chamberlynn and King, 2000; Saiki-Craighill, 2002). It could be assumed that the female former carers interviewed would therefore have found it easier to adapt to the way caring is home based. Furthermore, the high proportion of older females in the sample also meant an increased likelihood of the adoption of more traditional gender roles. As the male former carers would have more of an adjustment to make when caring started, and were not used to a home-centred life, it is not surprising they had a greater sense of freedom once caring ceased.

Whatever the reasons, this newfound sense of freedom was clearly enjoyable. Over half (twenty-one) said they were enjoying the opportunities they now had (these will be described in Chapter 7). There were several influences on this sense of enjoyment. Once again, the men predominated; three quarters of the males enjoyed their new activities compared to half of the females. Length of time since caring had ceased and length of caring were influential for all the former carers; the less time that had elapsed since caring ceased, the more new activities were enjoyed, and those who had cared for over the average of nine years were twice as likely to enjoy new activities. This enjoyment was expressed in different ways. Brenda's face became quite animated when talking about her membership of the Women's Institute and said "The WI is great! Now I can go because I couldn't before". When telling the interviewer about his new relationship with his "lady friend" Ted smiled and looked very happy when he said "Its very nice its very nice." Jo's new job made her "feel valued now". Derek simply enjoyed changes in "the world" that had occurred during his years of caring for his wife, which he had been unable to experience because of the restrictions imposed by the latter. He explained:

"The fact that I was er looking after her meant that I didn't have any time to pursue what I wanted to do in retirement. Er but er I think the thing that I felt most of all when she died apart from the initial, obvious grieving er was the fact that I was entering into er a society which was completely new to me. Er I mean as a practical sort of individual I'd never had the opportunity to go into Putby er the present Do-It-Yourself industry, and it was a whole, I was fascinated by a whole new world which I'd missed out on in a sense"

In addition, half (eighteen) said that they felt a sense of relief post-caring. The reasons given for this sense of relief were all connected to caring for their dependants. Four referred to the way they felt relieved because they no longer had to carry the “burden” of caring. Phrases such as “burden lifted off my shoulders” and “weight off my mind” were used. Two said they were relieved their dependant’s suffering was over. Pat sighed as she said “although you don’t want them to die, seeing how he was and his quality of life, it is a relief sometimes when they have gone. They are out of their suffering”. These explanations related to relief either for the carer or for the dependant. Lydia was the only one who said she was relieved for both her own sake and for her dependant’s sake. She said, “I was relieved for both our sakes really. I was relieved because I could pick up you know doing what I had done before and she wasn’t suffering”.

Although three said that they did not experience a sense of relief post-caring, the justifications put forward reflected alternative meanings attached to the causes of “relief” post-caring. For instance, Doreen could understand former carers feeling relief that the dependant’s suffering was over. However, her understanding of her husband’s illness was that it did not cause him to “suffer”. This was because she felt that “with Alzheimer’s they don’t actually suffer... they don’t know ... they laugh and they have fun”. As a result, she did not feel relief.

Eight expressed a sense of personal satisfaction about what they had done as a carer. A good example of this was given by Paddy who proudly said “nobody could have looked after her as I did”. Some focussed on their feelings about the overall experience. For instance, Lucy thought it was a “job well done” and Jenny felt she had “given something back to life”. Others felt a sense of pride in the fact they had achieved something more specific for their dependant. Sue felt she had been able to improve her dependant’s “quality of life ” and Molly felt she had granted her mother’s “last wish” to die “at home”. A further two felt a sense of

self-amazement that they coped, to quote Julie, “I just wonder how I ever did it, I often think back....it’s amazing”.

Yet another post-caring emotion that was clearly linked to the caring experience was a sense of personal change. Half the former carers (eighteen) reported experiencing some such change post-caring. It could be argued that such changes could have been equally associated with having lost a significant person in their lives. Indeed, the loss of a family member often leads to personal development and a change in social and personal identity (Lehman et al; 1993; Saiki-Craighill, 2002). However, the former carers interviewed indicated that they felt that it was the caring experience itself that had changed them. Claude provided a good example of this when he said “You could say, if one had the vocabulary um, that I had become a more complete person than I was before”.

Twelve of these eighteen had a more positive view of themselves post-caring. Two, such as Claude above, focused on their personalities as a whole. The others in this group identified specific aspects of their personalities which they felt had changed as a result of the caring experience. The development of skills during caring, already referred to, were identified as being instrumental in these changes. This was because the acquisition of these skills also led those concerned to see themselves as more “self-sufficient” and “independent”. Greg and Clive provided examples of these feelings. Greg felt “it makes you self-sufficient” and Clive said

“it makes you very independent. I think you become more and more independent as the caring period goes on. You know, you don’t feel bound by any limits um (*pauses*) I mean (*pauses*) I, I think it might be, I’d almost say, if anything it gives you a great deal of confidence in that you can do things”

Other positive personal changes resulting from the caring experience included being more assertive, understanding, patient and less selfish. A typical response was provided by Terry who said he was “more patientbecause you have to change your ways” during caring.

Nonetheless, not all the personal changes reported by those in this half of the sample were positive. Five felt that caring had caused negative changes to their personalities or aspects of their personalities. Three used words such as “hard” and “bitter”. As Frieda said “I think it’s made me hard quite honestly.” Others felt they had lost confidence mainly because the restrictions of caring had left them socially isolated and removed them from their workplaces. For instance, Penny said, “because I’ve come out of my work situation I think I’ve lost a lot of the confidence that I had”. Furthermore, seven said that they did not experience any type of personal change post-caring. A common expression used was “I am still the same person”. Different explanations for this were proffered. Two of the three that were in caring professions suggested that the lack of change was linked to their professional background. For instance, when Sandy said she had not changed, she added “whether it is because I’ve always been in a caring profession I don’t know”. Another explanation for lack of personal change given by Betty was that caring was part of her personality. She said, “I have always had that caring thing” and had “a tendency to care”.

Other variables, such as gender, length of caring and the amount of time since caring had ceased, had a limited influence on feelings of personal change. All the males said that they had changed personally whereas only just over two thirds of the females said they had done so. Nearly all of those who had cared for over the average of nine years (twelve out of the thirteen) said they had experienced feelings of personal change compared to three quarters (seventeen out of twenty-four) of those who had cared for less than this average. Finally, the less time that had elapsed since caring ceased meant a slightly increased likelihood of feelings of personal change; twenty-two of the twenty-six who had ceased caring less than the average of two and half years ago reported feelings of personal change, compared to ten of the fifteen who had ceased caring over two and half years ago.

Much of the discussion so far has focused on the positive post-caring emotions that were experienced as a consequence of the caring experience. Yet, negative emotions were also expressed. The predominant negative emotion post-caring that was linked directly with the caring experience was guilt. Nearly a third (eleven) of those interviewed mentioned this particular emotion. Seven of these felt guilty that they did not do enough for their dependant when they were caring for him or her. Julie gave a typical response:

“I just couldn’t get over the guilt feeling. I felt guilty about everything; guilty because he had to go into nursing care, guilty because I didn’t press enough for that brain scan”

Other reasons given for feeling guilty included having lacked patience with their dependant or feeling resentment at times. Doreen looked away as she said, “I did lose, I used to lose my patience sometimes. That sometimes worries me”. Sylvia experienced guilt because she had felt resentment about the impact of caring on her life.

“My husband was about to retire and we were thinking we would be free. We had had three children, then all of a sudden this comes along and it changes your life completely. I tend to feel a bit guilty now. Sometimes I think that I had him for such a short time that I have no right to say that”

There were only two who openly admitted they did not experience guilt and they both explained their reasoning. Both felt that they had met their obligations, either to their dependant or to others dependent on them. Molly said she “need not feel guilty” because she had fulfilled her obligations to her dependant mother by granting her “last wish”. Lydia felt that she had been able to meet her obligations to her husband and family because of the timing of the caring for her mother in her life, which compared favorably to her mother’s situation when she cared for Lydia’s grandmother. She calmly explained:

“I don’t have any guilt at all which I think, guilt is one of the things which is difficult to live with. I might have had guilt if it had ruined my marriage or if I’d had younger children and they’d been deprived of attention. I was at an age where it it was fortunate, um and I think you have to weigh up those things in certain circumstances, if you are caring for somebody when you’ve got young children they are the priority, there is no doubt about that and I know from my own parent’s point of view um my parents’ marriage suffered as a result of my mother having to care for her mother and she had to do that

for a long time and she was bedridden so their marriage did suffer. And they were just beginning to pick it up and be able to do things together when my father had a heart attack so it was all ended. So I know my mother regretted that always and I think she was burdened with guilt because she knew she had deprived my father of of of a marriage, you know, any happiness”

A further negative emotion that was clearly linked to the caring experience was anger. Five respondents said they still felt angry about different aspects of the caring experience. Two still felt anger at the injustice of their dependant’s suffering. For instance Julie said she felt

“bitterness against other people ...why should it happen to somebody who was a hard worker, young as such, I mean in his fifties, late fifties, and you get other people who are murderers? ...I mean is there a God up there you know? Why should it happen to somebody like that? He never done anybody any harm”

The strength of her feelings was obvious from the way she almost shouted during this part of the interview and was visibly angry. Three continued to feel angry about the level of support and professional care received during caring. Doreen was still so annoyed that she thought that “something should be done” and had planned to “sue” some of those involved in her husband’s care. Whilst the issue of support will be discussed in more detail in the next chapter, the fact that feelings about this aspect of caring persisted well into post-caring is noteworthy.

The evidence about post-caring emotions therefore indicated that the caring experience moderated the effects of the grieving process on the health of these bereaved former carers. This could have reduced the incidence of illnesses related to bereavement. It also showed that the caring experience and its cessation induced a mixture of positive and negative emotions post-caring generally, with an absence of a predominance of either. Nonetheless, besides acknowledging that these emotions could influence post-caring health, it was not feasible to provide an assessment of their impact. A similar conclusion was drawn about the next set of influences on post-caring health.

Attitudes to health

Attitudes to health have been shown to influence many different aspects of health. These include health behaviour, awareness and recognition of health problems, health seeking behaviour, responses to health problems, reported health status and health status itself (Department of Health and Social Security, 1980; Whitehead, 1987; Blaxter, 1990; Armstrong, 1993; Freund and McGuire, 1995; Graham, 2001).

There was evidence to suggest the post-caring attitudes to health of those interviewed could have played a role in their reported post-caring health and health behaviour, whether they had been bereaved or not. For instance, seven said their *health consciousness* had increased since the end of caring. In Jenny's words "what I do think now is that I'm very conscious with how I am with my health". Several reasons for this were put forward by those who expressed this view. Some were linked with the point made earlier about the way interviewees reported that they did not attend to their own health needs when they were caring. During their post-caring lives they were able to focus on their own health much more. As Joyce said:

"I mean when you are on your own and then afterwards you do think of every little ache and pain sort of thing *more* but while you are looking after someone, I mean you put that to one side, you know, for the benefit of the one you are caring for"

Others reasons were associated with the fact that their health had worsened and, as explained earlier in the discussions on post-caring health, ill health was now a major part of their lives for some. Bob is an example of those in this group as he was on "heart tablets, water tablets, rheumatoid arthritic tablets, and ...seven different pain killers". Such a range of illnesses and medications would obviously result in an individual being much more conscious of their health needs.

Some also showed an *increased willingness to use health services*; Clive felt that his attitude to the health service changed in that he is "probably" more willing to

use services when health problems occurred now that he had ceased caring. As he explained

“.....we didn't call the doctor, I think our relationship with the medical profession has perhaps changed..... we didn't use ours anywhere near as much as I think we should have done, particularly as a carer um you're conscious all the time of appearing, of not wanting to appear over, what's the word? Over careful, over cautious because um, you know if Helen had got a cold or you know, some minor ailment, if she'd got minor ailments it would never occur to us to have the doctor”

Therefore, during caring he had refrained from using medical services at times because he had been concerned about giving the medical profession the wrong impression. Now that caring had ceased, this concern was removed and he felt more relaxed post-caring about using medical services.

Finally, some seemed to have *reduced expectations of their health* because of their age. This was demonstrated by Una, (aged 63) when she said:

“Well (*pauses*) I'm not too bad with me health but er oh I don't know (*pauses*) you've gone through such a lot in your life I think when you come to my age that er you've just got to carry on in't yer”

As two thirds (twenty-five) of the sample was over sixty years (see Appendix 11), the age of those interviewed could have resulted in a reduced response to health problems and less health- seeking behaviour.

These attitudes could have had both positive and negative influences on post-caring health. For instance, increased health consciousness and use of health services could have had positive effects in that there was both more active health-seeking behaviour and greater use of health services in times of need. In contrast, reduced expectations of personal health could have had the opposite effect and led to a decline in post-caring health. The evidence was therefore ambiguous and it was not possible to draw clear conclusions about the influence of attitudes to health on post-caring health.

Thus, these discussions about post-caring health have shown that it can be influenced by a variety of factors. Whilst the discussions of the effects of some of the influences were inconclusive, it was possible to draw more general conclusions. These were that bereavement could have increased the number of illnesses experienced and could also explain some of the types of illnesses experienced by the former carers in this sample. However, the way that the caring experience modified bereavement for these bereaved former carers indicated that they may not have been susceptible to the full gamut of potential post-bereavement illnesses. Indeed the caring experience emerged as a dominant influence; irrespective of whether they had been bereaved, the caring experience of those interviewed meant that they could have been subjected to many influences on their post-caring health whilst caring. One was the way that the caring experience led to health problems during caring which continued into post-caring. It could also mean that health needs that arose during caring were not addressed because of the demands of caring. These then resulted in post-caring health problems. In addition, there seemed to be a “delayed reaction” post-caring to the emotional stress and heavy physical tasks of caring in that some illnesses developed after caring had ceased. The caring experience was linked to other possible influences on post-caring health, as shown in the discussions on post-caring emotions and changed attitudes to health post-caring. Furthermore, improvements in health or the absence of health problems for both bereaved and non-bereaved former carers could be explained by the absence of stress of the caring experience or the fact that health had been unaffected by caring.

Therefore it has been demonstrated that, whilst bereavement clearly played a part, there are also additional influences on post-caring, the most influential being the caring experience itself. As the influences identified have a variable impact and are interrelated, it was concluded that it was the sheer complexity of these influences and the way they worked, which led to the fifty-fifty chance of former carers experiencing health problems post-caring that was identified.

Conclusion

The evidence presented in this chapter about the main issues for former carers in their post-caring lives has indicated that there may be different processes involved in the post-caring experience. For instance, the “post-caring void” and some health problems were transitional, whilst some of the losses (such as the loss of social role and social network) and other health problems were more permanent. These processes are the subject of the next chapter.

CHAPTER 7: LIFE POST-CARING

This chapter addresses the daily lives of those former carers interviewed following the end of caring. The analysis and development of the core concept “Life post-caring” are presented diagrammatically in Table 5 on page 166 and discussed in detail in Appendix 14. Table 5 shows that there were three sub-categories – “closing down ‘the caring time’”, “constructing life post-caring” and “factors influencing life post-caring”. The first two concern activities, events and experiences associated with two phases in post-caring life whilst the third is about the influences on these. All three sub-categories are discussed in this chapter.

Closing down ‘the caring time’

During the first few months of post-caring life former carers went through a transitional period. Claude described this as the “wind-down period” as it involved a gradual winding down from caring and its associated activities. The three concepts within this sub-category were changes in routine, closure activities associated with a death, and closure activities associated with the end of caring.

For two, there was a dramatic departure from the routines of caring life in that they returned to work having taken extended leave to care. Although other changes in such routines were less dramatic, they had significance for those who reported them. Eleven found themselves having to consciously change aspects of their routines; Claude had driven his disabled wife around for eleven years and had been used to being an “an orange badge” holder. He said:

“I had to physically stop myself from driving into an orange badge spot and physically go and pay for car parking whereas previously all you had to do was get out the wheelchair”

This change of routine was forced upon him by the fact that he no longer qualified for an “orange badge” because he was not caring. Sandy found it was “very difficult to get

TABLE 5: DEVELOPMENT OF THE CORE CATEGORY "LIFE POST CARING"

"LIFE POST CARING"			
CORE CATEGORY <i>(Selective coding)</i>	closing down 'the caring time'	constructing life post-caring	factors influencing life post-caring
<p>sub-categories <i>(axial coding)</i></p> <p>concepts <i>(open coding)</i></p>	<ul style="list-style-type: none"> - changes in routine - closure tasks associated with a death - closure tasks associated with the end of caring 	<ul style="list-style-type: none"> - serial caring - families - interests and activities, - friendships and personal relationships - paid employment 	<ul style="list-style-type: none"> - personality - conscious efforts to reconstruct life post-caring - integration into the local community - health problems - age - income
<p>Indicators <i>(microanalysis)</i></p>	<p>sorting out funeral arrangements, sorting out possessions, sorting out paperwork, sorting out finances, visits to solicitors and bank managers, sorting out benefits associated with the caring, disposing of the equipment, time-consuming nature of these tasks, returning house to pre-caring state, overdue domestic chores, undone decorating, emotional stress dealing with own grieving, dealing with others grieving, changes in friends coming to the house, gradually less invitations from family, maintenance of employment status, change from the daily routines of caring, changes in the sentiment work of caring</p>	<p>now undertaking informal care, informal caring tasks for friends and neighbours, cared prior to most recent episode, cared more than once, rebuilding of family relationships, increased involvement with family, changes in roles in the family, more of a two way relationship with families, improvements in family relationships, less involvement with family, new interests and activities, development and extension of pre-caring interests, resumption of pre-caring interests, continuation of interests and social activities developed during caring, caring related interests, interests led to further activities and friendships, interests led to friendships, "picked up" existing friendships, expansion of role of existing friendships, no change in post-caring friendships, some couple friendships had lapsed, relationships with members of the opposite sex, changed job, part-time paid work post-caring, those who did not work did not need to, those who did not work could not undertake paid employment</p>	<p>demonstrated consciously taken steps to rebuild their lives by their actions, explicit about the fact that they did consciously try to reconstruct their lives post-caring, no efforts to rebuild lives, creating new routines and restructuring their time post-caring, importance of personality, knowing many people in the community, friends and family living near with whom regular contact was maintained, involvement in churches, schools, committees and community groups, permanent health problems, unable to cope with people, give up job, inability to concentrate, difficult to rebuild life, problems with longer-term relationships, physical activity limited, social activities were limited, unable to maintain some family contacts, adverse effect of advancing years on post-caring life on employment opportunities, adverse effect of advancing years on post-caring life in terms of death of friends, younger former carers found that their friends' social lives were geared around couples which made it harder to socialize with existing friends post-caring, men found it a little harder to adjust to not caring, harder for women to go out on their own, restricted disposable income, reduction in income</p>

out of the routine of caring” and talked about how, in the early days of post-caring life, she found that she “automatically started setting the tray in the morning” for her husband’s breakfast before she “went out in the morning”.

Such changes in routine also involved changes in the sentient work (discussed in Chapter 1) caring entailed. For instance, some found themselves still thinking of the dependant’s particular needs, such as the special food they required. Penny described how there were “certain things” in the supermarket where she used to buy for her father and that it was “really strange walking past these things” without buying them.

The changes described above that occurred during this early phase of the post-caring period were related to the fact that those interviewed had *cared for* their dependant. Other changes were those induced by bereavement (Worden, 1983; Parkes, 1970; 1996; Sanders, 1989; Vickio, 1990). Some of these changes were induced because they were coping with their own grief whilst others related to helping others around them deal with grieving over the loss of the dependant. Bob remembered how during “the first few weeks (*of bereavement*) I took too much alcoholic comfort and was smoking myself stupid”. As his son was in the middle of his finals at university, Bob also had to work at encouraging him to carry on; he said “I had to coax him on and make him realize that his mother would wish him to pass so he had to be strong and do it.” Joyce similarly had to focus her attention on the grief of others as her grandson had taken his Grandad’s death “very bad”, and she had to try to keep talking about “his Grandad” until he “settled down”.

Similarly, some activities in this period involved closure tasks that are inevitable after any death, such as sorting out funeral arrangements, possessions, paperwork, and financial and legal issues. Pat provided some examples of these tasks when she said “the first two weeks you have such a lot to do paperwork to sort out and wills, and maybe making a new will for yourself which I did, but there is a lot to sort out”. Sandy talked about sorting out her husband’s possessions and all the activities this involved. She described how she “bagged

up” her husband’s clothes on the Monday after he died “ because they would fit young people because Stuart was only very slim. I said would they be interested in the clothes and so I just bagged them all up and took them down to St Christophers”.

However, some closure tasks were more specifically related to the “winding” down process of caring; four had to sort out their benefits that had been associated with the caring. One of these was Joan who described how she had received a letter from “the registrar” a week after her husband died, asking her to return her husband’s “benefit books”. As she did not know where the benefit office was because they had “always dealt with it by post”, she had to ask her son to take her to the office. Upon arrival, she had to wait to see a member of staff only to find that she had brought the wrong benefit book and she was at the wrong office. She was given “claim forms to fill in” and was “told to go to the other office, which was in another part of the city”. Other activities associated with the end of caring itself were the closure of social activities related to having cared for a deceased dependant who had required care. Many focused on the way family and friends who previously visited their dependant during caring because they were ill or disabled came round for “the first month or two months” and then gradually, as Joan, explained “dropped off”. Three of the male carers commented on the way their wives’ friends came round for “the first months or two months”. Paddy gave a good example of this process when he described his experiences:

“Mabel, she used to come in every Wednesday to see, every other Wednesday, sorry, every other Wednesday, to have a cup of tea and biscuit with Betty and a natter. But you see when Betty passed away she came in once after that, you know, like you’re sitting there, and then that finished.and that stopped you see”

A further two talked about the way that that the initial frequent invitations from family members for meals only lasted until they “settled down” and gradually decreased. However, this is a change in routine that could have occurred after a bereavement and was not necessarily related to having been a carer.

Another closure task specifically related to the death of someone who had required care was the disposing of the equipment their dependant had required. Six talked about this and it was not a straightforward or quick task as Joyce explained:

“I mean I didn’t sit on it and let stuff hang about here, I mean I notified them, although it took them three weeks to come and collect everything back, but er, the handrail and that I was told they would stop as they are, you know. I must admit having a handrail is very useful for myself as well, so they said that was all sorted out and that was ours. But I mean all the other stuff I sent back, some of his stuff from the nurse that hadn’t been opened, that was still in boxes, you know they had all that back, you know. I mean there was quite a lot of ringing and doing, to cancel and all that you know”

The final type of closure activity associated with the end of caring was doing domestic tasks that had been left undone during caring. The lack of time for such tasks in the later stages of the caring experience was discussed in Chapter 2. Two therefore focused on their house; Jo caught up with household chores and said she wanted to “spring clean the house and get things all tidy.” Derek occupied himself “doing decorating of the house and things like that”.

Thus, some of these experiences in this early phase of the post-caring life were influenced by bereavement only whilst others were influenced by caring and its cessation. The findings therefore provided insights into the experiences of bereaved and non-bereaved former carers. These, as well as other influences, were also observed in the next phase of the post-caring experience.

Constructing life post-caring

Following these first few months of winding down, life post-caring was gradually filled in different ways. Those interviewed talked about getting “life together” again, and “coming up to the surface”. This phase was not delineated by time but appeared to end upon the commencement of another caring role. The concepts identified were serial caring, families,

interests and activities, friendships and personal relationships, and paid employment. The role each of these played in the reconstruction of life post-caring is discussed below.

