Caring and working: a hermeneutic phenomenology study exploring the experiences of working-age male family carers

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Abstract

Over 1.25 million men in the UK are juggling employment with caregiving, yet their experiences remain relatively unexplored. The competing obligations of caregiving and employment may affect their well-being and their paid work. An in-depth knowledge of how working–age men experience being a carer and employee is pertinent, as initiatives encourage carers to remain in employment, while the meaning of their work may change.

This thesis examines the lived experiences of male carers through a hermeneutic phenomenological approach. However, there are methodological challenges as caregiving has been historically conceptualised as a largely feminine activity. This potentially limits participants' willingness to describe their experiences of undertaking what might be seen as a non-stereotypical male role, but the methods used enabled increased rapport with the sharing of research interpretations with participants.

A purposeful-sample, of thirteen working–age male carers, were interviewed. Recognising the co-constitutive nature of interviewing, a first-person narrative summary was developed from the interview transcript. During the second interview, this narrative provided a platform to gain additive data and share emerging meanings, leading to richer, more experiential data.

Thematic analysis led to three themes. First, the negotiated nature of family caregiving, which entailed complex decision-making and changing support networks. Second, the obligated nature of time with participants structuring their time in particular work-related ways. Third, the reworking of identities as the carer role subsumed the roles of family man and employed man.

Theoretical reflection and insights offered by these findings are used to argue that male carers appear to experience caregiving as an alternative form of work, informed by their previous understanding of employment and the current demands of their obligated time. Conceptualising care as a form of work may provide an alternative lens through which to understand how working–age male carers give meaning to their roles.

List of Tables and Figures

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Chapter 1: Introduction

Introduction

Nearly 6 million people provide care in Great Britain and there is extensive evidence that being a carer can affect people's lives (Carers UK, 2009). Caring, or caregiving, is the act of providing unpaid support to a person who is ill, frail or disabled within the private home (Graham, 1999). Carers are a diverse group of people and as such have distinctly different experiences of caregiving (Eley, 2003). There is empirical evidence that male carers may have different experiences to their female counterparts (Kramer and Thompson, 2002).

There are approximately 2.5 million male carers in Great Britain, meaning that nearly half of all carers are men (ONS, 2002). Yet there remains within both the public and professional consciousness the idea that care will predominantly be provided by women (Miers, 2002; DH, 2008:1), subsequently male caregiving occurs within a social context that considers caregiving to be a gendered activity (Campbell and Carroll, 2007).

There is growing political and research interest in the ways in which carers may undertake caregiving alongside paid employment (DH, 2008; Yeandle et al., 2007). There remains, however, limited empirical evidence exploring the specific experiences of working-age male carers, yet this cohort of carers are the most likely to be combining caregiving with full-time employment (Yeandle et al., 2007). Therefore this thesis explores the lived experiences of a distinctive, but largely overlooked group of carers, namely male carers of working-age.

Caregiving a gendered activity

Exploring the caregiving literature, it became evident that research specifically exploring male carers' experiences might further understanding, particularly as empirical evidence showed that male carers experience caregiving in distinctly different ways to their female counterparts (Thompson, 2002; Fine and Glendinning, 2005). There are a number of explanations offered for this difference. Women of the family have historically undertaken the care of relatives, as they were most usually the ones available to fulfil this role, frequently being at home rather than in recognised paid employment (Ungerson, 1983; Stacey, 1988). The theory that women were the primary

carers was reinforced during the late 1970s and early 1980s with a movement to formalise and place value on care, a previously unseen and unrewarded activity (Land, 1978; Gilligan, 1982; Finch and Groves, 1983; Abel, 1986). Whilst the work of these, primarily feminist, researchers raised the profile of caregiving in the public and political consciousness, their efforts to value the unpaid work of women in an increasingly market-driven economy resulted in the caregiving undertaken by men remaining hidden (Arber and Gilbert, 1989).

When the census of 1985 revealed that 2.5 million men considered themselves as carers, commentators argued that men did not undertake the same types of care activities, or for the same amount of time as female carers (Qureshi and Walker, 1989; Parker, 1990; Twigg and Atkin, 1994). Nor did they experience the same decrease in health and well-being as their female counterparts (Zarit et al., 1980; Horowitz, 1985). However, more recent studies have highlighted that many male carers do undertake the same range of activities and levels of caregiving as female carers (Harris, 1998; Romeran, 2003). Also there is evidence that gender differences in carer psychological stress and physical burden may not be as great as previously argued (Zarit at al., 1986; Miller and Cafasso, 1992). Nonetheless, male carers may still experience being a carer in different ways to their female counterparts, because as men they may not acknowledge the need for support structures, preferring instead to focus on concrete tasks rather than emotional reactions to being a carer (Miller and Kaufman, 1996; McFarland and Sanders, 1999; Ekwell et al., 2005; Sanders, 2007). They may receive more or less statutory support (Bywaters and Harris, 1998; Pickard et al., 2000) and, most importantly, as a man undertaking a gendered activity they may give different meanings to their experiences compared to female carers (Boeije and van Doorne-Huiskes, 2003; Ribeiro et al., 2007). With such contradictions and potential differences between male and female carers, it was apparent that a study which sought to understand the meaning male carers gave to the phenomenon of caregiving had the potential to develop new knowledge about working-age male carers.

Working-age men in a gendered activity

There were limited numbers of studies explicitly exploring the experiences of working-age male carers. However, drawing on studies exploring the experiences of men caring for young children, it appeared that men undertaking traditional female roles may experience isolation and perceive that others are surprised that they are not in paid

employment (Grbich, 1997; Doucet, 2000). It may be that working-age men who undertake caregiving either alongside, or instead of, paid employment experience similar situations. Studies exploring the experiences of men in traditionally feminine employment occupations, such as beauty therapist and nursery worker, have also highlighted that these men speak of isolation and being perceived by others as performing outside of normative male roles (Simpson, 2004). In providing an opportunity for male carers' voices to be heard, this study might increase understanding of their distinctive experiences, because as Thompson (2002) argues, for too long male carers' experiences have merely been used to provide a contrast to female carers' experiences. Through exploring the meaning that men themselves give to caregiving it may lead to the development of policies and practices which are sensitive to the unique caregiving situations of male carers.

Male carers in employment

Just as carers are not a homogenous group (Eley, 2003), so male carers are in distinctly different caregiving situations. In Great Britain there are significant numbers of men, approximately 1.5 million, who undertake caregiving alongside paid employment (Yeandle and Buckner, 2007). It is estimated that men have a 40% chance of having provided 20 or more hours of care a week by their sixty-fifth birthday (Hutton and Hirst, 2000:20). Research into the experiences of employed carers suggests that they might have different experiences of caregiving compared to non-employed carers (Lee et al., 2001; Arksey, 2002). At the start of the twenty-first century it is particularly pertinent to explore the experiences of working-age male carers, as it is predicted by 2037 there will be a 60% increase in the number of carers and these people are likely to be of employment age (George, 2001). Significantly, male carers aged 55-64 outnumber female carers in the workplace and it is unlikely that this trend will be reversed (Yeandle and Buckner, 2007).

A recent body of work undertaken in collaboration with Action for Carers in Employment (ACE) exposed the ways in which carers managed the dual role of carer and employee, including the benefits and consequences of being a carer in employment (Yeandle et al., 2007). Highlighting that employed carers may experience concerns about the cared-for person's safety, increased personal poor health and limitations on the type and amount of paid work they can undertake, their research added to the understanding of carers in employment. Although the research did not seek to

differentiate between male and female experiences, other studies have suggested that men and women may give different meaning to both care and employment (Boeije and van Doorne-Huiskes, 2003; Ribeiro et al., 2007). Therefore it was appropriate to explore the specific experiences of employed male carers.

This rationale is further justified by exploring the statistical data on characteristics of carers. Male carers are more likely to be in full-time employment than their female counterparts (Haas et al., 2006), with 1.25 million men undertaking full-time employment alongside caregiving and a staggering quarter of a million men working full-time and undertaking over twenty hours care a week (Yeandle et al., 2007). Kimmel (2008), exploring masculinity, argued that employment has an important part to play in the construction of self, therefore male carers of working-age may have different experiences of being a carer to those who have retired from work. With government policy seeking to support carers to remain in, or re-enter, paid employment (DH, 2008), it is a pertinent time to undertake a study which could increase understanding of how working-age male carers experience caregiving alongside employment. Such an understanding has the potential to inform practitioners working with a group of carers whose experiences have received little attention in the caregiving literature.

Research Aim

Research with employed carers is an emerging field and those studies which have been undertaken tend to focus on the economic costs of being an employed carer (Carmichael and Charles, 2003; Evandrou and Glaser, 2003; Heitmueller and Inglis, 2007). The few studies which have sought to understand the experience of balancing caregiving and employment have either not differentiated between male and female experiences (Arksey, 2002; Philips et al., 2002), or have found that men have different experiences to women (Lee et al., 2001; Rosenthal et al., 2007). Therefore this study aimed to capture how male carers experienced and gave meaning to a traditional feminine occupation, whilst also being of an age where their communities and the government might expect them to have a responsibility to be in paid employment. Because this was an exploratory study which aimed to capture the lived experiences of working-age male carers, the use of a qualitative design enabled a contextual understanding of the experiences of male carers (Mason, 2002).

Research question

Consistent with an exploratory study, the research question was broad, facilitating a research design which enabled participants to talk of those experiences of being a carer which were important to them.

What is the lived experience of being a working-age male carer?

Following a literature review which illustrated the effect of caregiving on employment and the ways in which male carers experience being a carer, the following research objectives were defined, providing a focus for data collection and analysis:

Research objectives

⇒ To capture in-depth understandings of how men experience being a carer and an employee.

⇒ To explore why men may have moved from employment into full-time caregiving.

⇒ To illuminate what men feel about their roles and identities when in caregiving relationships and reasons for this.

Research design

Recognising that caregiving occurs within a complex web of social relationships and that cultural norms might shape how caregiving is provided (Forbat, 2005), a hermeneutic phenomenological design was developed. This design enabled the phenomenon to be captured as perceived by participants, whilst also acknowledging that as the researcher I would bring subjectivities to the study and particularly the analysis (Chesla, 1995; Dowling, 2006). Recognising the potential limits of single-point conversational interviews (Whitehead, 2004; Seidman, 2006), an innovative methodology was used. The sharing of narrative summaries, produced from the first interview, enabled emerging meanings to be further discussed between participants and myself. This methodology revealed how, at the first interview, participants tended to tell their story of 'doing care', but during the second interview, perhaps due to the

developed rapport and the opportunity to review their original story, they spoke more of their experiences of 'being a carer', exposing a more emotional side to their lives.

Central themes: caregiving and work

Two threads run through this thesis: caregiving and work. The interplay between caregiving and work was to have powerful resonance with the research aims of understanding the experiences of working-age male carers. The duality of care and work is evident in social welfare policy, where an adult worker model policy has consequences on the availability and types of care which can then be drawn on to support people who are ill or disabled (Lewis and Giullari, 2005). It has also been argued that the concept of care needs to be recognised within social policy as an alternative and valued choice (Daly and Lewis, 2000; Williams, 2001; Daly, 2002). There is evidence that being a carer may limit opportunities to undertake paid work (Lilly et al., 2007). In this study all participants were male carers and some were also in paid employment. The study aimed to explore if a balance could be achieved between caregiving and work, and further how the meaning of each was shaped. If a male carer is of working-age then there may be an expectation, both socially and politically, that he also undertakes paid work (Charles and James, 2005; Haas et al., 2006; Holter, 2007). Societal and cultural norms compound the complexities of the caregiving relationship and the different forms of work undertaken by the carer.

Participants experienced being a carer within a milieu of personal, social and political networks and so the reciprocal and negotiated nature of relationships was explored, acknowledging the complex social networks within which caregiving may occur (Thomas, 1993; Tronto, 1993; Forbat, 2005). Whilst there was a dyad of the carer and care-receiver functioning within their home, the participant and care-receiver were frequently positioned within other relationships comprising of family, friends, neighbours, colleagues and health professionals. Within these networks participants might be having to negotiate obligations and responsibilities, undertake defined activities and accept multiple roles (O'Conner, 2007).

Personal Journey

A personal interest in the experiences of working-age carers and specifically male carers developed when I was undertaking a study evaluating a community mental health provision (McArthur et al., 2006). During the study a man spoke powerfully of the isolation he experienced attending a carer support group when he was the only man. The impact of being a carer was further highlighted to me when colleagues were unable to continue a higher education programme because of the combined demands of their caregiving activity and their employment. These two episodes supported a growing awareness that being a carer could affect opportunities and specifically that male carers may experience isolation and lack of support. I recognised that I entered the study with presuppositions that caregiving may be detrimental to the lived experiences of carers and this contributed to the decision to adopt a hermeneutic phenomenological method, to facilitate reflexivity within the study (Finlay, 2003).

Thesis outline

This thesis explores two main theoretical strands: the concept of being a carer and the concept of caregiving as an alternative type of work. These are developed over the remaining chapters.

Chapter Two conceptualises caregiving and work drawing on a broad range of historical caregiving literature, before exploring how the experiences of male carers are constructed within current social welfare policy, drawing conclusions on how male carers' experiences may be shaped by both the gendered nature of caregiving and the political constructed identity of a carer. Chapter Three reviews empirical research, specifically exploring the experiences of working-age male carers, to understand their experiences and explore whether there is a likelihood that they may have distinctly different experiences to their female counterparts.

Chapters Four and Five describe the study methodology, design and ethical considerations. This includes drawing on the principles of hermeneutic phenomenology to guide a research design which could capture the experiences of participants in their life world. The challenges of an epistemological stance, in which meanings and knowledge are co-constituted, are addressed by incorporating an innovative method centred on returning narrative summaries to participants prior to follow-up interviews.

Chapter Six provides a context for the findings describing the participants and explaining the process of data analysis and the strategies used to enhance trustworthiness of findings. Chapter Seven, Eight and Nine present the findings through the themes of 'Being a male carer', 'Obligated time' and 'Self as carer-reworking identities'.

Chapter Ten critiques the strengths and limitations of the study, providing a context against which discussion points are then raised in Chapter Eleven. The discussion in Chapter Eleven focuses on the inter-relation of the concepts of obligation and work. Obligation is explored in the context of decisions made on becoming a carer and through the obligations inherent in, or absent from, support networks. The central tenets of work are mapped across the activity of caregiving, providing a framework for conceptualising the caregiving experience as an acceptable form of work, for these men. Chapter Twelve draws key conclusions from the study, exploring the implications for practice and suggesting ways in which the understanding of male caregiving and carers in employment may be developed.

Chapter 2: Contextualising the study

Introduction

The worlds of caregiving and work have frequently been presented as polar opposites: family caregiving is largely unpaid, often unseen and frequently perceived as being undertaken by one family member out of love and concern for another; whilst employment is mostly paid, provides distinctive public identities and roles within communities and is increasingly perceived as the ideal state, and the norm, for working-age people. Within particular social and political contexts, caregiving and work are terms which are given different meanings (Daly and Lewis, 2000; Williams, 2001). Caregiving may refer to the notion of providing practical help with activities of daily living, or conversely it may refer to the concern felt for another person (Forbat, 2005). The word 'work' has been used to name a number of activities which may be paid or unpaid, formal or informal but predominantly within everyday language it is taken to be synonymous with paid employment (Pahl, 1988; Ross, 2007). An opposition has been set up between these two terms. By defining work and using this as a basis for explicitly exploring how the concept of caregiving as a work activity has been discussed, it became apparent that an understanding of the social context of caregiving could be increase. Further, an understanding of the macro and micro political structures which both define who carers are, and which aim to support them, could contextualise the experiences of working-age male carers.

Defining work

This study explored the experiences of working-age men, exploring how they balance caregiving and employment. However, early in the examination of debates and evidence it became evident that in empirical literature and everyday language the word 'work' was frequently used synonymously with the word 'employment' (Ross, 2007). This creates difficulties where caregiving can also be conceptualised as a form of work and this called for a way to distinguish between formal, recognised, paid work undertaken as an employee, or in a self-employed capacity, and the informal, unrecognised, unpaid activity of caregiving. In this thesis the terms work and employment are both used, but each can be seen to denote distinctly different activities which are inter-related in the context of lived lives.

Employment refers to paid work undertaken within a formal structure for financial reward. Employment might be governed by legislation protecting the worker; it may take place outside of the private home and at hours set by the employer or be undertaken in a private home. Nonetheless it is distinctive in that there is direct financial reward for the activities undertaken and products produced. Participants in this study were employed as office-based employees, an engineer, a shop owner and a self-employed owner of a small business. If government policy documents or empirical studies refer to 'work' to describe the activity of employment, in this thesis the word work is prefaced with either paid work or substituted with employment.

The term work is used in the wider sense to refer to any activity which is undertaken in a purposeful way. Here work involves the physical and mental agency of a person to fulfil a task, but it may not result in financial reward.

To understand how caregiving has been conceptualised over time a scoping review of the caregiving literature was undertaken (Arksey and O'Malley, 2005). This review aimed to 'map rapidly the key concepts underpinning a research area' (Mays et al., 2001:194). The review was undertaken during the first three 3 months of the study to identify previous evidence of empirical literature in the caregiving arena. It explored the range, volume and nature of research which had previously been undertaken with carers, male carers and employed carers, enabling an understanding of the historical, social context in which definitions of caregiving developed. It also helped highlight specific gaps in the empirical literature undertaken with male carers leading to the development of four literature review questions, defined in Chapter Three, which subsequently guided the structured review of literature pertaining specifically to working-age male carers.

The scoping review explored and classified the literature enabling an understanding of how caregiving had been conceptualised since the late 1970s. A wide variety of literature was sourced using a range of methods. Initially seminal texts were read as these provided an understanding of how caregiving had been defined and specifically defined as a form of work (Finch and Groves, 1983; Dalley, 1988). Later texts illustrated the ways in which carers have become social constructed as a specific group of people with specific needs (Parker, 1990; Twigg and Atkin, 1994; Bytheway and Johnson, 1998). To achieve an overview of the range of research areas within caregiving, contemporary peer reviewed journals were read and references from papers hand-searched. This delineated several key areas in which relevant research had been

undertaken and that the primary focus of caregiving research studies had changed over time. Figure 2.1 provides a visual representation of ways in which male carers experiences have been studied, and makes some indicative links with key social and cultural changes.

Early caregiving research focused particularly on the experiences of female carers and their obligations to families, particularly with the development of community care policies (Finch, 1984, Dalley, 1988). Research exploring the experiences of male carers emerged subsequently, during the late 1980s, although many early studies sought to compare the experiences of male carers with those of female carers and to conclude that male carers did not experience the same obligations and burdens as female carers (Fisher, 1994; Kramer and Thompson, 2002). More recent work with male carers still focuses on the gendered nature of caregiving but the focus has moved from measuring burden to exploring the formation of identities and roles for male carers (Campbell and Carroll, 2007). During the 1990s a wealth of psychosocial studies sought to measure physical, emotional and economic costs of caregiving with carers (Carpenter and Miller, 2002; Adler et al., 2002). This focus has shifted in the twenty first century as more contemporary papers have discussed the ways in which carers may be supported, empowered and valued as partners with statutory services (Levesque et al., 2010; Seddon et al., 2010). Alongside the move to explore those choices carers might make, is a body of literature beginning to explore how carers may undertake paid employment alongside caregiving (Pickard, 2004).

Women as carers:

Male carers largely ignored; caregiving defined as women's work. Themes:
Physical labour
Emotional labour
Being a carer part of the identity of being a woman

1980

Development of community

care polices

Men becoming carers:

Recognising men as carers exploring their motivations to provide carer. Themes:
 Duty
Reciprocity
Only relative
Geographically closeness

Led into caregiving by wife or sister

1985

Census data

Comparing men to women carers:

Exploring the burden of care and the activities of care. Themes:
Men experience less 'burden'
Men undertake less physical and emotional care, delivering more organisational care and time limited activities

1990

Carer's national strategy

Carers as workers:

Increasing recognition of the numbers of carers in employment studies often do not separate by gender. Themes:
Economic consequences
Employment structures more likely to seek part time work
Benefits of being in employment, support, respite

2000 Employment Act

Carers as men: men as carers

Recognition of the contribution of male carers exploring their experiences through a gender lens
Exploring motivations to undertake care
Maintaining a masculine identity as a carer

Gender studies

Figure 2.1 Framework illustrating the themes within male caregiving research from 1980 to 2009

The volume of literature on caregiving proved to be extensive. For example searches using the term 'caregiving' as an abstract term in the database ASSIA returned 1551 hits. The scoping review revealed that male carers' experiences had frequently been presented as being distinct from women's experiences and that men were markedly more likely than women to combine full-time paid employment with caregiving. Therefore, when working up the research proposal such distinctions informed the decision to focus the critical literature review (presented in Chapter Three) on papers relating only to working-age male carers. However, even before this, the early scoping review pointed to the emerging conceptualisation of caregiving as work and how strongly social policy interfaced with the experiences of carers. These two concepts are discussed below to explore the notion that male carers may face a culturally-conflicted position in being expected to be in paid employment, whilst also having to negotiate obligations to care for their ill or disabled relative.

Caregiving as work

Caregiving as women's work

Whilst social care policy supports and recognises a socially constructed group of people called carers (Bytheway and Johnson, 1998), such policy does not differentiate between male and female carers. Yet, the experiences of male and female carers have frequently been presented in empirical literature as dichotomous variables (Thompson, 2002). There remains within western culture a perception that caregiving is an intuitively feminine activity; work which is predominantly undertaken by women (Campbell and Carroll, 2007). In part this may be because of the continuing influence of early 1980s studies which sought to increase the recognition and value of unpaid family care work completed predominantly by women in the home (Finch and Groves, 1983; Graham, 1983; Ungerson, 1983; Dalley, 1988). Such studies conceptualised care as an activity undertaken primarily by women in their private homes; within relationships and under terms which affected their material and emotional well-being. Exploring changing definitions of caregiving provided a more informed understanding of the work of a carer.

Caregiving as emotional work

Early conceptual definitions of caregiving developed in the sociological and psychological literature during the late 1970s and early 1980s (Land, 1978; Gilligan,

1982; Graham, 1983; Ungerson, 1983). Some discussion of the concepts of the ethics of care saw women as experiencing internal moral obligations to provide care, whereas men experienced a wider sense of moral justice (Gilligan, 1982). Graham (1983) argued that women were more likely to internalise a sense of self from prioritising the needs of others over their own. Ungerson (1983) took this further, suggesting that care was a form of work for women. These definitions of care developed at a time when there was a political impetus for economic employment, and work by feminist sociologists sought to increase recognition and the value of the unpaid care women undertook in the home. From research into women within their private homes, there developed a growing understanding of the volume and nature of care which was being provided to frail or disabled relatives and friends. At this time there was little recognition of male carers and definitions of care focused on capturing both the physical labour of caregiving, and also the emotional labour of the work.

In an early influential definition of care, Graham observed that 'caring demands both love and labour, both identity and activity' (Graham, 1983:13). She theorised that caregiving involved physical labour, or work, such as personal care, cleaning and food preparation. She also proposed an emotional element to caregiving, the caring about someone. This emotional aspect of caregiving was less directly tangible and it has become most closely seen as an intuitively feminine trait. Graham and her peers Ungerson (1983) and Finch (1984) identified the unpaid work of care as of equal value to paid employment, because of its importance in holding families together and assisting relatives who were elderly and infirm. Today the family unit is even more diverse as numbers of lone parents, step-parented, multiply-parented and same-gender relationships increase (ONS, 2000; Land, 2002; Chambers, 2006). However, these new family types still serve similar purposes through continuing to support relatives.

Caregiving as physical work

Whist providing care has long been given an emotional component, and the word itself carries powerful emotional overtones, a 1980s definition of caregiving offered by Qureshi and Walker (1989) in their study exploring family care of older people gave a more explicit emphasis to the physical aspect of care work, particularly quantifying the activity. They stated a carer must sustain 'practical assistance involving the complete performance of tasks such as laundry, shopping, housework at least once a week, or lighter tasks such as cooking, light housework at least three times a week' (1989:10).

Conceptualising care as merely either practical hands-on care or emotional support excluded many of the activities that other researchers found men were undertaking and referring to as caregiving, such as managing finances, maintenance of house and garden, and providing transport to the care-receiver (Horowitz, 1985; Rosenthal et al., 2007).

Caregiving as managerial work

Such organisational activities could be conceptualised as managerial or organisational care (James, 1992). There have been more recent attempts to categorise specific care-related tasks as either feminine or masculine (Szinovacz, 2000). Feminine activities in everyday caring would include tasks such as cleaning the house, preparing meals, and doing the laundry, whilst masculine activities include car maintenance, outdoor maintenance, and paying bills. However, the reality for most lone carers whether male or female is that they undertake all these tasks. Whilst accepting that becoming a carer may mean changing roles and identities, it would not increase understanding of male carers' experiences to begin within the constraints of a pre-defined gender debate. Instead, understandings of men as individual carers may be increased by acknowledging they may be potentially involved in providing all aspects of care. Campbell and Martin-Matthews (2003) explored factors that might influence whether a male carer undertook traditionally masculine, gender neutral or traditionally feminine activities. They found that the sense of obligation coupled with locality to the care-receiver were key in determining which types of tasks men undertook. However, in their sample all the male carers were found to undertake a range of gendered and gender neutral tasks, suggesting that to the carer the gendered nature of the work may be less important than the need to fulfil an obligation. Therefore, the holistic definition of caregiving offered by Cancian and Oliker (2000) was found to be the most pertinent to this study:

> 'Caregiving is a feeling of affection and responsibility combined with actions that provide responsively for an individual's personal needs, or well-being, in a face-to-face relationship. Caregiving includes physical care, such as bathing, feeding a person as well as emotional care, such as tender touch, supportive talk, empathy, and affection. It also includes providing direct services such as driving someone to a store, or adjusting the medications of a hospital patient' (2000:2).

Such a definition captures the variety of activities participants could be undertaking and which therefore might need to be considered as part of their lived experience. However, there remained a need to be sensitive to how participants might describe their roles. This

definition of caregiving as a process-orientated role is revisited in the discussion chapter in- light of the findings from this study. The scoping review highlighted that social roles may develop within cultural and social contexts, increasing awareness of the need for a methodology that could capture socially-developed meanings. With caregiving having been historically presented as a gendered activity, a study exploring male carers' experiences remains attentive to gendered stories.

The developing conceptual understanding of how caregiving had been shaped as a form of work raised awareness that carers function and negotiate obligations within complex social and cultural communities.

Acknowledging this, a critique of how caregiving and the role of carer have been constructed within the political sphere provided a context for conceptualising participants' experiences.

Contextualising male caregiving within social care policy

Politically, unpaid care has become the bedrock of community social care policy, and alongside policy there has been the social construction of a group of people called 'carers' (Bytheway and Johnson, 1998). Throughout history, family have provided support to relatives who are ill, frail or disabled, but since the 1980s there has been growing recognition and formalisation of this caregiving with a raft of policy initiatives and legislation seeking to define, support and legitimise the carer role (Ross, 2003). Whilst in the early 1980s carers were perceived predominantly as women at home available to look after others, either relatives, neighbours or friends (Twigg and Atkin, 1994), there is now growing recognition of the different needs of distinctive groups of carers: young carers, carers in employment, carers from black and minority ethnic groups, carers of people with mental health problems and other specific diseases (Eley, 2003). Nonetheless policy and legislation supports the generic carer rather than the specific needs of different groups of carers. Exploring government policy since the 1980s it became evident that working-age male carers were experiencing caregiving in a political, social and cultural environment where their needs may not yet have been fully addressed.

Development of community care

In British social policy, community care is a mixed economy of care provided by statutory services, voluntary groups and families (Symonds, 1998; Cavaye, 2006). The development of community care may be charted from the Poor Law of 1601 through to the public agenda for health and welfare in the Beveridge Report of 1942 (Bytheway and Johnson, 1998; Heaton, 1999). However, the concept of informal care provided by family and friends has only been formalised since the late 1970s.

Policy leading to the concept of informal care delivered by family and friends developed during the 1960s and 70s, with increasing government concerns about an ageing population and the associated costs to the public purse (Symonds, 1998; Twigg, 1999a). Research studies reporting poor quality care in the large institutions that were traditionally home to people with age-related social needs, mental ill health and learning difficulties, led to public unease about how care was being delivered to elderly and other vulnerable people (Bytheway and Johnson, 1998). A review of social care provision identified the impact of an increasing elderly population (DHSS, 1981). The White Paper 'Growing Older' (DHSS, 1981) formalised the concept of community care, indicating that care would and should come through 'the personal ties of kinship, friendship and neighbourhood' (DHSS, 1981:3). This policy shift away from institutional care for firstly elderly people and latterly other dependent adults occurred against a political background which sought to place high value on economic employment.

Towards the end of the 1980s the structure of community care became a mixed economy of care, consisting of public, private and voluntary sector providers but also relying heavily on the unpaid care of family (Symonds, 1998). The new structure became embedded in law with the National Health Service and Community Care Act 1990, resulting in significant changes in the structure of social care provision. Social services departments changed from providers of care to purchaser of services, thereby heralding a growth in voluntary and private organisations working with families to deliver community care (Symonds, 1998). Whilst there have been legal amendments to how funds and responsibilities are allocated within the social care sector, the principle of community care remains embedded within the concept that families provide carer support to a greater or lesser extent, following assessment by statutory agencies (Seddon et al., 2007; Seddon et al., 2010). Although the diversity of carers is now recognised,

during the development of community care provision women were presumed by many to be the natural carers (Parker, 1990; Twigg and Atkin, 1994). The premise that women would be at home available to provide care shaped many of the early policies and therefore such policies did not explicitly consider the needs of carers who were also in employment.

Women as carers

Community care policy was conceived at a time when full-time male economic employment was held as the ideal (Miller, 1999). Whilst the government suggested families would deliver community care, women were presumed to be fulfilling the role of unpaid carers (Finch and Groves, 1983; Bytheway and Johnson, 1998). The Equal Opportunities Commission reported that 'it is the closest female relative to whom the task of caring usually falls' (EOC, 1980:1). Their report highlighted that undertaking informal care may restrict the opportunities for women to undertake paid work. It was in this political context that feminist sociological writers produced works exploring the concept of care and the role of women in providing this care (Finch and Groves, 1983; Graham, 1983, 1991; Ungerson, 1983, Dalley, 1988). Research studies proliferated, particularly exploring the burden of caregiving, yet many studies did not explore male carers' experiences and there was little recognition of the numbers of male carers (Fisher, 1994; Fine and Glendinning, 2005).

Awareness of the numbers and characteristics of people undertaking care became increasingly apparent from census data. The 1985 General Household Survey[1] (GHS) countered the belief that women were the main group of people delivering community care. For the first time, the survey included a question to find out if people looked after or provided regular service to someone who was sick, disabled or elderly in their own home or another's home (Green, 1988). Estimates indicated that six million people identified themselves as carers and nearly half, 2.5 million, of these were men (Green 1988). The evidence that approximately 40% of carers were men, coupled with studies

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[1] An annual nationally representative sample of adults living in private household. Questions about whether helping or caring for another person were first posed in 1985.

exploring older spousal caregiving, raised awareness of male carers' experiences (Arber and Gilbert, 1989). There was growth in empirical studies reporting the burden experienced by carers and this, coupled with the growth of carer lobby groups, helped to promote identification of the needs of carers (Bytheway and Johnson, 1998; Twigg and Atkin, 1994; Twigg 1999a).

Despite almost half of carers being men, policy was non-gender specific and the experiences of female carers continued to dominate the research literature throughout the 1980s and early 1990s. Research recognising the role of men providing care remained limited and predominantly explored the experience of retired spousal carers (Arber and Gilbert, 1989; Fisher, 1994), meaning the experiences of employed male carers were not captured. Therefore little was known about whether they had distinctive needs when the government moved to develop legislation recognising the role of carers and increasing support for this role.

Initiatives to support carers

During the 1990s a raft of legislation was built to enshrine carers' rights in statute. The Carers (Recognition and Services) Act 1995 gave formal recognition to the services provided by carers. This act stated that if care-receivers had substantial needs there should be an assessment of a carer's ability to meet these needs (Montgomery, 2003). Here people were supported to enable them to fulfil their carer role, rather than recognising their right to undertake employment. Further policy initiatives during the 1990s recognised carers as a unique group (DH, 1999a, DH, 1999b) whose needs should be considered if they were to be able to support ill, sick or disabled people. By the end of the 1990s, carers were high on both the public and government agenda. Support groups had merged and developed a campaigning voice raising awareness of both the positive and negative experiences of being a carer (Bytheway and Johnson, 1998; Lloyd, 2006).

In 1999 the Labour government published its National Strategy for Carers, 'Caring about Carers' (DH, 1999c). This document set out three strategic aims. Firstly the strategy aimed to provide information for carers about government policy and decisions, secondly to give carers access to information on health advice, and thirdly to increase care for carers specifically through the use of respite breaks. Carers were to have a role in planning and reviewing service provision. However the document reaffirmed carers'

social obligation to provide care, stating that if people were not cared-for at home they may need to enter a residential, nursing home or hospital and this '...might be detrimental to the quality of life for some people needing care and would be at considerable cost to the taxpayer' (DH, 1999c:11). The policy has been criticised as failing to acknowledge the interdependence found in many caregiving relationships (Parker and Clarke, 2002). The policy made reference to carers and employment, explaining that carers would be encouraged to remain in work and return to work when their caregiving ceased (DH, 1999c:27). Whilst there was a short sentence which recognised that some carers may choose not to combine paid work with caregiving, the overriding emphasis was on supporting carers to access and remain in work. However, there was little detail on how carers would be offered informed choice (Lloyd, 2000; Carmichael et al., 2008).