Serial caring

One of the most significant findings was that another caring role had been part of post-caring life. This applied to the most recent experiences of caring and /or previous experiences of caring. Over two thirds (twenty-six) of those interviewed had cared informally more than once. Twenty had been carers prior to their most recent unpaid caring role, and six were now caring again. Two of the latter had also cared prior to their most recent unpaid caring role.

Thus serial caring featured in the lives of over two thirds of the sample. In Claude's words,, it becomes a "lifestyle". Indeed, in many cases those interviewed felt they had not had a choice about their serial caring because of familial obligations to parents, siblings and partners and /or spouses. With reference to the six who were currently caring again, age and gender were influential; these former carers were all female and a higher proportion were under sixty compared to the rest of the sample (two thirds compared to one third of the whole sample). All of their new caring roles involved the care of a very close relative such as a spouse, in-law, sibling or parent. In each case, it appeared that they had little choice as to whether they resumed the role of carer; somebody who was related to them had needed care. They consequently redirected their energy and time into the same role for a different dependant. An example was Peggy who explained that she now uses her time to care for her husband Ken as she no longer has to care for her mother.

"I reverted it all to Ken, since then he has got worse you see in the last two years, he had arthritis and he's had a couple of little heart attacks and now he's got the arthritis in his neck and spine and all sorts and I have to take him across there every week to physio, so it reverted to him you see"

There was some evidence to suggest that those who were not currently caring did seem to want to exercise some choice over whether they cared again; fifteen said they would only

care under certain conditions. For instance, nine would only care for family, four would care if they “had to”, one would not care on a full-time basis and another would not care for a severely disabled dependant. Four went as far as saying they would not care again, although three cited their age as the reason. The male former carers were more likely to say that they would care again (a half compared to a third).

A further eleven former carers mentioned that they did caring tasks for friends and neighbours. These tasks were not time-consuming and did not amount to taking on another caring role; one of the former carers in this group was Ethel who did “a bit of washing and ironing” for the elderly lady over the road although “she don’t need caring for”. There was no obvious explanation as to why this group undertook these tasks but three said they continued to feel that they wanted “to look after people”. Sandy’s account of how she came to undertake caring tasks for people in her village indicated that some were more likely to receive requests for help with caring when others knew they had the appropriate expertise. She was a nurse and explained “I know a ladyand she didn’t want to pay six pounds something to have a nurse to bath her. Rang me up, Could I do it. So I agreed to (*laughs*)”. Age did not seem to be a deterrent to this group; all except one were over sixty, six were over seventy and one was over eighty. Gender did not appear to be influential either as equal proportions (a quarter) of both males and females carried out such tasks.

Therefore, in addition to the findings about the role of serial caring in the post-caring experience, it emerged that just under half (seventeen) of the sample continued to do some sort of caring in their current post-caring lives.

Families

The role of the family in former carers’ lives changed in this phase of post-caring life. For most this meant an enhanced role which was viewed positively. In addition, there were examples of the rebuilding of family relationships that had been damaged during caring.

However, there were also some who had more negative experiences of their families post-caring.

In relation to the enhanced role of the family post-caring, nearly three quarters (twenty-six) were more involved with various members of their family post-caring. These included their own children, siblings and in-laws. This increased involvement helped to rebuild their lives and establish new routines. For instance, Paddy described the regular contact he now had with his daughter; she “comes, she’s just had her dinner here today. She comes in every Wednesday, every Monday and Wednesday for her dinner and I go round her house Sunday’s for dinner.” Peggy’s sister now invited her “to her house for the weekend sometimes” and Joyce was fortunate enough to have recently been on a “fortnight’s holiday” with her son and daughter-in-law.

Different patterns in this involvement emerged; some found that whilst they were more involved with their families, their role vis-à-vis the family had changed. As Joan said, “roles change” post-caring; she explained that when she was caring her husband “couldn’t go anywhere” so

.....everybody fitted in with us.....this house used to be a meeting point on a Sunday when Pete was ill. The family came here and friends came here um on a Sunday night and um you know we’d have tea and sit around and talk or watch the telly or generally talk over the telly you know”

Since caring ceased, she felt the roles had been reversed and said, “I’m having to fit in with them”. Thus, although the family did help to reconstruct post-caring life in this case, this former carer was now required to be more accommodating of her family’s own needs. In other cases, there was now more of a two-way relationship. The former carers’ families helped them to fill their time by inviting them out and so forth, but also the former carer helped out family members more now that they were not caring. Doris illustrated this when she talked about how her daughter took her line dancing “once a week” and how she also helped out with childcare and household tasks such as mending and cleaning.

Over half (twenty-two) felt that they had better relations with some of their relatives now that caring had ceased. Joseph found the irritation that he had felt about his sister's lack of willingness to help with caring for their mother dissipated post-caring, with the result that their relationship was easier. Derek now enjoyed a good relationship post-caring with the sister-in-law, referred to in Chapter 5, and said she would have him over "everyday for lunch" if he wanted to go. Other relationships had grown stronger since caring ceased. Clive explained that when his wife was alive, she "sort of let" their children "get on with their lives so to speak" and did not want them to feel they had to support her with her Multiple Sclerosis. Since he ceased caring for his wife, he was enjoying closer relationships with each of his three children. He explained that

".....since my wife has died we've been very close, closer, um (*pauses*) I go and stay with my elder daughter obviously in Sicily during the Winter and I see my youngest one every day with the baby, and er (*pauses*) my son is quite, there's a different sort of relationship with him. It's as though he understands. You know he's doing his own thing but he seems to have understood the situation..... he's become more er, well, we've seen eye to eye on a lot more things in that way than er we did before..... it has changed definitely, it's really got a lot better and the three children themselves um see a lot more of each other even though they are far apart but they also communicate with each other a lot lot more, some might say even more than they did at home"

A further three talked about spending time and energy rebuilding family relationships that had suffered whilst they cared. Paula provided a good example of this; as explained in Chapter 5, she felt that whilst she was caring for her mother, she had neglected her son. Once caring ceased she said "Jason came first again" and she worked hard at creating "normality" again for him, such as having his friends round and taking him on outings.

It is possible that such strengthening of relationships could have occurred post bereavement and in the absence of caring. However, the relationships in question had been adversely affected by the caring to varying degrees. Therefore their subsequent improvement and the ensuing positive emotions were simultaneously directly linked to the caring experience and

can be regarded as exclusive to the post-caring, as opposed to post-bereavement, experience.

In contrast, as indicated above, some had less positive experiences. Ten reported that they spent less of their time in general with members of their family than they had when caring. Doreen said she saw less of her son who lived locally since caring ceased.

“Um I’ve got one son who lives at East Norton You know, they used to come for meals every week. I mean East Norton isn’t far is it? Ten minutes at the most, and they have all got cars, but I never saw them (*sounds incredulous*). And even now, I’ve seen them once since Christmas and they are coming tonight. And um, I’ve been to their house, in four years since Jim passed away, I’ve only been once. And that only *just* East Northam. ever since Jim has been gone which is four years as I say I never, I’ve only been to my son’s home once, and I’ve never been out to tea”

Thus, families played a role in the reconstruction of life post-caring; although the fact that the former carers interviewed had been bereaved did affect the nature of this role, the experience of caring was clearly influential on family involvement and family relationships post-caring.

Interests and activities

The majority (thirty-three) said they pursued interests and activities post-caring. There were different patterns to the development of these interests, which involved a range of continuities and changes. They were therefore categorised into those who had taken up new interests and activities, those who had resumed their pre-caring interests, those who had developed and extended precaring interests, and finally those who continued with interests and social activities they had developed during caring.

Twenty-three had taken up *new interests and activities*. These involved sports activities such as weekly exercise classes, walking, badminton, swimming, working out in a gym, and bowling. Others had pursued their interests by attending classes in calligraphy,

computing, and cookery. One or two were fulfilling life-long ambitions, such as studying for a degree and travelling. Some had joined groups such as social groups, environment groups, an art club, and groups for disabled people. There were those who had become involved with their local communities, for example, joining the local church or becoming members of village committees such as pantomime committees; others pursued less group-orientated pursuits such as racing, walking, working on their newly acquired allotments and taking holidays. Although the actual evidence on gender differences in participation in the above was inconclusive, nine *felt* it was harder for women to go out on their own and undertake such activities because it was less acceptable for women to go out socially on their own. Gender did not influence the expression of such a view; this group comprised three males and six females which was in direct proportion to the number of male and female former carers interviewed.

Eight of these twenty-three former carers were now undertaking voluntary work associated with caring. This included work with disabled groups, volunteering at hospitals and hospices, membership of carers groups and former carers groups, and attending and helping out at a carers centre. Five were involved in campaigning for carers; four of these were on carers forums and one had become a Trustee of a national charity for carers (Carers UK). One of the reasons why these eight had taken up caring-related interests can be attributed to the general increase in awareness of health and social care issues that had occurred as a result of caring reported by over half (twenty) of those interviewed. For instance, Doreen said caring made her “more aware of how people could be, you know, I assumed up until that time, that whatever illness you had you could look after yourself.” Others talked about having increased understandings. Jo provided a good example of this when she described how caring had “deepened my understanding of the needs of the elderly in particular”. A further five had increased empathy for carers and as Paula said could “see it from their eyes.” Joseph was one of those whose increased awareness had stimulated him into undertaking voluntary work associated with caring; he explained that whilst caring for his mother, he had developed an interest in Alzheimer’s and as a result, he now goes “to the

home where she lived and sees the residents, they don't get a lot. I'm on quite a few committees, Carers Group at Norton”.

A further four had *resumed their pre-caring interests*, such as participating in local church activities, which they had been unable to pursue whilst caring. Six had *developed and extended the pre-caring interests and activities* that they had continued with, albeit on a more restricted basis, during caring. For instance, Ethel did more of the gardening she loved to do. Clive said his interest in the theatre was “perhaps a bit more extended now” in that he goes “to brass band concerts and things like that which we never used to go to”. He was financially very secure and thus able to pursue his interests in this way. Others may have been restricted by lack of financial resources.

Another pattern that was identified was amongst *those who continued with interests and social activities they had developed during caring*. This was particularly noticeable in the eighteen interviewees (discussed in Chapter 5) who had become involved with carers groups and undertaken voluntary work associated with caring for people with illnesses and disabilities.

The majority of those who had been involved with a carers group or attended a carers centre during caring continued their involvement post-caring. This involvement varied from continuing to receive newsletters, to regularly attending meetings and social activities. Only one, Ted, ceased his involvement as he did not want to be “reminded of the past”. However he did continue to meet informally with other carers that he had met whilst caring.

Although two had decided to discontinue their voluntary work for those needing care because, in Terry's words, they had “had enough of it”, four continued to do such work post-caring. This included membership of groups who helped to provide care, for example, voluntary groups for the elderly and /or disabled. A few were involved in more than one of these activities.

Other social activities associated with caring also continued to feature in some of their lives. Eight still maintained part of the caring social networks that had existed in their private domains. For instance, three were still in contact with the carers who helped care for their dependants. These included Terry and Madge who both continued to see one of the carers. Doris was in telephone contact with one of the carers who had helped her with her husband.

Possible influences on this ongoing involvement with carers were explored. Gender was dismissed as the proportion of males and females was relative to the numbers of male and female former carers in the sample. As the average time since caring ceased was the same as for the rest of the sample (two and a half years), length of time as a former carer could not be a contributory factor either. However, as fifteen of these former carers were over sixty, it is possible that their stage of life was influential as it meant that they were more likely to have the time to continue their involvement. A more general explanation could be that the former carers continued with these interests and social activities because they had developed contacts and friendships that they did not want to lose.

It was clear that the pursuit of *any* interests could lead to further activities. Clive described undertaking new interests as “opening the door” to other activities. He said it was like somebody “opening your door and saying ‘Well here you are go and explore’”. An example of how this occurred was given by Greg. He had joined an art club and explained that through his involvement with this club he now went to exhibitions to exhibit and sell his work.

“I started, because I joined this art group,..... they have two exhibitions and the one in November, I sold four then, I sold three in the Summer, and I’ve just sold three this weekend (*laughs*)”

Derek had joined a carers group and described how his involvement with this group now occupied him. He said

“it was suggested that I should join up with the er carers group in Norton. And that takes me out and about to Norton and other places”

Even those who pursued their interests in caring found that this involvement had the potential for augmentation. An example was Christopher who described how he had started to do voluntary work post-caring for “the Norton Association for the Blind... and the man who was in charge said would I like to do something different”. As a result he said he ended up working voluntarily for the “Council for the Disabled”.

Those who had continued with their existing interests found that the time they devoted to these had expanded. Paddy still went to his local carers group “every Tuesday night” and described the various trips he had gone on with this group since caring ceased.

“We go out on trips you know, like I said we’re going tenpin bowling the next time er get together and they set up a bus to take us to Cambridge you know in the Summer. We had a walk round Oxford, all free of charge. Now something I can’t understand, they had a letter from the Carers National Trust, which Princess Anne er is the head, they are taking us in June, which is a peak period at Pontins or Butlins for any carers and people they’re paying for to go free of charge..... In the Spring we went down to the south coast, free of charge again, no sorry, I had to pay for something. And then they hired a boat on the canal, you know a long boat, at Boxstone and we went up the river up the canal to a restaurant and we had a meal at the restaurant and then we come back”

Therefore, the amount of time spent on interests and activities expanded post-caring. Where this entailed regular attendance at groups and classes, this also helped to create routine in post-caring daily life. In addition, the nature of the increase in time taken up with interests and activities post-caring was not just a result of bereavement but strongly influenced by their caring experiences.

Friendships and personal relationships

There was evidence that friendships and personal relationships also played a role in rebuilding life post-caring. As with interests and activities, different patterns were

identified following saturation. These reflected both changes and continuities and are discussed below.

The interests and activities mentioned above, whether these were associated with caring or not had, in Christopher's words, helped them to "meet new people" which led to *new friendships* for fifteen of those interviewed. For instance, Derek said he had "established friendships with one or two people" through the carers group and Carers Forum he had joined post-caring. Molly said she had "made a lot of new friends through the church". Such friendships were often the gateway to other means of occupying their time as demonstrated by Molly when she said that her new friends asked her to "church events".

Six had "picked up" *existing friendships*. Some of those in this group of former carers had maintained some sort of contact during caring but had a more active post-caring friendship, such as going out for the evening together. One of these was Peggy who said she had been to the theatre with some friends she had known for "years but we used to just talk on the phone you see but now we see them physically." Others, such as Jane, now visited pre-caring friends whom she had not "seen for years and years". Claude worked at regenerating friendships which had lapsed completely during caring. He now wrote....

"...one letter each week and this is how I keep in touch with friends. I've got in the habit of writing letters and that is a good discipline. Not only does it keep contact with them but also I had my first official visitor back last month. These were some friends that I had worked with in the sixties and they'd never been here before.....it really was three days of absolute hilarity! (*laughs*)"

The formation of new, and the resumption of old friendships was obviously successful in helping construct post-caring life. However, over half (twenty-one) said that there had been no change in their friends post-caring. One of these was Terry who said "I have the same friends now as I had before". Indeed this may not be surprising for some, such as Michael, Lucy and Sylvia who only cared for a few months. Another reason why so many maintained that there was no change in their friends or activities post-caring could have been that they were still involved in caring in some way or another. A further three found

that some friendships had lapsed since caring ceased, but, this was mainly because they were no longer part of a couple and they were not included in invitations. Joan was one of those who had this experience and said, "I do find that couples that we used to go with don't include you now because you're on your own". This would obviously have also occurred post bereavement if caring had not taken place, and therefore was not exclusive to post-caring life.

Nonetheless, even when new friends did not feature prominently in post-caring life, there was evidence that the role of their existing ones expanded and provided ways of filling the spare time they had as a result of the loss of caring. Paddy explained how his friends took him along to their regular meetings and told him "you're still coming". Christopher described how his "friends in Florida pressed me several times to come to see them" and he had just returned from a visit there.

Another group had developed *new relationships with members of the opposite sex*. This was more common amongst the male former carers. Four out of the eleven males interviewed were in another relationship. In contrast, although one of the females (Joan) found herself "fighting off" the advances of a male friend, only one of the twenty-six females were in a relationship with a member of the opposite sex. These relationships were either with someone who had been involved in the care of their dependant or had been developed from an existing friendship.

The literature pointed to a potentially abundant supply of widows because men tend to predecease their wives (Davidson et al, 2003). There was also some evidence to support this in this study. For example, Sandy felt that...

".....its easier for the men, certainly to find a partner than the womenThe men, they're snapped up straightaway. I mean there's probably someone waiting in the wings for them to be honest. You know that someone has got an ill wife and there's probably about six women in the parish that are all on their own and would be quite happy to live with him or see him"

Interestingly, only one of the males in this study was involved in a relationship with a widow. Although an explanation for this did not emerge from the findings, a possible reason was suggested in a study by Davidson et al (2003); this research found that widowers tended to feel threatened by the presence of many widows amongst their friends and contemporaries. The outcome of this was that they felt cautious about interacting with widows in case it led to “gossip” about their intentions with regards to remarriage and their interest “in engaging in ‘intimate activity’” (Davidson et al 2003:176). Such reservations could have been shared by the widowers in this study and resulted in the lack of relationships between widowers and widows.

One of those who had formed a relationship with someone who had helped with caring for their dependant was Michael; he was in a relationship with the District Nurse who had helped care for his wife. Clive was one of those who now had a relationship with an existing friend. She was a long-standing friend whose spouse had also died. He explained:

“Well its funny because since my wife died, my (*pauses*) her best friend who we’ve known for 50 odd years, lost her husband. So she and I have got together erm (*pauses*), we go out for meals together and of course its very (*pauses*), what’s the word, its very easy to pick up a relationship like that because, particularly because you know the other party’s deceased partner erm you can talk about them quite openly, I find..... and um, we’ve been on holiday for instance”

As with the friendships discussed above, time was invested in these relationships. In Ted’s case, he went “out about once a week” with his new lady friend. Michael’s relationship had meant that he and his lady friend did a range of different outings and activities. These included concerts and theatre trips in various venues all over the Midlands, entertaining each other to meals and helping her with DIY tasks. These are described in the following extracts from his transcript:

“she said ‘I’ve got some tickets to go to er the Royal Hall’. I think she’d heard the radio when I was playing Mozart or Beethoven or something and er ‘Would you like to go?’ And I said ‘Yes I would!’ I didn’t at the time though know where she got the tickets from, I do now, but that doesn’t matter. Anyway, we

went, and then we went again and then we went to Nottingham..... Yes, I've been four times. We're going again in four weeks time to see 'The Dream of Gerontius'. Going to Norton er the theatre in Norton, can't remember it's name. We're going there to 'Joseph' in er, I think it's a week next Saturday, that's when we're going to see 'Joseph'. And we're going again on the 2nd December to see 'The Messiah'"

"we feed one another er I mean I cooked on Friday night, she cooked on Saturday night"

"Sue wanted a brick shed knocking down in her garden and I happened to know the right bloke to go and hit to with a hammer. And, I run a Range Rover, so took the trailer over and we took it away and things like that"

The style adopted in these relationships is similar to a Living Apart Together (LAT) relationship (Borrell and Karlsson, 2003). This is a previously unacknowledged arrangement, which is an increasingly popular alternative to co-residence (with or without marriage) for those who are over sixty. It is long-term, combining intimacy with autonomy and does not involve co-habitation as those involved maintain their own homes. It has few, if any, of the structural commitments of marriage (such as common ownership of resources and interwoven kinship networks) and is based on mutual emotional and moral commitment. The relationships identified in this study had many of the characteristics of LAT such as the lack of any expressed intention of marriage, and both closeness *and* independence. The main difference was that whilst all the men were over sixty, the women were not.

Thus, the role of friendships and personal relationships in post-caring followed a similar pattern to that of families and interests and activities. There were continuities and changes. In addition, their role was not only determined by the fact that the former carers had been bereaved but caring and its cessation also shaped the experiences reported.

Paid employment

Only twelve of those in the sample were under sixty when caring ceased, and nine of these worked after the initial post-caring stage. One who was in his eighties (Michael) was also working for his old company on a part-time basis. Those who did not work either did not need to, or could not, undertake paid employment. Lydia was an example of the former; she had never worked and her financial situation was such that it was unnecessary for her to have to do so; in her words “fortunately I don’t work, we’ve never been dependant on, I’ve never had to produce any money”. Joan had been unable to work post-caring; she had taken extended leave whilst caring to care for her husband and was now “on the sick ” because of back problems.

Five of those who worked post-caring were still working part-time in the same job as they had done whilst caring. Employment had not been continuous in all cases as some of them had taken extended sick leave time towards the end of caring. However, there was continuity in that they had returned to the same jobs. Two of these had been working full-time prior to, and during, some of the time whilst they were caring. These former carers said they were unable to progress in their careers as they would have wished because they had taken time out to care. Joseph, who was in his fifties had been a pantomime and comedy show actor and had been unable to return to this. He said that during caring he “almost packed in progressing at all.....Well with the sort of job that I have been doing ...I’m really almost too old now to get back into show business.” He now worked locally “hiring out stuff, doing odd weeks”.

Four had changed their job post-caring and all of them worked part-time post-caring. Two of these had worked full-time pre-caring and for some of the time whilst they were caring. Three had done or were now doing some sort of paid work associated with caring, and one of these was doing both paid and unpaid caring work. For instance, Paula was counselling at a carers centre, Ethel had worked as a paid carer for a Carers Agency and Jo was a lay member of PCT and was also on a carers forum in a voluntary capacity.

Thus, most of those who were of working age post-caring did undertake paid employment. Although this simultaneously created and maintained daily routines post-caring, they all worked part-time, even if they had not done so prior to and during caring. For over half of these (five out of nine), their post-caring employment was influenced by their caring experience. Those who felt that they had a choice about working, chose not to. It could therefore be argued that although caring influenced the nature of this aspect of their post-caring lives, the amount of time spent in paid employment did not expand in this post-caring phase and its role in the reconstruction of life post-caring was not as significant as other aspects of the former carers' lives.

Therefore the above discussions have shown the main ways in which life was reconstructed after the early phases of post-caring life. Whilst it was clear that bereavement and the caring experience were influential, upon saturation other influences on post-caring life in general emerged. These are explored in more detail below.

Factors influencing life post-caring

This sub-category comprised several concepts – personality, conscious efforts to reconstruct life post-caring, integration into the local community, health, age, gender and lack of income. The influence of each of these factors on post-caring life is as follows:

Personality

Over a third (fourteen) of the respondents felt that personality characteristics such as being able to “fight these things for yourself,” “face up to life” and “move on”, “pulling your socks up and getting on with things” and being “adaptable” were important in constructing life post-caring. Mead’s ideas about “the self” offer an insight into these findings. He sees the self as an individual’s distinct psychological character which is the driving force for the

individual's conduct (Mead, 1934; Cuff et al., 1998). Thus, Mead would argue that a former carer's personality played a role in their approach to post-caring life.

Conscious efforts to reconstruct life post-caring

The discussions earlier in the chapter gave examples about some of the decisions made in post-caring life, such as decisions about returning to previous employment or work, continuing with voluntary work and returning the house to its pre-caring state. Such decisions were influenced by the former carers' conscious efforts to reconstruct life post-caring. Indeed nearly all of those interviewed (thirty-three out of the thirty-seven) demonstrated that they had consciously taken steps to rebuild their lives by their actions. Furthermore, seventeen were explicit about the fact that they did consciously try to reconstruct their lives post-caring. For instance, Joan said "I made a conscious effort" and Greg felt strongly that....