Since the beginning of the twentieth-first century the rights of carers have been further strengthened with legislation designed to ensure that the assessment of carers takes place independently of the needs of the care-receiver. The Carers and Disabled Children Act 2000 and the Carers (Equal Opportunity) Act 2004 both gave carers the right to assessment even if the care-receiver refused a personal assessment. As well as support to provide care in the home, carers have had their right to assessment in the workplace enacted. The Employment Act 2002 gave parents of disabled children the right to request flexible working. The Work and Families Act 2006 extended this right to people who care for a spouse, partner, civil partner or relative within the carer's home. However, the right to request flexible working does not mean that employers will always accommodate requests (Arksey and Glendinning, 2008). Changes in employment legislation may facilitate access to employment, but there is as yet little empirical evidence exploring whether these legislative changes have enhanced the carer's experience.

Nine years after the launch of the first carers' strategy, the government published the latest strategy 'Carers at the heart of the 21st-century, families and communities: A caring system on your side. A life of your own' (DH, 2008). This document followed consultations with carers and carers' groups on the white paper 'Our health, our care, our say' (DH, 2006).

The strategy has a clear ten-year vision:

> 'by 2018, carers will be recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet the individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen' (DH, 2008:8).

Whilst funds have been allocated to meet commitments, including £38 million to 'enable carers to combine paid employment with the caring role', there has been only limited detail on how the commitments might be met. The strategy recognised that carers may wish to remain in employment and further that employment can be beneficial not only for people's financial well-being, but also for their psychological well-being. Such rhetoric was in line with other government initiatives, with work being identified as beneficial to a person's health and well-being (Waddell and Burton, 2006; Black, 2008). Nonetheless, within social care policy there remained little differentiation between forms of work. For example, questions could be asked about whether work needed to be paid, voluntary, part-time or full-time to be beneficial to an individual; full-time work alongside a heavy caregiving role maybe detrimental to the carer's well-being (Yeandle et al., 2007).

Over a period of only twenty-five years the concept of informal care and the identity of the carer became enshrined in policy and law (Clements, 2009). Policy makers recognised the difficulties of undertaking employment alongside caregiving; however, individual carers and carer lobby groups argue that policy initiatives have not always supported choice for carers, often failing to recognise that carers may not want to combine the two activities (Carmichael et al., 2008). There remained a political expectation that people would accept responsibility for frail or ill relatives, an expectation which Carers UK have challenged. They challenged policy wording which stated that carers *should* take responsibility for another, instead recommending that carers merely *offer* to provide care; this changes the emphasis, removing carers from a duty of care to their relative (Carers UK, 2003).

The schism between social welfare's aims of full economic employment whilst still relying on unpaid family care is likely to increase, with recent estimates indicating that by 2037 an extra 3.4 million people may need to undertake caregiving (Carers UK, 2009). Increasingly carers will be of working-age and the challenge of sustaining both

an economically active workforce and enough numbers of people to undertake unpaid care is an increasing concern (Daly and Lewis, 2000). Therefore it seemed a highly pertinent time to explore the experiences of men who undertake caregiving alongside employment.

The impact of policy for male carers

The needs of carers have been championed through the growth of carer lobby groups (Bytheway and Johnson, 1998; Twigg, 1999a; Carers UK, 2010). Informal care has been championed, politicised, researched, and ultimately presented within society as a distinct identity: 'I am a carer'. However, this identity and label is one that people may not want to adopt (Henderson, 2001; Stalker, 2003; O'Conner, 2007). It may be particularly difficult for men to recognise, or name, the work they do in supporting another person as care, particularly if they remain in full-time employment (Marks, 1998). In addition caregiving has been culturally conceived as a female activity requiring intuitively feminine traits, therefore men may struggle to use the term carer to refer to their activities, resulting in male carers remaining hidden from their communities, employers and service providers (Eley, 2003).

There was growing recognition of 'hidden carers', those people who provide a substantial amount of care, but are not identified by others as carers (Eley, 2003; Cavaye, 2006); male carers in employment may be part of this group. Although legislation provides 'visible' carers with access to assessment and flexible employment practices, there is debate as to whether social policy is too reductionist, with piecemeal policies failing to consider the holistic impact of caregiving on the carer's physical, emotional and social well-being (Pickard, 2001; Stalker, 2003; Twigg, 2008). It was a pertinent time to undertake this study as the government proposed to increase employment opportunities for carers (DH, 2008).

Although reviewing social care policy provided an understanding of how the socially constructed identity of a carer evolved, policy documents contained only bland statements of what a carer does. Policy makers did not seek to conceptualise the component parts of caregiving, or expand upon the definition of care as an activity, rather they provided an encompassing statement of who may be identified as a carer. For example, the recent Carers' strategy described a carer as someone who 'spends a significant proportion of their life providing unpaid support to family or potentially friends' (DH, 2008:19).

To take this definition further, in this thesis care or caregiving refers to the unpaid activities a carer undertakes to support a person, relative, friend or neighbour, who is ill, frail or disabled. Caregiving involves supporting another in the activities of daily life, such as bathing, dressing, eating. It includes more complex nursing care such as providing medication, undertaking care of urinary catheters or other specialised medical procedures. It also covers the activities undertaken in the home which indirectly support the well-being of the care-receiver, for example laundry, cleaning, cooking. Further managerial aspects of caregiving also fall within the definition of caregiving, including liaising with social care services and taking the care-receiver to appointments. Within contemporary literature the activity of caregiving may be referred to as care, informal care, family care, unpaid care, and lay care. The person receiving such care has been variously referred to as the cared-for, caree, care recipient or care-receiver (Twigg and Atkin, 1994; Forbat, 2005; Beach et al., 2005; Coutinho et al., 2006). Whilst acknowledging the debate about the labelling of the person receiving care and the fact that caregiving relationships are more frequently reciprocal than unidirectional (Henderson and Forbat, 2002; O'Conner, 2007), the focus of this study was on the men providing care; within this thesis the term care-receiver denotes the person the participants were caring for. Care-receivers in the study were either wives, mothers or adult children.

Within government policy and people's lives caregiving is intertwined with work, however just as there is not one policy or definition which suits all carers, so work can mean different things to different people at different times (Pahl, 1988). Therefore paid work, employment, is differentiated from unpaid caregiving.

Summary

The scoping review provided an understanding of how the experiences of working-age male carers are currently positioned within the wider caregiving literature and social policy, it became apparent that social welfare policy does not directly support their potentially and increasingly conflicted position of being culturally expected to be in paid employment whilst also being obligated to provide care for ill relatives. Rather, there appears to be a growing impetus to encourage carers to remain in employment, thus raising the question of how those men who may step outside of employment to provide unpaid care may experience this non-traditional role. Those working-age male carers who combine caregiving with employment also face practical challenges as they

endeavour to discharge their responsibilities to both unpaid and paid work. The challenges faced by male carers may be magnified, as historically caregiving has been conceptualised as female work with paid employment more often held as the norm for men. A study exploring how men of working-age actually experience caregiving would enable a better understanding of the importance of employment and other forms of work for male carers.

This review of the caregiving literature highlighted the breadth of areas covered by empirical research; therefore the decision was taken to undertake a structured review focusing on the experiences of working-age male carers. Such a review enabled the formulating of research questions.

Chapter 3: Exploring literature: reviewing the experiences of working-age male carers

Introduction

Reviewing the broad scope of caregiving literature, discussed in Chapter Two, provided insights into existing understandings of what caregiving is and how this emerged from historical conceptualisations of caregiving. This was important for this study, as caregiving research in the 1980s had presented a gendered, and possibly partial picture of caregiving, with female carers apparently assumed to constitute the majority of research participants (Fisher, 1994; Stoller, 2002). Recognising the predominance of female experiences in empirical studies helped signal the need for some critique of how male carers' experiences may have been discussed within studies which sought to compare and contrast male and female experiences; many studies used male experiences simply as a contrast to highlight the burdensome nature of female caregiving (Stoller, 2002).

A variety of literature, including discussion papers, books and journal articles, were initially used to develop a concept of how male caregiving was positioned and understood within the wider caregiving literature. Following the scoping review four questions emerged.

Firstly, the literature portrayed caregiving as an intuitively female activity, yet statistics indicated that almost half of all carers were men, so how did these men experience undertaking an activity predominantly portrayed as the labour of women?

Secondly, several authors suggested that men may have distinctly different experiences to their female counterparts, but there was little further explanation of why there were such differences or how such differences may alter the phenomenon of caregiving for male carers.

Thirdly, much of the literature presented a dichotomous view of the experience of carers illustrating that female carers experienced more burden and stress than their male counterparts, but there had been few studies explicitly exploring why men may experience caregiving in different ways to women.

Fourthly, as early caregiving literature tended to focus on the motivation to care, the tasks of the carer, and the burden experienced by the carer, there had been limited exploration of the experience of being a carer in employment.

To explore these questions a focused critical review of the literature, specifically pertaining to pre-retirement male carers, was undertaken which identified gaps in current understanding. Methodologies used in empirical studies were critiqued to explore whether they fully captured the male carer experience of the phenomenon of caregiving.

This chapter describes the literature search protocol, including inclusion and exclusion criteria. The selected studies were appraised and findings synthesised into four areas reflecting the key themes explored in male caregiving literature:

⇒ Why men undertake caregiving

⇒ How men undertake caregiving

⇒ How men retain their identity when in a caregiving role

⇒ How men experience being a carer and in paid employment

The chapter concludes with a discussion of the gaps in current understanding, leading to development of the research objectives.

Literature Search Strategy

Rationale for searching literature

There is some debate about whether an extensive review of the literature should be undertaken before starting a qualitative study, as to do so may lead to the researcher inappropriately entering the field with preconceived ideas, or whether such a review can usefully avoid re-inventing the wheel (Morse, 1994). I chose to review literature when beginning this study, recognising that well-developed understandings of the concepts of informal care already existed and to build awareness of how other researchers have undertaken studies with male carers.

Reviewing the literature at the beginning of the study enabled me to appreciate how the predominant concepts and theories about male caregiving have so far been developed. A critical review of methodologies and findings from previous studies exploring the

experiences of male carers helped ensure that the present study was designed specifically to add to the body of knowledge about male caregiving.

A structured rather than systematic search was undertaken with the purpose of capturing literature from a broad range of research areas, rather than a focused review of one application or intervention. Literature was reviewed using Critical Appraisal Skills Programme guidelines (PHRU, 2006), as these provided a framework for exploring the quality of individual papers.

Search strategy

Search databases

The literature was searched using the following electronic databases: ASSIA, AMED, CINAHL, MEDLINE, Pysco INFO, and Web of Science.

These databases were selected as they enabled access to a range of social science and medical peer reviewed articles in journals from a number of countries. Articles were also searched for through the electronic journal databases Wiley Interscience Journal, and SAGE Journals. Searches of Department of Health, Carers UK and The Princess Royal Trust for Carers websites also elicited policy documents and research reports. Further literature was obtained through hand searching of references in journal papers and books, unpublished theses and following up references from conferences and personal contacts.

Search terms

Search phrases were identified from abstracts and database thesauruses. Search terms used were 'male carer' 'family care', 'informal care', 'lay care', 'community care', 'shared care' 'caregiving'. These were then expanded and refined by using Boolean operators with the terms 'men', 'male', 'gender', 'choice' 'obligation', 'employment', 'work'.

Using these search terms an extensive body of literature was sourced. However, large number of the studies returned did not specifically seek the experiences of men aged below 65 years. The research interest was in men under 65 years, as such men might be expected to be economically active, therefore further inclusion and exclusion criteria were applied.

Inclusion and exclusion criteria

There is a large body of empirical studies on family caregiving within developed
countries. Therefore, to support the focus of the study Table 3.1 displays the inclusion
and exclusion criteria for papers selected for review.

Inclusion	Exclusion
Papers in English	Foreign language papers
English, European, Scandinavian, Australian, New Zealand, USA, Canadian and Japanese studies	Studies from developing countries
Studies which have included male participants	Studies with all female participants
Studies where some or all of the male participants are aged under 65 years	Studies where all male participants are 65 years and older, or where younger men's experiences are not made explicit
Studies were the findings make explicit the male carers' experiences	Studies where male carers are recruited but findings do not make explicit their experiences
Studies which explore either quantitatively or qualitatively the experience of being a carer	Studies which only evaluate an intervention

**Table 3.1   Inclusion and exclusion criteria to source literature relevant to the
proposed study of male carers in employment.**

Limited translation facilities prohibited access to articles which were not in English.
Countries included in the review have comparable social and family structures to those
in the UK (Lowenstein and Daatland, 2006). Studies can be selected from countries
which have a comparable Human Development Index[2] indicating similar levels of

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[2] The Human Development Index (HDI) is a comparative measure of life expectancy, literacy,
education and standards of living It is a standard means of measuring well-being,. It
distinguishes whether the country is a developed, a developing or an under-developed country,
and can measure the impact of economic policies on quality of life.

health, knowledge and standard of living for their citizens (United Nations, 2010). Whilst such countries may have differing health and social care provisions, this review did not explicitly explore studies exploring service provision. Papers where male experiences are explicitly presented in the findings were included. Studies where the experiences of male participants are subsumed with those of female participants were excluded as this study sought to explore male carers' experiences. Studies which only recruited from men aged over 65, or where the experiences of younger male carers could not be differentiated, were excluded because initial review of such papers indicated that older male carers appeared to have distinctively different experiences to younger men. The focus of the review was to explore and critique research which has added empirical understandings about the concepts and theories of male caregiving, therefore studies evaluating only service provision and interventions were excluded. Appendix 1 contains an example of the literature search process.

Critical review of research papers

Databases were searched from inception to December 2008. The retrieved literature is critiqued under four headings:

⇒ Why men undertake caregiving - discusses how becoming a carer may be influenced by a sense of obligation, reciprocity, lack of suitable alternative, or men may simply fall into the role without making a conscious choice.

⇒ How men undertake caregiving – discusses the tasks men undertake in the caregiving role and the strategies they use to adapt to the role of carer.

⇒ How men retain their identity when in a caregiving role – explores ways in which men talk of their own identity when in a carer role.

⇒ How men experience being a carer and in paid employment – discusses the experiences of combining care and paid work and the negative consequences on income and career prospects, also recognising the respite role played by employment and highlighting how employers may support carers.

Why men undertake caregiving

Since the mid 1980s, with the number of men undertaking care increasingly recognised, there has been a steady growth in studies explicitly exploring the experience of men

who are carers. Empirical studies indicated that there are a number of factors which might lead men to undertake the care of a relative or friend: namely obligation, reciprocity, and a lack of alternative provision. Often complex decisions led men into this non-traditional role. By understanding what motivated men of working-age to undertake the carer role it might be possible to develop an insight into the meaning they give to the activity.

Empirical studies have explored the obligation experienced by people of providing support to a friend or relative (Finch and Mason, 1993; Twigg and Atkin, 1994; George et al., 1998; Mosher and Danoff-Burg, 2004), indicating that obligation is frequently a negotiated rather than absolute condition. Men may experience an obligation to provide care, but this obligation may be experienced in a different way to their female counterpart. Men appeared able to more readily relinquish their obligations, frequently passing caregiving responsibilities on to wives or sisters (Globerman, 1996; Gerstal and Gallagher, 2001; Campbell and Martin-Matthews, 2003). Studies not predominantly designed to explore motivations for becoming a carer have found male carers undertake caregiving because they identify it as the 'right thing to do' (Horowitz, 1985; Harris, 1998; Mays and Lund, 1999), suggesting that there may be an ethical obligation to male caregiving.

However obligation imposed by society and family norms may be tempered by the concept of reciprocity within a relationship. Reciprocity, the process of mutual support with a relationship, rather than obligation, may be a motivator for men to undertake care (Neufeld and Harrison, 1998; Archer and MacClean, 1993; Parsons, 1997).

Nonetheless other studies have shown that whilst male carers may cite obligation and reciprocity as reasons for undertaking the role, many men explained that they undertook caregiving because there was no alternative (Globerman, 1996; Gerstal and Gallagher, 2001; Hequembourg and Brallier, 2005). These men may be the closest or only relative, or they may feel residential care is not appropriate for their relative. For some men becoming a carer was not a considered decision, rather they slowly increased carer responsibilities almost by default due to the slow decline of their relative and the corresponding increase in the range of activities they undertook to support their relative (Boeije et al., 2003).

Often a combination of reasons led men into the carer role, so whilst in this review each reason is discussed discretely it was recognised that male carers often made a complex range of decisions.

Obligation – 'the right thing to do'

Whilst normative obligation has been reported by social scientists as a reason for undertake caregiving, frequently when men were questioned on their reasons for providing care they did not use the word obligation, instead talking about the ideals of fairness and responsibility (Neufeld and Harrison, 1998; Campbell and Carroll, 2007). Obligation may be linked with a sense of reciprocity, but it may also be tempered by societal expectations of what is acceptable behaviour. For example, in marriage there is to a degree a societal expectation that husbands will provide care to their spouse (Parker, 1993; Henderson, 2001; Boeije et al., 2003). Fathers have also identified that they should care for adult children.

Mays and Lund (1999), interviewing ten husband and son caregivers of relatives with a mental health problem, identified that these men emerged into their roles rather than making an active choice. However, this may have been due to the nature of the illness because when asked if given the opportunity to leave the role would they chose to do so, participants indicated that they felt committed to the role. A father stated he felt 'obligated' to care for his children and that 'it is something a real man would do' (1999:25), suggesting not an innate nurturing, rather a sense of the proper thing to do. Gilligan (1982) proposed that female carers undertake caregiving because of an innate ethical sense of it being the right thing to do. However, male carers more readily refer to principles of reciprocity and natural fairness than an innate disposition (Campbell and Carroll, 2007). Men described it was their responsibility, they chose to be in the role of carer and others would also recognise that they had done the 'right thing'. The idea of being seen to do the right thing by family members may be an important influence to the meaning male carers attach to their activities and identity.

Obligation grounded in life experiences

The concept of caregiving being the 'right thing to do' may be embedded in previous life experiences. Men who provided care as a child, or who grew up within a caregiving family experienced caregiving as part of their cultural world and they subsequently appeared willing to undertake the activities of being a carer (Hirsch, 1996).

Hirsch (1996) interviewed 32 male carers aged between 21 and 79 years who were caring for a variety of family members or a friend. He explored the ways in which men 'gained access to family caregiving role' (1996:103), arguing it might be difficult for men to enter the role of caregiver because traditionally this has been perceived as a female role. Using a personality trait scale, participants were identified as having androgynous, masculine, feminine or undifferentiated personality traits. Participants scoring high on masculine traits spoke of how their prior experience and role models of their childhood had made them see caregiving as an appropriate male gender role. Many had been exposed to caregiving within the family home as a child. Early exposure to caregiving behaviours has been cited as a reason why men may chose to undertake the role in later life (Archer and MacLean, 1993; Jones, 2006). Other reasons Hirsch (1996) found for men to commence caregiving included love and affection for the care-receiver and a religious belief that it was the right thing to do. However one participant expressed concern about being a carer; being worried that others might see him as less of a man if he told them he was carer to his mother. Hirsch's study also found that some men only became carers on being made redundant from employment (1996). It might be that caregiving replaced other forms of work. There have been studies indicating that men may undertake care of a relative and children when paid employment is not available to them (Bytheway, 1987; Charles and James, 2005).

A sense of obligation together with life experiences may be factors which influence men to undertake the carer role. However, as suggested by Hirsch (1996), male carers may not think that being a carer is an appropriate male gender role and the constraints inherent within a carer role may be unpalatable to them. As a consequence some men may negotiate their obligation to provide care, providing reasons why they can or cannot be involved in the care of relatives.

Negotiating obligations – deserving of care

The obligation to provide care for a relative may not be absolute and Finch and Mason (1993) identified that often a process of decision-making took place. In their seminal sociological work exploring kinship obligations they found people made decisions on whether to offer support to relatives based on information they had about how these people came to need support. Participants in the study were provided with vignettes of situations where family members required different types of support, including financial assistance, a place to stay, and help with care. When responding on whether or not they

would support the person, participants made decisions based on how deserving they considered the relative to be, coupled with the impact of providing care on their personal well-being (Finch and Mason 1993). A later study by George at al. (1998) confirmed the early findings of Finch and Mason that people made considered decisions before offering support. However, the study by George et al. (1998) explored offers of help across friendships rather than family scenarios and suggested it may be easier to limit support to friends than immediate family.

The study by George et al. (1998) of 212 men and 325 women found that men assessed the control they would have over the task and whether they perceived the friend to be at fault before undertaking the helper role. This concept of the person being deserving of care was reiterated in a later study exploring helping patterns in undergraduates. Exploring the decision-making patterns of 214 undergraduates, Mosher and Danoff-Burg (2004) presented participants with vignettes of caregiving situations and asked if they would provide support to the caregiver. Whilst these participants were not carers themselves, their choices reinforce other studies, indicating that women feel a stronger obligation to provide support to others than men. In Mosher and Danoff-Burg's (2004) study the majority of female participants would offer higher levels of support than male participants, whilst male participants indicated that they would provide higher levels of support to employed caregivers than retired caregivers. This finding suggested that there were different decision-making processes taking place for men and women. The design of the study did not enable further exploration of why employed carers were offered higher levels of support, but it may be that participants perceived retired people to have the time to undertake caregiving as they had no other work commitments. Whilst these three studies did not explore the motivations of people who were providing long-term care, they added to the understanding of factors which may influence men's decisions to provide help to another person. They suggested that men may offer less practical help than women and that offers of help may be mediated by decisions over how deserving the other person is of support and the personal consequences of providing such support.

Negotiating obligation – flexible employment

Male carers appeared to consider the pragmatics of undertaking the role as well as their obligation. In a qualitative study of 30 son carers, aged 32 to 71 years, Harris (1998) found that as well as feelings of duty and love, sons became a carer because they recognised the need to take charge. They also had a level of flexibility in their working lives which enabled them to actively participate in the care of their parents. Harris

(1998) merged the findings of primary and secondary son carers; secondary son carers supported another person who was the primary carer. She justified this decision by explaining that both primary and secondary son carers undertook similar caregiving tasks; however she did not discuss the support, if any, provided by the primary carer to the secondary carer sons. Understanding how sons were supported by other relatives, particularly a female relative, is important as later work has found that male carers are frequently led into caregiving by wives and sisters (Gerstal and Gallagher, 2001).

A later study by Hequembourg and Brallier (2005) also highlighted the importance of flexibility of work. Interviewing eight pairs of male and female siblings they explored who within the sibling pair provided the majority of care to ageing parents, finding that those brothers with flexible work commitments were more likely to provide more help than men with more fixed employment patterns. A limitation of the study was that the eight sibling dyads were middle class with incomes which meant there was perhaps a higher degree of flexibility over whether, how and when brothers offered support. Men with higher incomes have been found to be able to pay others to undertake personal care (Campbell and Martin-Mathews, 2003). Through understanding how men make decisions about whether to undertake caregiving themselves or whether to pay another person could lead to a deeper understanding of the phenomenon of male caregiving.

Negotiating obligation – relinquishing obligation

Research specifically exploring the experiences of male carers has found further evidence of men negotiating their obligations. If there was a female relative available to undertake the caregiving men frequently relinquished their caregiving responsibilities (Horowitz, 1985; Globerman, 1996; Gerstal and Gallagher, 2001; Hequembourg and Brallier, 2005). Men might only become the primary carer when there was no female relative available. Horowitz (1985) undertook research exploring the gendered nature of caregiving. Interviewing 131 adult children caregivers of whom 32 were sons, she argued men may become carers in the absence of a suitable female relative, or because they lived substantially closer to the ageing parent than any other sibling. The female relative does not need to be a sister, as Globerman (1996) found that sons deferred their caregiving role to their wives.

Exploring the motivation of married adults to care for a parent-in-law with Alzheimer's disease, Globerman (1996) interviewed six sons-in-law and ten daughters-in-law and their spousal partners. She found a blood relationship did not always influence who

became the primary carer, with many daughters-in law identifying themselves as the primary carer. A limitation of the study was that it was unclear how intimate the relationship had been between participants and their parent-in–law before the elder developed Alzheimer's disease; a close relationship might have prompted caregiving rather than gender. Daughters-in-law took a more active part in caregiving than sons-in-law, who stated that they were there to help out with tasks, but they were not the managers of care, rather they supported their wives.

The findings from Globerman's study confirmed the theory that women undertake the majority of caregiving because they feel a stronger obligation to provide care to non-blood relatives than men. She found male participants spoke of obligation in a universal rather than personal way. They felt older people should be cared for because it was the right thing to do, as one son-in-law stated 'we did what we felt was right, what we had to do' (1996:39). Daughters-in-law, however, felt not only a personal obligation but also described how others expected them to undertake the carer role, suggesting that were cultural and societal norms about who should deliver care. Later work by Gerstal and Gallagher (2001) further supported the notion that men may undertake care in order to support their wives who are primary caregivers. In both studies the types of care provided by the male participants tended to be limited to traditional male activities, such as garden maintenance and providing transport, yet it might be that when the man is the primary or sole caregiver the experience and range of activities differs from when they are supporting a female primary carer.

Whilst male carers appeared to be able to legitimately negotiate their caregiving contributions to relatives, when they did provide care they did not speak of obligation rather they couched their reasons for providing care within the concept of reciprocity.

Reciprocity within caregiving

The concept of reciprocity in relationships is based on the mutual exchange of support and resources and has been cited as one of the reasons men give for undertaking the care of a relative, particularly a wife or parent (Archer and MacClean, 1993; Parsons, 1997; Neufeld and Harrison, 1998; Campbell and Carroll, 2007).

Archer and MacLean (1993), interviewing six male carers, identified that sons expressed a sense of reciprocity towards their mothers based on the nurturing they had received from her as a child. Parsons (1997), interviewing eight male carers, found reciprocity was an essential theme within male spousal and son caregiving. However in

Parsons' study the majority of participants were no longer providing care and therefore it is difficult to know whether these feelings of reciprocity were also present when they commenced caregiving or whether they developed as participants reflected on past caregiving experiences.

A larger study by Campbell and Carroll (2007) developed the idea that sons may care out of a sense of reciprocity to their parent. Campbell and Carroll (2007) interviewed 58 adult sons caring for parents to explore how these men perceived their masculine self. They found men were not reluctant to take on caregiving and that frequently participants stated that they provided care because parents had previously taken care of them. Campbell and Carroll (2007) suggested men were providing care as a form of 'quid pro quo' (2007:503) as they now cared for parents who had previously provided for them. This contrasted with the essentialist view that women provide care as an innate predisposition (Gilligan, 1982). However, in their study, 38 of the 58 sons interviewed were married and it was unclear how much support their wives provided with caregiving routines; this might influence the meaning these men gave to caregiving, as Gerstal and Gallagher (2001) found that men were frequently pulled into caregiving roles by their wives and it could be that the choices regarding care and types of care undertaken by the men in Campbell and Carroll's study were heavily influenced by the wives.

Whilst these studies have explored how the concept of reciprocity may have influenced men's decisions to undertake caregiving role, the work of Neufeld and Harrison (1998) took this further, considering the role of reciprocity in the continuance of caregiving. They interviewed 22 male caregivers aged between 33 and 87 years. However only four of the sample were aged under sixty and only three in full-time employment, so it is acknowledged that transferring these findings to a younger male population may be difficult. Nonetheless a strength of the study was in the longitudinal nature of data collection, with men being interviewed 3 or 4 times over an 18 month period, thereby adding credibility to the findings. Findings indicated caregiving might take place because of a past positive reciprocal relationship, with husbands now providing care because of experiencing a positive marriage. Other husbands provided care because of perceiving it as 'the right thing to do'. The concept of providing care through a sense of natural justice rather than through love or obligation has been seen in several other studies (Globerman, 1996; Mays and Lund, 1999; Boeije et al., 2003).

Of particular note in Neufeld and Harrison's (1998) study was the way in which caregiving through a sense of reciprocity frequently changed to caregiving through a sense of obligation, particularly as the length of time caregiving increased. This was evidenced in the findings, as out of 22 participants 12 spoke of providing care through a sense of obligation rather than because of reciprocity. Obligation appeared linked with the feeling that they 'ought' to care for a relative (1998:963). Neufeld and Harrison found when men cared from a sense of obligation they described negative feelings such as psychological stress, burden and isolation. Men who stated they cared because of reciprocity did not express these feelings. This finding has not been explored in other studies but it did suggest that the way in which men decide to undertake caregiving might influence the meaning they give to the experience of caregiving. This concept could be also be explored when men have relinquished an activity, such as employment, in order to provide care.

Lack of alternative

There was evidence that whilst men might relinquish carer responsibilities to a female relative when they were the only child or lived geographically closer than other siblings, men did also undertake caregiving (Campbell and Martin-Matthews, 2003), suggesting that they did not shun the role per se, rather they did not actively seek it. However, it is unclear whether this is due to male carers' decisions or women actively seeking the role, as women are more likely to perceive an elder relative requires care (Gerstal and Gallagher, 2001; Romeran, 2003)

Sons may be more easily able to negotiate caregiving responsibilities than husbands. Boeije et al. (2003) found with spousal carers, where the care-receiver has a deteriorating disease, carers 'drifted into the role without exercising genuine choice about their willingness or ability to give care' (2003:249). Although Boeije et al. did not explore this, it may be that drifting into the role makes it harder for men to identify that they are undertaking caregiving, thereby limiting their access to support services.

Gaps in understanding why men undertake the carer role

The findings of these studies show that at times men may make decisions to provide care based on normative beliefs around whether it is more appropriate for women to provide care and whether the caregiver is deserving of their care. Nonetheless there were also situations where men appeared to drift into the role and situations where men

undertook care because they described it as the right thing to do. Whilst some studies found male carers undertook care because they could fit it into their employment patterns, it was not possible to draw conclusions about whether being in employment influenced men's decisions to care. These studies provided an argument that men undertook caregiving not necessarily through an innate obligation, rather decisions to care were justified in terms of reciprocity, or being the best available person. However, it was beyond the scope of these studies to explore whether the different routes into caregiving influenced the meaning men gave to the experience of being a carer.

Having examined how men might become carers, the literature was further explored to gain an understanding of the ways in which men might undertake care.

How men undertake caregiving

Using the concept of care developed in Chapter Two, that caregiving involves practical care, emotional care and managerial care, literature was reviewed to develop knowledge of the types of activities working-age male carers undertook. Empirical evidence had suggested that men past retirement age undertook caregiving in similar ways to female carers (Arber and Gilbert, 1989; Chang and White-Means, 1991; Fisher, 1994), but in exploring how younger men undertook care there emerged a more complex picture, with some men seen to undertake care in distinctly different ways to female carers.

Obligation – influence on activities of caregiving

The types and level of obligation felt by some carers may influence the types of care they are willing to provide. Using data from the Canadian Work and Family survey, Campbell and Martin-Matthews (2003) found men experienced an obligation to provide care and the level of obligation influenced the types of care they undertook. Analysing questionnaire data on 773 men aged between 42-67 years, who provided care to at least one parent or parent-in-law, they found that when the son had high levels of perceived obligation to provide care for ageing relatives, there was a positive correlation with a willingness to be involved in care of a female relative. Further they were more likely to undertake traditional female care activities such as bathing, toileting and feeding. Campbell and Martin-Matthews concluded that 'feelings of filial obligation play a more significant and necessary role in the level of involvement' (2003:5354). However, there were predisposing factors which increased the likelihood of these sons providing such care, namely living with the parent and the absence of other siblings with whom to

share the caregiving. Therefore whilst the study linked filial obligation with men's level of involvement in gender-neutral and traditional female carer activities, such as personal care and emotional care, these findings need to be considered in light of the fact that these men may have had few alternatives but to undertake such types of care.

Filial obligation has not been found to be a predictor of men's involvement in traditional male tasks such as garden maintenance, suggesting that men do not need to feel obligated to the role of carer to undertake these more traditional male activities (Campbell and Martin-Matthews, 2003). It appears that higher levels of obligation to the role of carer are required before men will undertake more traditional female care activities.

Caregiving activities

Undertaking physical tasks

Studies recruiting male carers have tended to either recruit men who provide care alongside another family member, most usually their wife or sister, or they have recruited men who are the primary carer for a relative. The types of caregiving activities men undertake appear to differ depending on whether or not they are the primary carer.

Exploring the experience of spousal couples who provided care to another family member, Gerstal and Gallagher (2001) undertook a quantitative analysis of interview data from 94 spousal couples. They sought to explore whether household structures and family relationships impacted on the nature of male caregiving and secondly whether employment, both husband's and wife's, impacted on the nature of caregiving. They found family structure rather than employment influenced the type and amount of care men provided, identifying that wives drew the men into caregiving. For example, when the wife left the home to attend to a relative's care needs the husband would go as well, frequently to drive his wife; he subsequently reported this as joint caregiving activity. They also found men were most likely to undertake time-limited tasks, such a mowing the lawn and providing transport, whereas wives more frequently cited the emotional demands of caregiving and the need to physically be with the cared-for person. A number of studies have suggested that male carers may be more likely to undertake time-discrete, outcome-related tasks such as managing the finances, garden maintenance or household repairs. As a consequence they do not provide the same type or level of care as female carers (George et al., 1998; Gerstal and Gallagher, 2001; Hequemberg and Brailler, 2005; Jegermalm, 2006).

A gender division in caregiving activities was also seen when men spoke of how family members supported them in their carer role. Sanders (2007) used a phenomenological methodology to explore the support networks of male carers and found that family members often supported the male carer. Whilst the majority of participants in Sanders' study were men aged over 65 years, she highlighted the experience of one 41 year old man. He explained how his wife and son helped in him in the care of his relative, stating 'my wife does the bathing and toileting and my son is in charge of all the garbage' (2007:108). This evidence suggested a gender division in tasks, with the male carer seemingly avoiding providing personal care.