"...you've got to start trying to live again in a sense because your whole life is revolving around your wife or whoever it is you're caring for particularly when you've cared for a long time"

Of the five who did not show that they had consciously tried to reconstruct their lives, two gave the impression that the reconstruction of life post-caring was something that just happened and that they did not attempt to exert any control over. Jenny said her life had just "filled up" and Penny said that her social life "picked up again". Another two did not reconstruct their lives for justifiable reasons; Bob had been very depressed since caring ceased and said he could not contemplate reconstructing his life. Sylvia felt that her life was not changed much by the caring she had done as this had only been on a short-term basis.

Despite the emphasis on the routine of caring and the way it structured their daily lives, and evidence that the former carers did change their daily routines, only two were *explicit* about actually creating new routines and restructuring their time post-caring. For instance Paula said she had to "create routine" but this was mainly because she had a child, and she felt it was important for him after the disruption that caring for her mother in the same house had

caused. Although Doreen was restricted by age, ill health and limited financial resources, she still created a routine based around her home for herself. She describes this in the following extract:

“I do a job a day and that’s how I carry on. I have to do a job a day. And if I miss doing that job I’m thrown out you know I have to do a job a day, you know. Monday is my easiest day but I have been breaking the soil up around the garden this morning before you came..... my garden keeps me going”

Integration into the local community

The extent to which former carers were integrated into their local communities was influential on post-caring life. Over half (twenty-one) demonstrated that they were well integrated into their local communities. This took the form of knowing many people in the community, friends and family living near with whom regular contact was maintained, and being involved in churches, schools, committees and community groups. Michael was a good example of the way having plenty of contacts in the place of residence helps to rebuild life after caring.

“ I live, we live here and this village is a very very friendly sort of village, there’s a village atmosphereNow, (*pauses*) if I wanted 10 minutes or an hour’s company, I’d go down to the Keepers Arms at half 6 and have a glass of red wine, maybe two, and talk to people for an hour or an hour and a half and then come back and get my meal. And also, I suppose luckily in a way, I’m not a millionaire, now and again, I could go down there, meet somebody, have a couple of glasses of wine and they’d say ‘Are you going to stop and have something to eat?’ and I would stop and have something to eat”

He was also involved with several committees in his village which kept him busy.

“I’m also Chairman of the Men’s Fellowship in the village. I’m Chairman now so from September round to April, we meet every fortnight and have lectures and this sort of thing. Um This is what it’s all about. Um so I’m that, also I’m a member of a Horticultural Show er committee, and er and I’m also beside being Fabric Committee Chairman, I’m a member of the Parishioners Committee at the Church”

Thus, the extent to which he was integrated into his local community was clearly influential in helping him construct his post-caring life.

Health

Health was another influence on life post-caring. As discussed in Chapter 6, eighteen (half) reported that they had experienced or were experiencing temporary and permanent health problems post-caring. Further analysis showed it was the permanent health problems that were more likely to impact on post-caring life. Over half (eight) of those who were suffering from more permanent physical and psychological ill health post-caring felt that the quality of their lives and their activities had changed as a result of their health problems. Although the literature acknowledges it is hard to gain an understanding of the experience of being ill, grounded theory is particularly useful at gaining understanding of such life experiences (Morse, 1991; Senior and Viveash, 1998; Frank, 2001). The findings outlined below demonstrate how this study provided some useful insights into the impact of their health problems on these former carers' post-caring lives.

Bob talked about the way the depression that he had developed since his wife died affected him because he could not "make a new life", "concentrate on anything at any one time" or "give one hundred percent to anything anymore." He also felt that his depression had led to problems with the longer-term relationships he had had with women since he ceased caring for his wife. Ethel had become depressed during caring which had led to her being forced to give up her job. As her depression had persisted into her post-caring life, she could not return to her previous job and had only been able to take a temporary, lower paid job post-caring; as she explained "I can't cope with life any more" and "I can't cope with people at the minute".

Doreen's health problems restricted her post-caring activities. Her angina had worsened since caring ceased and she said this meant "I can't walk far and do too much because then the angina takes holdand I have to be careful." The panic attacks that had started since the cessation of caring meant that her social activities were limited because she could no longer travel:

“...I would love to go on holiday, or even for convalescence but it’s the travelling and going on holiday. I wouldn’t want to spoil anyone else’s holiday because you would do, wouldn’t you if you took poorly and that. I’ve been on the outings with Julie and that and I’m no sooner on the bus than I get my panic attacks and it’s more like a heart attack actually you know, she would tell you, until I’m nearly home I’m practically, as soon as I get home I’m just worn out with them. So that was going to Shelsea once and then Norton, I mean Norton is not far is it but I had them as soon as I started out”

She was also unable to maintain some family contacts because of these health problems; her son lived in Berlin and had invited her to visit but she could not accept because “there again it’s the travelling”. Further consequences of her post-caring health problems were that she had “been rushed into hospital one or two times” and she had frequent doctors and hospital appointments.

Therefore, the permanent physical and psychological post-caring health problems affected different aspects of the post-caring lives of these former carers. These included their relationships, employment opportunities and the type of activities that they could undertake. Members of this group of former carers now saw themselves as people who suffered from ill health. In terms of Goffman’s analysis of the effects of illness on identity, these changes in personal identity are akin to his concept of a “spoiled identity” that occurs with the onset of illness or impairment (Goffman, 1971).

Age

Thirteen mentioned their advancing years as adversely affecting post-caring life in terms of their employment opportunities and the loss of their friends because they had died. Greg provided an example of the latter when he said “at my age friends...they’ve all gone”. Conversely, a less advanced age could be equally disadvantageous. As previously mentioned, three of the younger former carers found that their friends’ social lives were geared around couples which made it harder to socialise with existing friends post-caring.

Income

Six referred to the effects of a lack of disposable income on their post-caring lives. Doris said, "I can't do like I did before" because of the reduction in her income post-caring. She regretted the limitations this imposed on her activities, particularly in terms of what she could do for and with her grandchildren.

Conclusion

This chapter has described two phases in post-caring life; the first entailed changing routines and the transition from caring to post-caring life. The second concerned the process of rebuilding life post-caring. Serial caring, family, interests, activities, friends and employment all played a role in this process. There were positive and negative experiences. There was evidence of continuities, such as continuation of involvement with carers groups and informal caring. Changes were also identified, for instance the development of new friendships and changes in the role of the family. As demonstrated, this reconstruction was an ongoing process that took place over a period of time rather than an instantaneous transition, and was one that was consciously undertaken by most of the former carers interviewed. Although these two phases were strongly influenced by the caring experience and its cessation, a variety of other factors, such as personality, integration into the local community, health, age, and income were also influential.

One of the most significant findings was the prevalence of serial caring in the respondents' lives and the way that over half (twenty-two) of all the former carers interviewed continued to be involved with caring in one way or another. This was through unpaid and paid caring roles, doing caring tasks for friends and neighbours, voluntary work, attendance at carers and former carers groups, carers forums, and carers centers. Indeed of the twenty-three that had taken up new interests post-caring, eight of these were interests associated with caring. This is addressed in more detail in Chapter 9.

CHAPTER 8: SUPPORT POST-CARING

The findings reported in Chapters 6 and 7 clearly indicate that those interviewed had a variety of support needs post-caring; all of them except one was struggling with a bereavement. Other reasons for support mainly centred on the losses they experienced upon the cessation of caring and their health problems. Indeed, it was clear that some of the losses they experienced upon the cessation of caring were caused by lack of adequate support to reduce the restrictions of caring and enable them to live their own lives more fully during caring. Furthermore, nearly half of the sample felt that they suffered from some form of ill health post-caring, and some of these felt this had a negative impact on the quality of their lives. Unsurprisingly, thirty-one out of the thirty-seven said they had needed post-caring support in the short and longer-term. The final aspect of the post-caring experience to be addressed is therefore the core category of “Support post-caring”

The analysis and development of this core concept is presented diagrammatically in Table 6 on page 191 and, as with the other core concepts, this is discussed in detail in Appendix 14. The three sub-categories were “sources of post-caring support”, “themes in post-caring support” and “improving post-caring support”. These and their associated concepts are discussed in this chapter.

In the previous two chapters, some differentiation between the effect of bereavement and other influences on post-caring experiences was possible. The analysis of the data on post-caring support did not enable differentiation to the same extent; this was because it was not always clear whether post-caring support met bereavement needs or needs specific to the post-caring experience. Therefore it was more difficult to establish the differences between the effects of bereavement and other influences on post-caring experiences of support; nonetheless, any distinctions that could be identified are commented upon.

TABLE 6: DEVELOPMENT OF THE CORE CATEGORY "SUPPORT POST-CARING"

"SUPPORT POST-CARING"			
CORE CATEGORY <i>(Selective coding)</i>	sources of post caring support	themes in post caring support	improving post-caring support
sub-categories <i>(axial coding)</i>	<ul style="list-style-type: none"> - multiple sources of support used - subtypes of support provided - satisfaction rates 	<ul style="list-style-type: none"> - general low level of support post-caring - satisfaction rate for statutory services continued to be the lowest - satisfaction rate for statutory services decreased - continued high reliance on the voluntary sector, family and friends and the local community for support - gender differences 	<ul style="list-style-type: none"> - suggestions about support during caring - suggestions about support post caring
Indicators <i>(microanalysis)</i>	<p>emotional, instrumental, support provided, organizations, Social Workers District Nurse, counsellors, voluntary sector provision for former carers, support from family and friends, local community support, level and quality, satisfaction and dissatisfaction expressed</p>	<p>least use made of statutory services post caring, second highest use made of statutory services during caring, bereavement support, lack of support specifically for former carers, support used provided a more limited range of support than during caring, support available addressed only some of the former carers post-caring needs, dissatisfaction with the support varied, satisfaction rates for the non-statutory sources 100%, satisfaction rates between the statutory and non-statutory services was greatest post-caring, less satisfaction with help from statutory services both during caring and post-caring than the other sources of help, continuities in the use of the voluntary sector, and family and friends, voluntary sector, family and friends and the local community for support continued to have high usage rates post caring, the voluntary sector and family and friends provided more support post-caring than during caring, support provided by the local community less than during caring, male former carers had more support than the females during caring and post caring, male former carers more likely to receive support from the voluntary sector, male former carers more likely to receive support from family and friends, male former carers more likely to receive support from the local community</p>	<p>instrumental support during caring to prevent post-caring health problems, instrumental support during caring in order to relieve the strain of caring, informational support during caring to help with preplanning, support should be tailored to individual needs, emotional support post-caring, group support, former carers groups, carers groups, disadvantages of groups, individual support, counselling, support specifically for former carers, bereavement needs, informational and instrumental support post caring, help with filling in the benefit forms, advice on benefits and pensions</p>

Sources of support

The concepts within this subcategory were multiple sources of support used, sub-types of support provided and satisfaction rates. These are not addressed separately as in other chapters but integrated into the discussions below about the different sources of support used post-caring. Therefore, the discussion of each type of support includes the sub-types of support it provided and the level of satisfaction expressed by those former carers who used it. The classification system for the sources and sub-types of support are the same as those used in Chapter 5 (as outlined in Appendix 1). The analysis showed that, with the exception of commercial organisations, all the post-caring sources of support were the same as during caring. This absence of the support experienced during caring from paid carers employed by commercial organisations and private care homes is to be expected given that their contractual obligations had been to the dependants.

Statutory organizations

Nineteen (half) said they received support with their post-caring needs from staff in statutory agencies. Fifteen received support from General Practitioners. This figure is not surprising given the post-caring health needs of half of those interviewed, and the fact that fourteen suffered from long term health problems (see Chapters 6 and 7). However, there seemed to be little support from GPs following the cessation of caring; only seven out of the seventeen who suffered from short-term post-caring health problems reported that they had received medical help for these. Furthermore, the support that was received seemed to have to be proactively sought by the former carers. Only one former carer said that their GP “came round” whilst six mentioned they had been proactive. It would seem that the others, in Paula’s words, “tried to work through it” on their own.

Support from Social Services carers was received by four of those interviewed. This ranged from one-off visits to more long-term support; Madge provided an example of the former when she said that she had seen “one of them since, one of the carers and bless her she actually came and gave me a card”. With respect to the latter, when talking about his wife’s Social Services carers, Terry said, “I still see one of the carers.

She says that she finds that when she stops caring for someone, she feels guilty about not seeing the one that is left. They ring her up and want to speak to her". This implies that she was supportive and the fact that she was still in touch with Terry indicates that he received longer-term support from her.

Another four received visits from District Nurses. However, these were not regular and were aimed at bereavement support as opposed to post-caring support. Joan gave a response typical of those in this group when asked about these visits when she said the District Nurse paid her a "bereavement visitonce or twice". Social Workers provided support to two on a short-term basis. For instance, Julie described how her social worker "kept in touch for a little while". Finally, on the advice of their GPs, two received counselling by bereavement counsellors and again this was short term. Molly was one of those who received bereavement counselling. She explained that she had "this grief bereavement counsellorfor six weeks".

The evidence showed that this support from statutory agencies was mainly informational and emotional; Molly received informational support from her Doctor when he "recommended" that she got "in touch with a counsellor" as discussed in the above example. Joyce gave an example of emotional support when she described how the District Nurse who had visited her husband now visited "the lady in the bungalow at the back" and "would always shout and say 'are you alright?' or 'are you coping?'" However, this support was on an informal basis as Joyce was not the intended recipient of the District Nurse's visit.

Moreover, much of this support was on an infrequent or one-off basis and only in the very early stages of their post-caring lives. In addition, there was evidence that most of the support, from General Practitioners in particular, had to be actively sought by the former carers. Another criticism that can be made of the support from statutory agencies is that it only addressed a few of the needs of the former carers, such as health and bereavement needs. Whilst the potential to meet other needs seemed to exist, it was not realized. For instance, Social Workers and District Nurses could have provided

valuable information about sources of advice about benefits or rebuilding lives post-caring.

Unsurprisingly, only a third of this group of nineteen (six) said they were satisfied with their post-caring support from statutory services. Any satisfaction was usually due to a more personal relationship that had developed with a member of staff in a statutory agency during caring because of their particular needs, and this relationship continued into post-caring. One of these six was Doreen who talked about how her GP was very encouraging and told her that she was “a lot better”. Comments were made about the level and quality of their support from statutory services. Pat felt that the level of support was inadequate and said “I think that the professional services, doctors, nurses, social work, I don’t know someone along those lines, could have kept in touch with me longer than they did”. Doreen was unhappy about both the level and quality of the support she had; she said her social worker “stopped coming” soon after caring ceased. When asked what he did to support her, she replied “not a lot, not a lot ” and added that she did not have “much faith” in Social Services. Further inadequacies in the support from statutory services were identified during informal conversations with District Nurses during the theoretical sampling. They revealed that they were supposed to do one follow-up visit after the death of the dependant. Whilst all of them agreed with this as a policy, most admitted to being unable to do this due to the nature of their workloads. Those that did felt that more than one visit was required.

The voluntary sector

Although two thirds (twenty-five) had obtained support from the voluntary sector, the study showed that it provided little support specifically for former carers. Julie went as far as saying “there is nothing for ex-carers”. Nonetheless, seven of this group obtained support within the voluntary sector that catered solely for former carers. Four of these attended a former carers group which had been set up, in Julie’s words, “by mistake”. She described the ad hoc way in which it had been formed in the excerpt from her transcript below:

“It was all by mistake. I’d been up to the carers centre, and just popped in, and Dawn who helped me at the hospital, she said ‘Oh Joyce, there are 2 or

3 people going out for a little car ride do you want to go along with them?' I said 'Oh I don't know about that'. She said 'Just go out with them for half an hour'. We went out to Foxton Locks, came back and Dawn said 'You know one of the ladies you went out here with, she's suggested that they get a little group up so that you can have a little social group..... So how would you like to have a go at it?' I thought, well I said to her 'I've got no experience of secretarial work or writing letters or anything'"

Despite her lack of confidence, Julie did organize the former carers group very effectively and those who attended were positive and used expressions such as "very good" to describe it. Social events were organized for members of this group. As Joyce explained

"...we meet at the Grand Hotel for a toasted teacake and a cup of tea and coffee on a regular basis, usually about every couple of months. There are usually about sixteen turning up there. Go on a Summer outing, I book the coach tickets"

Through these events, emotional and appraisal support was provided; Peggy said that they gave them a chance to be with others who "have been through it " which indicated that there were mutual understandings and sharing of experiences.

Three of those interviewed had received bereavement support from a local hospice. This hospice was particularly good at maintaining contact with former carers and offering longer-term emotional support if required. Joyce described her experiences in the following excerpt from her transcript:

"I had that opportunity if I'd felt as if I'd wanted to speak to someone, at LOROS.... last Christmas, I even had a Christmas card come from the carer that used to come out from LOROS and that, you know, so I mean they haven't, I mean they are always contacting me, different things, so although he was only there 4 days, they still kept you, you know, in touch and that with you. You're welcome to go you know, whenever you want to go up there if you want to or I'd got the option that I could go in and have a talk"

Eighteen of the twenty-five used voluntary sector provision for carers as they attended carers groups or carers centres. As explained in Chapter 7, all but one of those who had belonged to a carers group or attended a carers centre whilst caring continued to attend post-caring. Another had joined a carers group post-caring. Attendance at these groups and centres was a useful form of emotional and appraisal support post-caring for

different reasons. As explained already, they were a source of friendship that provided emotional support. In addition, some thought they were, as Doreen put it, “a prop” and gave them an opportunity to reflect on their experience, and “talk it over.” This indicated that attendance at such groups and centres also helped them deal with their experiences and were therefore a form of appraisal, as well as emotional support.

Brenda showed that such support could also meet other more complex post-caring needs, and this accounted for why former carers saw them as a valuable form of support post-caring. She felt that

“.....carers groups are great because they don't mind you coming even if you've finished caring. They like you to keep coming. I mean I know all the people. They have fresh people but they are happy that we carry on going..... it makes you aware that there are still others that need support. A lot of them come, and people ask for help, or they have experiences, you know 'I've done that' or 'I've done this'. You can usually help somebody, we've all been in the same boat as well”

Brenda intimates here that in addition to being a source of friendship, attending a carers group gave her a sense of belonging, and gave her a “role” that allowed her to use her caring experience to help others. Her attendance therefore seemed to help her address some of the post-caring needs that she was experiencing as a result of the cessation of caring. For instance, her new “role” could have compensated in some ways for the loss of her role as carer.

Therefore although there was a lack of consistency in the support for former carers, the support that did exist seemed effective in meeting some post-caring needs as all of those who used it seemed satisfied.

Family and friends

The changes in involvement with family and friends post-caring were discussed in Chapter 7. Over three-quarters (thirty) had support from family and /or friends and in most cases these relationships were supportive. Nineteen reported that they had received support from both family and friends, five only mentioned friends and six mentioned

family only. As during caring, this type of support was valued and viewed positively; all this group of thirty made positive comments about the role of the family and friends post-caring who were variously described as “very good,” “tremendous” and “brilliant”.

Family and friends provided instrumental, emotional and appraisal support. An example of instrumental support from families was financial help. For instance, when Joyce was charged arrears with her council rent she said her son “took me up” to the local council offices. He acted as her advocate when he insisted on “a real explanation for this ...you said she had no money to pay.” Both her son and her daughter also helped her financially as she said she only managed to survive financially at that time by borrowing “bits off me children”. Ted explained how his friends had provided him with practical help when “they gave me jobs in organisations so I’ve got to organise things”.

The way that positive relationships with family and friends post-caring entailed outings, visits, holidays and invitations to meals was also described in Chapter 7. Whilst it can be logically assumed that the very nature of these relationships led to the provision of emotional and appraisal support, many of the examples of such support from family and friends were implicit rather than explicit. For instance Paddy referred to his daughter as “an angel” when describing the many ways in which she had supported him. This implies that a full range of support was provided by this family member. When talking about her friends Doreen said:

“I have lots of friends, I have lots of friends. My phone bills are big and I imagine that my friend’s bills are big as well because they’re old friends you know. I’ve got lots of friends”

These lengthy telephone conversations with longstanding friends indicated to the interviewer that emotional and appraisal support was provided. More explicit examples of emotional and appraisal support included the way that family and friends helped with “talking things through” and were a source of physical affection. Madge illustrated the latter when she said of her adult children, “I had the children to give me a cuddle and talk to me”.

These forms of support clearly met some of the needs that arose from the personal, social and financial losses experienced when caring ceased. Such needs were met through access to financial resources, social relationships, social activities and social roles that family and friends facilitated. In addition, they were a conduit for the expression of emotions associated with bereavement post-caring.

The local community

As discussed in Chapter 7, being integrated into the local community in some way or another also helped over half (twenty one) of the former carers rebuild their lives post-caring. Such integration mainly provided emotional and instrumental support. Comments about involvement in the various community, church and school groups mentioned were that it was “supportive”, “brought me comfort” and a source of “support and concern”. Michael gave a good illustration of the way that a village community could help to meet some of the needs of former carers in the following extract from his transcript:

“The other thing is that helped me is of course is that people in the village, I think they are very helpful. Penny came to me one night and said, ‘I’ve cooked you a leg of lamb, duck. Are you coming over to have a meal?’ Marlene, she used to be our next door neighbour at Lidlington, rang up and said ‘Cooking you Sunday lunch Michael, are you coming?’ And, now that is a definite invitation and I would go. I cannot accept these invitations which aren’t invitations. I’m not going to ring up and say, ‘I’m lonely, can I come to lunch?’”

The fact that Michael was integrated into his community meant that people reached out to support him, which, in his words “helped me”. His story here shows that this support helped him cope with needs associated with the loneliness of post-caring life and bereavement.

The findings about post-caring support that have been presented in this section are summarised in Table 7.

TABLE 7: POST-CARING SUPPORT

source of support	% provided with support	% satisfied	type of support provided
statutory organizations	51 (males 36 females 42)	32	emotional, informational
voluntary sector	68 (males 54 females 46)	100	emotional, appraisal
family and friends	80 (males 90 females 77)	100	instrumental, emotional and appraisal
community	57 (males 81 females 58)	100	instrumental emotional

Themes in post-caring support

The five concepts in this sub-category highlighted similarities and differences between experiences of support during caring and post-caring. The first was the *general low level of support post-caring*. It is particularly interesting that statutory services support was 28% lower than during caring. In fact, least use was made of statutory services post-caring whereas it had the second highest use during caring. However, this was because much use of statutory services had been on behalf of the dependant and so was no longer required. Although there was some bereavement support, there was a lack specifically for former carers. Furthermore, the support that was used provided a more limited range than that which was received during caring, and addressed only some of the former carers post-caring needs. Despite this, it needs to be acknowledged that, as Table 7 shows, dissatisfaction with the level of support available was far from universal; some of those who felt that the existing level of support in general was adequate gave reasons for their views. For instance two argued that “the support is there if you go and look for it”. Personality and approach to life also meant that some saw support as unnecessary, and therefore the level of support was irrelevant to them. This was evident from the way in which six interviewees said they believed in self-help. Una was one of these and summed up their sentiments when she said, “you got to get on with it yourself”.

The second and third concepts focused on the fact *that the satisfaction rate for statutory services continued to be the lowest and had in fact decreased* (see Table 6). In contrast, satisfaction rates for the non-statutory sources were 100%. Moreover, all these, with the exception of the local community (which had been rated as 100% satisfactory during caring), had increased. Thus, the former carers were far less satisfied with help from statutory services both during caring and post-caring than the other sources of help. Indeed, the difference between the satisfaction rates between the statutory and non-statutory services was greatest post-caring, with fewer of those interviewed being satisfied with the level and quality of help from statutory services both during caring and post-caring than the other sources of help.

The fourth concept was the *continued high reliance on the voluntary sector, family and friends and the local community for support*. Although there were some differences, these sources continued to have high usage rates; the voluntary sector and family and friends provided slightly more support post-caring than during caring, whilst support provided by the local community was slightly less than during caring. There was also evidence of continuities in the use of the voluntary sector, and family and friends. For instance, nearly all of those that attended carers groups during caring continued to do so post-caring and three quarters had post-caring support from the *same* friends and family members that had been supportive during caring.

Gender differences in the use of support was the final concept identified. During caring and post-caring the male former carers received more support than the females. Male former carers were also more likely to receive support from the voluntary sector, family and friends and the local community than the female former carers.

It could be argued that the lower rates of satisfaction with statutory services meant that former carers used those non-statutory sources of help still available to them that had been found satisfactory during caring. As explained at the beginning of this chapter,

they no longer had access to the commercial organisations they had used because the role of these organizations is restricted to the caring period. In addition, there was no evidence that they used any new sources of support or help other than those used during caring. Consequently, their sources of help post-caring were mainly the voluntary sector, family and friends and the local community. Although these less formal sources, especially family and friends, seemed to have compensated for the lack of statutory support, they could not meet more formal needs (such as physical and psychological health needs) and therefore only met their post-caring needs to a certain extent.

The evidence about the use of the same non-statutory sources in caring and post-caring and the absence of evidence of the use of other sources of support post-caring, indicates that the former carers' experiences of support during caring had an influence on their use of sources of help post-caring. The discussions have also shown that other aspects of the caring experience and its cessation influenced post-caring support experiences; these included the need for new friends after the personal and social losses experienced and for a new role following the cessation of caring. As indicated, a further influence on these experiences were some of the bereavement needs of those interviewed.

Therefore, the main issues highlighted in these discussions about post-caring support were its limited range, the gender differences in the level of support and the fact that there was very little that catered specifically for the needs of former carers. Not surprisingly, two thirds of those interviewed (twenty-five) felt there should be more support for former carers.

Suggestions about post-caring support

The two concepts in this category were suggestions about support during caring and suggestions about support post-caring. These suggestions were based on the interviewees' perceptions of their post-caring needs and the inadequacies of the support available during caring and post-caring. They focused on the need for more formal support. As it was not always clear which of the suggestions about post-caring support were for bereavement or post-caring needs in particular, it was not possible to

distinguish between support for bereaved and non-bereaved former carers. Nonetheless, there were some useful suggestions around acknowledging gender differences in needs, more flexible support and a more proactive role for the statutory services. The support typologies that have been adopted throughout this chapter were used to categorize the suggestions.

Support during caring

The ideas about support during caring concentrated on instrumental and informational support only. Suggestions about instrumental support focused on preventative measures for some of the post-caring health problems. Seven said there should be more instrumental support during caring to relieve the stresses and strain of caring which they saw as the cause of some post-caring health problems. For instance, Lydia felt that carers should be supported in terms of the provision of respite care and nursing help to prevent them from becoming “exhausted.” Her reasoning was based on her experience of the way that her “District Nurse...didn’t allow me to become totally exhausted..... and arranged respite care and nursing help in the home.” She argued that this was why she had “no ill effects afterwards”. Similarly, Brenda thought good support during caring “takes the worry out of it ” and prevents post-caring health problems.

With reference to informational support, four suggested that financial and legal advice should be given before caring ceased so that some “pre-planning” could be done. Lydia took this idea further in that she did not limit pre-planning to financial and legal matters. She thought it would also be useful “to introduce people to the thought that they are going to have to build a new life for themselves” post-caring. Two of these former carers made the point this sort of support should be tailored to individual needs. Any form of what Paula referred to as “blanket cover” would be unsuitable because, as Claude pointed out, “caring is so varied for want of a better word, the advice can’t be detailed, and you can’t say this is a set route or whatever”.

Support post-caring

Suggestions about support post-caring focused on emotional, informational and instrumental support. In this instance, the suggestions about informational and instrumental support are dealt with together as they were interrelated in the ideas put forward.

In terms of emotional support, nine felt that there was a need to have “somebody to talk to” and that it would be “nice to be open with somebody”. Eight of these made the suggestion that such support could be provided through support groups. There were differences in the type of support groups proposed; six, such as Christopher felt these should be set up specially “to support former carers”. The other two felt that continuing to belong to the same carers group that had been attended during caring can provide this sort of post-caring support. As Greg explained...

.....if you can get involved in a (*carers*) group like that then you've got a contact for afterwards.....I think if carers could get together, can get together beforehand, then that association could probably continue afterwards.

However, some in this group did point out that groups did not suit everyone; four said that some former carers were not “group people”, and it was felt that there should be “individual helpers” with whom former carers could “talk things over”. Another three (all men) thought these groups could be less useful to men. This was because, as in Christopher’s experience “they tend to be elderly ladies, I’m the only man. They sort of talk a lot about their caring experiences and it’s developed into more like a social group than anything else”. As a result he said “I don’t get much out of it.” Paddy talked about the way that his carers group had overcome this problem; they had “a male section” which he felt was useful because “we sit down and talk, you know”. In his view, this was better than having to listen to the women talking about things in which he had no interest!

The other form of emotional support suggested was counselling. Four said more counselling services would be appropriate. Only one, Julie, referred to counselling

specifically for former carers; she suggested counselling services at the carers centres could be extended to former carers, and said of her own carers centre “They’ve got counselling which could apply to ex-carers.” The other three focused on counselling for their bereavement needs as well. One of these was Peggy who said she still felt “down” at times even though she had ceased caring for her mother two years ago. She said

“If I had had somebody after my mother had diedI would have been a lot better, someone to talk to, I needed it really, I mean you felt as if I had got loads inside and I kept crying and I felt if I had spoke to somebody I wouldn’t have had this stress”

She therefore felt that counselling which addressed her bereavement needs as well as her post-caring needs would have alleviated the emotional lows she experienced post-caring.

The suggestions about informational and instrumental support focused mainly on financial advice, and help with filling in the appropriate benefit forms. Eight suggested that former carers needed these two sorts of help. With reference to informational support, there was a need for advice on “benefits” and “ a bit of advice on their pensions”. Instrumental support was required in terms of help “with filling in their application thing for the benefit ...after caring” and with “checking” their “bank books” to help claim benefits.

Although a range of ideas was put forward, their implementation is potentially problematic. This is because the consensus in their ideas was limited; each of the different suggestions made had a relatively low number of proponents. The particular issue of bereavement in this study further complicated matters. Whilst the ideas presented are creative and based on lived experiences, the effectiveness of some support, such as counselling, can be questioned. As early as 1950s Eysenck (1952) said successful outcomes of therapy were no different to that of placebos, the passage of time or help from friends. Rogers (1957) agreed with this to some extent but says that friendships falter and are vulnerable to defensiveness and pretence. More recent criticisms address the effectiveness and exclusivity of counselling (Crouan, 1994; Bedi, 2000; Reid, 2001; Boivin, 2003).

Conclusion

This chapter has shown that the former carers' experiences of post-caring support were shaped to a greater or lesser extent by many factors. Some of these were related to caring itself in that their experiences of caring, and in particular their experiences of support during caring, were influential. Other factors were the cessation of caring, their bereavement, the general lack of more formal support that aimed to cater for their needs, the extensive role of non-statutory sources such as the voluntary sector, family and friends in various combinations, and their local communities.

Some aspects of their post-caring support specifically addressed their needs as former carers whilst other aspects of the sources of support met their bereavement needs. Although many were satisfied with their non-statutory sources of help, on the whole, most of them felt that their needs were not met adequately. Their many diverse and original suggestions highlighted two main issues; the first was the importance of extending support during caring so that it has the potential to address needs that arise post-caring. The other issue was the requirement to develop new provision for former carers that would meet their needs following the cessation of caring and those arising from their bereavement.

CHAPTER 9: DISCUSSION

This chapter discusses, reviews and evaluates the findings that have been presented in this study. It starts by summarising the unique understandings that emerged from the final data analysis. These are then discussed in relation to the existing literature, as presented in Chapters 1 and 2, before presenting the formal theory that was developed from these findings. This is followed by an outline of the study's contribution to knowledge. The formal theory is then explained theoretically; additional literature was explored for this purpose because the existing literature did not lend itself to the nature of the formal theory, and therefore could not provide an adequate theoretical explanation. Finally, there is a critical reflection on the study.

Summary of final analysis

A summary of the main findings from Chapters 5 to 8 and the outcomes of further analyses undertaken on them are presented below. Reference is made to Figure 2 on page 213; this is the theoretical schema of the post-caring experience developed from the findings and will be discussed in more detail later in the chapter.

The discussions about the analyses demonstrate that although the subject of the study was former carers, findings about both the caring and post-caring experiences of those interviewed were produced. As the reflection on the caring experiences in this study was retrospective and in-depth, it provided unique insights into the *whole of the caring experience*. Chapter 5 showed that although over half of the sample had enjoyed caring and reported positive experiences, such as enhanced relationships with family and friends, the all-encompassing nature of the role of the carer negatively affected many areas of their daily lives. Indeed half of those interviewed said their lives were restricted to the extent that they could not "live their own lives". For instance, opportunities to pursue interests and activities were restricted, and if they did have any interests, these were often associated with the caring role or were accommodated within the caring role. Other negative impacts were the loss of social life and friends, or changed friendships. Marital relationships suffered, as did relationships with other family members. There

was a loss of employment and depletion of financial resources. The specific demands of caring meant that the health of just under half of the sample was adversely affected. Although a range of emotional, instrumental, informational, and appraisal support was provided by statutory organisations, it was the voluntary sector and family and friends that provided the widest range of support. In addition, there was least satisfaction with statutory services.

In relation to the *post-caring experience* itself, the analyses of the issues, processes and support in post-caring life in Chapters 6, 7 and 8, highlight the changes that occurred in the post-caring lives of those interviewed after caring had ceased. During further analysis these were classified as “losses” and “gains” (as shown on Figure 2) to reflect the main themes in the post-caring experience. “Losses” referred to decreases or deficits in the lives of the interviewees following the cessation of caring. The term “gains” was used to denote desirable or undesirable additions to their lives. These “losses” and “gains” did not represent a zero sum situation and were not experienced by every former carer.

The most important loss to those interviewed was usually that of the dependant. This loss also meant the concomitant loss of friendship, companionship and daily routines. As nearly half suffered from new health problems, this represented a loss of health post-caring for those concerned. They also faced the loss of social role and social networks without immediate replacements. There was an overall decrease in levels of support, particularly from statutory services. In addition, some experienced financial losses.

The most significant gain identified was a further caring role following the latest and /or previous caring experience (this was the case for over two thirds of those interviewed). Some also experienced desirable gains in terms of improvements in health, their financial situation and employment (if of working age), more involvement with and better relationships with family, and more time for interests, activities, and friendships. There were also welcome emotional gains such as a sense of relief, satisfaction, freedom and positive personal change. Less desirable gains included new tasks, such as

the “closure tasks’ of caring (discussed in Chapter 7) in the early phases of post-caring, and new emotions such as anger, guilt and feelings of negative personal change. It was the male former carers who were more likely to experience more desirable gains post-caring. Examples were the way men were more likely to enter a new relationship and express a sense of freedom post-caring, experience positive personal change and more support post-caring.

Further analysis also identified that there were three phases in the post-caring experience; these were the “post-caring void”, “closing down ‘the caring time’” and “constructing life post-caring. The “post-caring void” occurred upon the cessation of caring and involved specific emotional experiences, such as a sense of loss, and feelings of loss of purpose, disequilibrium, and loneliness and emptiness. The process of “closing down ‘the caring time’” involved winding down the routines of caring life and closure activities that were required before post-caring life could begin. The third phase was the process of reconstruction of life that occurred through serial caring, family, interests and activities, friendships, employment and informal caring. The second and third phases were facilitated or inhibited by certain factors, such as the role of their own conscious efforts, personality, health, gender, age, income, and source, level and type of support.

These phases were not experienced in a particular sequence and there was overlap between them. However, the “post-caring void” and “closing down ‘the caring time’” were transitory for all and did seem to be followed by “constructing life post-caring”. The extent to which this third phase was transitory was more complex; although it was only transitory for six of the former carers after their last episode of caring (two of whom had also cared in the past) it had also been a temporary post-caring phase for twenty of the former carers in the past. This meant that over two thirds of those interviewed of those interviewed were serial carers, and therefore the “constructing life post-caring” phase had been transitory at least once for these former carers.

In addition, the study uncovered many interconnections between the caring and post-caring experiences that had not been identified in the literature. The impacts of caring on health in the first year of post-caring discussed in Chapter 6 provide some examples of these interconnections; some former carers saw their short-term health problems as a delayed response to the demands of caring, whilst the health of others improved because of the absence of the stress they had faced when caring. Another previously undiscovered aspect of the relationship between caring and post-caring was the way in which the caring experience created a need not only for emotional but also informational and instrumental support post-caring. Closely related to this were the continuities in reliance on the voluntary sector, family and friends and the local community for support during caring and post-caring. As several aspects of the caring experience were a form of preparation for the post-caring experience, it could also ease bereavement and adaptation to life post-caring.

However, the most striking connection between caring and post-caring was described in Chapter 7. This was the way that over half continued their involvement with caring in some way or another by undertaking another paid or unpaid caring role, voluntary work, carrying out informal caring tasks for friends and neighbours, and involvement with carers groups, organisations and networks. These findings also indicate that continued involvement with caring of some kind was a significant part of the post-caring experience.

The retrospective nature of the study also enabled it to yield more comprehensive suggestions from the participants about support than other studies. Not only were there suggestions about additional emotional and informational post-caring support, but it produced suggestions about instrumental and informational support *during* caring in order to help prevent some post-caring problems.

Relationship of the analysis to existing literature

The insights from the final analysis are supported by some of the existing general and more specific research discussed in the literature reviews in Chapters 1 and 2 about

caring and carers. These include the rewards and restrictions of caring, the range of tasks of caring and their unending nature, and the negative effects caring can have on financial situations, personal and family relationships. In particular, this study produced evidence to support the main conclusions about caring and health presented in Chapter 2. The range of adverse physical and psychological health effects of caring are consistent with the findings about carers' health discussed in Chapter 2 of the literature review. It also showed how carers view their health as secondary to that of the person they are caring for, as most "solider on" with minor and more serious conditions because they feel they have no alternative.

Many of the findings about dissatisfaction with the level and quality of support during caring concur with the existing literature. More specifically, the finding that the male former carers had more support than the females is consistent with the studies about gender differences in support that were reported in Chapter 2. Another overlap between the findings in this study and those from the literature is the way that many carers had not defined themselves as carers during their caring experiences, even though the role of carer is politically and publicly recognised. The analysis also confirmed many of the links between caring and post-caring, such as the negative effects of caring on social and financial situations post-caring.

Some of the deviant cases are supported by existing literature; the improved relationship between Lydia and her adolescent son discussed in Chapter 5 accords with the study by Beach (1997) of the impact of family caring on adolescents mentioned in Chapter 1. This study examined the experiences of twenty adolescents aged fourteen to eighteen who were the grandchild of an Alzheimer's patient cared for by his/her immediate family. In most cases the main carer was their mother. One of the main conclusions was that in general the experience created a more mature adolescent who could empathise with elderly people and carers. In particular their relationships with their mothers became far more intimate and supportive. Although Beach's study was small and limited to those caring for Alzheimer's patients, it does suggest that this exception to the more general finding in this study that family relationships suffered during caring may well be less exceptional than the data implies.

Thus this study confirms existing research into the *caring experience*. Furthermore, the findings it produced about the *post-caring experience* concur with those identified in the literature. For instance, the social losses that occurred post-caring, such as lack of social contact, loss of social role and status. It also highlights some of the same negative physical and psychological health problems in post-caring life, as well as the patterns of health. These included the way that some former carers' health improved post-caring, whilst others acquired new health problems post-caring or the health problems they had developed during caring continued into post-caring life. The findings about some of the post-caring emotions are consistent with those from other studies. Examples were the mixture of positive feelings (such as relief, satisfaction, and personal growth) and negative feelings (such as guilt, loneliness, loss of purpose and anger).

Certain aspects of the process of filling "the gap" (Lewis and Meredith, 1988:140) left by caring and reconstructing life post-caring are in accordance with the qualitative studies that have addressed the post-caring experience (discussed in Chapter 2). For instance the findings in the studies by Lewis and Meredith (1988), Brown and Stetz, (1999) and Bond et al. (2003) about activities undertaken just after caring ceased and later. The way that some former carers took on another caring role post-caring matched Lewis and Meredith's "vocation carer". The lack of professional help available when caring ceases identified in this study confirms studies by Cartwright et al. (1973) and Hancock et al (1994). Although some suggestions about post-caring support were made by those interviewed in this study, only one was the same as those in the literature. This was the suggestion about counselling post-caring. Finally, many of the influences of caring on post-caring life were similar to the findings of previous studies, for instance, the negative effects of caring on financial and social circumstances post-caring.

The final analysis therefore supports some of the existing findings about caring and post-caring experiences. The development of the formal theory from the findings also contributes additional knowledge about the post-caring experience in several ways. This is the focus of the next section.

Theoretical contribution to knowledge

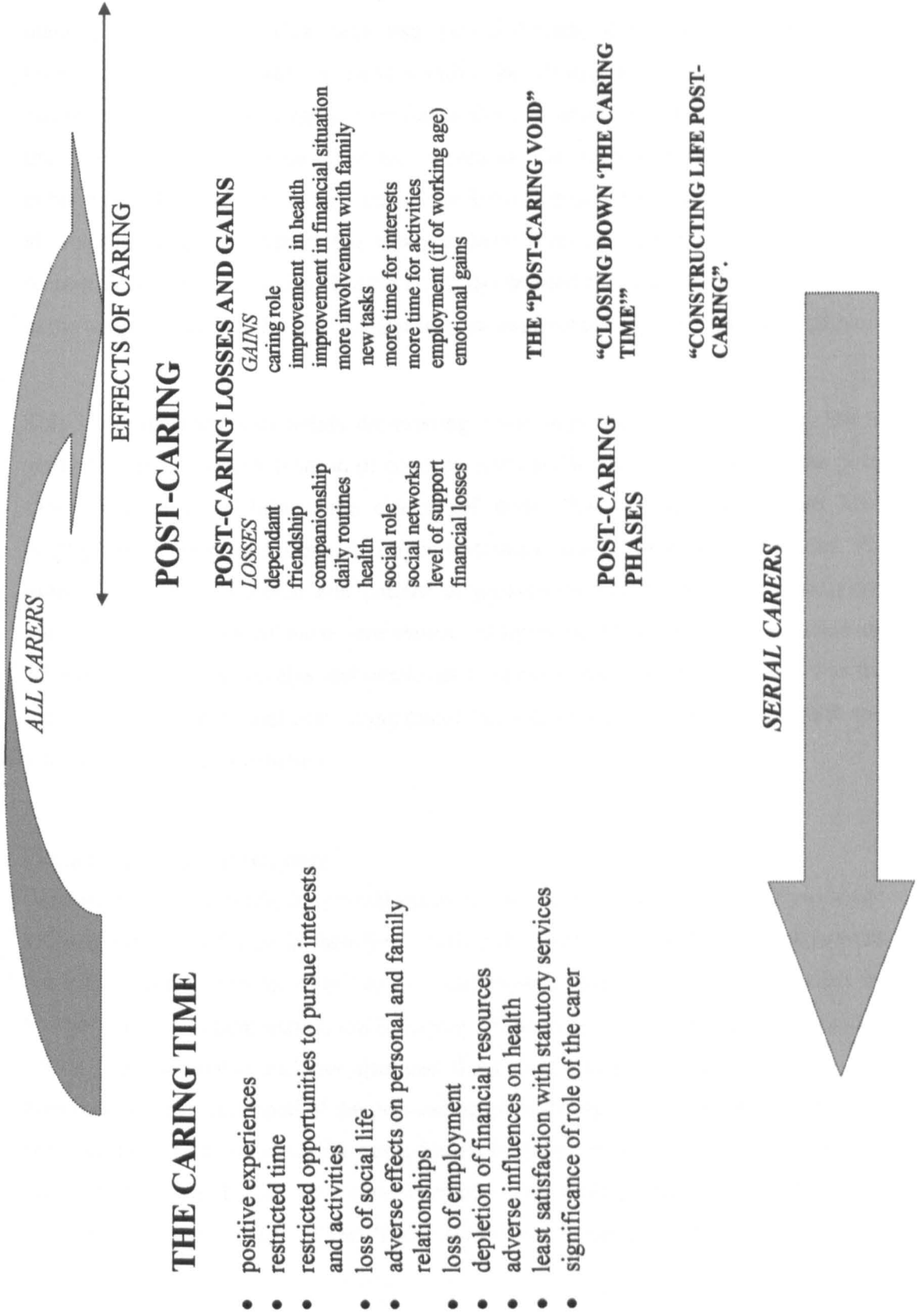
The substantive theory that emerged during the analysis was developed into formal theory through further integration of the categories identified throughout the process of the research. As mentioned above, this formal theory is illustrated in the schema in Figure 2 on page 213. This represents both the caring and the post-caring experience in order to contextualise the post-caring experience itself. The key features of the caring experience identified as a result of the analysis are included. The “losses” and “gains” experienced during post-caring life are set out in the part of the schema that relates exclusively to the post-caring experience. In the same section, the phases which constitute the post-caring trajectory are also shown - the “post-caring void”, “closing down ‘the caring time’” and “constructing life post-caring”. As these three phases were influenced by caring, this is also indicated on the schema. The schema shows that whilst all those interviewed went through the caring and the post-caring experiences described, 70% of them repeated the cycle again in their lives.

Thus, the findings about previous caring experiences increase and deepen existing theoretical understandings of *both the caring and the post-caring experience*. As a result, in addition to producing a schematic contextual representation of the whole post-caring experience for a range of former carers, (as opposed to particular aspects of it for specific groups of former carers) the study produced the following new concepts:

The post-caring trajectory

As discussed above and shown in Figure 2, the study established that post-caring life has an identifiable trajectory with three phases with distinct sets of experiences. Although Chapter 2 showed that Lewis and Meredith (1988) had already identified “the gap” left by caring, and there was some understanding of the very early phases of post-caring, the notion of a post-caring trajectory had not previously existed and extends this understanding in original ways.

Figure 2: Theoretical schema of the post-caring experience



With reference to the phases identified within the post-caring trajectory, the concept of the “post-caring void” draws attention to an experience common to those when they cease caring. As discussed in Chapter 6, this was unsettling and potentially created many emotional needs. This study also identified some of the factors leading to this void. Although a few of the experiences within the “closing down ‘the caring time’” and “constructing life post-caring” are similar to those in other studies about former carers, the development of these concepts increases the understanding of post-caring experiences. This is because they enable the identification of a point in post-caring life at which experiences change; the winding down from caring gradually ends and the reconstruction process begins. Furthermore, the detailed accounts of life in these phases in the trajectory give additional insights into the experiences of each post-caring phase.

This in-depth study also builds on existing knowledge about the post-caring life in general. It enabled identification of concepts such as “losses” and “gains” in the post-caring experience. Whilst some aspects of these “losses” and “gains” had been highlighted in existing literature, deeper understandings of them were provided. An example was how the type and pattern of post-caring health problems experienced impacted on the lives of those interviewed in terms of quality of life, restriction on activities, social relationships and employment opportunities. Another example was the identification of additional post-caring emotions, such as changed attitudes to health and a sense of personal satisfaction.