Globerman (1996), specifically exploring the experiences of in-laws providing care to elderly parents-in-law, suggested that in marriage women would predominately provide the majority of care, whether or not the person needing the care was a blood relative. However a study by Campbell and Martin-Matthews (2003) did not find that marriage made a difference to the types of care undertaken. Rather, they found it was the demographics of the siblings which most influenced the types of tasks undertaken by son caregivers, with men without siblings being more likely to be involved in all types of caregiving. This finding reinforced the theory that men undertake care because of a lack of alternative. The different data collection methods of each study may account for the different findings. Campbell and Martin-Matthews (2003) undertook analysis on survey data of 773 employed men who stated they undertook care of a parent; 92% of the cohort were married but the experiences of the wives were not sought in their study. Globerman (1996) interviewed 16 caregiving couples together and it may be that the presence of a wife, who herself felt involved in the caregiving, mediated the responses of the male carers.

The nature and duration of caregiving across gender was explored by Romoren (2003). He analysed longitudinal data from 227 adult children carers and found very few differences in the level and types of care undertaken by daughters and sons. Romoren (2003) explained that what differences there were might have been due to more sons than daughters being in full-time employment, meaning they had reduced opportunity to undertake care. The slightly higher levels of daughter caregiving may have been due to daughters recognising the need for, and so providing, support at earlier stages in their parents' decline.

However Romoren's (2003) findings were contradicted in a study by Hequembourg and Brallier (2005), who recruited eight brother and sister pairs who were caring for elderly parents. Using face-to-face interviews with each sibling they found in all cases the sisters were responsible for coordinating the care, directing the brother in activities he needed to undertake. They also found levels of care undertaken by the brothers differed depending on how involved in the caregiving they were. Four brothers were helper brothers who took on the traditional male carer tasks of car and home maintenance; these brothers waited for their sister or parent to ask for help. The remaining four brothers were 'co-providers' and there was equity in the care provided by brother and sister (2005:60). The co-provider men had flexible work and family commitments meaning they were more readily available to provide care. Nonetheless almost all of the sisters were also in employment, indicating that lack of employment cannot always be a mediating factor in level of care provided. More likely to be a mediating factor was gender, particularly as Romoren (2003) found men more likely to wait to be asked for help or to promote the independence of elderly relatives than women. However, once the man made the commitment to undertake care, the types of tasks they undertook were the same as their sisters, for example co-provider brothers undertook emotional support, personal hygienic and medical tasks such as assistance with bedpans and management of urinary catheters.

Undertaking intimate personal care

Whilst studies exploring caregiving across siblings have suggested difference in the types of care and levels of involvement undertaken by brothers and sisters, when there was not a female relative available to provide care male carers appeared to undertake exactly the same activities as their female counterparts (Horowitz, 1985; Archer and MacLean, 1993; Campbell and Martin-Matthews, 2003; Campbell and Carroll, 2007). Nonetheless providing personal intimate care appeared to cause unease amongst male carers, particularly sons caring for mothers (Arber and Ginn, 1995; Parsons, 1997). Spousal carers frequently accepted such care as part of their role, but they still explained that providing such care could change the nature of their relationship with their wife (Parker, 1993). However, when the carer was a son caring for his mother the feelings of unease increased. In a study of five spouse and three son carers, Parsons (1997) identified that sons found it harder to undertake physical care of their mother than husbands did of their wives. This was confirmed by a later study by Campbell and Carroll (2007) who, in a study of 58 son caregivers, identified that sons found it

particularly difficult to undertake personal care for their mother, nonetheless 'they just did what had to be done' (207:498). Several other authors have also suggested that whilst personal care may be emotionally difficult, if there is no other alternative male carers will undertake such tasks (Horowitz, 1985; Hirsch, 1996; Parsons, 1997; Harris 1998; Thompson, 2002; Kirsi et al., 2004; Campbell and Carroll, 2007). This finding suggested the assumption that men undertake different care activities to women, was not always founded, with male carers frequently undertaking a wide range of practical care activities. If men are undertaking the same types of caregiving activities as women it is perhaps the way in which men conceptualise their caregiving activities and roles that leads to them having distinctly different experiences to female carers.

Male carers appeared to compartmentalise their caregiving activities however, the studies reviewed so far have discussed the practical ways in which men undertake caregiving, with little reference to the emotional labour of caregiving. To explore how male carers provide emotional care two studies using a qualitative approach were evaluated.

Emotional care

Many of the studies exploring male carers' caregiving activity focused on the range of practical and managerial tasks they undertook. However, two studies used a qualitative approach to explore the meaning of caregiving to male carers (Parsons, 1997; Harris 1998). These studies provided a deeper understanding of the emotional aspects of caregiving. Parsons (1997), in her phenomenological study, interviewed five spouse and three son carers and identified eight emerging themes. These themes were 'enduring', 'vigilance', 'sense of loss', 'aloneness and loneliness', 'reciprocity', and specifically in son carers, 'overstepping the normal boundaries'. Within her study there was evidence of the men being emotionally involved in the process of caregiving. Participants spoke of their sense of loss and feeling alone as they lost the person they had known to dementia. They also had to be vigilant about safety, leading to loss of the care-receiver's autonomy and identity when participants had to take away objects or control from their relative in order to maintain their safety. For example, one man had to stop his father driving and he spoke about how part of his father had been lost now he could no longer drive. This study reiterated the idea that spouse and sons experienced providing personal care in different ways. The son carers expressed unease with providing intimate care to their mothers, illustrated through the theme of stepping over the

boundary. Whilst Parsons' study added to the understanding of the meaning of caregiving for male carers, it was not possible to identify how many of the participants were of working-age and how many, if any, were combining care with employment. It may be that these characteristics change the meaning of caregiving.

In a larger study exploring the meaning of caregiving Harris (1998) interviewed 30 son carers. Her study, whilst not phenomenological, used an interview guide and thematic analysis, therefore it is credible that the findings reported have captured the meaning of caregiving for these men. She identified five themes: duty, acceptance, taking charge, common emotions and work flexibility. The majority of sons spoke of their sense of duty to undertake care of their parent and, whilst expressing sadness at the decline of their parent, they accepted the reality of the situation. They spoke of taking charge, identifying this as part of their role as a son. This characteristic of male caregiving appears to have been contradicted by Hequembourg and Brallier (2005), who found that women tended to take charge of planning the caregiving. Harris states that 77% of her sample had siblings, the majority being sisters, and it may be that had the opinions of sisters been sought they would have stated that they took charge. The caregiving sons in Harris's study experienced a range of emotions including 'anger, resentment and guilt', particularly when they felt that had not fully fulfilled their caregiving obligation (1998:346). In a later work where she compares data from this study and another one exploring spousal carers' experiences, Harris identified that son carers were more likely to express negative consequences of caregiving such as stress and burden (Harris, 2002). She also found sons were more able to set boundaries to their caregiving, suggesting that spousal and son carers may have different experiences of being a carer. This finding may be important, as studies frequently subsume son and husband experiences together.

Both of these studies captured the emotional experience of being a carer, but a limitation was they only recruited men caring for a relative with dementia. It may be that the caregiving experience differs if caring for someone with a physical disability where the communication with the relative is not impaired. It was noted that in neither study did the men refer to any emotional support that they might offer their relative, although they highlighted the emotional difficulties of taking control away from a parent. It may be that male carers, through focusing on the physical rather than emotional needs of the care-receiver, are buffering themselves from the emotional

consequences of providing care. However, it may equally be that studies to date have not been designed to enable male carers to talk of the emotional support they provide.

Consequences of being a carer

Since the mid 1980s an extensive body of literature has developed suggesting male and female carers experience different levels of burden. Burden usually refers to the level of distress experienced because of their carer role (McFarland and Sanders, 1999). The majority of studies found that male carers experienced less psychological stress and burden than their female counterparts (Zarit et al., 1980; Horowitz, 1985; Chang and White-Means, 1991; Almberg et al., 1998; Dennis et al., 1998; Cousins et al., 2002; Hirst, 2003; Hirst, 2005; Pinquart and Sorensen, 2006; Robertson et al., 2007). However, the psychological stress and burden male carers did express tended to have different causal factors than female carers.

Almberg et al. (1998) recruited 15 male and 37 female carers of elderly people with dementia. Using a validated questionnaire survey they identified that the factors causing stress to male carers were their lack of positive outlook and a lack of social support, whereas female carers described health problems and strain in family relationships as the factors leading to stress for them. Levels of anxiety were also found to be higher in female carers than male carers (Dennis et al., 1998) and this may in part be linked to levels of self-belief in one's ability to undertake the activities of caregiving (Hagedoorn et al., 2002).

Whilst many studies provide evidence of physiological and psychological differences between male and female carers, a few studies have not found a significant gender difference (Zarit at al., 1986; Miller and Cafasso, 1992; Carlson and Robertson, 1993; McConaghy and Caltabiano, 2005; Baker and Robertson, 2008). There are a number of possible reasons for this disparity, including length of time caregiving, the age of the carer, levels of self-belief and whether or not the carer experiences role engulfment.

Firstly, Zarit et al. (1980, 1986) undertook a longitudinal study of carers of people with dementia and suggested that the length of time one had been a carer might affect the level of burden experienced. In the 1986 follow-up study Zarit et al. (1986) found that the differences between male and female carers recorded in 1980 was no longer apparent, with both genders now having similar coping styles. They argued that

differences in the caregiving burden reduced with the length of time a person undertook the role, leading to similar coping strategies and similar levels of burden. Hirst (2005), using survey data, also found that the levels of caregiving burden fluctuated over time, with psychological distress being most pronounced at the beginning and end of the caregiving episode. A limit of the study by Zarit et al. (1986) was that only husbands and wives were recruited and the age of the sample population suggested that the majority of participants might have exited employment. Therefore conclusions cannot be drawn as to whether younger son carers would experience the same level of burden as their sisters if re-interviewed after a few years of caregiving.

Secondly, age may be a factor explaining similar levels of burden in male and female carers, as older male spousal carers have been found to undertake the same tasks as their female counterparts, therefore they may experience the same involvement in care and subsequently experience similar levels of burden and strain (Fisher, 1994; Thompson, 2002). Further if younger carers are trying to combine caregiving with paid employment this might have a negative impact on their sense of well-being (Arksey, 2002; Philips et al., 2002)

Thirdly, it has been found that male carers may experience different stressors to their female counterparts and they may have high levels of self-efficacy which could buffer stressors (Hagedoorn et al., 2002). Finally, Greenberg (2002), exploring the experiences of parents of children with mental health problems, found that role engulfment was a predictor of great distress rather than the gender of the carer.

Reviewing these studies it was difficult to draw conclusions about gender influences on the consequences of caregiving. However, even if it is accepted that male carers may experience less stress than female carers, this knowledge alone does not expand the understanding of what aspects of caregiving cause or relieve stress in male carers. Many studies exploring burden and stress have used psychological quantitative methodologies and it may be that in-depth qualitative studies would provide male carers with the opportunity to share the aspects of caregiving that cause them the most distress. Understanding how male carers mediate stress may mean that similar strategies could be used with female carers.

Mitigating the stresses of being a carer

The literature revealed a number of ways through which men sought to mitigate the stress of being a carer. Male carers set targets, had high levels of self-efficacy, found respite in other activities and drew on social support networks.

Setting targets

Mays and Lund (1999) found that one of the ways male carers of people with mental health problems coped with caregiving was by setting realistic and action-orientated targets. This task-based approach had resonance with the caregiving activities male carers undertake which, unless the men are sole carers, tended to be measurable, time-restricted, discrete activities (Gerstal and Gallagher, 2001). McConaghy and Caltabiano (2005) also found that when both male and female carers focused on practical rather than emotional types of caregiving, they experienced higher levels of satisfaction in their role, suggesting that it is the emotional aspect of caregiving which has the most detrimental consequences.

Self-efficacy

There is evidence that men experience satisfaction from their role as carer and this may in part explain the different levels of burden experienced by men and women. In a qualitative study interviewing three husbands and three sons, Archer and MacLean found that all the men stated that they 'received an immense amount of gratification and satisfaction in their role as carers' (1993:16). A later study by Hagedoorn et al. (2002) found that men felt that they did a good job as a carer. Using a range of measurement tools to test the hypothesis that identity may be linked to stress in 32 female and 36 male carers, Hagedoorn et al. (2002) explored carers' self-belief in their role and found that male carers had higher levels of self-efficacy than female carers. This may explain why male carers frequently experience less burden and stress than their female counterparts. These findings suggested that self-identity might influence the meaning men give to the caregiving experience.

Respite from caregiving

Male carers also placed importance on time away from the caregiving role, either through formal respite arrangements (Harris, 1993) or for leisure pursuits (Archer and MacLean, 1993) or when undertaking paid employment (Arksey, 2002). In Archer and

MacLean's (1993) study only one of the six participants was in employment and the findings do not highlight whether he was as able to undertake the leisure pursuits that the others in the study found so beneficial to their well-being. Employment was another way in which male carers gained respite (Arksey, 2002). Yet employment, whilst providing respite from the physical work of caregiving, can lead to different stressors.

Social support

Social support was also found to enhance male carers' ability to cope with the role. For some social support came from family, but more frequently men found that family and friends did not offer much support (Archer and MacLean, 1993, Hibbard et al., 1996; Parsons, 1997; Pierce and Steiner, 2004). Nonetheless an earlier study by Kaye and Applegate (1990) identified it was not the frequency of help male carers received from their families but the man's perception that his family held him in positive esteem that impacted on his sense of well-being. Hirsch (1996) reinforced this idea, arguing that positive feedback from family members enabled men to sustain their non-normative role.

Gaps in understanding about how male carers undertake caregiving

Studies exploring how men provide care and the consequences of being a male carer frequently contradicted each other. Men who were the primary carer provided the same types of care activities as women, although they often conceptualise these in different ways. For example, they view an activity as a discrete measurable activity rather than part of their overall role. Yet when there was a female relative available to undertake caregiving men usually reduced the amount and types of care they provided. There is evidence that women may change the nature of caregiving for sons and husbands, therefore studies recruiting male carers might need to clearly define whether or not participants are sole carers or part of a caregiving family. When seeking to understand the benefits and consequences of being a male carer there is again contradictory evidence, with some studies suggesting men experience fewer burdens and strain than their female counterparts and others finding no significant differences. In part this may be mediated by the length of time the person has been a carer, although there was some evidence that men undertake caregiving in a task-orientated way and that they have high levels of self-efficacy. Such factors might explain why men often express less burden and strain and this is an area for further exploration. It might be that self-efficacy is

related to the way in which men perceive themselves and conceptualise their role. For example, men may see the role of carer as a distinct activity to be managed and achieved rather than an all-encompassing part of their life.

How men retain their identity when in a caregiving role

Since the late 1990s there has emerged a body of work seeking to explore how male carers conceptualise their identity. Understanding how male carers think of themselves may deepen understanding of how they experience the activity of caregiving.

Husband carers may experience a conflict over their identity and obligations as husband and their responsibilities as a carer. Henderson (2001), in a qualitative study exploring the impact on people's construction of identity, found that husbands whose partner had a severe and enduring mental illness experienced conflict between their roles of carer and husband. Spousal couples often stated that health professionals perceived them as carer and cared-for rather than equal partners; specifically spouses were encouraged to report their partner's non-compliance with medications. Participants described how being identified primarily as a carer created conflict with their husband role. This finding highlighted that people's perception of their self may conflict with health professionals' more realist view that family members are carers first and foremost and should accept those responsibilities.

There has been further debate about whether male carers develop a new sense of their masculine self. Campbell and Carroll (2007) explored how 58 men caring for elderly parents, 40 of whom were caring for their mother, conceptualised their gender; specifically whether they perceived themselves as differing from the hegemonic masculinity ideal proposed by Connell (1995). Using qualitative guided interviews they sought to explore how participants experienced their caregiving role. Findings suggested that the sex of the care-receiver did not affect the way in which male carers perceived their masculine identity. Whether caring for their father or mother, these men felt comfortable with their identity and their role as a male carer. Nonetheless participants still spoke of general caregiving in dichotomous gendered ways, explaining that female carers were better at the emotional and listening aspects of caregiving. Findings also showed that male carers adopted a 'take-charge' and 'just-do it approach' (2007:498). Campbell and Carroll (2007) acknowledge that single interviews were a limitation of the study as they were unable to follow up themes for the preliminary

analysis; therefore participants have not validated interpreted findings. However, earlier studies also found that male carers often adopted a take-charge attitude to their role (Harris, 2002; Thompson, 2002), suggesting that male carers may adopt problem-solving rather than emotional responses to caregiving situations. An assertive approach to life is cited as a masculine trait (Moynihan, 1998).

Men who become carers may leave employment and with this they lose a part of how they were previously defined. Harris (2002), reviewing her studies which had explored the experiences of 60 husband and son carers of people with dementia, found that taking control of the caregiving situation came naturally to these men as it was part of their male role in society. Nonetheless participants also expressed a sense of loss of their manliness, with one male carer stating 'you begin to lose your male identity' (2002:225); this was often coupled with loss of employment.

Gaps in understanding the identities of male carers

The literature exploring identity with male carers is in its infancy, but there is developing evidence that men undertaking a traditionally female role use strategies to maintain their masculine identity. Male carers may not talk about their carer role when undertaking activities away from the caregiving situation. They frequently justify why they are in the care role, for example being the only sibling, being geographically close to the elderly parent or explaining that they have a duty to reciprocate previous care of a parent. A study which includes male carers from a range of caregiving situations, including husband, son and father, may help to increase understanding about the ways in which these different family identities are maintained or conversely subsumed into a carer identity. Whilst male carers frequently state that they provide good quality care, they still revert to social norms by describing women as natural empathetic caregivers. This schism between self-efficacy in their activities and beliefs about who should most naturally provide care merits further exploration, as it may illuminate how and why male carers sometimes appear to experience less burden and stress than female carers. It remains to be explored whether being in paid employment alongside caregiving impacts on the ways in which male carers conceptualise their identity.

How men experience being both carer and in paid employment

The number of carers who combine paid employment with their caregiving role continues to increase, with demographic data suggesting that a growing elderly population will mean more people of employment age making decisions about combining employment with caregiving (Buckner and Yeandle, 2005). Therefore, it is pertinent to have an understanding of how male carers experience employment. The literature pertaining to the experiences of carers in employment is still relatively limited and many studies have focused on how women combine employment with either motherhood or carer roles. However, recent government initiatives have sought to encourage employers to adopt more flexible employment patterns, enabling carers to return to or remain in the workplace (Evandrou and Glaser, 2004; Work and Families Act, 2006; DH, 2008), meaning that both male and female carers may now be more readily able to combine caregiving with employment. Through exploring the literature around the experience of combining work and caregiving, a contradictory picture arose of carers experiencing both benefit and burden from undertaking paid work alongside unpaid caregiving. It appeared that, as with making the decisions to become a carer, others' expectations and carers' self-identity influenced how men experienced being a working-age carer. Understanding the motivations and experiences of working-age male carers added another layer of knowledge about the phenomenon of male caregiving.

Motivations for undertaking dual roles

As with making the decision to undertake the carer role, literature was reviewed to explore the reasons men gave for combining the roles of unpaid carer and paid worker, as such an understanding may contextualise the meaning they gave to the experience. The main motivator for remaining in paid employment for both male and female carers was financial security (Arksey and Glendinning, 2008). However, their personal sense of identity also played a part in men's decisions to remain in paid work. In a study interviewing 80 carers of whom 43 were in employment, Arksey and Glendinning (2008) found that whilst the main motivator was financial income participants also spoke of the importance of being identified as a working person. Whilst only 22 men were in the study and gender differences were not explicitly explored, the illustrative quotes suggested that in this study both male and female carers had similar experiences.

Those carers who perceived themselves primarily as an employed worker were more likely to remain in employment even when their caregiving commitment increased.

Researchers have found it difficult to theorise whether caregiving causes men to exit employment or whether absence of employment precipitates caregiving (Heitmueller, 2007). Bytheway (1987), in an ethnographic study of a mining village, found that when miners were unemployed they undertook caregiver roles, whilst still stating that if paid work became available they would return to employment. This suggested that employment was more important to these men than undertaking caregiver activities.

A later study by Campbell and Martin-Matthews (2003) found that type of employment impacted on whether men stayed or left employment. Those men in lower paid work were more likely to leave employment to undertake a carer role. The age of the male carers also appeared to contribute to whether men combined the dual roles of carer and employee. Evandrou and Glaser (2004) found that men who were near retirement age when their caregiving role commenced were more likely to leave work than those who started their carer role between the ages of 45-49. Younger men were more likely to make adaptations to their employment style, for example reducing hours or changing jobs, than to leave the employment sector completely (Evandrou and Glaser, 2004). This finding suggested that employment was more important to younger men, confirming the theory that men of retirement age and older men make similar decisions, and undertake care in similar ways, to female carers.

In a survey of a health authority workforce, Rands (1997) found the majority of participants in the study worked part-time but, as with other studies finding similar themes, it was not possible to make a causal relationship as to whether part-time working led to the opportunity to be a carer or whether being a carer led to part-time working. In her study the majority of respondents were women and there is evidence that female carers are more likely to work part-time than male carers (Yeandle et al., 2007).

Whilst there appeared to be a lack of conclusive evidence as to why carers may combine the two roles, there is a greater body of work exploring the consequences and benefits of being both a carer and in employment.

Consequences of being a carer on employment

A number of studies have explored the impact of employment for carers, often contrasting the male and female experience. The methodologies of such studies were usually based within an evaluative framework, frequently drawing on secondary data sources such as the British Family and Working Lives Survey[3] and General Household Survey[4] and their American and Canadian equivalents. Results have focused on the consequences of being in employment whilst undertaking care.

Being a male carer may negatively impact on employment in several ways. One of the consequences of being a carer in employment is financial. Carers are likely to earn less than their non-carer counterparts (Carmichael and Charles, 2003; Heitmueller and Inglis, 2004). They may experience reduced income due to having to take time off work (Mays and Lund, 1999). They are less likely to seek promotion and may well reduce their hours of work, or seek less demanding work roles (Stone and Short, 1990; Evandrou and Glaser, 2003; Henz, 2006; Bittman et al., 2007). For carers there are long-term financial consequences if those in part-time work or taking career breaks to undertake caregiving experience reduced pensions (Evandrou and Glaser, 2004). Despite these consequences Carmichael and Charles (2003) identified that male carers were unwilling to give up paid work even when providing high levels of care. Henz (2006) also identified that women were more likely than men to leave the workplace in order to meet their caregiving obligations. One consequence of this is that male carers may be providing high levels of care whilst still in full-time employment. Statistical data confirms that the majority of carers in full-time employment are male (Yeandle et al., 2007). The evidence that men are more likely to undertake caregiving alongside employment may suggest that they get more from being an employee than simply financial rewards.

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[3] A large-scale data set (n=9,139) with longitudinal information from a national representative British adult population. It provides amongst other data information on employment and informal caregiving

[4] An annual nationally representative sample of adults living in private households first posed a question on informal care in 1985

As well as the financial consequences of combining caregiving and employment, evidence suggested that working carers might experience poor physical and emotional health. Using interview data from 5,882 employed carers and non-carers, Marks (1998) hypothesised that being a carer in employment may cause stress linked with the difficulty of undertaking both the role of carer and employed person. She found higher levels of perceived family-stress spilling into work and work-stress spilling into family time for carers than non-caregivers. Amongst male spousal carers there were significant levels of work-stress spill over, however the impact of this on health and well-being was not significant. Men who were caring for someone other than immediate family also expressed a sense of personal growth, suggesting that stress caused by working does not always lead to a negative caregiving experience (Marks, 1998:963).

The emotional impact of combining carer and employee roles was also found in a later study comparing the emotional health of caregivers and non-caregivers. Lee et al. (2001) used secondary data from a health and retirement survey with a sample size of 254 caregivers and 273 non-caregivers. They explored whether being in employment whilst a caregiver had an effect on a person's emotional health. Results showed tentative findings that those people who occupied both caregiver and employed role were more likely to express greater depressive symptoms than people who occupied only one role, either a non-caregiving employee or retired caregiver. The authors suggested that combining paid work and caregiving might have detrimental effects on caregivers' mental health. They also found that higher levels of caregiving involvement were correlated to poor reported emotional health. However, a limit of the study was that measures on emotional health may be influenced by the stress inherent in the employment job and influenced by other commitments, such as care of young children alongside elders, limiting the extent to which a causal relationship may be made between poorer emotional health and caregiving.

In this literature search no other studies were found which explored the impact of employment on the caregiving experience, rather studies tended to explore either the financial implications or the health and well-being of the carer. An exploratory study may enable carers to discuss those aspects of caregiving and employment which are most relevant to their experience.

Qualitative studies designed to explore the subjective experiences of working carers found both positive and negative consequences for carers undertaking paid employment.

Going out to work provided many benefits to male carers and was one of the coping strategies used by son caregivers in Harris's study (1998). Carers in employment have spoken of the benefit of social contact and of feeling supported by colleagues (Rands, 1997; Arksey, 2002). Arksey (2002) in a qualitative study interviewed ten female and two male carers to ascertain their experience of combining caregiving and employment. Whilst participants did find colleagues a source of information and support they also described how combining caregiving with employment had a negative consequence on their health, frequently leaving them feeling exhausted and stressed. Data for this study were collected in 1998, prior to the implementation of the Employment Relations Act (1999) and Work and Families Act (2006), both of which offered more opportunities for flexible working to carers. Although Arksey's (2002) study used a small sample, similar findings have emerged from a larger commissioned project exploring the experiences of working-age carers in Britain (Yeandle et al., 2007).

Yeandle et al. (2007) surveyed 812 carers who were in employment and collected qualitative data from 93 of this cohort. They found that 21% of working carers reported poor health and that being in employment did not always ensure financial security, with 32% 'struggling to make ends meet' (2007:iii). However working-age carers who were not in employment were more likely to experience financial difficulties and be in poor health than their employed counterparts, suggesting that employment might have a positive impact on carers. The study also found the longer people had been a carer the more likely they were to make changes to their employment patterns, with many stating they undertook part-time work only because they were combining employment with caregiving. The study also highlighted that carers experienced differing levels of support from employers. Public and voluntary employers were perceived as more responsive to the carers' needs than private employers.

A later study undertaken by Arksey and Glendinning (2008), exploring choice for 80 working-age carers, found that it was not only flexibility in the workplace which influenced a person's choice to remain in employment but also their own health, their financial circumstances, the need to maintain their sense of identity and the nature and location of available employment. This study illustrated how a number of factors may influence the decision to combine caregiving with employment.

Whilst these studies and the five other reports produced for the commissioners Carers UK provided substantial statistical data and comment on the lives of working-age

carers, there is still an absence of research exploring what being in employment means to the caregiving experience.

Strategies for undertaking caregiving and employment

Arksey (2002) highlighted a number of strategies used by carers to manage the dual responsibilities. Working carers sought too reduce travel time to work; used their lunch hour to undertake caregiving activities; and changed their working hours and patterns. Flexible working was a great help to carers, with options such as occasionally working from home. Part-time working also offers more flexibility to carers for managing caregiving commitments, including appointments with service providers (Yeandle et al., 2007; Arksey and Glendinning, 2008). One strategy for managing caregiving and employment was to take days off work, frequently using up annual leave, to undertake carer activities (Rands, 1997; Mays and Lund, 1999). However, employers might not always be able to make workplace adaptation to meet carers' needs (Yeandle et al., 2007; Campbell and Martin-Matthews, 2003), resulting in increased stress for the carer.

Gaps in the understanding of male carers in employment

Whilst these studies have added to the pragmatic understanding of the ways in which male carers may or may not undertake the combined roles of care and employment, there is scope to explore this topic further, specifically developing the understanding of how being in employment may influence the caregiving experience. There remains scope to explore further the concepts of 'care' and 'work'. For example, are they discrete entities or are they intertwined in making the phenomena of caregiving a distinct thing? Findings from a number of qualitative studies have been limited due to small sample size. There is an absence of studies specifically exploring the male experience; in part this may be due to the hidden nature of employed carers (Eley, 2003). Yet there is evidence that employment is linked with self-esteem and identity (Rands, 1997; Stone, 2003) and whilst the traditional male breadwinner role is declining, frequently being replaced with a dual-earner model, there remains within the UK a sense of the breadwinner role being linked with masculinity (Holter, 2007; Aboim, 2010) so there is a need for a study which recruits men of working-age.

Summary

Reviewing empirical literature pertaining specifically to working-age men provided some understanding of the experiences and strategies of male carers in managing these

roles. However there were also a number of methodological limitations in the studies reviewed relating both to the adequacy of conceptualisation and the omission of important parts of the male caregiver experience.

General methodological issues

The review highlighted methodological issues common across many empirical studies of male caregiving. Often sample numbers were very small, convenience sampling was used and frequently care-receivers had dementia. This limitation resulted in findings which may be hard to apply to a more generalised male carer population (Houde, 2002; see Appendix 2 for review of methodological issues). Where gender differences were explored there has been a tendency to present gender as a dichotomous variable with little attention being given to the reasons for this (Bookwala et al., 2002). In studies recruiting only male carers the sample frequently consisted entirely of men of retirement age; where younger men have been recruited their experiences often cannot be isolated from those of their older counterparts. Yet this review has shown that spouse carers and particularly older spouse carers may have distinctly different experiences to other male carers. Baker and Robertson (2008), reviewing nine articles which explored the experience of men undertaking the care of someone with dementia, suggested that grouping together the findings from sons and husbands in studies was a weakness of methodology. However, it may not be the grouping together of findings which is a weakness, rather it is the use of methodologies and analysis which fail to bring to the fore the nuances of individuals' lived experiences that limits the usefulness of some studies. Studies which seek homogenous groups of participants, whether based on gender, age or the illness of the care-receiver, risk limiting the ways in which new understanding may be relevant to different groups of carers. Therefore, a study recruiting a heterogeneous sample may enable insights into the essential components of caregiving common across male caregiving situations. Such findings may be more transferable. A methodology that would enable deeper insights into the individual's experience would be phenomenology. Apart from Parsons' (1997) study only two other studies using a phenomenological approach have been found, but both these recruited only men aged over 65 years (Siriopoulos, 1999; Stoltz et al., 2006).

Addressing the literature review questions

In considering the questions which guided the literature, conclusions could be drawn about the ways in which men undertake caregiving and their experiences as carers.

Why men undertake caregiving

In exploring why men undertake caregiving it appeared that there were a variety of reasons, but male carers were frequently reported as making decisions to provide care to a relative based on the idea of it being the right thing to do. This may stem from an internal sense of justice or fulfilling an obligation. Reciprocity was cited as a reason for caring for both wives and parents. A few men provide care in the absence of any alternative, most often where there was no available female relative. Employment did not seem to greatly influence the ability of men to commence caregiving, although those with more flexible employment did state that this helped them when they were undertaking the role. Understanding more about the dynamics between employment and the commencement of caregiving may help in the development of policies which are sensitive to working-age male carers.

How men undertake caregiving

The synthesis of the literature showed conflicting findings over the types of activities male carers provided, however it appeared that when the man was the primary or sole carer he undertook the same range of caregiving activities as women. Nonetheless, it seemed that male carers may adopt a different approach to caregiving activities, using a more task-based focus, rather than becoming heavily involved in offering emotional care and support to the care-receiver. There was evidence that male carers experienced less burden and stress than female carers, so that understanding more about how they conceptualise their caregiving activities may lead to a developed understanding of how they manage the carer role.

How men retain their identity when in a caregiving role

There were very few studies explicitly exploring the concept of identity with male carers, however this is a developing field of research. The literature suggested that men appeared able to reconcile their masculine self with being in a traditionally female role. They did this by using strategies in caregiving which were similar to those used in

employment, namely task-orientation approaches and a take-charge mentality. Exploring identity specifically related to men of working-age would add to understanding in this developing field of research.

How men experience being a carer and in paid employment

There is a growing body of work exploring the experiences of carers in work, although few studies have concentrated specifically on the experiences of male carers. It appeared that combining caregiving and employment would have negative consequences on income, particularly as employed hours were frequently reduced. However, being in employment was often cited as a form of respite from caregiving. The majority of studies retrieved through the literature search recruited both male and female carers and did not differentiate the experiences of each. Further research about the impact of employment on the caregiving experience may increase understanding of the part employment plays in shaping the experience of being a male carer. Studies which have explored carers who are also employed have concentrated on understanding how carers experience employment. There has yet to be an investigation of how employed men experience caregiving.

Conceptual themes identified from the literature.

Whilst the four questions just raised effectively shaped a critique of the literature which led to an appreciation of the gaps in current knowledge of male carers' experiences, essential themes could also be seen across many of the reviewed studies. These themes went deeper than the pragmatics of types of tasks undertaken by male carers or the economic costs of caregiving, in also suggesting glimpses of distinctive lived experiences of male carers. Themes emerging from the retrieved data were: i) the temporality of the experience; ii) the particular importance of relationships, and iii) shifts in elements of their identities.

i) *The temporality of experience:* could be seen, as meanings male carers found in caregiving appeared to change over time*.* Such a theme of temporality suggests that meanings are shaped as past, present and future events are reflected on and understandings sought (van Manen, 1990). The ways in which meanings changed over time were seen in Neufeld and Harrison's study (1998), describing the changing meaning of reciprocity as the care-receiver became increasingly less able to contribute to the relationship. Parsons (1997) captured changing emotions alongside male carers' experiences of loss as the care-receiver's condition deteriorated. The choices men make

to undertake caregiving may also be shaped by their past and present lived worlds. For example Hirsh (1996) proposed that childhood exposure to a caregiving relationship may enable men to now experience caregiving as an appropriate male gender role. Considering the ways in which past experiences may shape current meanings exposed the possibility that employment histories of working-age men may shape their experiences of caregiving. Reflecting on the ways in which caregiving research has changed focus since the 1980s, increased awareness that the experiences of men recruited to this study could also be subjectively shaped by the cultural and social events in their lived worlds. Therefore, a methodology would be needed which enabled the acknowledgment of socially-constituted understandings. Whilst the passing of time and the reflection on past events shaped male carers experiences, men tended not to care as isolated individuals, rather the literature suggested they often provide care as one of a family, in relationships with others.

ii) *The theme of relationality:* could also be seen to emerge from the research literature; the concept that understandings of a phenomenon are shaped by others within a person's lived world. There was evidence of men undertaking caregiving while being encouraged by wives and sisters, rather than perhaps as a direct decision to support the care-receiver (Gerstal and Gallagher, 2001). Yet when studies recruited only spousal male carers there emerged themes of duty and unquestioning acceptance of the carer role to their wife (Harris, 1993). Although few studies were sourced exploring the support systems used by male carers, those that were suggested that relationships with others, including friends and health professionals, may shape the meaning of the experience often in a positive way (Kaye and Applegate, 1990; Hirsh, 1996). Understanding the ways in which contact with others may alter the meaning of experiences led me to reflect on the ways in which I, as an interviewer, may shape the narratives male carers chose to share.

iii) *A shifting sense of self*: was also evidenced for some male carers while for others identity was firmly grounded in their past experiences and reaffirmed through their occupational activities. Campbell and Carrol's study (2007) illustrated that male carers may have conflicting identities. Their participants appeared at ease with their identity as male carer, yet they still spoke in general terms of women having the characteristics which made an empathetic carer. Harris (2002) found that over time some male carers spoke of losing their masculine identity suggesting that the passage of time may change carer's experiences. The literature reviewed on employment had not focused on the ways in which employment may influence a person's sense of self, but considering the

ways in which time and relationships appeared to change the meaning of events it may be that the places and contexts of occupational activities may shape the meanings found within those activities.

Having identified the gaps in current knowledge of working-age male carers experiences and the conceptual themes which ran through their lived experiences, the research question could be defined as needing to understand the social phenomenon of caregiving from the perspectives of the men undertaking the activity, within a framework which would be informed by temporality, relationality and a potentially shifting sense of self.

The study

This study therefore aimed to address gaps in the current understanding of male carers' experience of caregiving, specifically working-age men. The study sought to develop a deeper understanding of the lived experiences of such men through designing a methodology which enabled them to speak of their experiences and foreground those aspects of caregiving which were important to them. Drawing out essential themes using this approach could provide answers to this type of research question and address the research objectives.

Research question

What is the lived experience of being a working-age male carer?

Research objectives:

$\Rightarrow$ To capture an in-depth understanding of how men experience being a carer and an employee.

$\Rightarrow$ To explore why men may have moved from employment into full-time caregiving

$\Rightarrow$ To illuminate what men feel about their roles and identities when in caregiving relationships and reasons for this.

The following chapter considers how a methodology based on the principle tenets of hermeneutic phenomenology might enable a study to be designed to capture data relevant to a research question about the experiences of male carers in employment and objectives which help unpack these.

Chapter 4 Defining the methodology

Introduction

This study sought to explore individuals' experiences whilst also recognising that culture and social worlds would shape the meaning of those experiences. The literature review highlighted that the life worlds of working-age male carers remain relatively under-explored and this might have bearing on how male carers may be perceived by those individuals, organisations and services which may be relevant to their work and identity as carers. Those studies recruiting older male carers suggested that male carers might have distinctive experiences shaped by the social worlds they inhabit. For example, caregiving remains a gendered activity and male carers may give different meanings to caregiving than their female counterparts (Campbell and Carroll, 2007). Those men who had lived through caregiving relationships in earlier life appeared to give different meaning to their experience of undertaking care in later life (Hirsch, 1996). Nonetheless, whilst life experiences may influence the meaning individuals give to caregiving, there was some existing evidence of commonalities within the experiences of male carers, suggesting there were some essential features to the phenomenon (Harris, 1993, 1998; Parsons, 1997; Siriopoulous et al., 1999; Russell, 2007). Therefore, a methodological approach was needed to enable the capture of an individual's personal experiences, whilst still enabling the exploration of essential features across the phenomenon of male caregiving. The methodology would ground the research design in a philosophical framework to enable the addressing of questions such as: the nature of knowledge to be generated, the types of truth claims which might be made by this study and the ways in which relevant meanings may be created (Caelli, 2001; Willis, 2007). Ensuring coherence between methodology, research design and new knowledge meant defining the characteristics of knowledge that this study sought to generate.

There are challenges in seeking knowledge about male carers' experiences in that the meaning each person gives to a phenomenon is embedded in their previous experiences. So whilst a qualitative study may facilitate an inductive exploration of the personal experiences of male carers, the understanding developed would be grounded within the personal experiences of both the researcher and the participant. Therefore the methodology would need to enable recognition of the interpretive nature of the research, whilst also capturing the essential themes of male carers' lived experiences. Within this

chapter, firstly the nature of knowledge is explored, leading to a critique of how the paradigm of interpretivism provided a set of assumptions which would guide the study. Then there is a discussion of the nature of being in the world, leading to a justification for embedding the design within a hermeneutic phenomenological methodology.

Establishing knowledge of men's caregiving experiences

Conceptualising the type of knowledge sought, and consequently the epistemological stance of the study, clarified the methodology that would most effectively guide its design. Thereby it ensured that the research design reflected the type of knowledge claims that the study sought to make (Mason, 2002). Epistemology concerns questions about 'truth', namely what do we hold as true and how do we know what is true (Grbich, 2007). Research broadly falls into one of two paradigms, either being within a positivism or interpretivism paradigm. A positivist approach might be used where there is knowledge of a phenomenon and theory is to be tested (Willis, 2007). A number studies exploring male caregiving had used a positivist approach to test a hypothesis and present findings as a set of objectively-established facts about the subject. For example, studies measuring the physiological impact of caregiving on male carers have produced reasoned, statistically-tested outcomes of how male carers physically experienced caregiving (Carpenter and Miller, 2002). However, such knowledge did not enable questioning and understanding of the subtleties of the phenomena or recognise how the individual and their personal experiences might change the ways in which they give meanings to being a carer.

In this study it was important to understand how individuals subjectively experience phenomena, as the meaning given to emotions and events may differ. Meanings may vary depending on the 'life world' of cultural and social structures which influence people's perceptions of their experiences (van Manen, 1990). This concept, that cultural structures influence meaning, may be seen through studies recruiting male carers which have suggested that male carers undertaking a traditionally female role find their 'being' in the world of caregiving and the subsequent meaning they attribute to that experience distinctly different from female carers (Hirsch, 1996; Ribeiro et al., 2007; Russell, 2007). There was also some support for the theory that male carers' experiences vary with age, relationship to care-receiver, length of time they have been a carer and if they remain in employment (Kramer and Thompson, 2002). Therefore, if people draw on previous experiences to find meaning in their current lives then the way in which

individuals experience phenomena might also differ. For example, the carer who has seen their relative relapse and improve may give a different meaning to a future relapse, than a carer who is experiencing a decline in their relative for the first time. So temporality of human life may influence the experience of being-in-the-world, as a person's present experience of caregiving will be understood through reflecting on previous experiences and predicting future experience (van Manen, 2003).

Understanding that people's history and culture influence their experiences of phenomena had resonance with the theories of knowledge proposed by Gadamer. His view is that individual's experiences are shaped by history with presuppositions shaping the meaning given to phenomena (Gadamer, 1975/1996). This stance sees knowledge as developing through a process of interpretation: here an object or event has no reality outside the consciousness of the person viewing or experiencing it (Fleming et al., 2003). Caregiving as a phenomenon will have meaning within the mind of the person experiencing being a carer, shaped by the social worlds in which they exist.

If knowledge and understanding are continually being constructed and reconstructed, then I may need to recognise multiple interpretations of what the 'truth' might be. Kvale (1996) has argued that knowledge does not exist with an individual, nor as an objective 'truth', but is found within an individual's relationships with their world. One challenge then was to consider how new knowledge and understanding could be developed and shared if meanings were subjective and restricted to the individual. One way of doing this was to recognise the commonality of culture which enabled some shared understandings between male carers and between the carer-participants and the researcher. Potential participants and I lived within a similar culture and would be likely to share some common beliefs, values, customs and behaviours (Hocking, 1994; Benner, 2000). Shared common beliefs have been evidenced in previous qualitative studies of groups of male carers, demonstrating some similar values and behaviours (Stoller, 2002). However, the essential structures, or essence, of an experience will not exist independently as facts, but will become known through the interactions between the participants and the researcher which constitute the research (Kvale, 1996; Holstein and Gubrium, 2003). Therefore, the approach used in this study would need to attend to those interactions.

The experiences of the participants would, therefore, be taken as the primary basis for knowledge (Draucker, 1999). To encompass the epistemological stance that knowledge

is constructed between people, within societies, an interpretivist approach would be used to guide the study design.

Using an interpretivist approach to engage with men's caregiving experiences

Understanding that participants' experience of caregiving would be constructed within their social worlds, the assumptions of an interpretivist paradigm which sees knowledge as developed through social interaction and interpretation is specifically congruent with the epistemological stance taken in this the study. Here knowledge is seen as 'subjective, constructed and based on shared signs and symbols which are recognised by members of a culture' (Grbich, 2007:8). Understanding may be gained through conscious activities within a historical context and further constructed through interaction between researcher and participants and the world around them (Gergen, 2009). These all need to be recognised and understood from the perspective of living experience (Laverty, 2003).

Such a stance does not set up new knowledge as fact but as representing the many voices of participants who have contributed to it. The ontological premise that a male carer may have a unique experience of caregiving resonates with the philosophy of hermeneutic phenomenology. This recognises the uniqueness of a human being's presence in the lived world (van Manen, 1990), which underlines how people constitute meaning through drawing on past knowledge, traditions, language and culture (Gadamer, 1975/1996). This is especially pertinent to a study exploring male caregiving, as the activity of caregiving has been almost wholly conceived as a feminine activity, which may generate tensions in male caregivers' relations with others. An interpretivist informed methodology is a way to enable both the participant and the researcher to consider the nature of their being-in-the-world.

An interpretivist paradigm, therefore, calls for different methods to those used to measure and test phenomena in the physical sciences (Patton, 2002).). Within an interpretivist paradigm, there are a number of related but discrete methodologies providing distinctive lens through which to view individuals' lived experiences (Denzin and Lincoln, 2000). The literature review exposed ways in which male carers may become defined by the roles they undertake and the types of activities they undertook, illustrating that a sociological approach such as social constructionism would enable the

study to explore the social construction of the lived worlds of participants and enable conclusions to be drawn about how the understandings and artefacts of male caregiving are created through social interactions and language (Henderson, 2001; Henderson and Forbat, 2002). Such a lens could help explore how policy and cultural references had shaped the meanings male carers gave to their experiences. However, it would not enable understanding of the situated experiences of individuals where meanings may be shaped through the temporal and relational nature of caregiving. In this exploratory study the aim was to explore conscious, lived through, experiences from the first person point of view. A methodological lens was required which could facilitate the exploring of situated experiences. Here a phenomenological approach encouraged the seeking of subjective experiences, acknowledging that individual intentionality would influence the meanings attributed to such experiences. Drawing on hermeneutic phenomenological approaches helps to develop a theory-based means of doing this by gaining 'insightful descriptions' of lived experiences (van Manen, 1990:9).

Using a hermeneutic phenomenological perspective to understand being a male carer

Phenomenological philosophical ideas can inform a framework to develop an understanding of how meanings are constituted through experience within an appropriate research design (van Manen, 1990; Moustakas, 1994; Munhall, 1994; Giorgi, 1997; Tordes, 2005; Rapport, 2005; Finlay, 2008; Smith, 2009). Phenomenological research seeks to explore the ways in which we experience 'things', how they appear in our consciousness, and thus the sense-filled meaning such 'things' have in our every day experiences (van Manen, 1990, 2003; Finlay, 2008). Such a philosophical stance would enable recognition not only of the essential features of the phenomenon of male caregiving, but also the way in which meanings are shaped by being situated in relationships and commitments.

While Husserl's original formulation of phenomenological study may have helped focus on the *essence*, or literal meaning, of the caregiving phenomenon, his requirement to bracket out, or *epoche*, all prior beliefs about the natural world (Moran, 2000; Dowling, 2007) did not fit with the epistemological stance to be taken in this study. Rather the concept that knowledge is subjective, and constituted within relationships within which personal values and beliefs are recognised, needed to be actively embedded with the research design (Fleming et al., 2003).

As the research aim was to understand the lived experiences of male carers, an approach which could look at the meanings of phenomena within life worlds would have a better fit with the aims of this study. Heidegger conceptualised phenomenology as the study of 'being-in-the-world', *Dasein*, exploring the meaning of 'things themselves' (Cohen and Omery, 1994; Moran, 2000; van Manen, 2000). This moved phenomenological understanding away from a detached description of how things appear in the pure conscious mind to a seeking of what it is to be in the world, thereby providing a conceptual framework from which to understand lived experiences (Dowling, 2007).

Within lived experiences reality does not exist outside of human consciousness, rather the experiences of phenomena are influenced by a 'notion of intentionality' (Barber, 2004: 108). Intentionality means that the visual and emotional response to phenomenon are influenced by the intention of the person bringing the phenomenon into their consciousness (Giorgi, 1997; Barber, 2004). An example of intentionality was evident in the phenomenological study of male carers undertaken by Parsons (1997). Here all male carers could be seen to provide intimate personal care to their relative, but the meaning that sons gave to the experience differed to that of husbands, with sons experiencing the phenomenon as 'overstepping normal boundaries' (1997:402). Parsons explained this with reference to differing historical relationships, suggesting that male carers may give meaning to their experiences not in an objective way but in the embodied intersubjective way of lived experience.

So taking a phenomenological stance, the act of feeding another person would be examined in terms of the meaning or intentionality of the event rather than for the objective process and outcomes of the action. The person doing the feeding and the receiver may describe in concrete terms their experiences and emotions when living through the act. Further, as acknowledged by Heidegger (1927/1962), the individual's experiences of the phenomenon would be shaped by their past experiences.

The work of Heidegger was further developed by his pupil Gadamer who developed the paradigm of hermeneutic phenomenology. Hermeneutic means to interpret or understand (Moran, 2000). Historically hermeneutics has been the discipline of interpreting texts; within hermeneutic phenomenology the texts for interpretation may be participants' interviews (van Manen, 1990). Hermeneutic phenomenology does not require the objective examination of pre-reflective experiences; rather than bracketing out any presuppositions, it is recognised that the researcher is situated within the life worlds of participants and therefore a more reflexive research approach is advocated

(Fleming et al., 2003; Finlay, 2008). Data were explored with an openness and a willingness to be surprised by how the phenomenon appears (Dahlberg et al., 2008).

An interpretative or hermeneutic form of phenomenology enabled two challenges of the study to be addressed within the methodology. Using a phenomenological framework to justify the design enhanced the possibility of the collection of concrete experiential data. Being guided by the principles of hermeneutics meant the co-constituted nature of knowledge was embraced, ensuring analysis was guided by the principle of multiple interpretations.

Meeting methodological challenges when exploring the experiences of male caregivers

Accepting that knowledge is not objective but rather emerges from multiple interpretations, it follows that the nature of 'being-in-the-world' would affect how knowledge was constructed. This understanding was important as male carers were experiencing a phenomenon which had more usually been seen as being a feminine activity, outside of male traditions. Therefore, the methodology had to facilitate insights into how male carers might, nonetheless, exist within their social worlds, the nature of their being in the world.

Caregiving takes place within a web of relationships and it is only through being-in-the-world that understanding arises (Geanellos, 1998; Johnson, 2000). For example, one can have some understanding of a phenomenon such as bereavement if one has lived through this experience. The meaning attributed to the experience of bereavement may differ for each individual, but there will still be some essential features, or essence, which all people are likely to experience, such as grief and loss. A hermeneutic phenomenological study seeks to expose and present the essence of the experience in a way which enables others, who may or may not have experienced it themselves, to be sensitive to the phenomenon (van Manen, 1990).

Whilst individuals have unique personal experiences the meanings they give to their experiences are always shaped by interpretation, which in turn will need to refer to what is already known (Fleming et al., 2003). For example, the phenomenon of making tea has different meanings within different cultures and at different times, such as a way of waking up, a remedy in an emergency or an elaborate social custom. Recognising that the meanings male carers give to the phenomenon of caregiving may be shaped by their history, culture and social structures posed a methodological challenge. The knowledge

would not be objective or measurable because it was created in a shifting social reality. Equally the data could not be 'purely descriptive' as a process of interpretation would occur between the participant and myself and further interpretation would occur during data analyses, so knowledge would be co-constituted. Similarly, information could not be plucked from participants and held up as unmediated knowledge, because taking part in the research could change the nature of their 'being' and the meaning of their experience (Holstein and Gubrium, 2003). Participants are active subjects who make meanings before, during and after the research interview. That there may be multiple interpretations of an experience is something hermeneutic phenomenology acknowledges (van Manen, 1990; Fleming et al., 2003). The methodology needed to enable the capture of participants' stories of 'being carers', but having a distinct history and research role I could not fully enter the conscious and unconscious lived world of participants through narrative interviews. Therefore an innovative method was needed to represent their stories by providing a means for participants to comment on the narrative they initially provided.

To enhance the sharing of meanings after the initial conversational interviews, data were transcribed and transformed into a narrative summary; this provided a reflective basis for a second interview and enabled sharing of emerging interpretations with participants. Accepting that presenting participants with a text of their lived experiences moves away from the basic phenomenology notion of the pre-reflective nature of 'being in the world'. It may be, however, that the pragmatics of doing real-world research means recognising that the participants are often already reflecting on experiences before data collection occurs. To meet ethical requirements, information was provided to participants about the aims of the study and the nature of data collection. They were aware that information was being sought about their experiences of being carers specifically in employment. As van Manen identifies, one can never capture the 'now' of a phenomenon as there is always a period of stepping out of the experience to describe the experience (van Manen, 1990:10). Therefore, the use of the narrative summary could be seen as consistent with the hermeneutic principle of striving for a sharing of horizons, views and understandings of an experience. Such sharing was encouraged by the participants reflecting on the narrative summary produced by myself. This was especially important for addressing the researcher-researched gap in understanding. However, multiple interpretations could develop from the process in which data were returned and shared and in which meanings emerged and this needed to be recognised when discussing the implications of the findings. Findings would not be

purely descriptive, nor would they be completely pre-reflective, rather they would develop through a process of re-thinking and re-flecting on interpretations (van Manen, 1990).

The benefits of using the narrative, in this study as a way of further engaging participants in co-constituting knowledge, were given more weight than the possibility that during second interview participants' experiences would be consciously in the forefront of their minds. Further the opportunity to return and share narratives may also mediate the ways in which the constructed event of an interview enables both the interviewer and the respondent to construct and present personas of their selves (Schwalbe and Wolkomir, 2003). Using narrative summaries and follow-up interviews, rather than relying on the elements of a single interview, would provide a means to enable participants to tell richer experiential stories of caring which moved beyond statements of action and factual incidents to stories contextualised in experience and being, thereby capturing phenomenological data (van Manen, 2008).

Summary

This study needed to capture the lived experiences of male carers whilst remaining congruent with the stance that meanings develop with social and cultural worlds and are interpreted. The scope offered by hermeneutic phenomenology addressed this, by its focus on re-questioning and further interpretation, making it an appropriate philosophical methodology to guide the research design which would collect data about male carers' experiences of being in the world of caregiving. A specifically interpretative or hermeneutic form of phenomenology addressed methodological challenges by identifying and collecting data well-founded in the lived reality of being a male carer in employment. Being guided by the principles of hermeneutics meant that the researcher's role in co-constituting the knowledge which was to be produced could be made explicit, enabling an analysis which could be seen to be informed by multiple interpretations.

These issues could be successfully addressed through an approach such as hermeneutic phenomenology, which recognises how human beings experience events through living through them in their social worlds, in this case fore-fronting the relatively unacknowledged world of male caregiving. In drawing on a hermeneutic phenomenological approach the chosen methodology guided a design which could recognise the social construction of meaning and actively seek and present alternative

meanings in analysis, whilst drawing the emerging themes together to present a thick description of the phenomenon of male caregiving. The acknowledgement of knowledge claims developed from this hermeneutic methodology ensured that multiple layers of meaning in interview texts would be illuminated to produce rich, rather than stereotypical, descriptions of the lived experience of being a male carer (van Manen, 1990). The innovative use of sharing narrative summaries with male carers may be seen to enhance opportunities for shared interpretations.

The reality of being a male carer can only be known to the men who undertake this role, but through an in-depth study of their lived experiences an interpretation could be made of the meaning they derived from their experiences. Therefore, whilst acknowledging there will be no single truth about what it is to be a carer, this methodology would help generate findings which should be both credible and provide transferable insights into the experience of being a male carer. This methodology provided a framework of concepts to guide the research methods and choices discussed in the next chapter.

Chapter 5 Designing and implementing the study

Introduction

To understand the lived experiences of male carers the research designed needed to ensure that there would be opportunities to capture their experiential data (van Manen, 1990). The challenge would be to capture the ways in which understandings and meanings were co-constituted in the life worlds of the participants. Therefore methods were needed to enable appropriate interrogation of the data and to facilitate the recognition and further questioning of new insights and changing interpretations. The research design was embedded in the hermeneutic phenomenological stance of the study and its emergent features offered the opportunity for researcher reflection and reaction to issues, such as whether recruitment, sampling, data collection and analysis were providing the diversely-detailed experiential stories needed to help generate fresh understandings of the phenomenon of male caregiving.

The phenomenological hermeneutic design principles prioritised here needed to enable me to share emerging meanings with participants to enable the challenging of presuppositions. To facilitate this joint engagement the research design required an innovative method compared with other phenomenological designs. Interpretations would be explicitly shared by further engaging participants through offering them the chance to review and reflect on summaries of their narratives constructed from the first interview. Given the underpinning philosophy of allowing for multiple interpretations of phenomenon, it was consistent to reflect this philosophy through developing the interactive fieldwork relationship between research and participants.

This chapter contains a detailed description and critique of the research design, illustrating how methods worked as they were implemented in the field. It covers the following areas:

⇒ The sampling framework – the inclusion and exclusion criteria; choice of geographical recruitment area and the sample characteristics.

⇒ Recruitment strategy – description of recruitment methods and sites and the reasons for using three recruitment methods, i.e. emails, letters and personal visits.

⇒ Data collection – the use of in-depth initial interviews and the production and use of narrative summaries and follow-up interviews to provide the opportunity to share and discuss emerging meanings.

⇒ Data analysis – outlining the data analysis framework and explaining its resonance with hermeneutic phenomenology.

⇒ Ethics – describing and justifying the ethical framework for the study.

Deciding who to study — The Sampling Framework

The study needed to engage with working-age men who had experience of caregiving by using a purposeful sampling strategy, as the study sought to 'examine meanings, interpretations, process and theory' (Rice and Ezzy, 1999:43). To ensure that men with relevant experience were recruited, a sampling framework was chosen which incorporated specific inclusion and exclusion criteria, to facilitate variation within the sample. Including variation within the sample enhanced the transferability of findings, as the essential themes which emerged from the data were common across a range of male caregiving contexts.

Inclusion criteria

Men aged 18-64 This is the culturally defined age range when British men in the UK are expected to be in paid employment (Charles and James, 2005; Holter, 2007).

Caring for 10 hours or more a week This is the level of caregiving which has been evidenced as having an impact on employment and carers' health and well-being (Carmichael and Charles, 2003; Buckner and Yeandle, 2006).

Exclusion criteria

Unable to work The study aimed to explore the dual role of working and caregiving, therefore men who could not work because of their own disability were excluded. Men younger than 18 years were excluded as statutory services identify them as children who are eligible for different services from adults.

Language barriers Anyone who required interpretation services was excluded, as the use of an interpreter might constrain the collection of sufficiently nuanced and experientially grounded data (Murray and Wynee, 2001).

Sampling Framework

Purposeful sampling generated a diverse participant sample, thereby ensuring that the sample population was consistent with the epistemological requirement of 'transfer of meaning and unique variation' (Holloway, 2005:278).

Five characteristics of the caregiving experience were identified to inform the sampling framework. Table 5.1 illustrates the sampling framework.

Characteristic of Caregiving experience	Rationale for inclusion in sampling framework
Carer in or out of employment	Provides access to information about why they left work. Offers insight into how they combine employment and caregiving, thereby meeting explicit research objectives
Range of relationships carer has with care-receiver	Evidence suggests men may make different choices when caring for a spouse rather than elderly parents (Qureshi and Walker, 1989)
Length of time they had been a carer	Evidence suggests consequences of being a carer intensify over time (Buckner and Yeandle, 2006)
Whether carer in receipt of voluntary and/or statutory services	This may indicate whether sample has covered the experience of 'hidden' carers (Cavaye, 2006)
Care-receivers experience a range of illness and disabilities	Ensures the focus of the study is not limited to experiences of caring in relation to a specific disease, rather than a range of experiences of combining caregiving and employment

Table 5.1 Sampling Framework

When men expressed an interest in the study their demographic details were collected. These were: their age, relationship to care-receiver, length of time caregiving, disability of care-receiver and type of employment. This information enabled purposeful sampling.

Geographical Sample Site

It was important to recruit from both urban and rural communities, as evidence suggested that carers in urban areas might have a different experience to those living in rural areas. Carers in deprived urban areas may have poorer health and heavier caring responsibilities than those in rural areas (Carers, 2004; Hanratty et al., 2007; Tommis et al., 2007). Nonetheless, carers living in rural areas may be more socially isolated and have fewer support services (McCann et al., 2005).

The sample population was drawn from the counties of Norfolk and Suffolk where recent demographic data indicated a population of approximately 145,000 carers (Carers UK, 2004), living in mixture of rural and urban communities, with areas of economic wealth and pockets of deprivation (Office Deputy Prime Minister, 2004).

Sample Design

The sample design needed to be sufficient to enable the capture of information-rich data whilst still being manageable within the resources of the study (Ritchie et al., 2003). Drawing on the experience of other hermeneutic phenomenological studies, it was apparent that it was not the number of participants but the way in which the experiences were shared and explored which influenced the richness of the data and the subsequent findings (van Manen, 1990; Parsons, 1997; Siriopoulos et al., 1999; Stoltz et al., 2006). Nonetheless the pragmatics of applying for ethics approval led to a requirement to state potential participant numbers, which were suggested as between 12 and 15 participants. However, the emergent design allowed flexibility to include more participants if it was found that new ideas and experiences were continuing to emerge.

After receiving ethical consent from the Faculty of Health Ethics Committee, University of East Anglia on 14th November 2007, recruitment to the study began.

Telling people about the study: recruitment strategy

Recruitment sites

Recruitment sites were selected for their potential for enabling a variety of routes of access to male carers. Employers, voluntary sector agencies and carer support groups were involved in the recruitment process. Before information could be disseminated contact had to be made with gatekeepers, people who would be willing to distribute recruitment material (Padgett, 2008). Following a period of negotiation with

gatekeepers, two employers, three voluntary agencies and four carer support groups agreed to disseminate recruitment material.

Employers Initially an educational establishment and manufacturing business were approached to disseminate information to employees. These companies were selected as they provided a variety of employment patterns and different skilled jobs. Manufacturing companies were included as there was evidence that men in manufacturing were more likely to have extensive caring responsibilities than office-based professions (Buckner and Yeandle, 2005). However, despite prolonged engagement with employers, including personal letters, telephone calls and visits to site, only the educational establishment agreed to send a recruitment email through its internal communication system (Appendix 3).

A second wave of contact with potential employers did not result in any further interest from manufacturing companies. However, a large retail group agreed to disseminate recruitment information through its internal magazine and in its staff canteens. A difficulty in recruitment through employment sites was that personnel managers frequently stated they did not have any staff who were carers; this may reflect the hidden nature of some caregiving.

Voluntary sector support agency Branches of Crossroads for Carers sent recruitment letters (Appendix 4) to male carers who met the sampling criteria. Crossroads for Carers is a national organisation providing social care workers in the care-receiver's own home, thereby enabling the carer to have short respite breaks from their caregiving responsibilities. Using this recruitment site ensured that men in receipt of support services were included, bringing another perspective to the experience of being a carer. A large funded carer organisation agreed to disseminate information through flyers at their centre, with their support staff providing male carers directly with flyers.

Carer support groups Contact was made with four carer support groups. Two groups were sent flyers and information for sharing with their members. Two groups offered support to carers of people who had Parkinson's disease, and motor neurone disease. These groups were selected because carers may be younger men. A more general carer support group and a group for carers supporting people with mental health problems received personal visits. Recruiting through carer support groups ensured that men who had been proactive in seeking support were included in the sample, thereby offering yet another distinctive perspective on the phenomenon of being a carer.

Recruitment methods

Recruitment materials were designed to raise interest in the study and enable people to make contact and receive further information. To ensure the clarity and comprehension of recruitment material a lay perspective was obtained from three reviewers: a male carer who was not involved in the study, a member of the local Public and Patient Involvement in Research (PPIRes) group[5] and a manager from Crossroads for Carers. Although changes were not suggested to the content or format it was suggested that participants were offered financial support to cover replacement social care costs, thereby ensuring they were not excluded because of care commitments (Disability Rights Commission, 2008; Scott, 2008). None of the participants accessed this financial support.

Recruitment information was disseminated through email, personal letters, fliers, posters, and visits to carer support groups. The range of recruitment methods reflected the diversity of the recruitment sites, with different methods correlating to the way in which each site might most easily disseminate information. Each of these methods had been used successfully in other studies.

⇒ Recruitment by email: employers willing to act as gatekeepers in the study were asked to send a prepared email through the internal computer system (Appendix 3). To encourage people to open and respond to the email various subject lines and text styles were piloted with male colleagues. The title line and text did not use the word carer or caregiving, as many carers do not attached these words to their activity. Email is a relatively new method of recruitment but has been used successfully in another study to recruit fathers (Philips 2007, personal correspondence). One man was recruited through this method.

⇒ Recruitment by personal letter: Local branches of Crossroads for Carers identified men on their data base who met the inclusion criteria of age and caregiving responsibility. To ensure confidentiality of their clients the organisation was provided with pre-printed letters and postage was paid, but Crossroads workers addressed and mailed the letters. Forty letters were sent out,

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[5] PPIRes consists of lay people who have an interest in research and who will provide advice to researchers.

resulting in a relatively good return of thirteen expressions of interest from male carers who had either left or remained in employment. This was the only method where Participant Information Sheets were included with the recruitment material (Appendix 5). It may have been that more details about the study increased male carers' willingness to participate. After sampling eight men were recruited.

⇒ Recruitment by poster or flyer: Carer support groups displayed posters and distributed flyers to their members (Appendix 6). Posters are recognised as a method of raising awareness, highlighting who may be eligible to take part (Carballo et al., 2009). There were very few expressions of interest using this method, perhaps because of the impersonal nature of viewing a poster. The two men recruited by this method had received the flyer directly from a social care worker, making it more personal than simply viewing a flyer.

⇒ Personal visit to carers' groups: personal attendance and explanation at carer support groups served to increase interest in the study (Sherr et al., 1996). However, to reduce the possibility of coercion, male carers were asked to contact the researcher later, providing them with an opportunity to reconsider their commitment. Two men were recruited from different carer support groups.

Managing recruitment

Recruitment started in January 2008 and it quickly became evident there would not be an extensive sample population. Therefore it was decided to recruit and interview the first three respondents during January, enabling reflection on whether the sampling framework was facilitating access to men with distinctive caregiving experiences. These three respondents had significantly different sampling characteristics: the first, aged forty-seven, was in full-time work caring for his wife; the second aged sixty-four, was a full-time carer for his son; and the third aged fifty, was a full-time carer for his mother.

During the remainder of January expressions of interest were received and sampling characteristics were recorded for eighteen men. Eventually thirteen men were recruited and interviewed. Letters were sent to the remaining five men informing them that they would not be interviewed (Appendix 7). The decision not to include these five men was grounded in the sampling framework. The sample had a good representation of the caregiving characteristics of these men. The five were spousal carers, over 60 years who had exited paid employment, whose wives had degenerative disease. (Table 5.2)

Pseudonym	Age	Length of time caregiving	Caring for	Employment F/T full-time P/T part time	Recruitment method
Philip	47	11 years	Wife	F/T employment	Employer's email
Bill	64	3 years	Son	Full-time carer	Carer support group, flyer
Martin	50	4 years	Mother	Full-time carer	Carer support group, flyer
George	63	11 years	Wife	F/T Self-employed	Crossroads letter
Andrew	64	5 years	Wife	P/T Self-employed	Crossroads letter
Bert	64	10 years	Wife	Full-time carer	Crossroads letter
Percy	61	12 years	Wife	P/T Self-employed	Crossroads letter
Peter	52	8 years	Wife	Full-time carer	Personal visit to carer support group
Jack	47	13 years	Daughter	Full-time carer	Crossroads letter
Daniel	51	2 years	Wife	F/T employment	Crossroads letter
Charles	63	2 years	Mother	F/T employed	Crossroads letter
Samuel	54	4 months	Wife	Full-time carer	Crossroads letter
John	56	Intermittently for 30 years	Wife	F/T employment	Personal visit to carer support group

Table 5.2   Characteristics of Participants

Reflecting on the sampling and recruitment process

The varying success of various recruitment sites highlighted the importance of personal contact with gatekeepers. Personal visits enabled me to answer questions and provide reassurance about employers' level of involvement. The method most successful at raising interest in the study was personal letters sent through Crossroads for Carers, suggesting that a personal request and information about the study predisposes people to think that they have a role to play in the research. It may also be that receiving information from an organisation already providing services to the potential participant increased the legitimacy of the study. Whilst email recruitment and posters may be a way of accessing 'hidden' carers, the impersonal nature of these recruitment methods may have discouraged higher levels of response.