The concept of the “serial carer”

Reference has been made on several occasions to the way many of those interviewed had cared more than once in their lives. Although Lewis and Meredith had put forward the idea of the “vocation carer” to describe those in their study who had taken on another caring role post-caring, the frequency of the recurrence of the post-caring phase during the life course had not emerged from their study. As the schema for this demonstrates, the likelihood of the post-caring phase being experienced more than once in a lifetime is high; serial caring was a feature of these former carers’ lives as over two thirds had cared before or were currently undertaking further unpaid caring. Consequently, the concept of the “serial carer” was developed through this study to

describe this phenomenon. This concept also conveys the way the so-called “reconstruction” of life post-caring is only partial in that it often involves recreating previous caring experiences.

Theoretical explanations of the findings

This study therefore contributes to knowledge in that it provides new insights into the post-caring experience and more in-depth knowledge about aspects that had already been identified in the literature. As discussed in Chapter 3, although this study adopted a broadly interpretivist approach, other approaches were used to address issues that arose during the research; the importance of using other approaches became particularly apparent when explaining the study’s findings about post-caring experiences. The nature of the findings and theoretical knowledge meant that several approaches were explored in order to account for some of the *new concepts developed, different aspects of post-caring life* that had been identified and the findings about the *post-caring experience in its entirety*.

With reference to the *new concepts*, several theoretical perspectives were applicable to the concepts developed to describe the phases identified in the post-caring trajectory. For instance, role theory’s explanation of retirement was applied to the concept of the “post-caring void”. Role theory is based on the functionalist approach; according to this perspective, the cessation of caring represents the loss of a valued social role which conferred “status in society” (Hockey and James, 2003:160) and was a means to being part of a “ set of mutual obligations” (Layder, 1994, 20). The role incumbent person no longer has a function and /or a means of integration into society. Thus according to role theory, as former carers do not fulfil a recognisable role, they are no longer part of the social system and would be viewed as functionless. (Parsons, 1951; Layder, 1994; Hockey and James, 2003). However, this theoretical perspective has been criticised; it has focused more on men as it argues that women have less of a crisis because of their traditional housekeeping role (Layder, 1994; Hockey and James, 2003). This means that it has limited applicability to the “post-caring void” because, as discussed already, there were more females than males in the sample. Therefore, it

cannot provide a totally satisfactory account of the experiences of 70% of those who took part in the study. Moreover, it is dated in that there is now a less rigid sexual division of labour in both the public and private sphere due to changes in traditional gender roles previously referred to (Adkins, 1995; Doyal, 1995; Baxter, 2000). Consequently it is also unable to address issues that contemporary women and men may be facing during the “post-caring void”.

The use of the life transitions model to explain the “post-caring void” offered some insights into this concept; a life transition has been defined as a “permanent and sudden life change..... that initiates a period of dislocation and adjustment at both the individual and network level.... important assumptions people hold about the world and their place in it may also be challenged” (Wells and Kendig, 1997:666). This model has been used in association with discrete events, such as retirement and first day at school. Studies about these transitions have shown that these transitions result in the reorganisation of internal worlds (such as shifts in perceptions) and external worlds (such as changes in behaviour, role arrangements, social and interpersonal relationships) (Wells and Kendig, 1997; Kramer and Lambert, 1999). Although the end of caring may not always be sudden, it can be argued that the end of caring through death meets the criteria of a major life transition because it is a permanent change. As demonstrated, the “post-caring void” also led to those interviewed experiencing feelings associated with personal and social disequilibria, identified in Chapter 6. Furthermore, adjustment was clearly required for the successful reconstruction of daily life post-caring. (Wells and Kendig, 1997; Brown and Stetz, 1999; Bond et al, 2003).

The findings about the “post-caring void” also suggested it was comparable to another major transition in life that has been recently identified - “the empty nest syndrome.” The “empty nest syndrome” is usually defined as the transitional period when the youngest child has grown up and left home. Although there are debates about the existence of this syndrome, it has been associated with the end of caring in other studies (Hareven, 1995; Brown and Stetz, 1999; Bond et al, 2003). Indeed Brown and Stetz, (1999) use a quote from one of their interviewees who said “now I understand the empty nest syndrome” to illustrate this association (Brown and Stetz, 1999:192). The

absence of someone for whom they have cared, the permanent loss of role in relation to a particular person and the vacuum that is created can be seen as similar to the “post-caring void” for the former carers in this study. However, the evidence in this study about serial caring indicated there were limits to any analysis of the “post-caring void” in terms of a life transition. This is because the “post-caring void”, unlike the empty nest syndrome and other life transitions, which are “one off” life experiences, can be a recurring event in life. Thus an approach that encompasses a repeated event in life needed to be developed to fully account for the “post-caring void”.

The “empty nest syndrome” could also be applied to the post-caring phase of “constructing life post-caring”. This was because similarities with the findings about life after the “post-caring void” were identified in the literature on life changes that occur as a result of the “empty nest syndrome.” This literature showed that parents have a variety of reactions when their children leave home. These lead to different outcomes in terms of the reconstruction of their lives. Indeed, some parents find it difficult and react negatively to their perceived state of disequilibrium; such reactions include “overwhelming grief, sadness, dysporia and depression” (Raup and Myers, 1989:180) and loss of identity. However, other parents successfully adjust by creating their own meanings, renewing marital relationships, forging new identities and engaging in new activities. Influences on these reactions include personality, age cohort, societal emphasis on maternal role, work force participation and the development of alternative roles (Adelman et al, 1989; Wilbur and Dan, 1989; Raup and Myers, 1989; Crowley et al, 2003). The range of positive and negative reactions and influences highlighted in this approach are similar to those identified in this study and therefore this approach, despite its limitations (as discussed above) was applicable to the findings about the reconstruction of life post-caring.

Other approaches provided additional contributions to the theoretical analysis of the experience of “constructing life post-caring”. These were the interpretive and social constructionist perspectives. The findings showed that individual factors (such as personality and motivation) and social factors (such as age, gender and income) influenced the construction of post-caring life. It was therefore necessary to

acknowledge the role of both individual and social influences in order to understand the reconstruction of post-caring life. In accordance with the interpretive perspective adopted in this study, such findings can be seen as demonstrating not only the importance of understanding the meanings and interpretations of the former carers concerned, but also of understanding how the aspects of the social context shape the construction of post-caring life. An interpretive explanation of the findings about the way that the social context featured in former carers' lives would be that it limited or increased their opportunities for rebuilding their post-caring lives (Clarke and Layder, 1994; Sarantakos, 1998; Schwandt, 1999; Browne, 2000; Denscombe, 2002).

In terms of a social constructionist approach, the social factors identified are examples of the "social, political, cultural, economic, ethnic and gender factors" in society (Guba and Lincoln, 1994:113) that shape lives. The view of many of those who adopt a social constructionist perspective would be that these social factors illustrate the ways in which former carers are connected to the world around them, and the sort of influences on their post-caring lives (Mead, 1934; Goffman, 1972; 1984; Freund and McGuire, 1991; Guba and Lincoln, 1994; Hockey and James, 2003).

Another new concept produced as a result of this study was that of the "serial carer". Insights into this concept came from symbolic interactionism. This perspective would view the finding that another caring role had been part of the reconstruction of life post-caring, either in the present or past post-caring phases for over two thirds of the sample, was evidence of the way that these individuals had "assimilated" the caring role into their "personal identity" and was "a kind of role internalization" (Holstein and Gubrium, 2000: 33). Thus the concept of the "serial carer" could be explained in terms of individuals' internalisation of the role of the carer. This explanation is also supported by the findings in Chapter 5 about the significance of the role of the carer for those interviewed.

Particular *aspects of post-caring life* could also be theoretically explained. One was the continuity in the use of sources of non-statutory support post-caring, such as voluntary

groups and organisations, family and friends and the local community. The concepts of social integration and social support were used to explain this continuity.

The concept of social integration was originally developed by Durkheim (1968) and is about the relationships between individuals and institutions in society. It focuses on the societal relationships, which means those between individuals and societal institutions in society, such as the family, employment, and religious, political and voluntary groups. Durkheim argued that integration into these societal institutions helps people to cope when facing stressful life events because they provide mutual moral support and access to resources which enable them to cope.

There is a constant interchange of ideas and feelings from all to each and each to all, something like a mutual moral support, which instead of throwing the individual on his own resources, leads him to share in the collective energy and supports his own when exhausted

Durkheim, 1968:210

Thus individuals do not have to depend solely on themselves. He hypothesised that the more people were socially integrated, the more they were able to cope with stress and were “protected” during life’s crises (Durkheim, 1968; Freund and McGuire, 1995; Nettleton, 1995). Criticisms of Durkheim’s work include the way that he does not acknowledge the physical and mental states of individual actors and their influence on the degree to which social integration is efficacious (Gerhardt, 1989). Although the concept of social support is similar, there are important differences. Berkman (2000) locates the concept of social support in Bowlby’s work on attachment theory developed in the 1960s and 1970s because it articulates individuals’ “needs for secure attachment for its own sake” (Berkman, 2000:845). It has also been used and refined in the many studies carried out in the past four decades on social networks, kinship and community. In contrast to the concept of social integration, it focuses on the interpersonal relationships individuals have in particular contexts at micro level, such as in relationships between friends, as opposed to relationships at a societal level. However, its effects are similar to those of social integration in that such social support can also act as a mediator for stress and offer resources in tackling life’s troubles. There are different explanations of the effects of social support. These include the way these

interrelationships enhance our “sense of security and self esteem” (Berkman, 2000:845) and “empower individuals” and are “a source of self-validation” (Freund and McGuire, 1995:114) (Oakley, 1992; Whelan, 1993; Berkman, 1995; Freund and McGuire, 1995; Penninx, 1997; Berkman et al 2000; Gabe et al, 2004).

Other approaches only offered partial explanations of the continued use of non-statutory support post-caring. For instance, social identity theory was helpful to some extent with explaining the continued membership of groups such as carers groups and attendance at carers centres. This theory argues that we obtain our social identity from the social groups we identify with, and provides insights into the value of “group membership” to individuals. It maintains that people tend to overvalue the groups to which they belong, sometimes at the expense of other groups, because they boost their self-esteem and make them feel better about themselves. Hence, if carers defined themselves as a carer when caring and consequently joined particular carers groups, when caring ceased, it may have been psychologically detrimental to have to become a member of another “group” even if one had been available. Therefore, an explanation using social identity theory as to why some former carers may have continued to belong to carers groups and attend at carers centres post-caring is that the sense of membership this entailed was psychologically beneficial to them (Lippa, 1994; Saiki-Craighill, 2002).

However, whilst social identity theory could account theoretically for the continued membership of carers groups, it was unable to account for the continued use of both carers groups as a form of post-caring support in particular, and all the other sources of non-statutory post-caring support identified. The application of concepts of social integration and social support proved to be the most productive in developing the explanation of the continued use of the non-statutory sources of support post-caring.

An explanation based around the concept of social integration would argue that societal relationships between individuals and institutions in society provide moral support and resources. (Durkheim, 1968; Freund and McGuire, 1995; Nettleton, 1995). As explained above, these “institutions” include those identified as providing non-statutory support,

such as the family, friends, voluntary groups and organisations, and the local community. Consequently, a Durkheimian explanation using the concept of social integration would focus on the way the aforementioned societal “institutions” were a form of social integration, which helped to “protect” them from, and cope with, the stresses of both caring and post-caring. It can therefore be argued that those interviewed used these “institutions” post-caring as a form of support because they provided the same protection from the stresses in their post-caring lives as they did when they were carers.

Some of the sources of non-statutory support also operated at an interpersonal level. These sources were those between friends and the informal one-to-one relationships in the local community, and provided the various sub-types of social support identified. In terms of the information about this concept presented above, such social relationships give a sense of self worth and self-confidence in coping with life as a carer and a former carer (Durkheim, 1968; Whelan, 1993; Nettleton, 1995; Penninx, 1997). Once again, this can help to explain the former carers’ continued reliance on them post-caring, and, in conjunction with the concept of social integration, can explain their continued use of the non-statutory sources of support post-caring.

The use of the concepts of social integration and social support suggest that the nature of these sources of support meant they provided former carers with the psychological protection and resources that met their deep and inner needs, both during and after caring, in ways that other sources could not. This could also explain the continued higher satisfaction rates for these sources of support expressed. The very depth of these needs could explain the absence of their recognition or acknowledgment by those interviewed. The additional role of social integration and social support in the health of individuals (Berkman, 1994) indicated that these concepts also deserved consideration when devising and implementing post-caring support (Oakley, 1992; Whittemore, 2000; Berkman, 1994; 2000). These issues will be addressed in more depth in Chapter 10.

Thus several approaches provided insights into various concepts and aspects of post-caring life identified in the study. As the theoretical schema showed, after caring ceased, there are identifiable sets of experiences (referred to as “phases”) which seemed to constitute a definite stage in the lives of those interviewed. A coherent and comprehensive explanation of the *post-caring experience as a whole* was therefore obtained by approaching it as a particular stage in life.

Social constructionist perspectives provided theoretical insights into post-caring as a life stage. These perspectives have drawn on the concepts of the life cycle and life course as a means to understanding the fragmentation of social life. The life cycle approach was introduced in the 1950s and 1960s in connection with the family and is now outmoded, mainly due to criticisms about its ethnocentricity, static and systemised view of the family and its failure to acknowledge individual agency and the diversity of family lives. The emphasis on the life course in sociology has developed rapidly from the 1970s and has remained an important approach in this discipline as well as others, such as psychology, anthropology and gerontology (Arber and Ginn, 1995; Holstein and Gubrium, 2000; Borrell and Karlsson 2003; Hockey and James, 2003).

There are different strands to the life course perspective, but there are distinctive features that can be identified; overall, its approach to life changes over time is more fluid and flexible than the life cycle approach. It argues that the “passage of a lifetime” is not comparable to the “mechanical turning of a wheel” (Hockey and James, 2003:5) and stages in life are not necessarily standardised, chronologically fixed, sequential or clearly gendered. However, there are constraints on these stages in that they are subject to social, historical and cultural influences. Moreover, whilst there are changes as each new stage begins there are also continuities as a result of the way that these stages are interlinked and the character of the previous stage may influence future alternatives and patterns. An example of the way that inequalities persist from one stage to another is given by Arber and Ginn (1995) when they talk about how “inequality in later life is related to employment status and socio-economic groups prior to retirement” (Arber and Ginn, 1995:35). Although there is some debate within the perspective, it is recognised that the transition from one stage to another means emotional turmoil to a

greater or lesser extent, depending on the nature of the circumstances in which this occurs (Harris, 1987; Cohen, 1987; Rosenberg and Turner, 1990; Arber and Evandrou, 1993; Arber and Ginn, 1995; Hockey and James, 2003). Indeed, early work on the life course perspective focused on the way that these transitions involve an initial period of ambiguity during which there is a loss of identity; following this there is a more creative period characterized by a surge of activity (Hockey and James, 2003).

Therefore, as well as recognising collective experiences, this perspective also acknowledges the diversity of experience. It has helped to analyse the influences on the life experiences of different groups at particular stages of their lives and the constraints on these. In addition, it has been useful in analysing the increasing number of, and variation in, life stages that have arisen relatively recently in historical terms. These include childhood, adolescence, adulthood, engagement, homeownership, parenthood, grandparenthood, and retirement (Aries, 1965; Harris, 1987; Cohen, 1987; Hareven 1995). Hockey and James (2003) have argued that the transitions into each stage, irrespective of whether they are age related, are now more intensely ritualized because “consumption patterns proliferate around” some of the aforementioned “turning points” (Hockey and James, 2003:64). They illustrate their argument by pointing to the wide range of specially designed cards, gifts, costly celebratory activities and floral tributes that are now available for “turning points” such as twenty-first birthdays, engagements, new jobs and retirement. Such ritualisations have been seen as rites of passage which help to produce the new identity for the next life phase and are gradually becoming more intensely marked (Rosenberg and Turner, 1990; Arber and Evandrou, 1993; Arber and Ginn, 1995; Hockey and James, 2003).

As mentioned above, there are different approaches within the life course perspective. One approach has been to focus on the social construction of further “discontinuities in the life course” (Hareven 1995:125), which then become new formal stages in life, such as those mentioned above. These are not just based on biological differentiation but are socially constructed through the cumulative effects of “socio-economic and cultural changes” (Hareven 1995:132). For example, in preindustrial society, retirement did not exist. As communities were self-sufficient, and older people were still land and property

owners, people worked for most of their lifetime. Families were also large, and thus they were afforded considerable continued economic social familial and social power. With industrialisation there were particular social, cultural and economic changes that led to loss of these sources of status (such as work, land and property), and smaller families who were likely to move away to the cities to work. This constellation of changes led to a “gradual differentiation in age groups” (Hareven 1995:127) and created a recognized formal phase of life for older people in society that was not solely related to biological aging (Hareven 1995; Hockey and James, 2003).

Other approaches within this perspective place more emphasis on the role of the individual, the interplay between private lives and public events and the dialectical interplay between structure and agency. However, post-modern ideas about individuals having the “choice and autonomy” (Hockey and James, 2003:98) to give them the potential to endlessly create and recreate their life course are not totally embraced because of the operation of structural features in the life course such as “class position, family income, gender patterns, ethnicity, regionality” (Hockey and James, 2003:95) (Harris, 1987; Cohen, 1987; Hockey and James, 2003).

A recent example of this second type of approach within the life course perspective is the work done by Holstein and Gubrium (2000). They argue that they put forward an “alternate standpoint” (Holstein and Gubrium, 2000:xii). Their view is that the life course is a social construction. It is variable, does not have static stages or “objective features” (Holstein and Gubrium, 2000:182) and that people work at it, construct it and produce “progressive or developmental contours to personal experience in relation to time” (Holstein and Gubrium, 2000:2). When doing this, people use “interpretive practice” (Holstein and Gubrium, 2000:2); this occurs through the talk and interaction people engage in during all aspects of everyday life when making sense of and interpreting what they encounter. “Interpretive practice” involves “typifications” which help to distinguish between normality and abnormality, predictions about what will happen in the future, ideas about competence and incompetence, and knowledge of individual’s biographies.

Many diverse images and resources are available during this continuous construction of the meaning of experiences, including conventional developmental categories, such as childhood and old age. However, these images and resources are subject to various constraints such as social, cultural and historical circumstances. Holstein and Gubrium therefore argued that although most of us are “unaware of the construction process” (Holstein and Gubrium, 2000:43) we are the “everyday authors of our own lives” within “circumstantial constraints” (Holstein and Gubrium, 2000:182). They also argue that the life course is becoming de-privatised because so much of our lives are now subject to scrutiny and management by social organisations and institutions.

The life course perspective in general has been accused of being “vague at the theoretical level” (Arber and Ginn, 1995:28) and not contributing to sociological theory. The justifications put forward were that whilst material influences on the transitions in social life are highlighted, their sociological significance (such as their relative power) is not addressed. It also has limited application in the informal care literature; only one such study could be found that used a life course perspective. This was by Henz (2004) and specifically explored the interrelationships between informal caring episodes and employment over the life span. Indeed, life course research has recently been used to study health inequalities and has focused on relationships between disadvantage at different life stages and adult health (Dike van de Mheen et al, 1998; Graham, 2002). Nonetheless, despite such criticisms, the life course perspective and the different approaches within it were useful in highlighting the emergence of the post-caring experience as a possible *stage* in the life course.

Chapter 2 demonstrated that being a carer and caring is now recognised as a stage in life because of the cumulative effects of political, historical and cultural developments. Simultaneously, it was argued that those who had ceased caring were just starting to be recognised. Symbolic interactionism offered insights into this lack of full recognition of the post-caring experience; as explained in Chapter 3, symbolic interactionist interpretations focus on the way that social norms are “formed, sustained, weakened, strengthened or transformed” by “socially defining” processes (Blumer, 1969:20) that

involve *individuals* attaching symbolic meanings to their situations and interacting with others. Thus, this perspective would focus on the way that the ideas about former carers and post-caring generated by individuals and modified through social interaction to date have yet not been adopted as a “norm” in society as a whole (Goffman, 1968; Blumer, 1969; Thoits and Virshup, 1996; Cuff et al, 1998).

However, the life course perspective provided a more comprehensive interpretation. The findings about the post-caring experience could be interpreted as having the characteristics of an emergent life stage as discussed in Hareven’s (1995) and Hockey and James’s (2003) work. The progressive emergence of post-caring as a new stage in life in contemporary society could be explained as the result of the gradual impact of the cumulative social, historical and cultural changes described in Chapter 2. The post-caring experience also had some of the characteristics of a life stage within the life course perspective, such as the way its occurrence in life is not necessarily chronologically or biologically determined. In addition, the life course approach could also be used to explain any further developments of the post-caring phase by analysing the impact of future social, historical and cultural changes.

Furthermore, the life course perspective could account for the interconnections between post-caring and caring that had been established, and the way caring experiences influence post-caring experiences. The emotional turmoil experienced during early post-caring life could be associated with the transition between the two stages of caring and post-caring. The life course perspective could also explain the co-existence of the collective and individual experiences of post-caring identified because of the way it emphasises the role of circumstantial constraints and individuals’ ability to construct their life course. Evidence of the former was seen in the way that the social context shaped the reconstruction of life post-caring. However, the evidence in this study that so many of the former carers interviewed had consciously tried to rebuild their lives post caring conflicted with Holstein and Gubrium’s view that most people are “unaware of the construction process” (Holstein and Gubrium, 2000:43). Another strand to Holstein and Gubrium’s approach that was unsupported by this study was their argument about the de-privatisation of the life course due to the increasing scrutiny and management of

our lives by social organisations and institutions. The high level of non-statutory support both during caring and post-caring indicated a lack of intervention by such organisations and institutions in this life phase.

In addition, the concepts in the formal theory about the post-caring experience developed in this study could be explained in more depth using the life course perspective. For instance, with reference to the “post-caring void”, the changes in the use of particular services and different organisations that occurred at this time could be loosely interpreted as changes in the “consumption patterns” Hockey and James (2003) refer to which centre around such “turning points” when new life stages begin. However, they could only be *loosely* interpreted as such and there was nothing else in terms of recognised rituals to mark this “turning point”. Thus the sense of loss and feelings of disequilibria experienced during the “post-caring void” can be seen in terms of Hockey and James’ argument that there is no established rite of passage to date, as with other life stages, that could help to produce new identity for the next phase.

The “closing down ‘the caring time’” and “constructing life post-caring” phases discussed in Chapter 7 can be compared to the early work on the life course perspective. As explained, this argued that the transitions from one life stage to another involve an initial period of ambiguity during which there is a loss of identity, followed by a much more creative and active period (Hockey and James, 2003). During “closing down ‘the caring time’” the former carers interviewed were in an ambiguous in-between phase where they were “winding down” their previous phase of life in the absence of an obvious replacement phase. As demonstrated, the “constructing life post-caring” phase involved much more creative activity in terms of constructing a new life phase as former carers, for instance, by pursuing and developing interests and friendships.

Holsteins and Gubrium’s work can be used to explain the concept of the serial carer. They emphasise our ability to be “the everyday authors of our own lives” within “circumstantial constraints” (Holstein and Gubrium, 2000:182) and move away from “identifiable ...objective features of the life course...through time” (Holstein and

Gubrium, 2000:182-3). Therefore, the fact that caring is not necessarily a fixed or sequential life stage and recurs in some individual's lives can be explained as the outcome of their own responses to circumstances in their lives at particular times.

As this study did not address the actual process of the construction of this stage in life in depth, it did not produce evidence of Holstein and Gubrium's "interpretive practice" and the resources used during this process (Holstein and Gubrium, 2000:2). Nonetheless, although the life course approach could not provide a complete explanation of the findings in the study, it did highlight their significance in terms of the post-caring experience being a potential life stage and the need for further theoretical development of this issue.

Evaluation of the research

Critical reflection on the study showed that its success in contributing to knowledge that is emerging about the post-caring experience can be attributed to several factors.

As mentioned at the beginning of the chapter, the research aimed to focus on post-caring experiences. However, retrospective, in-depth subjective accounts of the former carers' caring experiences were also produced. As discussed, this meant that the study provided unique insights into *the whole of the caring experience*. Simultaneously, the understandings gained from the in-depth subjective accounts of the former carers' caring experiences facilitated the comprehensive contextualisation and exploration of the conditions of the *post-caring experiences*; other studies have not provided this retrospective, in-depth perspective on the post-caring experience and therefore have not identified the full impact of the context in which these experiences occur. In addition, unlike other qualitative studies about former carers, the *study* focused exclusively on former carers. Therefore, although some insights into the post-caring experience had been gained from other studies, this study increased the breadth and depth of many aspects of the post-caring experience, and produced new concepts such as "the post-caring trajectory" and the "serial carer".

Other factors that contributed to the success of the study in developing knowledge about former carers were that it used a broad definition of a former carer, and it explored a much wider range of former carers' understandings of the post caring experiences than other studies. These former carers were also at different stages in their post-caring experience.

In addition, some differentiation was made between the post-caring and bereavement experiences. Experiences exclusive to post-caring life were identifiable because of their links with caring and its cessation as opposed to the death of the dependant. Examples of the differences between post-caring and bereavement experiences were found in the types of losses experienced by former carers, their health and in the three phases of post-caring life. With reference to the losses experienced by former carers, several were directly related to the care of the dependant. These included the loss of benefits received because the dependant required care, loss of the role of carer, loss of daily routines associated with caring, and contact with caring social network. Although the caring experience was the dominant influence on health, some illnesses and were attributed to bereavement. The caring experience and its cessation shaped the post-caring void because of the way it led to a loss of sense of purpose. However, some of the emotions, such as loneliness could also have been caused by bereavement. Similarly, the "closing down 'the caring time'" phase involved both experiences unique to post-caring life as well as those that are part of post-bereavement life. The former included disposing of equipment used during caring, and the latter sorting out the deceased's personal belongings. Finally, aspects of the "constructing life post-caring" phase which were clearly post-caring included the way that interests and employment were associated with caring. Bereavement led to the increased role of the family in some cases in this phase. These sort of distinctions meant that the findings had relevance to both bereaved former carers and to former carers in general. These strengths therefore increased the generalisability of the findings.

Another reason why the study was successful was that relevant guidelines were carefully used to ensure that a rigorous qualitative study was carried out. Although other

approaches were drawn upon, the overall approach was based on grounded theory, and the central features of grounded theory were consistently applied, as appropriate, throughout the study. More specifically, the techniques of grounded theory were employed to address important issues such as reliability, validity, generalisability and the constructive and explicit application of the researcher's theoretical sensitivities. In addition, grounded theory was used to address some of the particular problems of this research, such as interviewees' recall and self-expression (Strauss and Corbin, 1998; Denscombe, 2002).

The depth of the analysis of the findings was increased by the timescale of the study; as explained in the Introduction, due to competing demands on the researcher's time the study has taken seven years from beginning to completion. The period of time devoted to the analysis and writing up allowed considerable time for reflection which was used to enhance the analysis of the findings.

The critical reflection on the study also revealed that it did have several limitations. One of these related to the nature of the sample. Although the aim of sampling in grounded theory is not to establish a random or representative sample, and the extent to which any sample can actually be truly representative has been questioned (Bryman, 2001), bias could have been introduced into the sample. Despite the efforts to use a broad range of contacts, some groups of former carers, such as those from an ethnic background who had been carers, were not represented in the sample. Other groups of former carers, such as those who are involved with carers groups, forums and organisations, were over represented. There were also some imbalances in the sample. For instance, there was a much higher proportion of older former carers than there is nationally; two thirds were over sixty compared to the national average of a quarter. In addition, the proportion of males to females was not representative of carers nationally; only 30% of the sample were male and 70% were female, whereas the national figures (discussed in Chapter 2) show that 42% of carers are men and 58% are women (<http://www.carersuk.org>, 2006).

An analysis of the responses from the eleven former carers who completed a questionnaire but did not wish to be interviewed did not identify why particular groups of former carers were more likely to decline an interview than others. However, the fact that the definition of a former carer stipulated that a bereavement conferred the status of a former carer *could* have led to some former carers being disproportionately inclined to refuse to actively engage in the research. There was some evidence in the study and in the literature which suggested that bereavement could have influenced willingness to be interviewed. Of the four interviewees, mentioned in Chapter 3, who withdrew after offering to be interviewed, one explicitly said that her anxiety about the interview was that it would bring back memories of her deceased dependant. Murray-Parkes (1993) found that people become less willing to be interviewed after six months following bereavement. As all of those in the sample had been bereaved for at least one year (see Appendix 13), this could also have influenced whether some former carers volunteered to be interviewed upon completion of the questionnaire in the first place.

These biases in the sample could have had implications for some of the findings. An example is the incidence of serial caring; the numbers involved with, and received support from carers groups, forums and organizations in this particular sample could have inflated the number of serial carers that emerged from the findings. As discussed in Chapter 5, such involvement could indicate a stronger identification with the role of carer and consequently an increased likelihood of taking on more than one caring role. It was therefore concluded that greater steps could have been taken to ensure the sample was more inclusive. For instance charities and Social Services Departments could have been approached for further contacts (Groger et al., 1999).

The timescale of the study could also be viewed as problematic; the original literature review was based on the literature up to 2000, and the research was designed to fill some of the “gaps” in understandings of the post-caring experience in the literature at that point in time. The literature search was updated throughout the study and, in accordance with the grounded theory approach adopted, new developments in the literature incorporated into the analysis and discussions of the findings. For instance, in and around 2000 several studies were carried out in Australia that addressed the post-

caring experience appeared in academic journals. Nonetheless, practical constraints of the research meant that any updating could not be as thorough as the initial literature review.

Another factor that needs to be considered is the accuracy of the data on health that was obtained. As with all other areas of the experience explored in this study, self-reports only were used. However, self-reports of health are likely to be inaccurate and seriously underestimate health problems, which can be clinically identified (Blaxter, 1990). Other studies have also used more objective measures of health in addition to interviewees' own appraisals (Bond et al 2003). Although, the absence of the additional use of more objective measures of health can be criticized, the whole issue of assessing health is fraught with difficulties and much debated. One of the main arguments put forward is that only an 'infinitesimal amount" (Zola, 1983:11) of ailments are ever brought to medical attention. This has led to the development of concepts such as the "iceberg of morbidity" (Verbrugge, 1986). Furthermore, whatever the debates about the data, the discussions in this chapter have been successful in explaining the findings about post caring health.

Finally, although the pen-pictures in Appendix 10 are accurate, there are inconsistencies in the type and amount of details in some of them. This is because they were based on information that, in accordance with the use of grounded theory, was gathered as theoretical sensitivity increased throughout the study. This inconsistency in information about the interviewees also imposed some limitations on the analysis. For instance, as the socio-economic status of those in the sample could not be ascertained, this influence on the interviewees' experiences could not be analysed (as discussed in Chapter 4).

Conclusion

This chapter has demonstrated that the way in which former carers' perceptions and interpretations of post-caring life have been explored in this study has made a significant contribution to the development of existing understandings of post-caring life. This is because it has produced insights into post-caring as a stage of life and

generated new concepts such as the “post-caring trajectory”, the “post-caring void”, “closing down ‘the caring time’”, “constructing life post-caring”, and the “serial carer”. Although several theoretical approaches helped in varying degrees to explain the new concepts and different aspects of post-caring life identified, the life course perspective provided the most comprehensive account of the formal theory about the post-caring experience developed as a result of the study. A need for further theoretical development in this area of research was also established. This and other recommendations made on the basis of the findings will be addressed in Chapter 10.

CHAPTER 10: RECOMMENDATIONS AND CONCLUSIONS

This final chapter outlines some suggestions about future policy, practice and research based on the findings from the study. The thesis is then drawn to a conclusion.

Recommendations for policy and practice

Recommendations for policy and practice were made based on the findings from the study in general. Relevant literature is referred to as appropriate to support and supplement discussions about the recommendations. These mainly focus on the necessity of addressing potential post-caring needs *during caring*, and to ensure there is a range of flexible support for former carers in their *post-caring lives*. This dual focus is particularly important because of the extensive interconnections identified between the caring and post-caring experiences and the potentially high numbers of serial carers who experience the whole cycle of caring and post-caring more than once in their lives.

Several policy developments that help with possible after-effects of caring were mentioned in Chapter 2. In addition, there are more recent policy developments and campaigns which have similar aims. For instance the Carers (Equal Opportunities) Act 2004 (implemented on 1 April 2005), and Carers UK's latest campaign "Make WORK work", which aims to ensure that carers have the right to flexible working (<http://www.carersuk.org>, 2006). Whilst these address some of the issues highlighted above, this study showed that fundamental to meeting the needs of former carers effectively is better systems for the identification of carers and former carers. The importance of this and how it relates to the other recommendations about the dual focus on carers *and* former carers are discussed in more detail below.

The identification of carers and former carers

The study has produced evidence that many of those who are caring are not formally identified as carers. This is clearly problematic in terms of ensuring that their needs are met during caring and post-caring. Therefore, the identification of carers in the

first instance should be improved, and efficient records about them should then be maintained. Initiatives such as that being launched by Carers UK during their Carers Week 2006 which aims to find ways of “reaching out to ‘hidden’ carers in every community, and ensuring they know where support can be found” (<http://www.carersuk.org>, 2006) could be developed by statutory bodies to establish databases on those caring, within for example, a local authority. The first recommendation is therefore:

- *the development of improved systems for the identification of carers and former carers.*

Key workers

The study has shown that not only are there unmet needs during caring but that these can also affect the post-caring experience. It is therefore proposed that once carers have been identified, they should be allocated a key worker. This person would fulfil a similar role to the “named professional” in “The Single Assessment Process”, introduced under the National Service Framework for Older People, responsible for co-ordinating older people's individual social care to ensure continuity in the provision of this care (<http://www.dh.gov.uk>, 2006). These key workers would be specially trained to deal with caring and post-caring issues and have a designated caseload of carers and former carers. During caring, they would monitor carers with a view to not only addressing their needs as carers but also potential post-caring problems and difficulties (for instance, health and financial problems). This could include liaising with statutory and non-statutory organisations to ensure steps are taken to reduce some of the adverse effects of caring identified that lead to post-caring difficulties. For instance the restrictions of caring, the adverse effects on personal and family relationships, employment, social life and the possible causes of ill health (such as the emotional stress of caring, the physical strain of caring, and carers' inattention to their own health needs). This key worker could also help with preparing and planning for life post-caring, for example emotional, social and financial preparation.

In order to address post-caring needs effectively, it is important that the same key worker continues the relationship post-caring as he /she will understand the sort of issues in the former carers caring experience that are likely to affect their post-caring

experiences. Key workers should maintain regular contact with former carers in order to monitor their social, emotional, physical and financial well being, help them with any problems and act as a mentor in the reconstruction of their post-caring lives. As well as liaising with statutory and non-statutory organisations as appropriate, key workers should also be a source of information about post-caring support (see below).

It is therefore recommended that

- *Carers are allocated to a trained key worker who works with them during caring and post-caring*

Post-caring support

The study showed that support for former carers needs to have certain characteristics in order to be effective. As discussed in Chapter 9, the study identified three phases in the post-caring experience. The probability of these experiences recurring in people's lives was also highlighted. Support needs to be developed to ensure that appropriate emotional, informational, appraisal and instrumental support is provided *to meet the range of needs that arise from these different post-caring experiences and their recurrence*. This support also needs to be *flexible* to suit the variety of needs and preferences of former carers. An example was the preference expressed for same sex support groups. Those who have cared for a dependant who has died may also need particular support; Sankar (1991) argues that the most effective support post-caring is that which relieves the carer of competing adult roles for bereaved former carers because they go through a key life transition "from a particular relationship with the dying person to bereavement" (Sankar, 1991:43). Finally, sources of post-caring support should *acknowledge the value of the societal and interpersonal relationships* that result from integration into local communities and social networks. The beneficial effects of such relationships were discussed in Chapter 9 and it is now recognised that they have powerful effects on both physical and mental health (Wilkinson, 1996; Penninx, 1997; Berkman, 2000; Whittemore, 2000).

Information about post-caring support should be disseminated widely. More specifically, key workers should be familiar with all the different forms of support and discuss them with the former carers with whom they work.

The recommendations that follow on from this discussion are as follows:

- *The development of flexible post-caring support that acknowledges differentiation in, and repetition of, the post-caring experience and promotes societal and interpersonal relationships within local communities.*
- *Information about all forms of post-caring support should be widely disseminated*
- *Key workers should take a lead role in informing former carers about post-caring support.*

Recommendations for future research

In general, the nascent nature of the theoretical contributions to knowledge about former carers produced by the study indicate that these require further exploration. It is recommended that effective exploration should involve the adoption of a national focus and use a larger, more representative sample. This would ensure that issues not addressed in this study, such as race and socio-economic status, could be explored as well facilitating a more in-depth exploration of age and gender. In addition, variations identified in the experiences of the different types of former carers could be more clearly established – for instance, those who have been bereaved, those whose dependant has gone into a home and those whose dependant has recovered. The use of both qualitative *and* quantitative methods would aid comparison with findings from other studies.

There are also specific areas in which future research could be usefully carried out.

Examples of these are:

the post-caring trajectory: As mentioned In Chapter 9, the concept of a post-caring trajectory was unique to this study. Whilst it does increase understanding of the post-caring experience, further research is required in order to develop a more comprehensive understanding of the phases within the post-caring experience that can then be used to guide the provision of post-caring support.

serial caring: This study identified the frequency and potential effects of serial caring. Further research into the concept of the serial carer would contribute to wider acknowledgement of its frequency and enable more constructive ways of meeting carers' and former carers needs to be devised and implemented.

development of theoretical explanatory frameworks. The absence of a comprehensive theoretical explanatory framework was highlighted in Chapter 9. In order to increase the depth of understanding of the post caring experience, existing and new explanatory frameworks need to be developed.

Finally, it is recommended that any future research should continue to raise the profile of former carers and inform practice. To this end, research undertaken should not take place in an academic vacuum but should aim to establish the perspectives of former carers themselves and for policy relevance. If these objectives are achieved future research will help to ensure the needs of former carers are met.

Conclusion

The structure and content of this thesis demonstrates the achievement of the main aim and expected outcomes of this study as outlined at the beginning of Chapter 3; the methodological rigour of the study, as described in Chapters 3 and 4, ensured that respondents' subjective conceptions of their experiences were accurately represented through the in-depth qualitative analysis of the post-caring experience. The knowledge gained from their understandings of these experiences and their conditions and consequences was presented in Chapters 5, 6, 7 and 8. In Chapter 9 this was analysed further and theoretically explored to produce an increased understanding of a range of former carers' subjective experiences. The way that the aforementioned contributed to the knowledge that is emerging about former carers is also described in Chapter 9. The implications of the findings for policy and practice and issues for future research have been considered in this last chapter of the study.

In addition to achieving its aims and expected outcomes, it is hoped that this study and subsequent work by the researcher can be instrumental in improving the lives of

the growing number of former carers who have so unselfishly cared for dependent people in our society.

APPENDICES

Appendix 1: Key definitions and classification systems

Appendix 2: Substantive post-caring issues, themes and experiences identified in the literature review

Appendix 3: Focus group schedule

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Appendix 14: Summary of the development of the core categories

APPENDIX 1: KEY DEFINITIONS AND CLASSIFICATION SYSTEMS

carer: The following definition was developed by the researcher from the literature review for the purposes of the research:

A carer cares for a dependant who cannot care for themself because of a disability /illness (not just because of immaturity) and for whom improvement/recovery is impossible. He/she feels a sense of obligation towards the dependant and carries the main responsibility for their care. The caring duties include both mental and physical support. These are not carried out on a paid professional basis and, excluding benefits, are unpaid. They impose more restrictions and complications on his/her daily life than when/if the dependant was 'normally well' or 'not disabled'"

former carer: The following definition of a former carer was developed for the purposes of the research from the literature review, and from the analysis of the focus groups and pilot study which formed the preparatory stage of the study:

"A former carer is someone does not necessarily identify themself as a former carer but who has experienced an episode of caring in the past that ended with the death of their dependant. This caring was not carried out on a professional basis, and excluding benefits, was unpaid"

health: Interviewees' own perceptions of their health were adopted as opposed to more formal definitions of health, such as those used by the World Health Organisation or those that have been classified as medical and non-medical (Williams, 1983; Blaxter, 1990; Freund and McGuire, 1995; Naidoo and Wills, 2001). However, as interviewees made reference to broad concepts of psychological and physical health, some of the concepts of health integral to such definitions were used. Where appropriate, health issues were therefore loosely grouped into those that were psychological and those that were physical. Psychological health issues were defined as those where mental state was emphasised, and where health problems were due to mental/emotional distress or disturbance. Physical health issues were defined as those where the emphasis was on physical condition. Any physical health problems could be attributed to a lack of physical fitness, infections or disease. However, a clear distinction between the two was often difficult because of the interrelationships between both types of illnesses (Blaxter,

1990; Miles, 1991; Bowling, 1991; 1995). When this occurred, it is acknowledged and addressed. The very nature of the study and the methodology adopted excluded measurement or verification of the interviewees' health or their interpretations of their health status.

Temporary health issues were defined as those that were only present during the first post-caring year. Permanent health issues were defined as those that were present both during the first and subsequent years of their post-caring.

“Social Services carers”: During the interviews, there was sometimes a lack of clarity in the usage of the concepts related to the concept of the carer. For instance, on several occasions the phrase “Social Services carers” seemed to embrace those employed by the commercial sector as well as those employed by social services. As verification systems were unavailable, the perceptions of those interviewed were used for the purposes of classifying the sources of support used during caring.

sources of support: Whilst some of the sources of support were classified using accepted classification systems, others were based on the interviewees' interpretations. The first three sources of support listed below were grouped using the Kendall and Knapp (1996) classification system in their work on the voluntary sector. The others were developed from the self -definitions of those interviewed.

Statutory services. These included services to which those interviewed had a legal right, such as Local Authorities, Social Services and Health Services. They were paid for out of taxation, their function prescribed by law, and had a large bureaucratic structure.

Commercial sector services. These services were those that were privately funded for profit. Fees were charged for the services and their funding came from payments from the customers. They were accountable to

owners and run by a corporate board of directors. Examples were privately run carer agencies and private care homes.

Voluntary sector. Defining the voluntary sector is problematic as it covers a diverse range of activities from the small-scale activities of local volunteer groups to large national charities and non-profit making bodies. It is also politically and ideologically contested and changes over time. This is evident from the way voluntary organisations have become increasingly large-scale and professional in their organisation over the past decade. For the purposes of this research, voluntary organisations were those whose primary source of funds was grants, fees, payments contributions and fundraising activities. They were self-governing, with their own internal decision-making structure and were not directly controlled by a private (for-profit) entity or by the state. Indeed, they were non-profit making and there was a meaningful degree of voluntarism in terms of money or time through philanthropy or voluntary citizen involvement. Examples were carers groups, carers centres and hospices (Kendall and Knapp, 1996; Baggott, 1998).

Family. Those who were referred to as “family” by those interviewed. They were relatives that formed part of their nuclear and extended families, including in-laws.

Friends. People who the interviewees called “friends” with whom they had either new or longstanding friendships

Local community: As demonstrated in Chapter 1 “community” is a contested concept which eludes a common definition and meaning. Such debates did not seem to have affected those interviewed as community to them meant their involvement with individuals, groups and organisations in their locality. This definition is therefore used.

types of support: Berkman et al's (2000) four subtypes of support were used. These are as follows:

Emotional support refers to love, sympathy, understanding and value. This is usually provided by a friend or confidante but can be provided by someone who is less intimate under prescribed circumstances.

Instrumental support is practical help with life's daily problems. It includes domestic chores (such as shopping, cooking, cleaning, childcare) and financial matters (link to support with the physical caring).

Appraisal support means help with decision making, dealing with feedback and agreeing courses of action.

Informational support is the provision of advice or information to meet particular needs.

The distinction between these subtypes is not always unequivocal. For instance, emotional, appraisal and informational can be hard to disaggregate. There are further problems in their use as analytical tools as there can be variation in the type, frequency intensity and extent of support provided. Some social relationships provide several types of support while others are specialised and provide only one type. Although there are other definitions, these subtypes proved to be the most useful in defining the support provided by each source identified.

APPENDIX 2: SUBSTANTIVE POST-CARING ISSUES, THEMES AND EXPERIENCES IDENTIFIED IN THE LITERATURE REVIEW

General themes:

- former carers may have ambivalent feelings about the end of caring and their post-caring experiences
- gender can influence the post-caring experience
- post-caring experiences can be linked to caring experiences
- grieving manifests itself in different ways and its possible impact on experiences respondents describe should be considered

Post caring experiences

employment

pension

social status

mental and physical health and any health problems

use of health services

illness behaviour

other ways of dealing with health problems

effects of the loss of restrictions and complications that caring imposed on their lives

use of time, social life, attendance at clubs, holidays, energy levels etc.

social networks e.g. friends, community participation

relationships with the immediate family e.g. any changes in personal relationships and family dynamics

interaction and relationships with the wider family

stress/anxiety levels

emotions experienced

confidence

self-esteem

sense of identity

feelings about caring experience e.g. bitterness, fears about ageing,

grieving process

emotions

effects of the loss of the total commitment that caring involved

relationships with formal services

changes in adaptations to home/physical environment that occurred as a result of the cared-for person dying

APPENDIX 3: FOCUS GROUP SCHEDULE

Introduction: *¹As I explained earlier, part of my research requires a proper understanding of what being a carer is. Therefore I would welcome your thoughts on who/what a carer is.*

1. Opening questions

Before I start, I would like to know you better - ask name (and who care for in the "carers" group).

2. Introductory questions

Ask for definition of a carer /explanation of what a carer is e.g. what is a carer? Follow-up any clues about the participants perceptions. These clues can also be woven into the discussion later in the session. If participants offer answers to introductory questions that are completely unexpected, follow these up later too.

3. Transition questions

Move the conversation to the key questions that drive the study. Get the participants to go into more depth than the introductory question.

4. Key Questions

Leave sufficient time for discussion of these - 10 to 15 minutes each.

So we've discussed what you think a carer is. Think of people you know who are not carers. What makes carers different from these people who are not carers? (may need to get them to reflect on this question). Discuss each point raised. The following questions could be used in each group to stimulate the discussions:

"carers"	"non-carers"
<i>what do you think makes someone a carer?</i>	<i>what do you think makes someone a carer?</i>
<i>why do you people say you are a carer?</i>	<i>what distinguishes a "carer" from a non-carer?</i>
<i>what distinguishes you from a non-carer?</i>	<i>lets draw up a job description for a carer?</i>
<i>lets draw up a job description for a carer?</i>	<i>lets draw up a job description for a carer?</i>
<i>when did you realise you were a carer?</i>	<i>what sort of tasks do you think a carer does? How are these different from, say those that a parent does for their child?</i>
<i>what made you realise you were a carer?</i>	
<i>think about the sort of things/tasks you do as a carer, how are they different from those of a non-carer?</i>	
<i>how many hours a day do you spend caring?</i>	

¹ This schedule was used for the both the "carers" and the "non-carers" group. It includes guidance for the researcher and the questions used. Italics denote the researcher's dialogue.