Whilst the sampling framework ensured a variety of information- rich caregiving experiences, a limitation of the sample was that the level of variation resulted in only one or two participants having similar carer and employment responsibilities. Therefore when drawing conclusions about findings I would need to ensure a degree of tentativeness in proposing implications and identifying transferability of interpretations. Nonetheless, within phenomenological studies rich experiential stories may mean that evocative descriptions of meanings within life worlds emerge from very few participants (Van Manen, 1990). Further, any common patterns emerging from the data may capture the essential and core elements of male carers experiences (Patton, 2002).

Figure 5.1 provides an illustration of the contact points with participants during all stages of the study.

Figure 5.1   Flowchart of Participant Involvement

Hearing male carers' experiences: data collection

Using in-depth interviews

The basic methodological premise of the study was that participants would have experience of being a male carer; and through a process of sharing descriptions of their lived experiences an understanding of the phenomenon, male caregiving, could be developed. In-depth interviews were used for data collection as such interviews are designed to enable participants to talk of those experiences which are important to them (Kvale, 1996). The challenge of using interviews in this case was to enable participants to focus on experiences which were important to them whilst also ensuring that data was relevant to the research objective, namely understanding the experience of combining employment with caregiving. Therefore, a guide-list of topics for exploration was used rather than preset questions. The topic list (Appendix 8) provided reminder prompts whilst still enabling researcher questions to follow on from the focus of the participant's conversation (Rice and Ezzy, 1999).

Reflecting on the interviews

To develop an interview event which would enable rich experiential data to be collected the following factors were addressed: place of interview, length of interview, managing performance anxiety and types of questions.

Considering the situation of the interview and the desire to reduce anxiety and minimise disruption, participants were offered the opportunity to have the interview in their own home or an alternative place. The majority elected to have their interviews in their own home enabling them to share artefacts of their caregiving experience such as equipment and pictures, also providing me with an opportunity to meet the care-receiver, thereby facilitating the recording of contextual data about their lived space. Although the care-receiver was at home for eight interviews, the severity of their illness meant that only two wives made limited contributions to the interview. Two participants chose to have both interviews at their workplace and one participant had his first interview at the University and his second in his home. The context of the interview did not appear to change the type of data collected.

When deciding the potential length of the interview a number of points were considered: the time it would take to develop rapport and help participants feel at ease, the amount of time they might reasonable be able to give considering their other

commitments. Patient information sheets informed male carers that interviews would last about an hour. The literature suggested that an hour interview could elicit rich data and provide sufficient time for trust and rapport to develop (Mason, 2002). To increase participants' access to the study, interviews were undertaken at times of the day to suit them, including evenings and weekends. Interviews lasted between 45 and 65 minutes, however they were not stopped abruptly, rather they all came to a natural end. Interviews ended when participants' did not appear to add new information or experiences to their stories. This was evident when they began repeating stories or appeared eager to return to their other activities. To facilitate the opportunity to share further information the ending of the interview was fore-grounded with the statement, 'we are coming to an end ' a little before the final point of asking 'is there was anything further you want to add?'. This created the opportunity for participants' to share anything not already covered in the interview.

Performance anxiety may occur when the data collection event is fore-grounded as a specific event in which everything the person says will be recorded and dissected (Holstein and Gubrium, 2003). A number of steps were taken to reduce performance anxiety. Firstly, to help participants feel at ease there was a period of settling where pleasantries where exchanged and consent negotiated, before turning on the audio recorder. Then, the recorder was positioned to capture both the participants and the interviewer's voices but placed out of direct eye line to reduce concern about being recorded. Secondly, in trying not to frame the event as a question and answer interview participants' were asked to describe their day with follow up questions being grounded in their stories.

Interview questions

This phenomenological study aimed to encourage participants to discuss their feelings about their experiences rather than trying to rationalise why they thought things had happened to them (Wimpenny and Gass, 2000). Kvale and Brinkmann (2009) describe how within a phenomenological perspective interviews may become an conversation, whilst still having a distinctive research purpose. Questions were used for different purposes: to open the conversation, to elicit deeper descriptions, to probe and to clarify information and particularly in the second interview to share interpretations.

To open the interview and to reduce setting the context as a probing interview participants were asked to 'tell me about your day'. This helped phenomenological

questioning, as I was able to develop questions from their stories and ask them to describe in more detail their feelings or to provide examples of experiences (van Manen, 2008). A particularly focus in phenomenological studies is on description rather than explanation so if, for example participants began listing the people they saw when undergoing carers assessments the interview was refocused with questions such as 'how did you feel at that time?' If it seemed the participant had more to say about an experience then reflecting their words back as a statement frequently prompted further discussion 'so you feel you've got those jobs out the way?' encouraged them to continue the conversation. On occasions questions were used to clarify information such as 'This job you have now, am I right in thinking is nine-to five?' Using such questioning strategies resulted in rich descriptive stories of being a carer. The follow up interview was used to not only obtain additional data, but also to share interpretations.

There was a subtle shift in the aims of the two interviews, with the first interview seeking to capture in-depth experiences using open, experience-seeking questions. In the second interview the aim was not only to provide participants with an opportunity to add to the experiential data set, but also to share emerging interpretations, therefore questioning included more directive questions about meanings attached to experiences, alongside opportunities to provide more examples. An example of a more directive question was 'You said last time that you felt that people don't understand what carer's go through' which prompted the participant to talk at length about his relationships with his family and friends.

These example questions have illustrated the ways in which questions were used to elicit experiential data about participants' experiences. Further examples are found in Appendix 9. Nonetheless, there remained methodological challenges with using interviews.

Methodological challenges of interviews

There were two main methodological challenges with using in-depth interviews. Firstly, as I was seeking potentially sensitive phenomenological experiences, there needed to be a rapport between participants and myself in order that they felt able to talk about their lives. However, other researchers have found that rapport can be difficult to develop with male participants, with participants being reticent to express emotion and trying to control the interview, or present a persona to the unknown researcher (Holstein and

Gubrium, 2003). Consequently the research design needed to ensure sufficient opportunity for the development of trust and rapport between participants and myself.

The second methodological challenge concerned the nature of knowledge created during an interview. The methodological premise of the study was that meanings are created within a person's social and cultural history. Therefore responses and interpretations made during the interview would be influenced by both my own and the participant's cultural understandings. Knowledge would be constructed during the interview which would be a dynamic and constructed rather than a neutral act (Coupland, 2007). To encompass this methodological stance the research design needed to actively involve participants in sharing interpretations with me, thereby recognising multiple meanings and facilitating a fusion of horizons (Gadamer, 1975/1996).

To address these challenges and aid the process of collecting 'thick' contextualised data that captured the lived experiences of participants (Geertz, 1973:6), the research design included the return of a narrative summary and a follow-up interview. This innovative method provided an opportunity for sharing emerging interpretations and increased engagement with participants, adding to the development of rapport. Producing narrative summaries provided an early opportunity to undertake preliminary analysis of interview data. However, to ensure that data were not lost or ignored too early in the analysis, hermeneutic data analysis was undertaken with the raw data from both interviews. Undertaking analysis on the full transcripts was important as there was the potential that the pragmatics of reducing interview texts to four pages for the narrative summaries could have led to important insights being cut. As Lindseth and Norberg (2004) state prolonged immersion in the raw data may help to ensure that intuitive insights emerge from stories which at first reading appear inconsequential and it is only when considering emerging patterns that one comes to understand the importance of other data.

Using the narrative summary

The methodologically informed production and return of the narrative summaries served a number of purposes. Firstly, the narrative summary prolonged engagement with the data for both participants and myself. Prolonged engagement increased the opportunity to develop a deeper understanding of the phenomenon. Secondly, reducing the interview transcription into a short narrative summary provided a first step in analysis (Blauner,

1987; Webster and Mertova, 2007), enabling emerging meanings to be shared and further explored. Table 5.3 illustrates the procedure for producing the narrative summaries and the purpose of each step.

Procedure	Methodological Purpose
Full interviews were transcribed and checked against audio recording	To ensure accuracy of data
Speech repetitions and content not related to the experience of male caregiving were removed	To 'clean' the transcript, reducing it to about half its length, thereby creating a document which is easier for the reader to consider as a whole (Elliott, 2005:52)
The narrative was sequenced to display the thread of the participant's story	This is the first stage of interpretation as decisions are made by the researcher on how to order the participant's story
The text was further reduced so that only sentences and phrases which evoked the meaning of the experience were retained	This stage reduces the narrative to a text which focuses on the essence of the individual's experience of caregiving.

Table 5.3   Producing a narrative summary

The process of producing a narrative summary reduced an interview text from forty pages to just three or four pages (example of a narrative summary in Appendix 9). However, the wholeness of the story was maintained, unlike in participant validation where often only descriptive categories or themes are returned to participants (Patton, 2002). It was this wholeness of their lived story which made the narrative summary a method that participants could more actively engage with.

More than a form of validation

The structure and purpose of the narrative summary differed from participant validation, or member checking. Qualitative research designs frequently involve participants in checking and validating analysis, providing them with opportunities to comment on and add to findings (Punch, 2006). However, this stage is usually undertaken after data collection has ceased (Watts and Teitelman, 2005). In contrast, as well as providing some elements of member validation, the narrative summary was designed to engage participants in further reflection and shared meaning-making. This was achieved through specifically using the narrative document as a platform for the follow-up interview, thereby underlining to participants that the research was trying to capture

meaningful elements of their lived experience and seeking their engagement in doing this; so explicitly addressing the co-constitutive nature of interview data. To provide participants with time to re-engage with their stories, the narrative summary was returned about ten days before the follow-up interview.

The follow-up interview not only prolonged researcher engagement in the field but also provided an opportunity to explore whether participants recognised their experiences in the reduced text, thereby seeking to explore whether and how early analysis may have captured the meanings they gave to the phenomenon of caregiving. Undertaking a second interview also increased engagement with participants, enabling the opportunity for developing rapport and trust, which in turn appeared to lead to richer more experiential data. This developed rapport was evident in the way in which the majority of participants' stories moved from stories of 'doing' a carer role to stories of 'being' a carer. Gergen and Kaye (1992) identified that people can find it difficult to display or verbalise emotions, presenting stories of 'doing' an activity rather than 'being' in the experience. The change in the nature of the story told by participants suggested that some level of rapport had been developed, encouraging new perspectives and further experiential disclosures in the second interview.

Interpretation of the data was not something which was delayed until the later work with transcribed interviews. Rather it began during the interview interaction when queries arose about what participants meant and clarifying questions were used. Early analysis began when producing the narrative summaries, which called for decisions to be made about the content and structure of the narrative. Nonetheless the data analysis was informed by the key principles of hermeneutic phenomenology. A critical account of how far this innovative research design may have facilitated both data collection and participants' empowerment is offered in Chapter Ten.

Interpreting and understanding the stories: data analysis

The epistemological stance of the study, that knowledge was co-constituted during a research interview leading to multiple meanings within a text, meant that the data analysis framework had to enable researcher reflexivity. Such reflexivity could be embedded within an iterative hermeneutic analysis, as the process enabled repeated returning to the text and questioning of the data and emerging findings, ensuring that analysis was undertaken in a 'systematic, explicit and self-critical' way (van Manen,

1990:11). The data analyses framework encompassed three methodology aims. The primary aim of analysis was to enable interpretation of raw data, ensuring that emerging meanings remained embedded in the interview texts. The second aim was to reduce the volume of data, whilst still ensuring sufficient contextual data to provide a rich description of the setting and participants' lived experiences. The third aim was to undertake analysis in a reflexive way, enabling me to remain open to new and different interpretations.

Management of the data

Transcribing interviews

To provide a written text for analysis, each interview was transcribed verbatim. Reading the transcribed text whilst listening to the audio recording served two purposes. Firstly, there was the opportunity to check transcriptions for accuracy. Secondly, there was the opportunity to become immersed in the emotional content of the interview (Grbich, 2007). Recognising and recording where participants were upset, or struggling to find words helped to contextualise the data, thereby resituating the written word within the physical context of the interview.

Producing the narrative summary

A process of reading, re-reading, and editing produced the narrative summary. Examples of this process are displayed in Appendix 9. Whilst producing the narrative summary early thoughts and questions about the meaning of the text were recorded in the margin of the text. (Holloway, 2002). These memos ensured that later in the analysis process, first impressions could be reconsidered in light of developing interpretations which arose from a further analysis of the full interview transcript after the second interview. This helped to ensure that when the interview text had been reduced and segmented, interpretations could still be linked to original thoughts. During this first stage of the analytical process, immersion in the individual participant's stories enabled prolonged exposure to the texts as a whole before the process of data reduction and regrouping into descriptive categories occurred, meaning that there was a heightened awareness of the individual's whole experience which helped to contextualise the phenomena (van Manen, 1990).

Breaking into meaning units

After producing the narrative summaries and undertaking follow-up interviews, the full transcripts from each participant's two interview texts were returned to them. Data were reduced, only including those aspects of text which added to understanding of the research questions. Segments of text, or meaning units which appeared to capture the experience of male caregiving, were underlined and retained (Fleming et al., 2003). Areas where participants talked of things not related to the study, perhaps asking how my journey had been, and where they used figures of speech, such as 'you know and er', were removed. Continually moving between the whole text and parts of the text when producing meaning units encouraged immersion in the data and facilitated the proactive thinking and questioning needed to make sense of the spoken words. This activity was consistent with a hermeneutic approach (Lindseth and Norberg, 2004).

Revisiting narrative summaries for each participant and comparing these with meaning units developed from their full transcripts illustrated that emerging meanings had resonance with those parts of their interviews previously selected as capturing the essential features of their experiences. A high level of consistency was found between the text of the narrative summaries and the text of the meaning units, providing some reassurance that there was consistency between earlier interpretations and emerging meanings.

Building the descriptive categories

After reducing data to segments of meaning a period of explication followed where patterns and themes were found in the data (van Manen, 1990). At this stage analysis occurred on individual transcripts. However insights and emerging patterns across the full data set were recorded in a research journal. Using a research journal enabled reflection on whether early insights still had resonance when analysis was more developed.

To construct descriptive categories, which were a way of seeing patterns both within individual texts and across the whole data set, meaning units were grouped for similarity. Firstly meaning units were grouped across the individual participant's two interviews, then across all full-time carers and then all employed carers (Appendix 10). The purpose of analysing the data from full-time carers and those in employment separately was to explore whether these two groups of participants had distinctly different experiences. As analysis continued it became apparent that there were more

similarities than differences between the experiences of participants in employment and those who were full-time carers. This suggested that there were aspects of the phenomenon of male caregiving that were common across the cohort of male carers, indicating that essential themes were emerging. There follows an example of how descriptive categories were named and a brief description provided of their meaning.

Meaning unit in text	Interpretation	Category	Theme
I have to do the food shopping as well (R10 1:25) In the evenings I get to go and do the laundry and clean the house, clean the bathroom, make the bed (R10 1:22)	Have to do it He does it	Sole responsibility	Self as carer-reworked identities
I just do the washing up, do the breakfast, do some washing, anything that needs doing, tidy, tidy up a bit, trying to fit that in the morning when I've got time to do it (R11 1:17)	Finding the time	Structuring time to do the activities	Obligated time
I can do things but it's just the time but it's you know things like the cleaning, the cooking has to be done, you have just got to prioritise everything you know, keep the week ticking over and leave things for the weekend like a Sunday afternoon or whatever (R1 1;18)	Lack of time Prioritise use of time	Structuring time to do activities	Obligated time
do all the housework, do all the shopping, all the ironing, (R4 1:3) well I don't do the ironing but [laughter] carer who comes in on a two week basis on a Friday she insisted on doing the ironing (R4 1:3)	Have to do it Draws on others to provide help	Sole responsibility Using support	Self as carer Being a male carer
get home about half-past six in the evenings, I then have to do the washing, cooking, ironing, everything about round the house really (R13.1:1)	Have to do it He has to do it	Sole responsibility	Self as carer
I have a cleaner in because I got to the point where I'm saying I'm doing so much work I'm actually neglecting it (R5 1:16)	Draws on others to provide help	Using support	Being a male carer
I'm a domesticated man now (R6 1:12) I'm a good, I've become a good cook now (R6 1:12)	Pride in achievements	Reworked identity	Self as carer – reworked identities
during the day when he's out, usually have to plan what meals he's having… make sure it's out the freezer and thawed out before he comes home because he usually comes home starving hungry (R2 1:11)	Have to do it Meeting needs of other	Time obligated by needs of son	Obligated time

Table 5.4   Illustrating the process of moving from transcripts to themes

Reflecting on immersion in the data

The development of descriptive categories occurred over a period of several weeks as my analytical thoughts continued to develop. It was a period of writing and rewriting with each new understanding leading to further questioning and deeper understanding. Each occasion of rewriting led to a reordering of illustrative quotes and a reconceptualising of descriptive category headings. Memoing the text continued, particularly notes indicating the degree of tentativeness with which a meaning unit had been placed in a descriptive category. Memos also included questions and thoughts of how understanding of the data may have been influenced by my personal history, gender and culture. During this stage emerging findings were shared with others to help identify differing interpretations and to highlight any areas where I might have bias or narrowness of interpretation. Descriptive categories were shared with participants through the process of participant validation (Appendix 11). Other researchers, who formed my supervisory panel, probed the systematic nature and explicitness of the process of analysis. People from the wider carer community were invited to review emerging findings to discover if such findings had resonance with their experiences (Appendix 12). This process is discussed further in Chapter Six, which critiques the trustworthiness of the study.

Working with the data for a prolonged period enabled me to realise that there were many similarities between the experiences of both employed and full-time carers, which encouraged me to retain the focus on themes which ran through the whole data sets rather than trying to force themes into dichotomised sets, namely full-time carers and employed carers.

Challenges of combining individual stories

Consistent with a hermeneutic approach, preliminary interpretations of data started from the beginning of data collection. Such an approach recognised that data were constructed in an interpreted event and enabled questioning of meanings to be used as the basis for further data collection (Rapley, 2001). Nonetheless direct questioning and challenging of meanings with participants did not occur until the follow-up interviews, as the phenomenological aim in the first interviews was to capture experiences as they occurred in a pre-reflective state (Seidman, 2006).

As each participant was considered as a case whose experiences were constructed within a distinctive social world there needed to be a way of recognising the individuality of participants' stories whilst also being able to find the commonalities in the stories leading to an understanding of the essential features of the lived experience of being a male carer (Benner, 2000). Table 5.5, adapted from Ayres et al. (2003), displays where in the analytical process individual texts were explored and where interpretations were made across the data set.

Analytical purpose	Within or across case	Strategy	Product
Immersion in interview data	Within each case	Close reading of individual text and listening to audio recording	Sense of lived experience for each participant
Engaging participants with data collection and interpretation	Within each case	Producing narrative summaries	Opportunity to share emerging interpretations
Identify important aspects of the experience	Within each case	Close reading, memoing of reflections and identifying meaning units	Identification of significant statements in each text
Seeking emerging patterns	Within and across each case Initially subsets of employed and non-employed carers	Removal of meaning units from individual texts and looking for patterns and relationships between meaning units leading to descriptive categories	Identification of meaning units common to participants within the two groups
Seeking alternative interpretations of meaning	Across cases within subsets of employed and non-employed carers	Returning descriptive categories to participants. Sharing with other professionals and carers	Refinement of interpretations. Increased opportunity for reflection
Seeking the essential features of the experience	Across all cases	Intuiting and free writing to develop descriptive categories into themes	Identification of themes which capture the lived experiences of being a male carer

Table 5.5   Analysing within and across cases

By analysing both within individual texts and across texts it became possible to recognise not only commonalties but also participants who had distinctly different experiences to others. Recognising and reporting divergent experiences and alternative explanations helped ensured credibility in the findings, increasing trustworthiness (Whitehead, 2004).

Defining the essential themes

There was not a discrete point in analysis when the themes emerged. From early reading of data there emerged common threads running through the transcripts. There were three threads. Firstly, the sense of caregiving being an occupation within which support may be refused by or sought from others. Secondly, a sense of time being obligated and the ways in which participants managed the obligated nature of caregiving. Thirdly there emerged a concept of 'self', with participants experiencing challenges to retain previous selves, such as employed man, and many reworking identities. These three threads could be seen running through the descriptive categories and were also identified in the whole texts and short narratives of participants. The consistency with which these ideas emerged in the data has led to the defining of three themes: being a carer, obligated time, self as carer-reworking identities.

Themes differed from descriptive categories in that they encapsulated the essence of the phenomenon of caregiving for these men at this time (Morse, 2008). This research design sought to ensure that data were collected in a timely, systematic way, facilitating collection of information about the phenomenon of male caregiving, which would enable the exploration of new understanding. Nonetheless, during design, steps were taken to help to promote ethical conduct and decisions. Whilst the procedures adopted in ensuring informed consent and anonymity of participants were quite standard within qualitative research, more complex ethical challenges arose around the decision to return narrative summaries.

Embedding ethics in the study.

The study was submitted for ethical scrutiny to the Faculty of Health Ethics Committee, University of East Anglia in 2007.

Preparing the study for the ethics committee clarified how procedures would support informed, voluntary consent, sharing of data, confidentiality, and promoting the safety of both the participant and the researcher. Recognising that returning narrative

summaries could present ethical challenges, a reflexive methodology was adopted enabling reflection on and action to address ethical issues as they arose. Here a reflexive methodology helped actively establish that the principles of ethical conduct were clearly understood and the concepts of consent and protection of participants could be renegotiated in the field (Guillemin and Gillam, 2004).

During data collection three occasions led to reflection on the ethical protocol of the study and the remaking of ethical decisions. Firstly, one participant expressed surprise at the information he had shared during the first interview. Secondly, another participant became angry at the way he was presented in his narrative summary. Thirdly, a participant disclosed that his relative was abusing him. These examples are drawn on here to illustrate how the ethical decisions made during the research design enabled researcher responses to these challenges. Ethical strategies within the research design are discussed under the following headings:

⇒ Informed, voluntary participation

⇒ Sharing and negotiating use of data

⇒ Confidentiality and anonymity

⇒ Protecting the participants and the researcher

⇒ After the study

Informed, voluntary participation

Information about the study was provided in a way which aimed to ensure male carers could make an informed decision, using methods which facilitated voluntary participation. The majority of those men who were ultimately recruited as participants found out about the study through letters or flyers. They made contact with me through telephoning or writing to express an interest in the study. Figure 5.1 illustrates the points of study contact with participants. Nonetheless some carers were informed about the study through my personal visits to carer support groups. Here carers may have experienced subtle coercion to express an interest in the study simply to please me as a visitor. Therefore to enhance the voluntariness of participation they were provided with a participant information sheet and asked to make contact again when they had had the opportunity to read the information and reflect on whether they wanted to take part.

To try to ensure carers had sufficient information about the purpose of the study, their role and the potential benefits and risks of taking part, and to support informed consent, a two-page Participant Information Sheet was provided either with the introduction letter from Crossroads, or when male carers made the initial telephone call to express interest in the study. After this they were re-contacted to offer them an opportunity to clarify any uncertainties they may have had or to withdraw from further involvement if they wished. If they were still interested a date for the first interview was agreed.

Informed consent was negotiated both through formal written consent forms (Appendix 13) initially and informally through conversation at several points throughout the study (Holloway and Wheeler, 2002). Renegotiating consent enabled a response to ongoing or later concerns. For example, prior to signing the consent form for the second interview, one participant said he was surprised by how much he had disclosed during the first interview. This could have meant that he had not understood the nature of data collection, or that he felt uneasy with the information he had shared. At this point I checked if he was comfortable with what he had disclosed and if he was willing to continue with the study, reiterating the purpose of the study, degree of anonymity and his right to withdraw. He then explicitly stated that he was happy to undertake the second interview.

Sharing and negotiating use of data

Whilst sharing data from the first interview through the narrative summary helped to meet the methodological challenge of recognising and sharing differing meanings, there was potential for participants to become distressed when receiving their life experiences re-framed within a narrative form which might highlight and bring to the fore distressing events and relationships (Forbat and Henderson, 2005). To reduce the risk of distress each narrative was structured to ensure that the summary closed on a positive statement. An example of this can be seen in the exemplar narrative summary in Appendix 9. Yet there was still a risk that a participant, when seeing their spoken words in text may have wanted to withdraw their data maybe because they did not want their reality exposed, or they could not embrace the persona presented within the narrative. Forbat and Henderson (2005) identify the ways in which participants may be challenged when receiving transcripts and seeing spoken language and spur-of-the-moment thoughts committed to paper. The reduction of transcripts into narratives in part mediated this effect. Participants were informed that they could withdraw from the study at any time, but that if they did withdraw after joining the study their data would

still be used unless they made clear that they did not want data from their first interview included.

Only one participant went on to raise concerns about how his data had been presented. Before his follow-up interview he voiced disagreement on phrases in his narrative. He said he had been portrayed as a person who chats to people in the supermarket queue, stating this made him appear a 'sad' person lacking in friends. He was offered the opportunity to withdraw the data from the study, but was also reassured that all data were anonymised and that the words in the summary had been taken directly from his interview transcript. Being reassured he then consented to the extract remaining in the data set. He agreed to take part in the second interview, during which he again spoke about talking to people in the supermarket. This provided reassurance that the meaning of his words had not been changed during the production of his narrative summary.

The event increased my attention to the moral responsibility of qualitative researchers to ensure they handle participants' data reflexively (Finlay, 2003). It also provided a prompt to reflect on the methodological challenge of whose interpretation of meaning would be privileged, if any. Whilst the research design provided the opportunity to explore further with participants their first interview by sharing discussion about their meanings and my interpretations, the follow–up interview would also be a co-constituted event and again differing interpretations could have arisen. In striving for a fusion of horizons ultimately I had responsibility for interpreting the data and presenting the findings in ways in which others could see the essence of participants' experiences, but remain able to make different interpretations.

Confidentiality and anonymity

The personally descriptive nature of qualitative data means that there is the potential to breach anonymity and confidentiality, either through poor storage of data or lack of anonymity when publishing findings. To ensure data confidentiality all research documents were held securely in a locked drawer, or on a password-protected computer in my university office. To facilitate audit, transcripts will be held securely in the University archive for five years. Electronic data were deleted.

To ensure anonymity interviews were anonymised during transcribing. Participants were informed that a transcriber would have access to the recorded interviews whilst personal identifiers were still present. The transcriber also signed a confidentiality agreement. In providing rich contextual data within the findings, the uniqueness of

participants' experiences may have made them identifiable within their communities. Therefore to reduce the risk of compromising anonymity pseudonyms were used. The pen portraits presented in the findings section were sent to participants to offer them the opportunity to pick out what they saw as personal identifiers and to have them removed. No participant requested that their pen portrait be altered.

Protecting the participant and the researcher

Participants were engaged in discussion about emotional aspects of their lived experience within their private homes, raising a number of potential risks: for participant distress, for observing potentially abusive practices, and risks to the researcher's personal safety. Qualitative research can entail a prolonged and transformative process so there had to be a procedure for disengaging from the research setting (Briggs et al., 2003; Dickson-Swift et al., 2007). The following measures were implemented to reduce the risk of harm to the participant or researcher.

To ensure participants were aware of the personal nature of the interview they were pre-warned of indicative topics through the information sheets, although it was not possible to know what areas participants may have led the interview down. In case of participant concern and questions about caregiving issues, information about additional support services for carers was taken into the interview setting. During the study none of the participants became distressed and additional support did not seem to be called for and was not offered.

Caregiving can place a strain on relationships and there was the potential of observing behaviour suggestive of potential abuse (Forbat, 2005). The information sheets explained that if abuse of vulnerable persons was seen or suspected the researcher had a duty of care to report such instances to the Adult Social Care Department of the relevant local authority. Whilst recognising that participants may disclose unexpected experiences during in-depth interviews, including abusive practices, I had naively not anticipated that the carer would be the person who was being abused (Guillemin and Gillam, 2004). Yet one participant during his first interview made repeated comments about the care-receiver physically assaulting him; he showed me marks on his arms. During the interview I elicited that he had told health professionals about this behaviour, therefore, in consultation with my supervisory research team, it was decided to record this concern but take no further action at this stage. At the second interview he

again referred to the physical abuse, but stated that both he and his relative were now receiving support and the abusive behaviour had stopped.

To increase the ability of carers to participate and to ensure that they were in a familiar environment, I elected to enable participants to be interviewed in their own homes (British Sociological Association, 2002). Recognising that this could place my personal safety at risk, several steps were taken. Safety procedures included checking the vicinity of the interview and having a protocol for calling for emergency help. Such measures meant that the interview setting could be safely entered, enabling the focus to remain on the interview itself. Although this was not an overly sensitive research area, there was potential for both myself and the transcriber to become distressed (Dickenson-Swift et al., 2009). To alleviate potential distress, any issues of concern were discussed in confidence with academic colleagues. The transcriber was supported to indicate if he found any of the tapes were to be upsetting. Data were not found to be overly sensitive or distressing.

The research design involved contacting participants on a number of occasions over a year. To formally close their role and to recognise, in a small way, their contribution to the study they were sent a £10 gift token of thanks and a letter formally marking the end of their activity in the study.

After the study

Another ethical responsibility was to share findings with both the participant and other stakeholders (Wolcott, 2001). This may have given participants some benefit from taking part, as this would enable them to see how their experiences had shaped research-based understanding and possible recommendations for practice. As planned in the study timeline, the findings were shared as early as possible through academic conferences, a public research engagement event, through speaking to carer support groups, planned future research and other publications.

Summary

Methods of data collection and analysis needed to reflect the underpinning methodology and to be seen to effectively engage with the research problem, namely how best to explore male carers experiences in-depth. The recruitment and purposeful sampling focused selection to ensure that men with a variety of caregiving experiences were recruited to the study. This variety may increase the opportunity for findings to be

generalised to similar settings and groups (Holloway, 2005). Reflection on the various methods of recruitment suggested that male carers show most interest in the study when they are directly targeted with information about their role within and the purpose of the study.

In-depth interviewing enabled participants to talk of experiences which were pertinent to them, yet the use of a topic guide meant that their talk could be prompted for aspects of their experience which related specifically to the objective of understanding the reality of men who either combine caregiving with paid work, or who choose to leave employment. Including the innovative, within phenomenological interviewing, use of a narrative summary and a follow-up interview was found to greatly add to the depth and relevance of the intimate data collected. In most follow-up interviews there was a greater level of rapport and richer experiential data was shared.

An inductive, hermeneutic data analysis framework enabled prolonged immersion with the data and a growing understanding of the phenomenon. This framework also facilitated the movement from descriptive findings to interpretive findings of what caregiving meant in this case, which is a premise of hermeneutic phenomenology (Cohen et al., 2000).

A range of ethical challenges arising from the research design included some risk to participants of coercion and loss of anonymity. These were reduced by modifying study protocols to include procedures which aimed to reduce these risks and to actively empower participants by building in ongoing negotiation of consent and the sharing of data and analytical themes. The active involvement of participants in co-constituting of knowledge and meanings though sharing the narrative summaries and emerging analytical themes further strengthened the trustworthiness of methods, as well as reducing ethical problems in exploring an area of participants' lives which had often required some difficult choices and issues.

However, while a well-designed study may help to reduce the ethical risks, other unanticipated decisions made while immersed in the field may also affect whether participants are ultimately offered informed consent and protected from harm. The three examples of unanticipated ethical challenges set out here indicated how participants were routinely informed of the option to withdraw from the study. By highlighting the robust measures taken to guarantee anonymity and confidentiality and by explicitly identifying, evaluating and addressing the level of risk faced by participants,

participants' concerns about the portrayal of their personal caregiving experiences were reduced.

Recognising and reinforcing the concept of the researcher as an active participant in the research also brought a requirement to reflect on and make explicit both how my own history, culture and language have been interwoven within the interpretations and how my presuppositions were challenged by others, including members of the public and academic peers (Hertz, 1996). In a study where the researcher was neither male nor a carer it was especially important to use an approach which embedded reflexivity, thereby helping to increase the trustworthiness of the study (Finlay, 2003).

Chapter 6 Contextualising the findings

Introduction

Within the interpretivist approach adopted in this study interpretations would be made through the analysis of the meanings these male carers gave to their lived experiences. Hermeneutic analysis would involve the questioning and re-questioning of data (van Manen, 1990), but within this approach there would be increased potential for my personal subjectivities to influence the interpretations being made. Therefore to ensure that others could have trust in the findings and interpretations drawn from this study it needed to be clearly acknowledged that in this qualitative research the researcher was an integral part of the study, interacting with participants in an emergent research process. This presents an epistemological challenge when collecting and analysing data (Geanellos, 1998). As the central research actor I would bring understandings which were embedded within my personal frames of reference. The knowledge which developed could not be an objective presentation of the 'truth' of being a male carer, rather it would be an interpretation developed through specific, contextualised interactions both between participants and myself and myself and the data. Yet if interpretations derived from data were to be meaningful to practice and to have resonance with the wider carer community, the analytical decisions needed to be made explicit. This was so others could see my viewpoint, and see what I saw whether or not they agreed with the interpretation (Giorgi, 1975:96; Sandelowski, 1998; Finlay, 2003).

To ensure consistency between the methodological stance chosen and the new knowledge to emerge in using it, a critical reflexive stance was called for to provide opportunities to reflect on and question the plausibility of the emerging findings. Recognising the way in which personal historicity will shape the analysis, the research design needed to enable questioning of interpretations (Whitehead, 2004). This would enhance trustworthiness in the claim that findings reflected the lived experiences of participants. The questioning of analytical decisions and interpretations occurred in a number of ways. Firstly, the study design was grounded within a reflexive approach, meaning there was constant self-questioning and recording of personal frames of reference, leading to consideration of how this may influence emerging findings (Alvesson and Skoldberg, 2000). A reflective research journal was used to record decisions about aspects of the design and the rationale underpinning them. Beliefs and expectations developed before, during and immediately after the interview coupled with

thoughts and interpretations made during analysis were recorded for two purposes. Firstly, the use of a research journal facilitated the sharing of aspects of the research process with other academics, professionals working with carers and carers themselves, increasing opportunities to be self-reflexive. Secondly, adopting a consciously reflexive stance enabled possible bias during the data analysis to be actively addressed, particularly around whether gender was a theoretical concept in this study.