5. Ending Questions

Summarise key points for 2/3 minutes. Capture common themes and key phrases but also acknowledge differing points of view. Add what was left out and could have been said, and then ask the participants if the summary is adequate.

APPENDIX 4: INITIAL INTERVIEW SCHEDULE

1. Introduction

Present interviewer's official identity. Briefly restate the purposes of the research again, present the explanation about the research on the sheet of headed De Montfort University paper and ask the interviewee to sign the consent form. Invite the interviewee to "just talk" and explain that the interviews were not about saying the right or wrong things or saying what is required for the research.

2. Possible post-caring experiences to explore are listed below. Any new themes, concepts and interpretations that emerge from the ongoing literature review and the data analysis will be used to determine changes to this interview schedule.

Financial situation

financial situation
employment
pension
social status

Health

mental and physical health and any health problems
use of health services
illness behaviour
other ways of dealing with health problems

Social relationships

effects of the loss of restrictions and complications that caring imposed on their lives
use of time, social life, attendance at clubs, holidays, energy levels etc.
informal support received
social networks e.g. friends, community participation
relationships with the immediate family e.g. any changes in personal relationships and family dynamics
interaction and relationships with the wider family

Psychological legacies of caring

stress/anxiety levels
emotions experienced
confidence
self-esteem
sense of identity
feelings about caring experience e.g. bitterness, fears about ageing, grieving process

emotions

effects of the absence of cared-for one in the home

effects of the loss of the total commitment that caring involved

effects of having cared for someone who could not care for themselves because of their disability/illness

effects of having cared for someone for whom no improvement was possible

Contact with formal services

Forms of formal support received and /or would have been helpful

relationships with formal services

changes in adaptations to home/physical environment that occurred as a result of the cared-for person dying

3. Other Points to consider as the interviews are conducted:

1. The interviewer needs to be “open” to interviewees’ personal interpretations of such experiences for the following reasons:

- former carers may have ambivalent feelings about the end of caring and their post-caring experiences
- gender can influence the post-caring experience
- post-caring experiences can be linked to caring experiences
- grieving manifests itself in different ways and its possible impact on experiences respondents describe should be considered

2. Double check the interviewee meets the criteria in the definition of a former caregiver that is being used for this research.

APPENDIX 5: INTERVIEW CONSENT FORM

CONSENT FORM

This interview is being carried out as part of a research project about former carers at De Montfort University, Leicester by Mary Larkin. The project aims to explore former carers experiences since they ceased caring, in order to gain a better understanding of these experiences. All interviewees are assured of complete confidentiality.

Please sign below if you consent to being interviewed for this project by Mary Larkin.

SIGNATURE _____

DATE _____

APPENDIX 6: FINAL INTERVIEW SCHEDULE WITH SUMMARY OF AMENDMENTS

1. Introduction

Present interviewer's official identity. Briefly restate the purposes of the research again, present the explanation about the research on the sheet of headed De Montfort University paper and ask the interviewee to sign the consent form. Invite the interviewee to "just talk" and explain that the interviews were not about saying the right or wrong things or saying what is required for the research

2. Possible post-caring experiences to explore

Financial situation

financial situation (*any problems? - FC8 15/09/00*)
employment (*any changes in employment post-caring? - 22/05/01 after preliminary analysis of FCs who worked. These were FCs 26-30*)
pension (*any problems? - (FC8 15/09/00)*)
social status

Health

mental and physical health and any health problems
use of health services
illness behaviour
other ways of dealing with health problems

Social relationships

effects of the loss of restrictions and complications that caring imposed on their lives
use of time, social life, attendance at clubs, holidays, energy levels etc. (*differences in use of time and social life between men and women - FC8 15/09/00*)
informal support received
social networks e.g. friends, community participation
relationships with the immediate family e.g. any changes in personal relationships and family dynamics
interaction and relationships with the wider family

Psychological legacies of caring

stress/anxiety levels
emotions experienced (*e.g. relief, depression - 5/01/01 after ongoing literature review. Any positive emotions - 18/03/01 during analysis of*

long-term carers. sense of freedom - 23/04/01 during analysis of some of the male carer. Regrets - FC31 24/05/01)

confidence

self-esteem

sense of identity

feelings about caring experience e.g. bitterness, fears about ageing

grieving process

emotions

effects of the absence of cared-for one in the home

effects of the loss of the total commitment that caring involved

effects of having cared for someone who could not care for themselves because of their disability/illness

effects of having cared for someone for whom no improvement was possible

what has helped with coping with such legacies of caring in the post-caring experience? e.g. personal experiences, personal resources, job - 03/08/00 after reanalysis of FC1 and FC5. Feeling that they had done all they could for their dependant - 5/01/01 after ongoing literature review. Having another "caring role" - FC14 19/02/01

ways in which the experience of caring changed him/her as a person - FC7 8/09/00 positive and negative ways in which the experience of caring changed him/her as a person - after preliminary analysis of FC35 and reanalysis of earlier transcripts

ways in which the experience of caring had influenced employment/career choices FC12 16/02/01

Contact with formal services

forms of formal support received

relationships with formal services (*nature of relationships since caring ceased, change in number of contacts with formal services, less stressful than when caring - FC1 29/06/00 and ongoing literature review*)

changes in adaptations to home/physical environment that occurred as a result of the cared-for person dying (*note evidence of lack of any such changes - 22/05/01 after further analysis of any long-term carers*)

suggestions about other forms of support that would have been/would be helpful post-caring - 29/06/00 FC1 and ongoing literature review.

Advice that could have be given during caring about post-caring - 07/06/01 after preliminary analysis of FC35 and reanalysis of earlier transcripts

3. Other Points to consider as the interviews are conducted :

1. The interviewer needs to be "open" to interviewees' personal interpretations of such experiences for the following reasons:

- former carers may have ambivalent feelings about the end of caring and their post-caring experiences

- gender can influence the post-caring experience e.g. women's pension rights - 18/03/01 during analysis of long-term carers class can influence the post-caring experience - 5/01/01 after ongoing literature review.
- length of caring can influence the post-caring experience - 7/02/01 after on going data analysis)
- number of times been a carer can influence the post-caring experience - 10/05/01 after initial analysis of interviews with serial carers
- cultural attitudes towards care can influence the post-caring experience - 04/06/01 after preliminary analysis of FC35 and reanalysis of earlier transcripts
- post-caring experiences can be linked to caring experiences e.g. level of support and help received during caring - FC11 9/02/01 and after ongoing literature review. Circumstances which led to caring - 18/03/01 during analysis of long-term carers. Worked while cared - 18/03/01 during analysis of long-term carers. Ways in which the caring experience is a preparation for post-caring - 4/04/01 during reanalysis of FC13 and 14. Number of people cared for at any one time - 05/06/01 after further analysis of FC17 and initial analysis of FC32.
- post-caring experiences can be linked to who was being cared for and their biological relationship to the former carer- 28/02/01 after re-analysis of FC10, 11, 12
- grieving manifests itself in different ways and its possible impact on experiences respondents description should be considered

2. Double check the interviewee meets the criteria in the definition of a former caregiver that is being used for this research.

APPENDIX 7: KEY INFORMANTS

Contact	Date	Reason for contact	Issues discussed
Research staff at Carers UK	December 1998	to explore emerging concept of the former carer	Nature of existing research on former carers, need for more research, type of research required, interest in research into former carers
Chairman of a Carers Forum	September 1999	to set up focus group for carers	issues identified in data analysis about caring, such as the nature of caring, emotional, social and financial effects of caring
Senior academic who had carried out extensive research into carers	September 1999	to discuss ways the study could extend existing knowledge	current knowledge, possible sources of literature and information, possible contacts
Carers Centre Research worker	September 1999	unplanned meeting at Carers Research Group	former carers support group run by her carers centre, developing the sample issues identified in data analysis such as lack of support for former carers, support needs of former carers
2 District Nurses	March 2000	to explore the lack of recognition of former carers' needs by professionals that had been identified in data analysis	requirement for post-bereavement visit to former carers, practicalities of carrying out and frequency of such visits

Co-ordinator of carers' organisations	June 2000	to develop theoretical sampling	possible participants issues identified in data analysis such as the effects of bereavement on former carers, sense of loss of purpose at the end of caring, support needs of former carers
Co-ordinator of carers' organisations	July 2000	to develop theoretical sampling	possible participants issues identified in data analysis such as the effects of bereavement on former carers, sense of loss of purpose at the end of caring, support needs of former carers
Bereavement counsellor	July 2000	effects of bereavement on post-caring experience that had been identified in the data analysis	distinction between bereavement and post-caring emotions, influence of bereavement on health, influence on the grieving process
Senior academic	January 2001	use of procedures in grounded theory	adaptations of grounded theory, data analysis, studies that had used and adapted grounded theory

**APPENDIX 8: QUESTIONNAIRE FOR THEORETICAL SAMPLING
QUESTIONNAIRE**

The information you provide on this form will not be given to anyone else. In addition, you do not have to give your name and address if you do not want to.

1. Who did you care for?

2. What was the nature of their disability/illness?

3. Were you the main carer?

4. Did you work while you were caring for this person?

5. How long did you care for them?

6. When did you cease caring for this person?

7. Have you cared for anyone else?

8. Are you caring for anybody else now?

9. In which age band do you fall (*please tick*)
18 - 29 30 - 39 40 - 49 50 - 59 60 - 69 70 - 79 over 80

The next stage of my research involves interviewing about 40 former carers. If you are willing to be interviewed, please put you name, address and telephone number below.

TITLE (Dr/Mr/Mrs/Other) _____

NAME _____

ADDRESS _____

TELEPHONE NUMBER _____

Thankyou for completing this questionnaire. Please return it to Mary Larkin in the SAE enclosed.



DE MONTFORT
UNIVERSITY
LEICESTER

Department of Health and
Continuing Professional Studies

Ext. 8766

FORMER CARERS RESEARCH PROJECT

I am based at De Montfort University, Leicester and am carrying out research into the experiences of carers after they have finished caring. The main aim of my research is to try to gain a better understanding of these experiences and I hope that the research findings will be used to improve the situation of former carers, whose needs are only just beginning to be recognised.

I would like to ask if you could just spend a few minutes completing the attached short questionnaire in order to help me with my research. A prepaid envelope is also enclosed so that it can be easily returned to me. Any information volunteered at any stage in the research will be treated confidentially.

Thankyou in advance for your help. If you would like to discuss my research with me further, please do not hesitate to contact me.

A handwritten signature in cursive script that reads "Mary Larkin".

MARY LARKIN

APPENDIX 10:INTERVIWEE PEN PICTURES

This appendix contains brief pen pictures, based on the researcher's perceptions, of all the interviewees. They were all given pseudonyms and appear below in the order in which they were interviewed.

Julie was aged between fifty and fifty-nine and had cared for her husband, who suffered from dementia for a year. He had died four years before the interview was conducted. She had given up her part-time job as care assistant at a residential home when caring ceased. The local carers centre had asked her to set up and chair a support group for former carers. She clearly had many friends and was well integrated into the community. Her son and daughter lived nearby. She looked after her granddaughter twice a week. Three of the others interviewed were members of her former carers support group and they all spoke highly of Julie and what she did for the group.

Peggy was aged between sixty and sixty-nine. She was very willing to talk and described how she had never stopped caring and always seemed to be "caring" for someone (aunt, mother, father-in-law) and was now caring for her disabled husband. She had been carer for her mother, who died two years before the interview, for twenty years whilst simultaneously carrying out caring tasks for her disabled husband. She had obviously enjoyed caring for those she had cared-for. She and her husband seemed to exist on very little money but did not seem to resent this - the caring seemed more important to them. Whilst she still had caring role (sister and disabled husband) she had developed some new interests such as swimming and exercise classes. She belonged to Julie's former carers group and enjoyed it very much.

Doreen was over eighty. She was also very willing to talk about caring for her husband for whom she had cared for three years. He had suffered a very bad stroke and went in and out of residential homes as there were times when she could not cope with caring for him as she was in poor health herself. Although she had a son who lived locally with his family, she had very little family support. Her husband had died four years before the interviews. She said that she had also cared for her grandparents as a child. The house was absolutely immaculate! She belonged to Julie's former carers group and carried on going to a carers centre.

Jenny was a very sociable lady aged between sixty and sixty-nine who had cared for three people (her mother, brother and partner), none of them for longer than three years. The last episode of caring ended two years prior to the interview. She had kept up her social life whilst caring and had developed new interests since caring ceased and seemed to enjoy being interviewed - she talked a lot about her herself, her experiences and the effects on her as a person. She was very involved with her family and frequently helped

her two daughters out with babysitting. Although she now had a very full life, she said she would like to undertake paid caring work

Sue was in her forties. She was likeable but she seemed to take on too much all the time and lived a chaotic life! For instance, she had done several courses, and in addition to caring for her neighbour for ten years, she had also cared for several people (such as her parents). She had ceased caring for the neighbour four years ago. She was now helping to care for her mother-in-law, and said her husband had criticised her getting “too involved” with caring for others.

Una was sixty-three and had shared caring for her mother with her sister for twenty-two years. Her mother had lived in a bungalow nearby and died a year before the interview. Una had been very close to her mother who obviously had a very strong personality. Una was a sensitive, open, warm and welcoming person with plenty of interests. She was well-integrated into local community which included being very involved with her church. Since caring ceased, she had taken up new interests - keep fit classes and swimming. She had done paid caring work in the past and now did voluntary work at the carers centre.

Joyce's husband had died eighteen months before the interview and she cared for him for the last ten months of his life. Although she came across as a quiet person, it was obvious that this lady, who was in her sixties, had hidden emotional resources from the way that she had coped with caring for her husband. She had much support from her daughter and her son, indeed her son and family lived next door and her daughter-in-law walked past the window and into Mavis's back porch to help herself to vegetables during the interview. There was also evidence that she was well known in the area as people waved or called out as they passed by her house.

Pat was aged between fifty and fifty-nine and had cared for her husband for fourteen months as he was dying of lung cancer six years ago. She had cared for others (mother-in-law and her own parents) and worked part-time as a nursing auxiliary in a local hospital. She was a gregarious and capable lady – for instance, she talked about lots of friends and one of her best friends telephoned at the end of the interview. She was also very involved with her own family, especially her three grandchildren.

Michael cared for his wife for many years, but intensely for the last eight months of her life. Earlier in his life he had helped to care for both his mother and mother-in-law. Although he had been the “breadwinner” in the traditional sense he had not adopted such a traditional role at home as he had also had carried out many domestic duties such as cooking. This resilient, self-sufficient and capable eighty year old was very well integrated into the local community. He was now friends with the District Nurse that helped with his wife and has a close relationship with her (they go out together and cook

meals for each other), and felt that this had helped him through the two years since his wife had died.

Paula, at thirty-three, was the youngest of the interviewees. She had cared for her mother, who died a year before the interview, for seven months as she was dying of bowel cancer. She had also cared for her grandmother before that and said that she may have to care for brother as he is currently having tests for bowel cancer. A very capable and articulate person who had coped well with being the single parent of a five year old son as well as caring for her mother. She was currently doing a Masters Degree in Systemic Psychotherapy, working at carers centre and on carers forum.

Lydia was in her fifties. She had cared for her mother for two and a half years and finished caring four years ago. Her mother was in bed for about the first twelve months due to problems with an operation and subsequent treatment. During that time, caring was intensive but Lydia had plenty of support, some of which she paid for herself. She had also never had to work and felt that the absence of financial pressures helped particularly during caring. Her mother then improved and was able to stay with other members of the family. In the end, she died of old age when staying with relatives

Jo cared for three people – her grandmother, a male friend and her mother. She cared for the last two for a total of ten years and some of this was concurrently. Caring had ceased 2 years before the interview. This lively sixty-four year old retired teacher was now very interested in caring issues. She was a lay member of a Primary Care Group and aimed to keep carers on the Primary Care Group's meeting agenda all the time. She said that wanted to take part in the research to help to bring the plight of former carers to policy maker's attention and give them a higher profile.

Brenda was aged between seventy and seventy-nine and had cared for her husband for eight years. She had also cared for her mother and helped to bring up her sister during the war. Although her husband had only died two years before the interview she showed that she had adapted well to post caring life. She had much support from members of her family who lived nearby and enjoyed participating in many activities in her village. She was a very quite person, but had found inner resources whilst she was caring and found that she had learned to cope with the demands on her well.

Greg's wife had suffered from rheumatoid arthritis for twenty years and had died two years ago. He had taken early retirement from a managerial position in the newspaper trade to care for his wife when caring for her became more intensive in the last years of her life. He felt that at his age (late seventies) many of his friends had died but he had become involved in an artists group and had exhibited his work. He only had one child, a son, who was single, lived nearby and took him out regularly.

Freda was very reluctant to talk about her post caring experiences and kept returning to her caring experiences. She was aged between seventy and seventy-nine and had cared for her husband, who suffered from Multiple Sclerosis for thirty-nine years until his death two years previously. Whilst caring for him, she had also run her own business and studied for qualifications. She was very involved in a group for disabled people which provided her with plenty of contacts and friends. One of her two sons was very supportive, emotionally and financially.

Paddy was also aged between seventy and seventy-nine. He was a capable, resilient, resourceful and practical man. He kept himself busy with an allotment and was still involved with the carers group he attending during caring, even though he had ceased caring eighteen months prior to the interview. His only daughter, who lived locally, and was also very supportive. He was fiercely proud of the way that he had cared for his wife for seven years and talked about how much of a relief it was to know that she did not have to go into a home.

Claude was a retired Land Surveyor in his fifties who had taken early retirement at fifty-five to be with his wife. The firm was offering redundancy packages and he had wanted to spend more time doing things with his wife who had been in a wheelchair for many (eleven) years. He had cared for her since 1985 when she broke her spine. Prior to that he had helped to care for his mother-in-law. His wife was diagnosed with breast cancer in 1997 and died two years later (just over a year before the interview). His twenty-eight year-old son lived with him and ran a gardening business. He was sociable, had an active social life and was well integrated into the community.

Ted was an ex-managing director in his seventies who had taken retirement at sixty-one to look after his wife who had Picks dementia. He had cared for her for eleven years until her death two years previously. During three of those years, he also cared for his mother who had lived down the road. Although he did not have any children, he had much support from friends and was well integrated into the local community, in which he had grown up. He seemed to have a good social life and he also had a "new lady friend". He kept in touch informally with some other carers (one of whom was also a former carer) but did not want to belong to any formal groups.

Derek was over eighty and lived in a very well kept house. He had been an engineer in the family firm but when that had to be sold at the end of his career, he worked part-time as a Resources Technician at the local school. He had spent much money in trying to get a diagnosis for his wife who had ME for fourteen years and had died five years ago. He was a caring, thoughtful, practical man who had become Deputy Chair of a carers forum since he ceased caring, and did some caring tasks for a friend. He had two daughters who had never married, one of whom was an Anglican priest.

Lucy had cared for her terminally ill father for about six months. He had died three years ago but since then she had cared for her university-aged son, who had mental health problems and had recovered. She was a part-time social worker in her fifties. She was clearly well integrated into her family and local church community, and had several supportive friends. She wrote to me after the interview to say that she thought that caring for her father had adverse effects on her children as they have both had mental health problems.

Doris was a lively seventy-five year old who had spent ten years caring for her husband and sister-in-law, at times simultaneously. Her alcoholic husband had predeceased her sister in law who died a year ago. Although there was not much evidence of disposable income in her small council flat, she was resilient and self-sufficient and refused to feel sorry for herself despite all the adverse things that seemed to have happened to her. She was very involved with friends and family locally and often helped her son and his family out.

Christopher was a Methodist lay preacher in his seventies who lived in Methodist sheltered accommodation. He had two sons from his first marriage, one son had always been supportive but both sons were now supportive. He had cared for his two wives and also helped a neighbour from time to time. His second wife was diabetic and had strokes as a result of this. In the two years that had passed since he had ceased caring for her, he had become involved with caring groups and voluntary organisations, and had taken several holidays with friends.

Elizabeth, who was in her seventies, had cared for her diabetic husband in his last year of life and had taken early retirement to do this. More recently, she had cared for her mother for about seven years until her death a year ago. Although she had held an important position in the BBC she said accepted her caring roles as her duty. She seemed fairly isolated as she had no children and no contact with her only sibling and said that many of her friends had died.

Madge was a lively resilient eighty-year-old mother of seven. She had cared for her sister for a year at weekends when she had to be institutionalised permanently. She had also cared for her second husband who suffered from Alzheimer's and had died a year before the interview. She said that she did not feel sorry for herself and felt that you had to make a new life for yourself post-caring. Most of her children lived locally and she was very well integrated into the local village.

Bob was a sixty-year-old man who had cared for his wife, who had had MS, for nineteen years. He had been told to give up work when they received the diagnosis, and had brought up their only son as well as caring for his wife. It transpired that he had also had responsibility from the age of seventeen for his mother and sister when his father died.

He had also done and continued to do caring tasks for neighbours and friends. He had developed several health problems since caring ceased six years ago and found that his depression meant that he lacked any enthusiasm for life.

Ethel lived with her disabled husband in what had been her parents' house. She had been main carer for her mother (who died two years ago) in the house for thirteen years, worked during caring until six months before her mother died and also carried out caring tasks for her husband. Although she was still only in her fifties she had not returned to full-time work since caring ceased but has undertaken various paid carer jobs for agencies and "keeps an eye on the old lady across the road". She seemed very bitter about her experiences but this could have been because of the depression, which she still suffered from. She loved gardening and had a very elaborate garden.

Molly was an unmarried woman in her mid to late forties who had lived with her parents all her life. She cared for her mother for eight years, and gave up her job as supervisor of the typing pool at the City Council about a year before her mother died as it became too difficult to care and work. She had made various improvements to the house since her mother died two years ago and had also made new friends as a result of joining the local church. She now had a part time clerical job in a local solicitors office.

Clive was an ex-local government officer in his late sixties who had worked for a firm of solicitors at that the end of his working life. He had previously owned a "big house" in Northampton but had managed to get a flat in a Church of England retirement complex. He had cared for his wife who suffered from MS for thirty-two years. Although two of his three children lived abroad, they are all very supportive. In the year since his wife had died, he had developed a new relationship with the widow of a couple he and his wife were friendly with and was now enjoying a social life that was different from the one he had had before.

Joan was a very welcoming, thoughtful and friendly lady, with a good sense of humour. Initially she had not really wanted to be interviewed as her husband, for whom she had cared for seventeen years, had only died a year ago. She was also "looking after" her father. She was well integrated into the community and had made a conscious effort to develop new interests post-caring and become involved in many new activities. Her son and a daughter both lived locally. Although she was only in her fifties, she was not working as she was still "on the sick" and had developed diabetes since caring ceased.

Sandy was a part-time District Nurse in her sixties. She was a very organised and capable person who had worked part-time whilst caring for her husband for five and a half years and was still in the same job. She had also cared for her mother for the some of the time when caring for her husband. Although she said she did not have a "social life" she did go out walking with friends and to the gym. She was very involved with her four

children and their families, and did caring tasks for people in the village. Her husband had died six years before the interview.

Beryl had divorced her first husband on the grounds of cruelty, and ended up caring for her second husband who was in and out of a residential home during the five years that she cared for him until his death six years previously. He had mental health problems and ulcerated legs. She was aged between seventy and seventy nine and suffered from poor health herself (severe arthritis). Although there was not much evidence of disposable income, she did go on holidays. Indeed, she had met her a man on one of her holidays and was due to remarry in June 2001.