This constant questioning and re-analysing of data embedded a principle tenet of hermeneutic phenomenology, addressing the concept that knowledge is constructed and the meaning of experiences develop within temporal, cultural and social contexts (Gadamer, 1975/1996). However, although reflexivity, enabled me to remain more conscious of how my experiences and subjectivities may have influenced the meaning found in participants' interviews, it did not fully address the criteria of ensuring that findings had resonance with the wider carer community. The phenomenological aim was that essential meanings derived from this study could be seen by others living through the phenomenon, as reflecting their own experiences (Rapport, 2005). Further, I wanted to explore whether new understanding developing from the findings might be seen by practitioners as transferable to their settings. Therefore, validation techniques were used to explore whether interpreted data continued to have resonance with the lived worlds of the participants and others, rather than to establish an indisputable objective truth.

Within this chapter I examine how remaining reflexive and striving to explore alternative explanations helped establish trustworthiness in this study and its findings. Three examples of reflexive activities undertaken during the study are examined: first how I challenged presuppositions about the meaning of housework; secondly how gendered presuppositions were addressed, and thirdly how I recognised the importance of language semantics when presenting findings. Discussion then moves on to describe the ways in which findings were shared with participants, other carers and professionals who support carers, to develop trustworthiness in my interpretations.

Re-thinking, re-flecting, re-cognising presuppositions

Van Manen's (1990:131) account of the hermeneutic process as a continual reading and questioning of the text encouraged the development of interpretations through 're-thinking, re-flecting and re-cognising' meanings within data. Adopting a consciously

reflexive stance encouraged alertness to possible bias during data analysis. Reflection was a concentrated activity of looking back at specific actions and events and thinking about what happened and why (Finlay, 2003). A reflexive stance was appropriate, as within a hermeneutic methodology there is a process of moving back and forth between the texts and the researcher's understanding, with one bringing aspects of the subjective self to interviewing and data analysis (Rapport, 2005). An example of reflexive practice occurred in the early stages of analysis.

Challenging presuppositions about the meaning of housework

The first example of how my thoughts developed during prolonged immersion in the data is evidenced through the developing interpretation of meaning men may give to housework: chores such as cleaning, cooking and shopping. Many participants spoke of the housework they undertook. When first reading the transcripts I made a memo that most adults have to complete such household chores and that perhaps participants were seeking recognition for activities which are undertaken by many people. However, through rethinking about the meaning behind participants' words I became able to reconceptualise housework as an occupation which has to be completed within the role of caregiver, thereby recognising there may be layers of obligation in the activity of housework which may not be there for people who are not caregivers (Bittman et al., 2004). For example, if a participant did not do the cleaning, washing or shopping, this might directly impact on the care-receiver, a person who in most cases is totally reliant on the participant for food, warmth and hygiene. Recognising there may be alternative interpretations to the statements participants made about housework, it became possible to understand the meaning behind these texts. Through prolonged engagement and reflexive journal-keeping, I came to understand that the talk of housework chores may be an example of obligated time for the carer. Further, the gendered nature of the work meant doing the housework might, for many male carers, compound their realisation that their wife was no longer able to complete activities which were previously her responsibility. This example illustrated the need to remain open to multiple interpretations within the text of participants and to set aside presuppositions of meanings (Dowling, 2007).

Adopting an iterative approach

Gendered presuppositions were further explored when during the early stages of analysis I became aware that memos and early patterns in the data could indicate that experiences were specific to the participants being men. In this second example of reflexivity, academic colleagues constantly challenged me about whether female carers would or would not have similar experiences.

Challenging presuppositions about the gendered nature of caregiving

I reflected on whether I was acting on a presupposition, partially formed by reviewing the literature, that there would necessarily be gender differences between men and women carers. Recognising this potential bias I reviewed data using a more deductive approach, searching explicitly for examples where participants had made reference to their gender or sex. This made it evident that when participants talked about "being a man" this was usually in relation to being different to other men, or their experience of being a man in or out of employment, rather than explicitly related to their caregiving experience. This exercise established that whilst there was a need to highlight where gender made an appearance in the findings, it would enhance the credibility of the study to discuss gender through descriptive categories rather than presenting gender as an overarching theme. This analytical decision that some findings might apply to all carers was affirmed when presenting findings to a carer support group. The audience's comments indicated findings had resonance with both female and male carers (Appendix 12).

Another challenge arose around the use of language. Whilst recognising I had a responsibility to stay true to the data and immersed within the hermeneutic circle of analysis (Finlay, 2008), I also considered using metaphors to evocatively portray the essential meanings of the phenomena (van Manen, 1990). However, a public engagement event where I presented a poster of emerging findings challenged me to reflect on the meaning that others gave to words which I had understood in distinct ways.

Challenging the meaning of language

The third example of reflexivity occurred during a public-research engagement event which provided the opportunity to share the study and emerging findings with a variety of audiences. I selected and presented findings for a particular purpose: to raise public awareness and to present the study in a way which might engage interest. In doing so I was reflecting decisions made about how to order and present the findings in a way which sensitively reflected the experiences of participants, whilst still capturing the attention of other readers (Holloway, 2005).

Challenging presuppositions about the meaning of language

During the event and later I reflected on aspects of my study. Awareness increased about the presuppositions brought to the early analysis, that these men would have a distinctly different story to tell to their female counterparts. Further, it became evident there were not always shared meanings to be found in the language (Willis, 2007). Figure 6.1 illustrates the public-research engagement and the conversations which prompted reflection on emerging interpretations. There follows a critique of the concept of language as a means of sharing meanings.

The event

Poster presentation in a public forum.

Poster displaying benefits and challenges of being a male carer in employment (Appendix 14).

Used illustrative quotes to support the findings. Aim of the event to engage with public and raise awareness of postgraduate research.

Language

Paid social carers identified with being a carer

Men with babies stopped and said 'that's me, I care for my children and do part-time work'.

Why use the word 'challenges of employment' rather than difficulties?

Gender

Single mothers said 'well that's what I do' Elderly lady said 'that is exactly how it was for me 50 years ago'

Raised the question, is the phenomenon the same for women carers?

What's the purpose?

What are you going to do with findings?

Is this to further the cause of carers?

What do I personally aim to get from it?

Figure 6.1 Illustrating the areas for my reflection following a public-research engagement event

Multiple meanings in language

Language is the way in which people share information and stories. However, language occurs within a social situation, therefore language may be given different meanings by different people, in different social and cultural contexts (Gadamer, 1975/1996; Holstein and Gubrium, 2003). An example of this was found with the word 'carer'. I assumed

115

other people would share my meaning of the word 'carer'. During the public engagement event people used the term 'carer' to name their roles, but in three different contexts: professional paid social care workers, fathers of children and informal unpaid family carers. Through reflecting on how the word 'carer' can be used to refer to both professional and informal carers, I became aware of the need to repeatedly provide working definitions of terms and the importance of selecting words appropriately for their purpose. Language may be adapted to suit a range of purposes and audiences, but each reader will approach written and spoken words from their own individual perspective and this may influence the meaning they find in the text.

A further challenge to my perception of who would consider themselves a carer and what their role would be, arose when fathers, accompanied by young healthy children, stated 'that's what I am, a working carer'. This led to a reflection on the differences and similarities between men who provide childcare for their family and those who undertake the unpaid care of an ill adult. I noted in my research journal I had justified the assertion of differences by pointing out that in childcare there is an expectation children will become more independent, but generally in caregiving the cared-for person's health remains static or deteriorates. Reflecting on this incident I recognised fathers and male carers may have similar experiences; certainly both groups of men undertake practical activities which are traditionally perceived as feminine activities (Grbich, 1997; Thompson, 2002).

During the event three men identified themselves as carers for relatives and they seemed eager to use the term 'carer'. This challenged my belief that the term 'carer' might have stigmatising qualities, such as 'burden' and 'emasculation'. Perhaps this audience were seeing positive attributes in the word 'carer', such as supportive, protective or helpful, rather than seeing the word 'carer' as a label and burdensome role. I acknowledged the need to remain sensitive to people perceiving caregiving as a positive personal attribute, rather than as the negative burdensome role often portrayed in research studies. Since language and words can mean different things to different people, when analysing interviews there was a need to consider the language participants used to name themselves.

Reflecting on the language used on the poster I chose the phrase 'challenges of employment' rather than 'difficulties in employment', perceiving difficulties to be a disempowering word. However, I had not considered how participants talked about going to work. When presenting findings by drawing more directly on the words

actually used by participants themselves, there was less opportunity for ambiguities of language to occur.

By remaining reflexive during analysis I was prompted to acknowledge the contextual nature of language and went on to present findings in ways which offered audiences a degree of clarity in how meanings were developed, thereby adding to the trustworthiness of the study by enhancing the validity of the claims made (Polkinghorne, 2007).

Embedding trustworthiness in the study

The challenge within this hermeneutic phenomenological study was to ensure that knowledge claims made were consistent with its epistemological stance that there may be multiple meanings found in participants' texts. Adopting a hermeneutic approach meant acknowledging texts were open to multiple interpretations, yet there was also a methodological aim to represent the essential features of the lived experience of male carers. Therefore, to enhance the plausibility of the study's conclusions, the trustworthiness of the findings needed to be demonstrated (Koch and Harrington, 1998; Whitehead, 2004). Trustworthiness has been enhanced using a number of recognised strategies, including prolonged engagement, participant validation, and emerging findings being tested against alternative interpretations. Doing this meant that the researcher's interpretations were not automatically privileged over others interpretations (Mason, 2002).

The seminal work of Lincoln and Guba (1985) remains well-cited when exploring frameworks for assessing the quality of qualitative studies may be assessed. They married the terms dependability, credibility, transferability and confimability with the positivist terms of reliability, internal validity and external validity. Credibility rests with the way the researcher describes and interprets the research process and data. Transferability reflects the extent to which others can imagine the findings being transferred to another setting. Dependability of findings rests with the way in which others can follow the decisions made by the researcher. Confirmability rests within the way in which the researcher makes apparent interpretations. These criteria contribute to the trustworthiness of the data (Guba and Lincoln, 1989:77)

However more recent works have argued that the absolute transfer of quality concepts from a positivist paradigm to an interpretivist paradigm is not possible (Guba and

Lincoln, 2004; Polkinghorne, 2007). In this study validity was not sought in the sense that there was a single truth in the findings. Rather, using a variety of strategies it was hoped to make explicit the ways in which multiple interpretations of the data were sought, and how as the author of the work I recognised and addressed subjective beliefs which may have influenced interpretation of the data and presentation of the findings. Both within the research design and at the analysis stage I strived to increase plausibility and credibility to develop trustworthiness within the study that the collected data had captured lived experiences of male carers (Mason, 2002).

Trustworthiness throughout the study design

Sample

To ensure men with experience of the phenomenon were recruited, participants were recruited through purposeful sampling (Patton, 2002). This strategy increased trustworthiness by ensuring that the sources of data were embedded within the phenomenon being studied (Patton, 2002), increasing the likelihood that findings would have resonance with other groups of male carers and practice settings. This increased the likelihood that findings would resemble other male carers' experiences, making them more transferable (Willis, 2007). Whilst no other carer will have exactly the same lived experiences as any of the participants, there will be sufficient resemblances within each caregiving situation to mean that new understanding and knowledge may be applied to different settings.

Engagements with participants

Through reflecting on how data collection events were constructed it became evident that early interviews had been structured as a specific research event with the interview framed by the phrase 'my first question…'. By changing the opening remark to 'please tell me about your day…' I was more likely to encourage participants to talk of those aspects which were important to them, or which they felt safest talking about first.

The research design adopted a prolonged rather than passing engagement with participants, so increasing opportunities to develop rapport and trust, leading to more detailed stories. Rapport and trust developed through consistently fulfilling obligations to participants, whether telephoning at set times or returning narratives. An example of this developed rapport was evidenced when one participant explained he had not liked

to complain about his situation in the first interview, but at the follow-up interview he was able to talk about the negative experiences of being a carer.

Such prolonged engagement was carried through into analysis, to enrich its validity. Prolonged engagement with the data in various formats facilitated a reflexive process of analysis, repeatedly questioning and challenging findings to seek evidence that themes represented the experiences of the participants. Trying to complete the analysis over a shorter time may have resulted in superficial and subjective findings.

Shared interpretation

It was important to recognise and address the co-constituted nature of the knowledge constructed during the first interview in order to reinforce the methodological principle that an understanding of lived experiences may be multi-layered and constructed by the participants within their life worlds (Edwards and Titchen, 2003). Returning the narrative summary was a way to both confirm and increase understanding of participants' experiences and the social context in which meanings were developed. Constructing the narrative summary using the first person voice gave participants the opportunity to re-engage with their stories and consider whether they had told all they wished to in the first interview; also whether the essence of their experience had been captured. This helped ensure more credible data, as illustrated by the example of one participant who could not recognise his experiences within the narrative. In the follow-up interview, he stated that the narrative did not reflect his lived experiences. He requested that his friend, a paid social carer, be present to support him during the follow-up interview, during which he spoke of his sense of experiencing the enormity of responsibility as a carer and how all aspects of his life were affected by his decision to become a carer. The opportunity this offered for additive data enhanced the credibility of findings, enhancing confidence that emerging themes did authentically capture and describe the phenomenon of being a male carer. Trustworthiness was also enhanced using validation procedures.

Trustworthiness in the findings

Validation procedures were embedded within the research design to ensure the findings had resonance with both participants and the wider community, rather than to validate some absolute objective truth. Findings were therefore shared with several distinct

groups of people: participants, other carers, health and social care professionals and academic research colleagues, to provide alternative views. A potential limitation in using validation procedures was that peoples' understandings cannot be separated from the context in which they live and make meanings which support their understandings (Angen, 2000). Therefore practitioners may find meanings in the data which differ from those of participants, and participants' meanings may change over time as new experiences shape their understandings. Nonetheless, validation procedures do enable dialogues and negotiations between the researcher and others about any conflicting interpretations, which could help ensure that findings would have resonance with the wider carer community. This was an opportunity to share interpreted findings rather than check raw data.

Participants

Participant validation was used to further engage these men in sharing meanings, not only from their personal texts, but also in the descriptive categories emerging across the data set of employed carers and the data set of full-time carers. To provide participants with an opportunity to comment on whether they recognised their experiences within the emerging categories, they were sent a summary of emerging descriptive categories. (Appendix 11).

 A strength emerging from this strategy was the opportunity provided for participants to add to their narratives, encouraging me to reflect on interpretations. For example, in the summary, next to the descriptive category 'going to work can offer a break from being a carer: work can be a respite from caregiving', a participant added the comment 'but the cared-for person is never out of your mind'. This statement had not been made during his interviews but mirrored those offered by another participant, prompting me to reflect on my interpretation. I came to understand that whilst work could be a form of respite this did not mean that the carer responsibility had ceased.

A limitation in returning data to participants lay in the temporal nature of understandings; over time participants may have changed the meaning they gave to their lived experiences. Whilst one or two participants may have offered changed interpretations, particularly if they experienced dramatic changes in their caregiving, such experienced changes, this did not arise in this study. If participants could not recognise their lived experiences in data collected four or five months previously this would raise concerns over whether findings could have relevance to practice. However

in the nine returned validation documents all agreed with the statements and some took the opportunity to add additional comments.

It is not known why others chose not to return the document. There may have been a number of reasons: lack of time, change in caregiving circumstances, the participant found they no longer agreed with these types of comments, or perhaps they were feeling disengaged from the study, as four months had elapsed between follow-up interview and the validation document.

Other carers

Findings were also shared with other carers in settings beyond the study interviews through research posters and oral presentations. Considerable resonance was expressed by such carers between their experiences and those of the study participants, suggesting that the findings may be transferable to other settings. At these events I was made aware by female carers that they also recognised within the findings their experiences of combining caregiving with employment. This reinforced the decision that gender was not a theoretical construct of this study.

Health and social care professionals

Findings were shared with a variety of health and social care professionals through an advisory steering group, seminars and conference presentations. Frequently practitioners confirmed that findings had resonance with their experience of working with carers, but occasionally they challenged interpretations, further encouraging me to remain reflexive and open to multiple interpretations. For example, when considering why participants were reluctant to have paid male carers attending to their relative, I thought it might be linked with beliefs about the appropriateness of men providing intimate carer to strangers. However, a colleague suggested that an alternative interpretation may be that participants felt their unique position of expert male carer may be challenged if another man provided care to their relative. This discussion prompted me to re-explore the data and consider whether I was imposing gendered assumptions from earlier reading of the hierarchy of carers suggested by Qureshi and Walker (1989).

Health and social care professionals expressed a high degree of resonance with the findings, suggesting their potential transferability to other settings. Nonetheless, a challenge with seeking validation from multiple sources is that different people may have differing interpretations, and that using strategies for remaining reflexive and open

to hearing others' interpretations intensified the weight of responsibility on me to finally develop the themes (Mason, 2002).

Academic research colleagues

Raw data and emerging descriptive categories and themes were shared with academic colleagues for two reasons. One was to explore whether other people and I found similar meaning units in a short piece of raw data. This instance of sharing data showed that, despite different professional and personal histories, very similar meaning units were highlighted, enhancing confidence that others may make similar interpretations.

A particular strength of this validation was that peers provided intellectual challenges and enhanced researcher reflexivity (Angen, 2000). I was constantly pushed to consider and justify the interpretations I was making and to ensure my interpretations could be seen as coherent and persuasive.

Summary of enhancing trustworthiness in the findings

This chapter has offered arguments that understandings of the essential elements of a lived experience of male caregiving may emerge from a multiplicity of perspectives. A range of specific personal and external factors may influence interpretations. Those factors may be personal presuppositions, or the way in which meanings are developed within a social, cultural context, or agendas held by various audiences. The very existence of the phenomenon of male caregiving may challenge assumptions commonly held within this context or in these agendas, including my own. There was a need to be reflexive and consider factors which shaped the study. This increased sensitivity to the knowledge claims which might or might not be made on the basis of this work.

Recognising the way in which presuppositions were shaping interpretation of meaning, the technique of reflexivity was used to challenge how interpretations were perhaps being influenced by previous personal experiences and the empirical literature. Acknowledging such presuppositions enabled the data to be explored firstly in an inductive, then in a deductive way, so helping realise the aim of remaining open to new insights.

Through reflection prompted by the public-research engagement event, I came to understand that reflexivity is not a solitary soul-searching exercise designed to lay bare preconceptions and bias in order to increase the trustworthiness of the data. Rather, reflexivity is a proactive, interactive process which occurs in all stages of the research.

When being reflexive it was not enough to reflect merely on personal values and beliefs; there was also a need to remain aware of the agendas of others. I was not able to fully understand the motivations of those who volunteered to take part in this study, or those who might choose to read or act on the findings. However, it was important to ensure that through remaining questioning and reflexive whilst undertaking the hermeneutic analysis, the findings might have resonance with others.

Strategies to enhance the trustworthiness of the findings were embedded throughout the research design, enacted in a way that took account of the particular context of this study, through a reflexive approach to data collection and analysis. Recognising the ways in which multiple-layered interpretations can develop when data and experiences are revisited and shared with others situated within differing social and cultural life worlds, validation procedures where used to create a dialogue between differing groups rather than to identify an objective truth. While findings and conclusions continue to be situated within temporal and cultural domains, the shared and similar interpretations which emerged from differing groups provides some confidence that findings and implications for practice may have transferability to other carer communities. By making explicit the knowledge claims which may be made within a hermeneutic phenomenological framework it should help others understand the processes from recruitment to analysis, making apparent the reasoning behind interpretations made here, even if others do not share the conclusions reached.

Having provided an illustrated defence of analytical challenges I now move on to present the findings of this research. Firstly, in order to provide a context for their voices, there are pen portraits of the thirteen participants.

Findings : The participants

Thirteen male carers were recruited to the study, all sole carers for a family member. Participants were aged from 47 to 64 years old and had been caregiving for between four months and thirteen years. At the time they were recruited, six participants were full-time carers for their relative and seven were undertaking some form of employment. By the second interview one man had left employment to become a full-time carer. Another participant had remained in employment but placed his wife in full-time residential care. Table 5.2 in Chapter Five sets out the demographic characteristics of the participants. Most interviews took place in participants' homes, although two

participants were interviewed in their workplace and one interview took place at the university. All participants undertook both interviews and were contacted for data validation.

Participants needed to be seen as individual people with distinctive experiences. Whilst hermeneutic phenomenology aims to discover the essence of the experience, trustworthiness of qualitative data may be found within the rich contextual description of the research setting and relationships (Holloway, 2005). This chapter therefore concludes with the presentation of a short pen portrait of each participant. Understanding the uniqueness of each participant's caregiving situation should help increase the sensitivity of both the reader and myself to the similarities and differences in their experiences. This helps make more apparent occasions where a participant had distinctly different experiences to others, so that non-conforming experiences could also be discussed. Referring to examples were participants differ in their experience from the essential experience of the others adds a further layer of credibility (Patton, 2002). To help ensure the anonymity of participants, their pen portraits where shared with them to see if they wanted any details withheld. Participants were offered the opportunity to remove any specific information which they felt might identify either them or their family, but none required changes to be made.

Participant pen portraits

Philip

Philip, aged forty-seven, has been sole carer for his wife, who has a degenerative disease, for eleven years. He was in full-time employment working as an advisor within a re-employment charity; it was here that his interviews took place. Philip's situation was unusual in that his wife remained in full-time employment. She forwarded the recruitment email to him. Interviews took place in his workplace. Philip told a story of a life which was frequently run separately to his wife's. They did different things at different times. Philip talked extensively of the impact of being a carer on his employment and felt that his career was on hold as his priority is to take care of his wife.

Bill

Bill, aged sixty-four, has been a full-time carer for his son for three years. He gave up working in an agricultural company when his wife died. She had been the carer for their son since his brain injury eighteen years ago. Bill was quite actively involved with a local carers' group and was recruited through information provided by the organisation. Interviews took place in his home. Bill explained that he felt it was expected that he and his wife would look after their son, but that they were willing to do so as their son's disability was not his fault. Whilst experiencing fatigue and feeling governed by his son's needs, Bill also explained how he got pleasure from his son's company and seeing his son's achievements.

Martin

Martin, aged fifty, has been a full-time carer for his elderly mother for four years. Prior to this he was undertaking a degree leading to a professional qualification. Martin was actively involved in a local carers' group and was recruited through information provided by the organisation. The interviews took place in his home and although his mother was in the house she was not involved in the interviews. He stated that leaving his degree programme and caring for his mother was a considered choice and one which suited him at that time. Throughout his interviews Martin referred to how he was too young to retire and how he viewed being a carer as his job.

George

George, aged sixty-three, was self-employed full-time running a post office. He has been sole carer for his wife, who is disabled following a stroke, for twelve years. George was recruited through Crossroads for Carers. The interviews took place in his home which was attached to his workplace. He explained that living and working in the same physical environment helped him balance work and caregiving. George said that he had a number of hobbies outside of work which he was able to undertake in the evenings. George stated that he is the sort of person who faces problems head-on and tries to sort them out.

Andrew

Andrew, aged sixty-four, was a self-employed electronics engineer. Over the last ten years he has altered and reduced his working commitments to care for his wife, who has a degenerative disease, working partime for the past five years. Andrew explained that he only undertakes small projects which can be managed alongside his carer role. He was recruited through Crossroads for Carers. The interviews took place in his home and whilst his wife was at home but she was not present during the interviews. Andrew explained how he is renovating their home, but the demands of his caregiving role frequently hinder the progress of this work. He discussed the strain of now being the person in the marriage who has to make all the plans and decisions.

Bert

Bert, aged sixty-four, has been a full-time carer for his wife for ten years. Bert gave up working in a shipyard when his wife's degenerative illness led him to become worried for her safety. Bert was recruited through Crossroads for Carers. The interviews took place in his home. His wife was present, but because of her disability she was unable to contribute. He explained that his wife has been his life since they were youngsters and that he missed the communication he used to have with her. Bert explained that his wife has always been a good wife and now he is taking his turn to look after her and the home.

Percy

Percy, aged sixty-one, was self-employed and had reduced his business hours to part-time work. He has cared for his wife, who has early onset dementia, for over twelve years. Percy was recruited through Crossroads for Carers. The interviews took place in his home. His wife was present, but because of her disability she was unable to contribute. Percy asked one of the care assistants he employed to be present during the second interview. Percy explained how his wife had previously been in residential care but he felt the quality of care was so poor he chose to care for her at home. He stated that work is respite from caregiving.

Peter

Peter, aged fifty-two, has been a full-time carer for his wife for eight years. A year after marrying, his wife underwent an amputation of a leg. Following her amputation Peter gave up work as a shop manager to become her carer. Peter was recruited through a carer support group. The interviews took place in his home and his wife was present during the second interview. Peter explained that he offered both physical and emotional support to his wife, but that it was sometimes difficult to balance his wish to care for his wife with her wish to maintain her independence.

Jack

Jack, aged forty-seven, has been a full-time carer for his daughter for thirteen years. His daughter was born with profound disabilities. During her early life Jack had periods in and out of paid employment within a shipyard. After the breakdown of his marriage he became the sole carer for his daughter. Jack was recruited through Crossroads for Carers. The interviews took place in his home. Jack stated that caregiving was hard work and that he was constantly alert to the needs of his daughter, whether she is at home or in day care. He explained that sometimes he felt that people thought he was lazy because he does not have paid employment.

Daniel

Daniel, aged fifty-one, was employed as an engineer. For the past two years he has been a carer for his wife, who has Alzheimer's disease. Daniel was recruited through Crossroads for Carers. The interviews took place in his home. His wife was present during the first interview. At the second interview Daniel explained how he had become so concerned for his wife's safety whilst he was at work that he had made the decision to place her in a residential home. He talked of feeling bereaved. Daniel visits his wife daily after work.

Charles

Charles, aged sixty-three, was employed within a large insurance company. He had lived with his mother for several years and became her carer two years ago when she started to become confused. By the second interview she had experienced a serious fall and Charles had left work to become her full-time carer. Charles was recruited through Crossroads for Carers. The first interview took place in the university, the second at his

home. Charles explained how flexibility of employment hours had helped him when he was working.

Samuel

Samuel, aged fifty-four, was a full-time carer for his wife. She had a form of degenerative dementia. Samuel had run his own building business; this gave him some flexibility to reduce his working hours prior to giving up paid work. When recruited through Crossroads for Carers he had been a full-time carer for only four months. The interviews took place in his home. Although his wife was at home she had a social care worker with her and did not contribute to the interview. Samuel stated that since leaving work he had more freedom in how he used his time. He explained that it is important that both he and his wife keep active and occupied.

John

John, aged fifty-six, was employed in an accountancy office. He was recruited via a carer support group. John's wife experienced periods of severe depression. Both interviews took place in his office. During the first interview John explained how all aspects of his life were affected by his wife's illness. He stated that his wife might occasionally hit him, or stop him from leaving the house. At the second interview John explained how his wife's illness was now improving. He now felt that their marriage was more of a partnership. He said that he felt more of a carer because he was able to implement strategies to help his wife manage her condition.

These men's experiences are now presented through three findings chapters which address: Being a male carer (Chapter Seven), Obligated time (Chapter Eight), and Self as carer-reworking identities (Chapter Nine). Illustrative quotes link findings with participants' specific personal experiences.

Chapter 7 Being a male carer

Introduction

In exploring the meaning male carers gave to the phenomenon of caregiving it emerged that in becoming and being the primary carer for their relative, participants talked about how their life changed as they moved from being employed men supported by wives and mothers, to having sole responsibility for the care of another person. They faced new responsibilities and competing obligations, having to make complex decisions about whether they could undertake the care of their relative and subsequently whether they could undertake this care alongside employment. Caregiving was a new occupation for them and skills such as managing the home and undertaking personal care had to be learned. Some participants sought specific types of support as they found themselves losing communication with their relative. Although frequently they expected support from other family members, this was not always forthcoming and they described the factors which mitigated support from other family members, including conflicting obligations and conflicting expectations. All the men discussed their view of how life might be in the future.

Through exploring the findings under four emergent categories it became possible to see the sequential journey participants made through first deciding to become a carer. Then findings are presented about the participants' lived experiences of being a carer, including how the work of being a carer was structured and undertaken alongside the competing demands of employment. There is an exploration of the ways in which participants drew on both formal and informal support structures. The final emergent category presents findings about how these participants viewed their future.

The meaning of becoming a carer: When participants realised their relative would require care, they reported having to engage in complex decision-making processes about whether to take on the caregiving and what this might mean for them. Part of reaching these decisions was about considering how their relationships and responsibilities led to obligated commitments to provide care to their relative. They also considered other features of their relationships, such as previous reciprocity and their perception of whether the care-receiver was deserving care. Consideration went wider than simply their relationship with their relative, participants also considered the suitability of alternative care and whether becoming a carer might provide them with a route out of employment. As they took on the role of carer they searched for

information from a variety of places enabling them to learn new skills. Some participants strove to learn new skills prior to commencing their carer role, but for all, new skills were refined as they become immersed in the reality of being a carer.

The meaning of being a carer: These participants described the experience of being a carer not only as providing care directly to their relative, but also they reconstituted the activity as a means to engage in a purposeful activity. Several explained that their responsibilities went beyond simply providing care to their relative, to also acting as their advocate and managing the household tasks, an activity which frequently had previously been undertaken by the care-receiver. They described these various activities as a form of work, experiencing them as demanding obligations which led to discord between their responsibilities as a carer and as an employee. Several of the participants spoke of the difficulty of combining caregiving and paid employment and how their concerns for the welfare of their relative led them to reconsider the care they were able to provide. Participants found that when concerns for the safety of the care-receiver mounted they were faced with further decisions about whether to stay in employment, or leave and become a full-time carer.

Using support networks: Although participants frequently said they were alone as a carer they also reported instances where they tried to draw on networks of support, with differing levels of success. Formal and informal support networks did not always meet their needs and they then went on to seek and identify alternative support networks.

Facing the future as a carer: Although the study was designed to capture the lived experiences of male carers, phenomenological theory proposes that people live with a sense of temporality and several participants raised issues about looking towards the future. They expressed specific concerns about what would happen when they could no longer care, however there was a sense that they avoided contemplating the future.

The final part of this chapter raises a number of discussion points about the meaning of caregiving, reflecting that the obligated commitment to care may not be absolute and that there may be competing obligations embedded within paid employment. The ways in which participants may for the first time be experiencing the negotiated nature of familial support systems are summarised, together with an exploration of how they appear to have constructed new support systems through their carer role.

The meaning of becoming a carer

All participants talked about the time when they moved into becoming carers, although the circumstances prompting this differed in each case. For some it was caused by a sudden trauma and resulting disability to their relative; for others their relative had a degenerative disease leading to a gradual increase in the level of care participants were called on to provide. Two men became carers when their wife stopped being the primary carer, due to divorce and bereavement. Regardless of the different ways they became carers, all made a decision to stay and provide care to their relative. They justified this decision in different ways:

⇒ Caregiving as an obligated commitment

⇒ Care-receiver deserving of care

⇒ Lack of acceptable alternative care

⇒ Caregiving as a substitute to employment

However participants frequently did not provide a single reason for becoming a carer. Rather there were a range of obligations, beliefs and personal consequences which influenced the decision. The complexity of the decision is explored specifically through looking at Bill's narrative:

⇒ Complex decisions

Caregiving as an obligated commitment

Participants framed their reasons to provide care within the concept of an obligated commitment. However only one participant used the word obligation, others spoke of 'duty', 'love' and 'reciprocity', suggesting that whilst there were obligated responsibilities influencing the choices they made in relation to care of a relative, their decision was made without an expectation of inherent burden. Rather, this was an obligated decision purposefully made by these men within their roles and responsibilities as spouse, sons and fathers.

All participants within a spousal care relationship talked about how providing care was 'just part of being husband and wife', explaining, 'you look after your other half' (John).

Only George referred to obligation using that term, in this case describing obligation as arising from his marriage vows:

> *You are actually obliged to…you get married and it's for better or for worse, you either stand by that or you don't*

Philip and Peter explained that as they had known about their wives' health problems before the marriage, they felt a duty to provide care when their wives' conditions deteriorated. For all participants who were spousal carers the obligation was experienced as an internal sense of duty and linked with the concept of being married 'for better and for worse'.

Only Bill presented other people's expectations of him to be a carer as a reason for feeling obligated to do so. He said health professionals expected he and his wife to become carers for their son following his accident, explaining he felt 'pressurised into it' and that it was 'expected of the family'. This suggested that health professionals considered it normative behaviour for parents to provide care to adult children.

Several participants talked about the qualities of their relationship with the care-receiver when justifying their decision to provide care, suggesting reciprocity rather than duty framed their sense of obligated commitment. Bert explained he cared for his wife because she had always been a 'good' wife. He talked about having a choice about whether to become her carer, 'I could have walked away from the situation and said "I don't want to know", but he stayed and provided the care 'just for the love of my wife'. Nonetheless there was a sense of obligation inherent in his story captured when he said it was 'inevitable that I was going to devote the rest of my time to looking after her'. Reciprocity occurred not only in spousal relationships but also in son-mother dyads.

The two participants caring for their mother also talked of caregiving because of previous support they had received from her. Martin discussed a complex range of reasons for deciding to provide care to his mother, suggesting a need to move beyond seeing caregiving as simply a duty. Firstly, he referred to loving his mother and dismissed the idea of it being a sacrifice, 'I'm not saying it's a sacrifice because I love it to bits and I do it because I love her'. Then he appeared to contradict himself over whether he felt an obligation to undertake the role 'well, it is a sense of duty'. However, his sense of duty was tempered by the justification that she had been a good mother, 'I feel as though she made a really good job of bringing me up and all I'm doing now is repaying her'. These few lines displayed a range of justifications; several other participants also gave a variety of reasons why they provided care. Participants

who were caring for a mother or adult child, justified their decision to become a carer in more diverse ways than the participants who were spousal carers.