Jane was aged between sixty and sixty-nine. She had cared for her husband for eight months when he was dying of cancer. He had only died eighteen months previously. She was a courageous lady who lived in a spotless, well-maintained council house on a rough estate where crime and drugs were a great problem. She had cared for one of her sisters when she was young. She was now also caring for her critically ill ninety-three year old mother with another one of her sisters. She had many friends and her two daughters were supportive.

Terry was in his sixties and had cared for his wife for about six years. She had needed much care because of a severe stroke and had died about eighteen months before the interview. He had kept some interests up during the caring and had continued these and developed new ones post-caring. He had taken early retirement from his technician's job at a local university before his wife became very ill. He was a very capable and resilient person and had adapted to post caring life well with the support of his children and their families and long-standing friends.

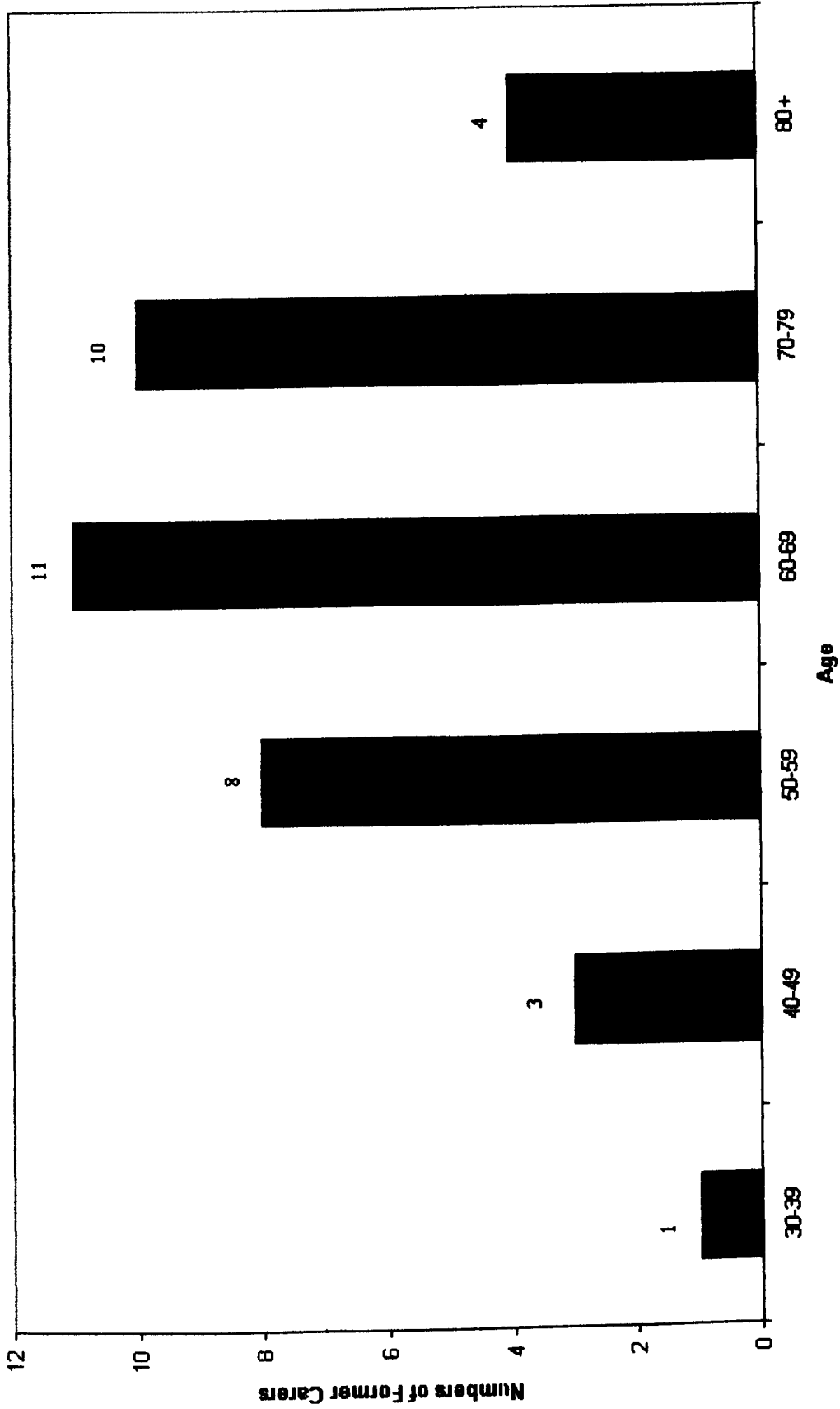
Betty was aged between seventy and seventy-nine and had cared for her second husband for ten years. He died eighteen months before interview. She still continued to do "caring" things, such as volunteering for Age Concern. She had friends locally with whom she undertook various activities. She also seemed well-supported within the local community and by her family, for instance, she often went to her son's for a weekend.

Penny was one of the younger former carers interviewed as she was in her forties. She was a teacher, but was now just doing supply and working as a Teaching assistant in a Nursery to fit in with the family. She had cared for her father who had died a year ago. As she was an only child, she had given up her job to help her father to care for her mother and then cared for her father who lived with them for two years. They had combined the proceeds of the sale of their house and his after her mother died and bought a bigger house for them to both live in.

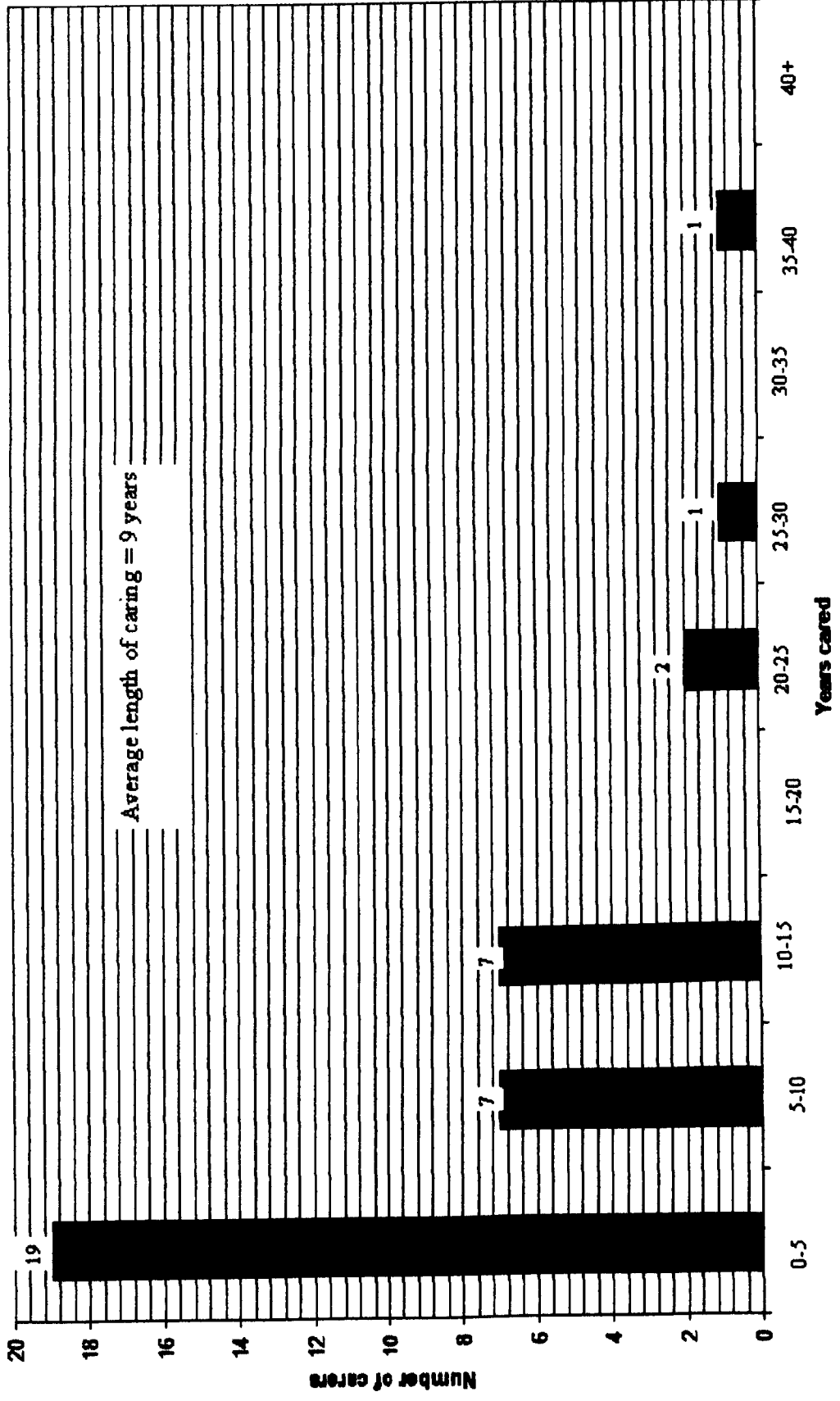
Sylvia was an ex-teacher who had cared for her father-in-law for four months. He had died just over five years before the interview. She was in her sixties they had had a big Victorian house, which had enabled them to give her father-in-law a bedroom and sitting room when he came to live with them. They had also had various alterations done to the rooms they gave him, such as the addition of a toilet and washbasin. She was well integrated into their village and on various committees, including being Chair of the School Governors. She had three children and was very family orientated, for instance, she had supported her daughter through a divorce.

Joseph was a pantomime and comedy show actor who used to do pantomimes and summer shows at seaside resorts. He was in his fifties and had been main carer for his mother (who had suffered from Alzheimer's) for about five years. He lived in the parental home and was involved in the local community; he had also become involved in an art group, carers groups, carers forums and helped with various voluntary organisations since he finished caring two years ago. He now only supplied and made costumes and did the odd show locally. He indicated that he may have to move out of the family home when his sister's entitlements in his mother's will were eventually sorted out.

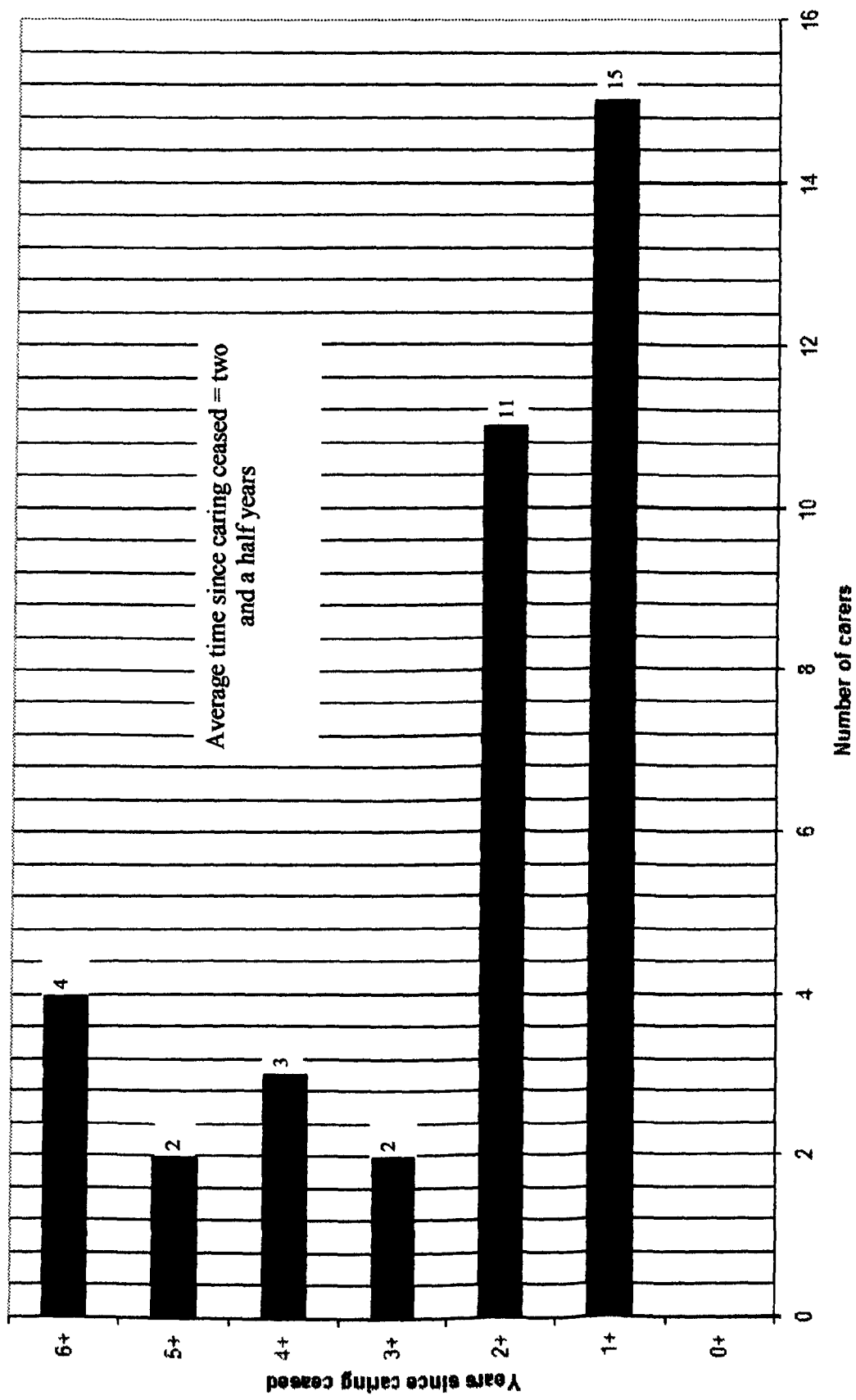
APPENDIX 11: AGE DISTRIBUTION OF SAMPLE



APPENDIX 12 — LENGTH OF TIME SPENT CARING



APPENDIX 13: LENGTH OF TIME BETWEEN CESSATION OF CARING AND INTERVIEW



APPENDIX 14: SUMMARY OF THE DEVELOPMENT OF THE CORE CATEGORIES

The development of four core categories is discussed below. Reference is also made to relevant chapters and tables in the study.

1. The caring time (Chapter 5)

Working from the bottom of the Table 3 (page 103), the indicators used for this core category that were labelled during microanalysis are listed in the first row. The second row shows the concepts that emerged when similarities and differences between the indicators were identified during open coding.

For instance, the concept of *“social life”* was developed from the indicators “lost social life”, “limited social life”, “social life restricted by dependant’s illness”, “social life restricted by nature of dependant’s illness”, “advancing age affected number of friends” and “positive experiences of friendships”. The concept *“emotional stress”* was developed from “behaviour of the dependant”, “time-consuming nature of caring”, “rigid routines”, “lack of control over daily life”, “conflict with services and service providers”, “emotional labour of caring”, “guilt”, “anger”, “friction with the dependant”, and “fear”. Under the sub-category *“caring and support”* the concept of *“multiple sources of support used”* was devised from many of the indicators such as “statutory organisations” “General Practitioners”, “Social Workers”, “Hospitals”, “District Nurses”, “Social Services carers”, “Occupational Therapists”, “chiropodists”, “benefits”, “grants for building alterations”, “respite care”, “privately run carers agencies”, “private care homes”, “carers groups”, “carers centers”, “hospices”, “family and friends”, and “local community”. The concept of the *“significance of the role of carer”* was derived from the indicators labelled “wanted to tell the interviewer about their caring experiences before and during interview”, “returned to the story of caring experiences when the interviewer tried to end the interview”, “longest responses to comments or questions by the interviewer were about the caring experience”, “details about the personal nursing care that they had provided for their dependant”, and “continued presence of equipment and accessories

required for caring in their homes". Finally, the concept "*recognition of the restrictive nature of caring for the carer*" was developed from the indicators "encouraged to pursue interests", "encouraged new activities", "created opportunities for leisure activities", and "acknowledged need for carer to have a break from caring".

Some of the same indicators were used in different concepts. For instance, the concepts "*social life*" and "*emotional stress*" shared the indicators "time-consuming nature of caring", "rigid routines", "restricted opportunities to pursue interests and be involved in activities outside caring", "lost social life", "limited social life", "social life restricted by dependant's illness", and "social life restricted by nature of dependant's illness".

During axial coding, the concepts were integrated to form five subcategories. These were "**caring and daily life**", "**caring and health**", "**caring and support**", "**caring and the role of carer**" and "**caring and the cared-for person**". The core category of "The caring time" was then evolved from these subcategories.

As explained in Chapter 4, the process of developing core categories was not sequential, and the different types of coding often took place concurrently as the theoretical scheme was continually refined. An example was the way that further microanalysis was carried out during the development of the sub-category "**caring and daily life**". The concept of "*restrictions of caring*" was originally developed from the indicators but, upon saturation, additional microanalysis showed that these restrictions were multidimensional. They affected not only the amount of time available during caring but many areas other areas of daily life, such as opportunities to pursue interests and activities, social life, and personal and family relationships. As a result, the original concept was refined and new concepts developed.

2. Issues in the post-caring experience (Chapter 6)

The indicators, concepts, and sub-categories identified during the development of this core category are set out in Table 4 on page 135. As in Table 3, the indicators used for this core category that were labeled during microanalysis are listed in the first row.

During open coding, several concepts were developed. Examples from each sub-category were as follows. The concept of *“financial losses”* was developed from the indicators “improvement in financial situation”, “lost benefits”, “lack of adequate life assurance”, and “financial hardships whilst finances were sorted out”. The indicators “loss of purpose”, “feelings of loss”, “disequilibrium”, “loneliness” and “emptiness” were used to form the concept *“experiences of a void”*. The concepts of *“absence of ill health”* and *“improvements in health.”* were developed from different combinations of the indicators “no health problems”, “no after effects of caring”, “resolution of health problems”, “felt better”, and “looked better”.

There were interconnections between the indicators within each concept. For instance, some of the losses under the sub-category **“cessation of caring”**, such as loss of daily routine and loss of social network were closely linked to the indicators under the sub-category **“the post-caring ‘void’”**. Similarly, the concepts developed were interrelated. An example was the way the concepts under the **“the post-caring ‘void’”** were linked to some of the more negative health experiences highlighted by the concepts under the sub-category **“post-caring health”**. Relevant literature was also used in the development of some concepts. The literature on bereavement helped to identify illnesses that were the outcome of bereavement and the grieving process in order to establish that these were influences on post-caring health. The development of this core category differed from that of “The caring time” in that there was more of an imbalance between the number of concepts developed for each sub-category. This was mainly due to the number of dimensions of each sub-category identified through the indicators and concepts upon saturation. The number of concepts does not increase or lessen the importance of a sub-category, but merely shows the extent and density of the data available. Refinements were continually made to concepts and sub-categories during the different stages of the coding process. An example was during the development of the concept of *“social losses”*. The concept that was originally developed as *“loss of social role”* focused on the indicators about loss of the role of carer. However, during further microanalysis and open coding for other concepts, indicators about loss of social networks and lack of recognition of the concepts of “former carer” and “post-caring experience” emerged. These were integrated into the aforementioned indicators and the broader concept of *“social losses”* developed to

acknowledge the loss of social networks and absence of an identifiable social role following the cessation of caring

Axial coding was used to develop the three subcategories. These were then integrated during selective coding to develop the core category of "Issues in the post-caring experience".

3. Life post-caring (Chapter 7)

The development of this core concept is set out in Table 5 on page 165. Examples from each sub-category of the way indicators identified during microanalysis were integrated into concepts during open coding are as follows. With reference to the sub-category "closing down 'the caring time'", the concept of "*closure tasks associated with the end of caring*" was developed from the indicators "disposing of the equipment", "returning house to pre-caring state", "overdue domestic chores", "outstanding decorating", and "sorting out benefits associated with the caring", "change from the daily routines of caring", and "changes in the sentient work of caring". The indicators "now undertaking informal care", "informal caring tasks for friends and neighbours", "cared prior to most recent episode", and "cared more than once" were used in the development of the concept "*serial caring*" that formed part of the sub-category "constructing life post-caring". Within the final sub-category of "factors influencing life post-caring", the concept of "*health problems*" resulted from establishing similarities and differences between the indicators "permanent health problems", "unable to cope with people", "gave up job", "inability to concentrate", "difficult to rebuild life", "problems with longer-term relationships", "physical activity limited", "social activities were limited", and "unable to maintain some family contacts".

There was some sharing of indicators between concepts. For instance, the indicators "change from the daily routines of caring", and "changes in the sentient work of caring" featured in the concept of "*changes*" and the concept "*closure tasks associated with the end of caring*". Saturation led to discovery of different dimensions; when "increased involvement with family" was saturated it was

discovered that there also was a reversal in roles in the family in that former carers now had to accommodate to the needs of the family more. Therefore further indicators, such as “changes in roles in the family” and “more of a two-way relationship with families” were produced. In addition, the concept “*informal caring*” was originally developed from the indicators “now undertaking informal care”, and “informal caring tasks for friends and neighbours”. However, upon saturation, two new indicators emerged. These were “cared prior to most recent episode” and “cared more than once”. Twenty had cared prior to their most recent episode of caring and twenty-six had cared more than once. When the implications of the numbers of former carers to whom these indicators applied were considered, the additional concept of *serial caring* was developed. It also embraced the indicator “now undertaking informal care”.

The use of numbers also helped with the refinement of other concepts within this core category. An example was the concept of “*enhanced role of families*”. This was finalised by counting the frequencies of positive and negative indicators about the role of the family post-caring. Far more indicators denoted a positive role of the family post-caring than a negative one.

Axial coding was then used to develop the three sub-categories. There were some interconnections between the concepts within each sub-category. The concept “*lack of disposable income*” under “**factors influencing post-caring life**” was partly linked to the concept of “*paid employment*” in the sub-category “**constructing life post-caring**”. This was because the lack of and nature of employment in post-caring lives of those interviewed did not provide opportunities to increase their incomes. Finally, the core category “The processes of post-caring life” emerged during selective coding.

4. Support post-caring (Chapter 8)

The development of this sub-category is set out in Table 6 (page 190). As above, indicators identified during microanalysis were developed into concepts during open coding. Starting with an example from the sub-category “**sources of post-caring support**” the concept of “*multiple sources of support*” was devised from many of the

indicators. These included “statutory organisations” “General Practitioners”, “Social Workers”, “District Nurses”, “counsellors”, “voluntary sector provision for carers”, “voluntary sector provision for former carers”, “family and friends”, and “local community support”. The development of the concepts within the sub-category “**themes in post-caring support**” was based on a more complex process. It involved the use of concepts and indicators from the sub-category “caring and support” that featured in the discussions about the core concept “The caring time” (as discussed above and in Chapter 5). For instance, indicators such as “satisfaction expressed”, “dissatisfaction expressed”, “level of support for their dependant was inadequate”, “the level of support for carers was inadequate”, “services were unsuitable”, “staff were unsympathetic”, and “quality of support” as shown in Table 2 were used. In addition, further microanalysis took place. The second concept in the third sub-category - *support post-caring* – emerged from the indicators “emotional support post-caring”, “group support”, “former carers groups”, “carers groups”, “disadvantages of groups”, “individual support”, “counselling”, “support specifically for former carers”, “bereavement needs”, “informational and instrumental support post-caring”, “help with filling in the benefit forms”, and “advice on benefits and pensions”.

Axial coding enabled the identification of the aforementioned three sub-categories. During this process there was much integration of the concepts within the sub-categories “**sources of post-caring support**” and “**themes in post-caring support**”. Specific examples were the concepts in each of these sub-categories that focused on satisfaction rates. Selective coding established the core concept of “Support post-caring”.

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