A sense of obligation and reciprocity were not the only factors influencing the participants' decision to undertake the role of carer. Often decisions were tempered by a belief that the care-receiver deserved their care.

Care-receiver deserving of care

When justifying their decision to care for their relative, two participants indicated they considered the character of their relative, making judgments on whether they were deserving of care. Bert said:

> *If my wife had of been a prostitute, alcoholic, a drug addict, I wouldn't be looking after her, but she didn't ask for that illness and I mean she's always been a one, like a one man woman*

Bill decided to care for his adult son following a car accident, when it became evident that his injuries were not self-inflicted. He explained 'if he'd been drunk or on drugs…I don't think we'd have done what we'd done', suggesting that he may have been able to negate his obligation to care if his son had been 'to blame'.

The belief that their relatives were deserving of care appeared subtly in other narratives. For example, Martin's mother had done a 'good job', Peter's wife had 'been honest about her condition' and Percy's wife had been a 'good wife', suggesting that an obligation to care was linked with the person being a suitable recipient of such care. As well as the decision to care being influenced by obligation and the deserving nature of the care-receiver, the decision also seemed to be influenced by participants seeing no other acceptable alternative.

Lack of acceptable alternative care

Most participants did not see other providers of long-term care as offering anything they would find acceptable. They all spoke of alternative forms of care solely in terms of a residential home. Their discussion of any alternatives explicitly did not refer to whether they had considered the wishes of the care-receiver. This may indicate how these men had taken on a manager role, deciding which forms of care would suit them and their relative, minimising the involvement of their relative in making such decisions.

Poor previous experience of residential care led two participants to discounting this form of alternative care. Martin explained whilst his mother was receiving respite care

in a residential home she became ill and he perceived her condition was 'worse when she came out'. This led to an increase in the amount of care he was now called upon to provide, so he had not used this form of respite care again. He used these negative experiences to justify why he had become her carer.

Martin explained:

> *I know that I can do it better than anyone else, I don't mean that in a sort of supercilious sense, but I mean in the sense that I feel if she was in a nursing home she'd just be one of a number and her needs would not be met*

Percy viewed the care his wife received whilst in residential care as unsatisfactory and this caused him distress:

> *…and then times I went down there and she'd be in tears sitting at the dinner table and everybody else has ate theirs and gone, the carers didn't have time to feed her so she went down to five and a half stone; she was sat in the dining room on her own again crying and she said "help me, help me" that was it, that done it, that finished it, I said I'll take her home and I'll make arrangements*

Seeing his wife upset in residential care had increased the emotional distress he was experiencing and as a direct consequence he took steps to move her out of care and to care for her at home. He explained that although his financial circumstances meant he now had to pay for all her care, he intended to continue to pay for private nursing to enable her to remain at home.

Even when residential care had not been used there was a perception that this type of care would not be of good quality and could even be detrimental to the care-receiver's health. George said 'if she'd gone into residential care she'd be dead by now'. George's beliefs about residential care led to a justification of why he cared for his wife, 'that's why I try and look after her at home'.

Most participants talked about wanting and working towards keeping their relative out of residential care. However, Charles explained that his mother might need residential care in the future if he became unable to fulfil the role of carer. Here he presented residential care as a last resort, but also as a safety net if caregiving became too onerous for him.

As with residential care, participants tended not to use longer periods of respite care. Only Jack regularly used this service. Any alternative care was usually provided on

daily or hourly sessions through day centres or Crossroads for Carers. There was general satisfaction with this form of short, specifically timed, community-based care.

Bill and Jack's wives had originally been the primary carer for their children. They became sole carers in the absence of their wife, suggesting that where there was a suitable alternative they were able to step away from the carer role. Jack described how when his wife left the marriage 'it was just put on me and I've got on with it'; not so much an obligated commitment as a string of events which left him making the decision to become a carer. Whilst Jack said he could perhaps have chosen to leave he did not see it as a realistic option, because his daughter was a young child at that time and a package of educational care was in place. Bill's wife died after being the primary carer for their son for thirteen years. He described how at the time of his bereavement he felt he could do 'nothing else' but continue the work of his wife, explaining he owed it to her to continue to support their son at home.

Caregiving as a substitute to employment

Since becoming carers seven of the thirteen participants had decided to leave paid employment and become full-time carers. Whilst all described aspects of being employed they missed, for Bill and Martin becoming a full-time carer provided a route out of an employment situation, which they were experiencing as increasingly challenging. Martin explained he experienced depression and the training course he was doing did not meet his expectations. He describing missing the comradeship of previous colleagues and feeling unsupported on his training programme. Bill also experienced difficulties in the workplace where his boss was accusing him of 'gross misconduct'. Becoming a carer provided a way out of demanding employment situations.

Complex decisions

Participants provided complex interwoven stories of how they became a carer, but all of them appeared to have considered several factors when making a decision. They considered their obligation, whether the care–receiver was without blame, whether they perceived alternative care arrangements as suitable for them and whether being a carer might be a benefit to them. Bill talked at length in both interviews about the reasons why he had become a carer, capturing the complexity of reasons and particularly highlighting contradictions, which suggested becoming a carer was not simply an

obligated commitment but rather a complex decision which participants considered and justified in terms of their obligation to their family and their sense of natural justice.

Bill talked about his internal obligation inherent within his role as a father and his sense of duty towards his deceased wife. He presented other explanations which bolstered relationship obligations. He explained he chose to provide care as the accident was not his son's fault, and had it been he said he would have left him in a residential home. When questioned further about whether he could have chosen not to provide care for his son Bill reasserted that has his son been at fault and caused the accident he would have left him in a home. This explanation appeared to be in conflict with his perception of alternative care. He had experienced the quality of care his son received from statutory services as very poor, explaining that by being cared for at home his son was reaching his full potential. As well as obligations which might or might not be implicit within being a father, he also explained that health professionals expected he and his wife as parents to take their adult child home. However, becoming a carer was not entirely altruistic, as it provided a route out of an increasing difficulty employment situation. Yet he expressed concern that he was not really old enough to retire. Nonetheless, he talked about how it was better that he had left employment as he did not feel he could 'juggle' the two in case his son was unwell and needed him.

Exploring the complexities of Bill's decisions it became evident that participants gave meaning to their decision to become a carer in many different ways. Once the decision to take on the role of carer had been made there was an active process of learning how to do the job.

Learning to be a carer

Being a carer was a new and unfamiliar role and participants found they needed information and new skills to fulfil their responsibilities. They wanted to learn about the illness and also about the financial consequences of being a carer. They talked about having to learn new skills, such as how to provide personal care and how to manage the household. They learned these things in a variety of ways. Some learned through observing social care workers to find out how experienced professionals provided personal care and managed challenging behaviours. Some talked to other carers, finding them a particularly helpful source of information as they could draw on similar experiences. Others found it easier to source written information, particularly if time constraints and employment commitments made it difficult to access information in

person. Participants talked about where and how they found the information and the difficulties they had in accessing information.

Finding information about caregiving

Most said they had actively looked for information to help them in their carer role from a variety of sources, such as learning from other people's practice and using written information. Percy prepared to take his wife home from residential care by observing, recording and reflecting the actions of paid social care workers. He described a very structured learning activity. Firstly using observation:

> *I watched what the workers were doing and how they done various jobs and how they cajoled them into doing something that they perhaps didn't want to do; ...made a mental note,*

Then he kept written information, 'and then when I got out into the car-park in the car I used to write bits down'. He expressed concerns not only with the achievement of practical care tasks but also with how to preserve his wife's dignity:

> *The easiest way to change a pair of slippers or, keep them with a bit of dignity when you're changing them and explain what you're going to do before you actually do it so they're not surprised*

Percy was unusual in that his wife was in residential care for a period of several months before he took her home. Those with more limited time and lack of access to professional social care workers tried to prepare for their role by seeking information on the Internet, as this was a source they could easily access in the limited time they had.

Most of the participants had visited carer support groups at some stage, but with varying levels of satisfaction. Some found that support groups did not meet their needs. A few participants explained the groups had not made their relative welcome and others explained that the times the groups were run were not compatible with their employment and carer responsibilities. However, those who did access the groups found other carers were the most appropriate to pass on practical tips as they had direct experience of being a carer. Samuel referred to this when he explained that a carer information day, run by professional staff, had not met his expectations:

> *I was expecting more sort of advice on how to care and what to do and that sort of thing and, and that really wasn't available*

He found the information he wanted came directly from other carers attending the event, 'you've probably got as much from the other carers that were there and their

experiences', suggesting that professionally delivered information may not be targeted at the things carers are eager to learn about.

Learning new skills on the job was a common experience. Participants explained they had to learn not only how to provide physical care such as personal hygiene and feeding relatives, but also how to manage the home.

A few participants talked of having difficulty finding any information which could either help them understand their relative's disease or enable them to manage the care that their relative required.

Difficulty in finding information about caregiving

Both Daniel and Andrew found it very difficult to access the relevant information when they needed it. Particularly financial information about benefits they might be entitled to. Andrew described it as an 'an absolute nightmare' and explained he believed that he had not accessed all the social security benefits he was entitled to and therefore had had to draw more extensively on his savings than he had wished to.

When they started their carer role, all participants were in paid employment and had little time to search for the information they needed to make an informed decision about how being a carer may impact on their lives. Then, having made the decision to undertake the carer role, they were faced with the reality of being a carer. If they left or reduced their employment they experienced reduced financial income and a few had to draw on savings, as they were not aware of social security benefits they were entitled to. Others found the reality of being at home all the time very challenging. Martin described feeling frustrated and that 'it took a long while to get into a bit of a routine and for my stress levels to come down'. This was a role and responsibility for which they had received little preparation and the reality of being responsible for the care of another was challenging and at times overwhelming.

The meaning of being a carer – 'Doing it all'

All participants spoke in detail of the daily activities that shaped their experience of being a carer. They talked about particular ways in which they provided care to their relative. They also spoke about the ways in which they now managed the household. Managing the household appeared to develop alongside their carer role and 'doing the housework' was an important part of their experience. Despite having gained some information about the practicalities of being a carer and having made a considered

decision to take on the role, most participants found doing the work more challenging than they had anticipated, partly because everything was their responsibility. They were not only responsible for providing care but also for running the house.

George explained:

> *Nothing I've come across describes the role, there is no job description, but you are responsible for everything, from washing the clothes to the financial arrangements*

All participants talked about 'doing-it-all' with most listing the variety of tasks they now had sole responsibility for both doing and organising. Andrew said, 'I'm a cook and hairdresser and nurse, you name it, you do it all'.

Participants gave different reasons for carrying out the range of caregiving tasks that they did. Some activities, such as providing personal hygiene and managing medication, were care activities directly supporting the care-receiver. Other activities, such as cleaning and shopping, were about running their home. The examples they provided presented these men as managers both of care and of the household. The concept of participants being the manager, rather than merely a provider, emerged through the way in which they spoke about undertaking and organising the various tasks.

Manager of care

Participants described the activities they undertook as a carer, frequently explaining why they did a particular task or conversely justifying why they did not do a particular task in the wider context of managing their role. The four main aspects of care they provided were:

⇒ Proving purposeful activity

⇒ Promoting physical movement

⇒ Delivering health care

⇒ Advocating for care packages

Providing purposeful activity

Several participants wanted to ensure their relative was occupied, particularly if they lacked the cognitive or physical ability to do activities for themselves. They held the belief that being occupied and undertaking activities benefited the care-receiver.

Samuel captured this when he first explained he needed to 'sort of occupying her during the day'. He had the responsibility for doing this because 'she's not able to think "we'll go for a walk"' therefore he needed to provide alternatives which would 'stimulate her'. A consequence of not providing activity was that she 'just wanders around the house'. This made him feel that he 'should be occupying her in some way or giving her something to do'. He went on to explain how he organised activities to share with her, such as cooking, watching DVDs and going to the gym together.

A range of activities were instigated and managed by participants, with many involving both the carer and the care-receiver. George explained that he took his wife for a drive 'to change the scenery, I just don't want her sat in one place'. Most participants talked of the benefit of doing some activity, for example, Andrew described why he encouraged his wife to get out of bed:

> *Sometimes she wants to stay in bed and I'll say to her no, no you've got to get up, you've got to sit up, because you know that gives you strength, she's better if we go out and I take her up the town, she'll be tired in the evening, but the next day she'll be better for it*

Bill was unique among the participants because his son experienced a brain injury and instead of his condition declining he made steady improvements in his abilities. Bill was eager to ensure his son became engaged in activities which increased his mental and physical skills. He looked for and found confirmation from professionals that keeping his son active was the right thing to do, 'I've looked for professional help with a clinical psychologist and he said you can't do any more than what you're doing'. Bill suggested inactivity was a negative state, explaining that being involved in activities stopped his son 'skiving'. Not only did Bill provide activities but he also recognised the ways in which his son's day care services stimulated him:

> *He will spend quite a lot of effort skiving if you will let him, he will work harder at skiving then he will at doing anything, but now we've got this one-to-one he's encouraged to work and do something, be constructive*

Bill took pride in the achievements of his son, describing how friends who had known his son before his accident could see an improvement in his abilities.

Jack had a different experience to other participants. He explained he got very little response from his daughter, who experienced profound brain damage at birth. Jack tried to engage her in activities but he 'didn't get responses and didn't see things doing any good'. As a result he explained 'you just go into a lull and I wouldn't say sit her in front of the telly and that's it … but you do very little because of the response, in the

situation you feel that you couldn't doing anything'.

Jack then justified his actions saying:

> *I know it sounds blunt and callous, but for your own sanity you do have to do that a lot of the time…because if you keep i.e. painting or talking and getting her to touch things try to get her to pick things up day after day after day and you don't get anything back it cracks you up, that's what I mean by sanity*

This extract captured the essence of Jack's experience, revealing that as a carer he provided the physical care 'the feeding, the drinks, cleaning, washing, dressing, making sure she's in bed on time' whilst not purposefully engaging her in other activities, suggesting that positive outcomes needed to be linked with an activity in order for him to be able to continue.

Philip did not instigate activity for his wife who was in full-time employment and active at home, managing the online banking and purchases. However, he still appeared to experience increased demands on his time. It was difficult to discern whether this was due to meeting the needs of his wife because of her disability or because of her employment. He explained he thought the caregiving situation was more difficult for him than other carers as she was in employment. He explained 'she's been at work for the day, she comes back, chances are she's still working, and obviously then that has a bearing on me because whilst she's doing one thing I do the cooking and stuff'. He then explained the consequences of her being in employment on their relationship, 'she does tire out quicker so because of that I tend to get the fall out'. Further on in his narrative he again linked her condition with her employment, explaining he did the shopping because 'she can't do it with her condition and with the job she does'. Philip was the only participant whose relative was in employment; his narrative captured the difficulty of separating caregiving activities from the activities of supporting an employed spouse and running a home.

Promoting care-receiver's physical health

Just as participants actively engaged their relatives in activities to keep them stimulated, so they managed aspects of their physical movement both to ensure their safety and to limit further deterioration of their condition. All participants whose relatives had a degenerative illness undertook physical handling and transfer of their relative, with some also providing passive exercises and applying splints. They appeared to be experts on such procedures, occasionally explaining that they had found more appropriate methods than the professional health care workers. Andrew, referring to health care

workers, said 'they have their techniques and I started their ways and I thought no, no some of these are not as good as we could get so we have our own techniques'. Some participants offered to show me the range of equipment they used and I observed several occasions where the participant competently re-positioned their relative. However, their management of the physical movement of their relative went further than just using the equipment provided; there was also a desire to ensure the best care was provided. Every day Jack put on his daughter's spinal brace as he did not trust social care workers to do it. Andrew used his skills from previous employment to adapt equipment in an attempt to increase his wife's mobility:

> *I just make sort of bits for it (the exercise bike) and we're going to try and use it again and see if we can get some strength back in her legs.*

Andrew drew on his professional occupation as an engineer to enhance his caregiving role, illustrating a transfer of employment skills to the carer role. As the health of the care-receiver declined so the extent of care that participants were required to provide increased, with several of the participants providing complex medical care.

Delivering health care

Participants were responsible not only for their relative's medication but also for more complex health care tasks which required more comprehensive medical knowledge. For instance, Bert understood the need to increase his wife's fluids in order to stop her supra-pubic catheter from blocking. Most participants helped their relative with aspects of their intimate personal care and they talked of this experience being 'alien' to them; it was undertaken as part of their role as a carer rather than husband or son. However, participants who were spousal carers explained they would rather undertake intimate care for their wife than have others coming in to do it. Martin and Charles, both son carers, experienced delivering intimate care in differing ways. Martin explained that he was happy to bathe and toilet his mother but he expressed the opinion:

> *You've got to be a certain sort of person ... I've always been sort of in the caring professions. I'm not at all squeamish about bodily functions or all the rest of it so that's not a problem at all.*

He explained because it was his mother, providing intimate care was perhaps easier than if it had been someone else, 'also it's my mum, you know, it's not sort of somebody that's not family'. However, Charles employed a social care worker to support his mother with bathing, although he did help her access the toilet. These contradictory responses illuminate the tentativeness of interpretations drawn from a small sample.

Advocating for care packages

Participants not only provided stimulating activities and direct personal care, they also acted as advocates for their relatives by liaising with statutory agencies. They had defined ideas about the type of care and support their relative should be receiving and several told of how they had to be persistent with support services to get the care package they felt that they and their relative needed. Peter talked about having to 'push for more than they [social services] are prepared to offer'. Unlike when they were providing direct care, now participants frequently had to wait for others to take action and they expressed frustration both with difficulty accessing support service providers and having to wait for action to be taken.

Peter explained 'you're in a situation where you need help and support and you need it now, not four five months down the line'. Andrew also experienced anger about the inflexibility of services; when trying to access the citizen's advice bureau to find out about benefits, he said, 'you couldn't make an appointment, and that really angered me… you're going in and out of these places all day long'. Uncommitted time was limited for both full-time carers and those in employment, meaning that not having preset appointment times made it difficult for them to plan their routines.

As well as organising services to support them in their carer role, participants also undertook the day-to-day care of their relative including nursing care, feeding, personal hygiene and providing medications. They had a responsibility to ensure the health and well-being of their relative. Andrew, explaining how he felt when his wife's condition deteriorated, captured the sense of responsibility all participants experienced: 'it's my fault I didn't notice what was going on and she wasn't complaining, but then when we looked one day and I'm thinking she's taken off a lot of weight'. He continued to talk about how this episode resulted in her being hospitalised, making a direct link between her being in hospital and the subsequent decline in her mobility, thereby reinforcing the sense of responsibility he experienced for her well-being.

Alongside the management of care all men had to manage the running of the home and for most this was a new role.

Manager of the home

All of the participants talked at length about the domestic tasks they undertook in the home and it was a subject which several spoke of in a self-deprecating way as novices in this arena.

Prior to starting the role of carer the bulk of the domestic cleaning, shopping and washing had been undertaken by their wife or mother. Only Martin lived alone before taking his mother into his home, however during this time he was in full-time employment and had a cleaner and gardener. Participants were often self-effacing about their abilities. Jack explained:

> *Well, you have to dust now and again. When you have to start stepping over the dust you have to clear it up a bit*

Philip went further, explaining that he does not see when cleaning needs to be done:

> *I'm not big on household chores, I will do the ironing and hoovering, but the rest of it, to be fair I don't see it, I'm not just using that as an excuse, I really don't*

However, a few took pride in their new skills with some assimilating the role into their sense of self. Bert called himself 'a domesticated man', suggesting that domestic tasks had such significance and meaning to him that they had become part of how he defined himself. Housework was another skill to learn and another activity to be fitted into the day. Frequently, participants talked about managing the home as a form of work. They talked of their working day and having time away from the home and their workplace, this concept is explored further in chapter eight.

Being carers all participants undertook a variety of roles and tasks from being the manager of care, providing activity, physical care and managing care delivery through to maintaining the home. All participants appeared to have adapted to their new roles and most took pride in their achievements, but there were still sources of frustration including relying on service providers. Six participants had left paid employment in order to focus fully on being a carer; the seven who remained in employment frequently experienced conflicting responsibilities.

Managing caregiving and employment

All participants were sole carers for their relative. Four combined this role with full-time employment, three reduced to part-time employment and the remainder left

employment. In the same way that participants made considered decisions when they moved into the carer role so there appeared to be considered decisions about whether or not they should, or could, leave employment. Several expressed concern for the care-receiver's well-being, but there was also evidence of more pragmatic concerns influencing their decisions, such as whether they could afford to leave work, and where their obligations lay.

Leaving employment

Most participants made a considered decision to leave employment based on:

$\Rightarrow$ Being financially able to leave employment

$\Rightarrow$ Concerns for the safety of the care-receiver

$\Rightarrow$ Facing competing obligations to relative and employer

Financially able to leave employment

Leaving employment led to reduced financial income. For most participants concern for their relative's safety overrode concerns about reduced income, but some planned how they would manage financially as full-time carers. Martin explained, 'I literally got a bit of paper out and looked at the finances'. Samuel described how receiving a social security benefit gave him the financial freedom to leave work. These comments suggested that financial security may be a factor influencing participants' decisions to leave paid employment.

Safety of care-receiver

Whilst several participants discussed financial concerns, ensuring the safety and well-being of their relative was given as the main factor influencing their decision about whether to leave or reduce employment. Andrew, who had reduced employment from fulltime to part time explained:

> *I had to do it, she couldn't stay on her own, as simple as that. Would I like to carry on working, yes, I quite enjoyed my work*

Andrew also spoke about the financial consequences of his decision, 'it cut the income down considerably'. However, he accepted this, 'that's the situation you're in, there's not a lot you can do about it'. This suggested that although participants appeared to make considered decisions, they could not always control for the consequences of such decisions.

145

Competing obligations

Concerns over the appropriateness of alternative care, and the desire to ensure relatives received what participants perceived to be the best possible care, influenced participants' decisions around whether to remain in employment. Those who made the decision to leave employment to become full-time carers explained they believed they could not do the best for their relative if they remained in employment. Peter captured this feeling when he said 'I couldn't give my wife a hundred percent if I stayed in the job'. Samuel reiterated the potential conflict between unpaid care work and paid employment describing a 'confrontation between your carer responsibilities and your work responsibilities'. Sometimes this confrontation arose around concerns for the care-receiver's safety and how these concerns impacted on the participants' ability to undertake paid work:

> *I can't do my work and look after and worry about my wife at the same time, because when you're working up high, one move and you're dead (Bert)*

Other times the confrontation was grounded in a sense of responsibility to the employer:

> *Going to work you've got to put a hundred percent into your work and have your mind on the work (Jack)*

Responsibilities to the employer were coupled with the responsibilities to the care-receiver, leading to a belief that being in employment would conflict with the carer role:

> *I would be concerned and worried about how she is all day and I wouldn't have thought you could work and get home by three 'o clock (Jack)*

The decision to leave employment was often triggered by a specific event. During the first interview Charles was in full-time employment. He explained he did not need to worry about his mother's welfare during the day because she had social care workers coming in 'well somebody's there twice a day, if there's any problems you're going to get to hear about it'. However, between interviews his mother fell and he left work to become her full-time carer. At the second interview, he made several references to how his mother needed twenty-four hour care and a change in his perception of risk was evident when he explained that he wanted to warn his friend who was also a carer 'don't leave her on her own, but I know he does; it's like I really need to warn him about that'. This illustrated how participants' attitudes to caring responsibilities and roles may be influenced by the health status of their relative.

Although not all participants left employment, all experienced some change in the nature of their employment on becoming carers, either reducing hours of work, adopting

flexitime, refusing overtime or changing jobs. John was the exception in that he did not reduce his employment responsibilities, instead he took on more paid employment during his wife's illness. He did his wife's cleaning jobs to ensure she could return to them when her mental health problems receded. When combining employment with caregiving, participants had diverse experiences, with some drawing distinctive benefits such as using employment as a form of respite, but others found work a further burden, or a cause of distress. These experiences are explored further in the next two chapters under the themes of obligated time and shifting identities. When participants decided that they could not leave employment they took other steps to ensure the welfare of their relative.

Changing the delivery of care

A few participants explained that they could not leave paid employment, usually because of financial concerns, but they still took action to reconcile their concerns about their relative's safety with their need to remain in employment. Daniel did not see leaving employment as an option as he had a mortgage to pay, so when his concerns for his wife's safety increased, he decided to place her in a residential home. He explained this had not changed his role as a carer for his wife, 'I feel I do more caring now than I did when I was here, because my wife's worse, needs more caring now than she did here'. Nonetheless not having his wife at home had an impact on his well-being, 'I didn't want her to leave me, it feels like we've split up'. He spoke of this time as a period of bereavement:

> I was quite upset and emotionally that was horrendous, you know, I was just coming home here and I just wasn't interested in going to work and when I was at work, yeah, that's just like, it's a bit like bereavement really and you've got to try and get used to it

The sense of loss if a relative moves to residential care may be a less discussed reason why carers find residential care an unacceptable alternative. Moving a relative into residential care may also cause uneasiness within families.

Daniel talked about how moving his wife into a residential setting changed the type of support he received from his family. He explained support had previously consisted of phone calls, visits and general queries about his welfare, but since his wife entered residential care these occasional contacts had stopped. Not only was there a lack of support, he also experienced direct criticism from his wife's family about his decision.

Daniel experienced not only the loss of his wife as she moved out of the family home, but also loss of relationships with his wider family.

Support from family friends and health and social care professionals was a feature in all participants' experience of being a carer, but support was not always unconditional and frequently did not come from the traditional routes of family and friends.

Using support networks

All participants drew on a variety of support systems including family and friends, statutory organisations, care support groups and social care workers. However they found differing types and degrees of support within each. Participants had differing expectations around how much support they could expect from family and friends, with some explaining that family should provide more help and others feeling that family were not obligated to help. Occasionally families disagreed with the carer's decisions and actions and this led to uneasiness in relationships and reduced support. Participants drew on alternative forms of support. Those participants who accessed carer support groups found them helpful, but others found barriers in accessing and using this type of support. Statutory and voluntary organisations provided day care facilities for the care-receiver which released participants from their unremitting responsibilities to always ensure the well-being and safety of their relative, but this did not provide emotional support to the participants. An alternative source of support emerged as participants talked of the paid social care worker who provided direct care to their relative in their home. They spoke of them as the person they most readily turned to for emotional and practical support.

Participants looked for support from three distinctive sources:

$\Rightarrow$ Informal support from family, friends, work colleagues and care support groups

$\Rightarrow$ Formal support from statutory and voluntary organisations who provided care for their relative

$\Rightarrow$ Alternative support from paid social care workers

Informal support

Informal support may be found within already present social structures such as family, friends and neighbours, work colleagues, or it could be drawn from social structures which were specifically linked with being a carer, such as carer support groups.

Participants found that informal support changed when they became carers and that support from family and friends was not given in an unconditional way.

Support from family

Only Samuel spoke positively about the support he received from his family. Most other participants experienced a lack of family support, with some 'getting fed up asking people'. When participants talked about why support from their families may not correspond with what might be traditionally expected or needed, three distinct reasons emerged.

Firstly, two participants did not expect their family to help because of their concerns over the appropriateness of sons caring for their mothers. George said of his son, 'I can't resent it, you know, it's not his responsibility'. He explained it would not be 'proper' for an adult son to provide care to his mother. Other participants' expressed personal views about whether the sex of the carer was of consequence. Some talked about how it would not be appropriate for a male social care worker to provide intimate care to their relative, saying their wife would not want to be cared for by a male. Others such as Andrew did not explicitly refer to paid social care workers, but did suggest that daughters and daughters-in law would be most likely to provide care participants were unable to do so themselves.

Secondly, participants explained that when there were disagreements over the types of decisions they made concerning the care of their relative, they experienced a reduction in support from family. Percy and Philip explained their family did not fully support their decision to become a carer; both gave this as a reason why family did not offer support. Percy, talking about his children's reaction to his decisions to remove his wife from residential care and care for her at home, explained, 'I got the distinct impression that they didn't want me to bring her out and I think that's part of the reason I don't get much help from them'. This mirrored the experience of Daniel, whose extended family reduced contact with him after disagreeing with his decision to place his wife in residential care. Philip's disapproval from his family was more indirect, being related to the effect caregiving had on his employment. He said of his mother, 'she thinks that my wife has held me back, right across the career spectrum so to speak'.

Whilst this disapproval caused additional upset, Philip explained how he dealt with it:

> *I just found at times you can't do right for doing wrong but at the end of the day it's my life, and I've got to do, deal with it and do things as I see fit and I can't go around pleasing other people*

At times in their narratives most of participants made similar reference to having to just do what they perceived as right for them and their relative.

Thirdly, Peter experienced uneasiness when the family voiced their belief that he should be delivering care in a different way and this led to him deliberately reducing contact with the family. He decided to move him and his wife away from their relatives, saying:

> *We prefer it like that, family not getting involved, because they tend to be a bit more outspoken if they feel you're not doing something and you should be doing something else*

Although none of the participants saw family as obliged to offer them support, their accounts conveyed an underlying sense that the family did not understand the carer role. Bert said 'especially your family, if they can't see you need help it's a sad affair', reinforcing the idea that participants felt they were shouldering the burden alone.

As well as relationships with family changing, relationships with friends and neighbours also changed often because of reduced contact. Support from these people was also experienced as negligible.

Support from friends and neighbours

All participants explained that, like their families, neighbours and friends had other commitments and perhaps did not have time to support them in any practical way, although they would have welcomed the opportunity to talk to others. Participants found that rather than friendships being maintained and enhanced, many friends withdrew support. Their accounts suggested painful emotions related to the experience of friends withdrawing their friendship.

Percy likens it to bereavement:

> *They just disappear, they can't handle it can they. It's like when somebody dies*

He commented on friends' embarrassment that his wife was ill, yet this was a time when he desperately needed emotional support:

> *They don't want to confront you in case you get upset…whereas invariably at that time you want somebody to talk to…*

He found his informal support networks had markedly reduced:

> *I used to have dozens of friends but gradually over a period of time they all disappear*

Only Bert appeared to have a well-developed friendship support system. He explained when his wife was first diagnosed he received lots of support from the close-knit community in which they lived. However, due to his wife's increasing care needs they were re-housed about ten miles away from their original community. Bert nonetheless had successfully retained old friendships and developed new support networks by regularly attending clubs and pubs in his old community. Other participants who changed neighbourhoods because of their wife's increasing health needs found the time commitment of full-time caring made it difficult for them to develop local support networks.

Even though Bert had an extensive network of friends, he still captured the sense of loneliness experienced by all the participants:

> *When you shut that door and we're sitting here…you just feel as though you're isolated from the rest of the world*

Evening was described as a particularly lonely time when 'someone to talk to' would have been beneficial, especially when the care-receiver had communication difficulties and the television was the only source of company.

Whilst combining caregiving with paid employment did reduce the amount of time available to maintain friendships, there was no clear pattern between the types of support offered and used by full-time carers and those who remained in employment. It did not seem that being in employment provided alternative support structures.

Support from work colleagues

Neither participants who were full-time carers nor those who remained in employment spoke of work colleagues as providing them with any sustained type of support. Those who had left employment explained they did not get support from past work colleagues, finding it hard to maintain these friendships because of lack of frequent contact. Bert explained once he had left work he was 'out of sight out of mind'.

Some of the participants still in employment spent a large proportion of their non-caregiving time with work colleagues, yet they did not identify colleagues as a source of support to help them with caregiving or concerns arising from being a carer.

Rather than support, they acknowledged a sense of camaraderie:

> *I get to see a lot of people I've known for a long time...we'll go out for a lunch or something, so yes a bit of comradeship (Andrew)*

Two participants in employment received advice from colleagues who had personal experience of helping an ill relative. John and Charles were both signposted by a colleague to external carer support groups. Nonetheless, participants explained that the majority of time when they chose to tell colleagues about their carer role they found them to be unsupportive and unsympathetic. Workplaces were not environments that encouraged participants to disclose their carer role.

Daniel explained the nature of his job meant colleagues changed frequently, therefore he found it a burden to repeatedly disclose his circumstances. He explained he could not be 'bothered to explain it all to these guys again, I'm fed up with it'. John said he did not tell colleagues because 'certain people, it's not worth talking to them about it because you just know that they're not going to be sympathetic'. Frequently participants only disclosed their carer role when an emergency at home meant they could not fulfill their employment commitment.

Support from carer support groups

Several participants had experienced attending a carer support group, but only four regularly attended carer support groups. Whilst those who attended such groups found them very helpful in enabling them to share practical and emotional experiences, other participants did not access the groups. They talked of having experienced carer support groups in negative ways, for example their relative was excluded from the group, making attendance difficult or they believed carer support groups only took place during the day and therefore were for older, retired carers, not men in employment.

Those who did attend a group experienced sharing information as an important part of such attendance. However, they spoke more frequently about the emotional support they got from the group. This went further than just the opportunity to talk to others, the carer support groups seemed to offer a place to relax and talk about the caregiving experience. Percy explained:

> *If you joke about it they think there's something wrong with you, you shouldn't be joking about dementia or somebody with dementia*

John also talked about the laughter generated in his group, affirming the carer group meeting was an opportunity to 'have a good time'. Carer support groups appeared to provide a safe place where participants could find humour in their situation.

Some participants experienced informal support from family, friends and work colleagues as meeting their needs, but more usually the complex conditions under which support from families could be offered and accepted meant that this type of support led to uneasiness. Whilst friends may have provided support, there was a withdrawing of contact from friends who appeared not to know how to effectively communicate with the participants. Work colleagues were not usually seen as a source of support either, because they lacked empathy with the participant's experience or because the participant had chosen to keep his caregiving hidden. Those who accessed carer groups regularly found them extremely supportive on both practical and emotional levels, but some did not attend carer support groups due to difficulties with access and non-supportive experiences. Participants also drew support from statutory services. Support was offered to participants through more formal statutory structures such as day care facilities which enabled carers to have respite from their carer responsibilities.

Formal support

Most participants reported receiving formal support following an assessment of their needs. This was provided in a combination of ways. Nearly all, except Philip, Peter and John received support from Crossroads for Carers equating to a few hours of respite each week. Martin, Bill, Bert, Jack and George's relatives all accessed day care services. Only George and Jack used longer-term residential respite care when they wished to take a holiday.

Weekly respite care enabled participants to have time away from their caregiving responsibilities. They experienced this as 'freedom…I can just go off and do my own thing'. Sometimes they used this break to access social events or carer support groups, but more usually it was spent in solitary activities such as shopping, or house maintenance, suggesting that whilst providing physical time away from caregiving participants received little emotional sustenance from this type of support. Martin explained that respite offered him 'that four hour slot when I can do exactly what I want'. This comment suggested that at other times his freedom to choose his activities was curtailed by the responsibilities of being a carer.

Alternative sources of support

Participants commented on how traditional support networks such as family and friends and colleagues did not fully meet their need for emotional support and time away from caregiving. Rather, family disagreements over care management decisions coupled with participants' judgements over who could be expected to support them meant that uneasiness occurred within family relationships. Friends and work colleagues provided limited support, and statutory respite and day care services, whilst providing time away from care responsibilities, did not provide emotional support. Yet participants did find emotional and practical support through the relationships they developed with the paid social care worker who was employed to attend to the care needs of their relative. Social care workers were employed in a variety of ways: some were social care assistants employed by adult social services, three were privately employed by the participants and one worker was paid from the disability living allowance of the care receiver. In each case the carer-social care worker relationship had moved on from being purely professional one to one of friendship. This friendship was evident in the way in which participants spoke of the types of relationships they had and the distinct types of support they obtained.

Participants asked social care workers for practical advice about how to dress their wife, or provide intimate care. They described this as particularly helpful and as one of the ways in which they learned about being a carer. They talked about getting emotional support from the social care worker. Frequently the emotional support was inherent within the opportunity to talk to someone who would listen and understand what they were experiencing. Jack said:

> *In the early days of me being on my own she was a big support really…well just somebody to talk to*

They experienced having someone to listen, who was visiting the home, particularly important when other support networks were shrinking.

Bert described how having a regular social care worker with whom he had developed a rapport led to the early recognition of his increasing burden in caregiving for his wife. Bert explained how his social care workers recognised he was experiencing additional strain:

> *They seen me getting uptight and down and they say 'why don't you let your wife go to the day centre' I suppose I was getting lower and lower and the decision's more or less made for me really*

These professionals suggested an intervention, so giving Bert 'permission' to decrease his carer input.

Other merging of employee, paid carer and friend roles was captured in examples where it appeared the social care worker had stepped outside the boundaries of paid worker. One participant described how a social care worker paid a portion of the bill for a computer fitness machine, explaining she would be able to use it alongside the care-receiver. Another man explained that when he travelled for his employment occasionally the social care worker would make unpaid night visits to ensure the well-being of his wife. Bert explained 'she's like the daughter we never had', giving the impression that the social care worker was replacing absent family.

A sense of responsibility for the welfare of the other was reciprocated with participants expressing concern for the well-being of the social care worker. Jack felt guilty when he could see the stress his long-term social care worker was experiencing:

> *I can see she's stressed, heading for depression, I can see a change in her...I know it's not my fault but I can feel guilty about the situation*

When participants privately employed a social care worker, the responsibility shifted from concern for the social care worker's emotional health to concern to ensure their financial security. Charles, who employed a private carer, explained that increasing the amount of care he provided for his mother would result in a decrease in the social care worker's hours and he had an obligation to her. He said 'I'm her main employer at the moment; she changed a few people around so she could do more hours for me'. There appeared to be an obligation to continue to provide employment and financial payment to the social care worker.

The relationship between participant and social care worker was complex. The social care worker was a frequent and intimate visitor to the participant's home, which led to a relationship more like a friendship, than one governed by statutory obligations and roles. This enhanced relationship had the accompanying benefit of emotional and practical support for the participant, but it also held responsibilities for each other's welfare.

Continuing to be a carer

Part of the lived experiences of male carers may be to consider the future of for both themselves and their relative. During their narratives several participants spoke of how

they saw the future. Most knew that the end of their journey would come when their relative died, but they appeared to repress this knowledge and live for the day. Martin described this as 'I'll worry about tomorrow when it comes'. In part, participants may have been avoiding confronting the death of their relative, but it seemed that previous experiences were shadowing the ways in which they now viewed the future. Percy captured the feelings of all participants that the future could not be planned for:

> *Look after today and try and not think about tomorrow or what's going to happen next week, not that you can predict it*

Previous life plans had been obliterated, now participants were living for the moment, although there was some underlying concern about what would happen to the care-receiver if they were unable to fulfil the role of carer. Every participant was living through the immediate experience and planning for the future seemed to be limited to 'next month maybe, but not next year'. They were living within the moment, experiencing being a carer and making decisions about how to best manage their role.

Summary

This chapter illustrated the decisions participants made to undertake the carer role, the ways in which they experienced and gave meaning to becoming and being a carer, how they built their role as carer and the types of support systems they drew on. On becoming carers they made complex decisions about whether they should stay in the caregiving situation and provide the care needed, or leave. These decisions could be seen to be embedded within a sense of duty to care for family, but justified through a concept of being the 'best' person to provide such care. They reached junctures where they were faced with further decisions about whether to stay in or leave paid work. Decisions to leave employment were influenced by concerns for the safety of their relative, but tempered by concerns for their financial security. They experienced developing a range of skills in managing the home and managing the caregiving. They talked of developing competence in these skills and of recognising that they now had sole responsibility for managing the home and the care of their relative. Whilst they reported trying to draw on a variety of existing support networks, frequently they found family, friends and work colleagues were not as supportive as perhaps they had expected. Many found the care-receiver's social care worker provided them with the most empathetic and practical support. It was apparent that although participants did not dwell on the future, they had considered what would happen if they were no longer able to provide care to their relative. These findings raised four points about decisions to

care, learning appropriate skills, responsibilities and obligations to employers as well as family and access to support structures, which will be discussed further in Chapter Eleven.

First, participants made complex decisions to become a carer; they did not 'fall' into caregiving. They justified their decisions by referring to duty and obligated commitments. However, duty and inherent obligations carried the caveat that they saw their relative as deserving of care for a variety of reasons. The phenomenon of being deserving of care differed from the concept of reciprocity, as decisions were based on the character and actions of the care-receiver. Whilst all participants explained they chose to stay and care it is questionable how easy it would have been to leave, as there appeared to be a lack of acceptable care alternatives. Linked with their perception that the quality of alternative care was generally poor was the finding that most participants made little use of holiday respite care.

Secondly, participants talked about having to undertake a number of new roles and responsibilities; many of which required them to learn new skills. Employed participants had difficulty in accessing information at times and in venues which were convenient to them, indicating that information should be reviewed to ensure relevant information is accessible at the right stages of caregiving and through the right media.

Thirdly, their decisions to leave employment were based not only on a sense of responsibility to their relative, but also a stated sense of responsibility to the employer. This suggested participants experienced the need to be able to commit fully to the workplace; the risk of letting others down appeared to limit access to employment. This provided one understanding as to why participants did not inform work colleagues of their participant role. The concept of male carers presenting alternative selves in different social settings is explored further in Chapter Nine.

Fourthly, these findings provide an insight into the support networks which were experienced as important by participants. Rather than drawing on support from family, friends and work colleagues, they found the most effective support came from either carer support groups or their relative's social care worker. This may be because of the close relationship which developed between care and social care worker, but crossing the boundaries between worker and friend may prove challenging as relationships continue. The changing structure of families, increasing movement in workplaces and

the changing structure of welfare support may influence where participants will draw support from in the future.

Participants experienced changes in their roles and responsibilities over time. Changes in the care-receiver's condition happened over time, which meant that all were able to take some time to consider their options in relation to undertaking care and leaving employment. They talked of how they became a carer and of the meaning they now gave to doing the care but they did not spend time thinking or planning for the future rather they lived for the moment. In experiencing the moment they conveyed a sense of time working in different ways, sometimes to support them on their journey, occasionally to hinder them, frequently to obligate them to certain activities within certain time periods. The next chapter explores how these men experienced obligated time.

Chapter 8 Obligated time

Introduction

As carers, participants' experienced increased demands on their time, frequently speaking of the tasks that they had to undertake; each activity of being a carer placed new and sometimes competing demands on how these men used their time. The ways in which time was used and the meanings of the activities undertaken within time periods shaped participants' experiences of being a carer. Conceptualising the activities of caregiving as being obligated occupations it became possible to interpreted the data through four strands of time: necessary time, committed time, contracted time and free time (Harvey and Pentland, 2004). Firstly, necessary time encapsulates the requirements of self-maintenance: grooming, sleep, nutrition. Participants' rarely referred to their self- maintenance, instead focussing on how they maintained the personal care of the care- receiver. Secondly there is committed time: for example undertaking household work, meal preparation, and maintenance of the garden and vehicles. For these men committed time included care of a relative. Thirdly time is contracted in that there were contracted obligations to attend the place of employment. Contracted time may be synonymous with payment. Finally, there is free time; this being the period of time left when the previous three obligations have been met.

The meaning of time for these participants' resulted in them sometimes experiencing being a carer as a role which engulfed their time. They had new and added demands on their time and frequently experienced their time as obligated in specific ways to meet the needs and requirements of others. They needed to recognise and meet the care needs of their relatives and to do this participants talked of planning when care events would occur and when they would have time to undertake other activities. However, they did not have absolute control over how and when the care-receivers received care, as they were also required to ensure that their relative was ready to attend day care services. Throughout the data there were recurrent stories of how participants used time during the day and the consequences of having too little time to undertake activities. Most talked of having to carefully plan how they used their time, often making set times for carrying out a range of activities, such as shopping and leisure activities. Several participants spoke of wanting to use time purposefully. However, it emerged that most had little control over how they managed their time; rather time was obligated by the need to meet the requirements of others, including employers, relatives and statutory

service providers. Consequently, participants used time in distinct ways, striving and sometimes failing to find any free time for themselves.

The ways in which participants used and experienced obligated time is discussed under three emergent categories. These categories illuminate how time was an essential component in the ways in which participants found meaning in their role as carers and employees. Participants frequently reported experiencing time in its most literal sense, as the passage of minutes and hours through their day, but also in a subjective temporal way suggesting that lived time shaped the meaning of their experiences. The ways in which time was obligated and used affected the meaning they gave to their experiences of caregiving.

Committed Time - meeting obligated commitments: Under the concept of committed time participants appeared to structure their time in ways to meet both external commitments and internal commitments. Time was seen to be explicitly structured either by the participant as a means of creating order to their day, or by the obligated commitment to meet needs of the care-receiver. Several described how having a structure to their day enabled them to manage the tasks of caregiving. Activities had to take place at times specified by others, such as health and social care service providers and employers, or the care-receiver themselves. For some participants this structure influenced their decision to undertake employment. A strategy used to enable obligated commitments to be met was to use time in segmented discrete ways. Several participants described how they internally segmented time into discrete periods. Sometimes this was seen as a benefit enabling different activities to be completed at different times of the day, creating a mental and physical divide between the roles and responsibilities of carer and employee. However, others found themselves undertaking multiple discrete activities within the same segment of time. This frequently led to talk of being 'stressed'.

There was also a need to ensure that obligations to contracted time activities such as paid employment could be met.

Contracted time - Making time for paid work: Participants reported attempting various strategies to make time available to access paid work. These strategies included using flexible employment hours and selecting the types of employment they perceived as being compatible with being a carer.

Whilst striving to meet their obligations to fulfil their responsibilities to both their committed and contracted time activities participants sought the opportunity to access free time.

Free Time - Finding time for self: Participants talked of how they used time to undertake activities which either provided them with support or which gave them pleasure. They spoke of how having time for themselves helped them maintain their well-being. Nonetheless, a few participants spoke of having no time for themselves and of being engulfed by the carer role.

The final part of the chapter raises a number of discussion points about the meaning of time, highlighting how factors both within and outside the participants' control constrained the opportunities they had to choose how they used their time. Nevertheless, when they were able to take control of what they did at given times of the day they experienced activities as more positive and developed a sense of well-being from them. Conversely when the requirements of employment and statutory day care services led to participants experiencing restrictions and obligations on how they used their time, this led to caregiving being experienced as burdensome and engulfing.

Committed time

External commitments structuring time

Participants found their use of time and the activities they undertook in any given time structured by external drivers. They talked of actively managing their time by using time in a planned, structured way; they faced external drivers which dictated when activities had to be achieved by and what they needed to be doing at given times of the day. For example, participants planned their day to meet the needs of care-receivers, health and social care providers and their place of employment. This led them to experience time as not always being under their control; rather time was obligated by the needs and demands of others. The concept of external commitments structuring time is discussed under the following headings:

⇒ Time obligated by the needs of others

⇒ Carer's working time

⇒ Employment structuring committed time

Time obligated by the needs of others

Whilst participants talked of being self-directed in how they structured and used their time, their stories also captured an underlying meaning that their time was not used to meet their personal needs. Rather, they reported using their time to meet the needs of others, either the care-receiver or their employment.

Bill explained how the needs of his son governed his time, capturing the obligated nature of committed time. Firstly, he said when his son was at day care he was not governed by his needs, explaining, 'I've got about five hours in the day when I'm really not governed by my son'. However, as he continued to speak it became evident that although his son was not present Bill used his time to fulfil his carer responsibilities. He said 'I still have to make the beds and do the washing and things, so in a way it is still governed by my son, but he is not here'. This comment suggests that even when the care-receiver was not physically present time was used to discharge care responsibilities.

Peter also used the term '*governed*'. His wife was still relatively independent and he said 'I'm not sort of really governed that I have to get up and shower her, wash her or anything like that'. Nonetheless, he acknowledged this might be what the future held for him.

All participants who accessed health and social care services experienced externally set demands on their time. They had to make appointments or have their relative ready for day care at times to suit the service provider, rather than at times which suited them. However, a few used these externally-set structured times to help them manage their roles, for example Andrew organised his private cleaner and hairdresser to come in on the same day as the Crossroads social care worker, thereby providing him with time to undertake a small amount of paid work. Yet others found the rigid time structures of day services did not support them or their relative, rather it created extra burden.

Daniel explained he tried to enable his wife to be ready for day care transport by preparing and laying out her clothes before going to work, as her dementia had resulted in her being unable to make decisions. Yet despite his intervention she was often not ready when day centre transport arrived and therefore they did not take her to an alternative care provision; this resulted in increasing anxiety for Daniel. He recognised the nature of the alternative care provision meant that the transport 'can't wait because there's other people on the bus', but when she was not taken to day care he would

receive a telephone call at work informing him that she was alone at home. He described how receiving this information directly increased his level of concern about her safety, 'so she ends up on her own, that's a bit worrying you know she can do anything, wander off, anything'. As he worked some distance from their home and in a relatively inflexible employment situation, he was unable to do anything to ensure her safety. He went on to explain how there were further consequences to him when she did not attend day care 'so when I get home, I have to rectify things, things in the wrong places, keys they're all over the place, doors are undone, lights are on, taps running'. Daniel's experiences illustrated how the preset time of service providers did not always help participants balancing the dual roles of carer and employee.

Participants not in employment could ensure their relative was ready for day care transport, but whilst day care provided respite from caregiving, the necessity of managing the day around structured preset times remained a concern for the majority of full-time carer participants. They experienced day care as limiting their freedom of choice over how they used their time. Bert illustrated this when he said Thursday was the day he and his wife 'can do more or less what we want to' suggesting they had a choice over that day's activities and could engage in activities together rather than apart. Martin decided not to increase his mother's day care, explaining that the lack of choice over what time she attended meant that the effort to get her up and ready did not justify the few hours respite he would get.

Even when participants had sufficient time to choose to take on leisure activities, the obligation to the meet the needs of the care-receiver continued to affect the ways in which they accessed leisure time. For example, Andrew explained how he managed his time to enable him to access golf, an activity he finds relaxing:

> *The only problem we start golf at half past eight but I have to get up at six o'clock, because I'll have to get the wife up and washed and dressed and have her breakfast and get her all sorted out, that takes me about two hours by the time I've got myself up*

His description captured the length of time it can take to fulfil the necessary time activities in just one aspect of the carer role. A concept reinforced by Martin who explained 'from our point of view we've just had breakfast, but for most people's point of view it's nearly lunchtime because it's about eleven, half past eleven before we've done all that'. All participants were dedicating large periods of the day and night to their carer roles.

As well as dedicating large amounts of time to meeting the needs of care-receivers, participants also experienced a corresponding loss of spontaneity in how they used their time; the demands of committed time created an interface with free time. Philip talked about why he no longer took holidays with his wife:

> *It's like a military operation to get everything dotted and in place and I would find that extremely stressful, I would be worn out...so the spontaneity is lost, it has to be mapped out.*

All participants talked in some context of the loss of spontaneity, whether it was to undertake activities for themselves or whether it was in the routine of being a carer. Percy described how, 'You have to plan everything, you can't do anything without having some sort of a plan'. Samuel expanded on this aspect of caregiving, explaining he experienced the responsibility of doing all the planning and found it a burden, 'I've been stressed from the point of view that you should like plan everything in, in quite minute detail, otherwise you don't achieve it'. This need to plan led to a lack of spontaneity in both larger issues such as planning a holiday and in the smaller daily choices. Yet participants accepted this lack of spontaneity in how they used their time, and they developed a number of strategies to break up their routine, including taking short breaks, meeting other people or accessing employment.

Accessing other time within committed time

Samuel explained short holidays helped him break up the routine: 'just to go away for a weekend like once a month that sort of breaks the month up and gives you something to focus on, gives her something to look forward to'. Samuel had only recently left full-time employment and explained that he was not currently worried about his financial security and although his wife was experiencing early dementia she was fully mobile. The majority of participants were not able to easily access holidays away from home, either because of financial constraints or the high care needs of their relative. They had short breaks away from caregiving during the day, but this was not in the company of their relative

Martin described how he stepped away from his caregiving responsibilities for short periods and met other people: 'I spend a lot of time in isolation here with mum so when I do go out and about I do tend to sort of chat to all and sundry'. The opportunity to chat to people in the shops was important for his well-being. For others, employment provided a break from the routine of being a carer.

When talking about their structured use of time full-time carer participants spoke of their day as a working day, suggesting they experienced obligated caregiving activities as a form of work.

Carer's working time

Some full-time carers described their use of time as if they were in employment, here committed time in which they fulfilled responsibilities to others blurred with the concept of contracted time but for full-time carers there was no financial reward. Martin explained how he changes his use of time in order to create a weekend in a week where he is at home all the time:

> *The weekends I tend to treat as a weekend in that, I do very little because I've done all the food shopping and, I actually spend a lot of time here at the weekend*

Others spoke of their activity as a job, highlighting the number of hours they worked. Jack captured this when he explained that as a carer he was in a 'full-time job' working 'twenty four hours a day'. The experience of activity providing structure to the day was also apparent within the narratives of participants who were in employment.

Employment structuring committed time

Some participants talked of set employment hours as being important, enabling them to compartmentalise their time and identify different tasks for different parts of their day. Here they experienced committed time and contracted time as different activities often taking place in different physical settings, but most importantly as aspects of time which they could manage to help themselves.

Philip explained he had changed jobs, as his previous employment had long hours and heavy demands for preparation at home. His employment was now contained within the hours of nine to five; he described how this 'lifted the pressure off me'. Philip's previous employment had required additional work to be undertaken at home leaving little time for household tasks; now he found such tasks could be managed before and after paid work, thus enabling him to effectively manage the dual roles. Yet, other participants, particularly George whose place of employment was attached to his home, sought flexibility within their working day, explaining this enabled them to fit their carer responsibilities around paid work.

George described the benefits of having his home and workplace in the same building, 'it truly is a bit of a blessing, no worries about what time she arrives home, if she's early you're here anyway'. His wife went to day care five days a week. If she had been at home it may have been more of a challenge to combine the two roles. Certainly Andrew, who tried to do some paid work at home, found himself frequently interrupted by his wife requiring assistance.

Percy, who was self-employed, explained that whilst he left his home to access employment, his hours of work were flexible enough to enable him to manage his caregiving responsibilities. He explained 'if we have a problem and I get to work late or I have to leave a bit early at dinner times or something, most of them [*customers*] know the situation, they don't worry, they'll leave a message on the answer phone'. This comment suggested that being self-employed offered more flexibility than being contracted to set employment times, also that if others knew of their carer responsibilities they may be more accepting of the participant's need to leave employment.

Percy's employment situation could be contrasted to that of Daniel. Daniel had set employment hours, and frequently worked with colleagues who were not aware of his carer responsibilities. He repeatedly talked about the difficulty he had reconciling his carer responsibilities with his employee responsibilities. Discussing an occasion when he had refused to do overtime, he said, 'I said, no, I'm not doing it. That didn't go down too well of course'. He went on to express concern that he was letting work colleagues down, 'I would try and I would help out because we work as a team'. However, he also experienced an obligation to be with his wife, 'can't do overtime because I've got to be here looking after my wife'. This extract illustrated the competing demands participants experienced on their time and the ways in which they experienced obligations from both their carer and employee roles. Some participants managed these competing demands on their time by segmenting periods of the day into discrete activities.

Whilst much of the day and week was described as being structured with activities happening at set times, there also emerged a sense of the use of time being internally driven, shaped, segmented and used for discrete activities. Segmented time was sometimes experienced as doing different activities at different times, but on other occasions, participants experienced an overlapping of roles and responsibilities within

the same segment of time. Overlapping roles and responsibilities within segmented time appeared to increase the burden participants experienced.

Internal drivers shaping the use of time

Where participants' time was not shaped by their commitment to need to meet the demands of external commitments such as health and social care providers and employers, they appeared to use internally motivated strategies to manage their use of time. For some there was a high degree of structure within their day; they distinctly divided their time, their responsibilities, obligated and contracted commitments into clearly defined times and activities. Some participants grouped these smaller parts of time into discrete segments, enabling them to achieve distinctive tasks in different time periods, such as having a dedicated period of free time for leisure and another for contracted employment and another for the commitment of caregiving For others, the smaller parts of time overlaid each other and multiple activities occurred within the same time period. Participants sometimes actively managed their time to enable them to fulfil their roles and complete tasks, but for some self-management of their time seemed beyond them and they faced competing demands to meet their obligations to both committed and contracted activities.

The concept of internally managed time is explored through the ways in which participants' self-managed time to achieve obligated commitments. There is an exploration of how undertaking single tasks in discrete segments of time enabled participants' to have a sense of internal control over their activities. Conversely where there was an overlap with multiple commitments within the same time period there appeared to be an increase in stress in the participant

⇒ Self managing to achieve tasks

⇒ Discrete segments of time – illustrated how participants divided time into short periods enabling them to achieve distinctive tasks.

⇒ Overlapping segments of time - here participants experienced competing demands on the segments of time, leading to feelings of stress and fatigue.

Self-managing time to achieve tasks

Several participants developed complex ways of structuring their time, enabling them to achieve a range of carer and employee tasks. The purpose of this structuring differed depending on whether they were in employment or not.

167

Those in employment described having clearly defined routines to their morning which enabled them to achieve the caregiving tasks they had responsibility for before they moved to the workplace. There was a sense of industry in how they described their mornings. Both Percy and George, who had social care workers supporting them in getting their wives up, explained they started caregiving tasks but handed over to the social care worker. Handing over the activity of caregiving to someone else enabled them to move into the time of employment; they then received the carer role back after finishing their paid work. Percy provided a summary of his day which captured his use of time:

> *I usually get up about half past six or seven. I get myself ready first, have my breakfast, wash and get dressed. Then the carer gets here about quarter past eight, she's taking her [his wife] upstairs, gives her a wash, we get her dressed. Back downstairs by quarter to nine and I go to work. I work till one, and the carer does my dinner for me, she usually gives my wife her dinner about twelve. I come home, leave work at one, the carer has my dinner ready so I have my dinner by about half-past-one quarter-to-two and then do whatever housework needs doing from then on. My wife has two more changes during the day, one about four and then another one before I put her to bed about nine. In between I obviously do whatever housework needs doing, ironing or washing.*

In this description he captured how he structured and self-managed his day with activities clearly taking place at set times, thus providing order to the day. This level of structure enabled him to combine caregiving and employment. Nonetheless, there was a lack of opportunity for movement away from the timetable, a lack of spontaneity. Tasks had to be undertaken at preset times to correlate with the availability of the social care worker, the care needs of his wife, and his employment responsibilities.

Philip also described a structured morning during which both he and his wife prepared for employment. For Philip his use of time involved separate activities leading to them both being able to access their places of work on time. He explained, 'it's sort of coordinated, while she is in one place I am doing something else, you know, like a herring bone, it sort of fits in'. The phrase '*like a herring bone'* suggested this structured routine was helpful to Philip, because order in the morning enabled him to go to work knowing he had completed domestic tasks. This was evident when he explained 'before I came out this morning I was working in a kitchen, putting the washing on and dish-washer and I felt good because I know full well it won't be a mess when I go back'. Through managing his time and achieving tasks, Philip said that he then felt good.

Whilst many participants' were seen to have routines through the day that enabled them to achieve tasks and undertake a range of roles, it was striking within participants' narratives that the majority consistently spelt out the exact time that they undertook each activity. This suggested they structured their days tightly by clock time. Jack particularly captured the concept of his day being governed by time in this way:

> *You have to clock watch always all the time: oh got to be home she's got to be dropped off from day service, oh time for her meals, time for her medication, oh better give her a drink.*

Whilst some participants in employment started their day early and strived to complete a variety of tasks before going to work appearing self-managing and self-motivated, Charles described a different start to his morning. He talked of being unable to become motivated to use the time available to him. Firstly, he explained he had negotiated flexible working hours enabling him to fulfil his carer responsibility of ensuring his mother was out of bed and downstairs before he left for work:

> *I've arranged that I going into work about eleven, eleven thirty, and I often make sure that my mother gets up okay if she's going to get up for the day, then work through till seven, seven-thirty, sometimes a bit later*

The use of the word 'often' implied he did not always succeed in getting her up. He went on to discuss his mother's reluctance to get out of bed, explaining he thought it was better for her health to be up. He gave the impression of being up early and home late, but when I commented he had a long day, Charles explained he does not always get up early, explaining

> *I must admit I don't get up, I mean I was up early today because I had to take a car in for a service so I was up about seven o' clock which I wouldn't normally have. I'd get up about half past eight, I have twenty to eight, about twenty to eight normally*

He moved on to explain the additional time gained during the morning was used to do household tasks:

> *I just do the washing up, do the breakfast, do some washing anything that needs doing, tidy a bit, trying to fit that in the morning when I've got time to do it*

However, again he provided conflicting accounts of whether he actually used the time in the morning, explaining, 'I don't always want to do it when I get up, I just can't be bothered'.

Charles's narrative provided a contrast to the industry found in other participants' narratives, whose stories portrayed them as constantly using their time in structured

ways to achieve outcomes. Rather, Charles described the experience of not wanting to be bothered with the everyday tasks of being a carer, explaining 'I just want to sit or watch television, or sleep'. He appeared exhausted by the competing time demands of full-time employment and full-time caregiving.

For Daniel his evening routine enabled him to deal not only with household tasks, but also to continue his carer role. Describing how he managed his evening since his wife moved into full-time residential care, he said, 'so I got this routine together … I leave work and go to the care home, by that time as soon as I get there it's evening meal time, so I have my evening meal with her'. He spoke of drawing comfort from knowing there was a time when he would see her every day.

Employed participants appeared to benefit from setting distinctive times when they could do different tasks, finding that this enabled them to combine employment with caregiving. Yet, it also emerged that those participants who were full-time carers talked about planning their days in a structured way. This managed use of committed time enabled them to fulfil their carer responsibilities and meet the demands of others.

Martin explained he had devised routines to help him manage his caregiving role, 'there has to be routine otherwise I wouldn't get everything done'. Routines also helped his mother, 'if I have a routine mum knows where she is'. Whilst routines where generally helpful in enabling tasks to be achieved, they were also experienced by Martin as being constraining, 'I try to think of different ways of breaking up the routine'. This comment may indicate an element of boredom in such predictability. Andrew also found caregiving monotonous, 'I'm either looking after my wife or doing up the house and it gets monotonous'. Although participants developed routines to help them manage their use of time, such routines were predominantly structured around the needs of others and were developed to enable them to fulfil carer obligated commitments rather than necessarily enabling access to free time. In order to create opportunities to undertake both contracted and free time activities participants' spoke of segmenting their time.

Discrete segments of time

Participants talked of using segments of time to complete different activities and fulfil different roles.

Different time - Different activity

Initially, during their first interview, participants tended to tell a sequential story of their

day, from getting up to going to bed. However, after beginning by depicting a linear use of time their conversation often moved to explaining how they used smaller segments of their time. A picture emerged of them actively breaking the day into smaller periods, with tasks fitted into these segments of time. Martin reported this vividly:

> *it's almost like there's the little slots in the day of half an hour, or an hour of when you do things, to get things done*

There was evidence he planned which activities might be achievable within given time slots.

Martin explained:

> *she'll then sleep guaranteed ... so I know then that if I need to go to the supermarket or go to the post office or run round and do a few chores that's an opportunity for me to do that*

Yet despite the planning, tasks were usually found to take longer than expected or they were never fully finished, commonly leading to frustration. Such frustration was evident when Andrew explained 'you plan to do things and they just don't get done anywhere near as quick as they should, simply because other things take over'. The inability to finish activities was a cause of distress for some participants, resulting in them feeling time was beyond their control. Philip captured the experience of all participants when he stated he felt under 'time-pressure'.

'Time pressure' was managed by organising time into discrete periods for distinctive activities. However, participants experienced a lack of spontaneity in how they used these discrete time periods. There needed to be long-term forward planning to organise respite for holidays and even a simple household task required forward planning. Philip described planning to undertake car maintenance.

First, Philip gave notice, including the length of time he would need:

> *I usually state a couple of days notice and say Sunday afternoon or Saturday afternoon I want to drop the oil off my car for half an hour*

Then he explained he had to ensure his wife was occupied and not requiring his support, ' wife will know what I'm doing and she will be on the Internet'.

Forward planning and segmenting time could ensure the well-being of the care-receiver. For example when his wife was on the Internet Philip explained she was safe as her risk of falling was reduced. Several other participants also explained how they ensured their relative was safely occupied before they started other activities. Andrew would ensure

his wife had the television, a drink and a buzzer before he embarked on house maintenance and George explained he was able to keep popping in to check on his wife watching television whilst he painted the kitchen. These examples captured the responsibility of participants to ensure the safety and well-being of the care-receiver remained at the fore of their minds.

Planned activity not only achieved a task, but also provided time away from the being a carer. Philip said of the time when he was maintaining the car:

> *I'm quite happy getting my hands dirty and doing something, I am focussed for half an hour*

Then the use of time changed when the activity was completed:

> *Then when you stop, and putting everything back together, and everything goes back to normal.*

Philip did not expand on what 'normal' was for him, but this extract illustrated that he gave different meanings to different activities. Here maintaining the car was time away from the 'normal' of his routine weekend activity of being a carer. There was further evidence that undertaking activities not related to caregiving benefited participants.

Different time – Time for self

Through segmenting time for different activities, some of the participants were able to ~~find~~ use free time for hobbies, producing physical and mental time away from caregiving:

> *You forget about all your other problems … once you're out in the garage there under the car you're not thinking about anything else … you might have something that's buzzing around in your head, while you are doing a hobby you're not thinking about it (Percy)*

George described the importance of physical exercise as an activity which enabled him to continue in his carer role. However, other participants talked of being unable to find time in their day for themselves and these men frequently spoke about feeling stressed and exhausted, suggesting they were experiencing burden frequently linked with being a carer. Several participants reported drawing on short respite periods provided by social care workers to get un-committed and un-contracted time to themselves. They did not describe seeking extended respite time, just attempts to capture an hour or two when they could undertake activities for themselves without also being concerned for their relative.

Different time - Different roles

As with managing tasks within the home, some participants managed paid work by having distinct activities at different times of the day. These men talked about how they were able to compartmentalise their roles, physical space and time. Percy explained, 'When I'm at work, I work and then when I come out of there I forget about it, shut the door and come out'. He went home and moved into his carer and spouse activities, leaving work problems behind. Having discrete employment and carer times meant he could contain concerns about either activity. In order for this separation to occur, alternative care had to be perceived as being of high quality. For example, Percy '*trusted*' his wife's social care workers. Philip said that when his wife is at work she was '*someone else's responsibility*'. Not all participants were able to compartmentalise their unpaid and paid time, leading to an overlapping of roles and activities within the same time period.

Overlapping segments of time

All participants experienced caregiving as a twenty-four hour, seven day a week role, but it was predominantly within paid employment that participants experienced an overlap across roles and tasks. Whilst George, Philip and Percy managed to compartmentalise paid employment from their carer role, for others being a carer was a role they still actively undertook whilst at their place of employment. For these participants segments of time were not discrete but, committed time activities and contracted time activities overlaid each other, sometimes resulting in increased burden.

Carer tasks overlapping into paid work

Overlaid activities meant lunch breaks were used for ordering tablets and trying to organise additional day care. Daniel explained that he only received a short lunch break and he had to use this to make phone calls and order medication.

He described the difficulty of this limited time and the consequences:

> *I've got to try and do all this ringing round in my lunchtime and grab a bite to eat and a cup of tea in thirty minutes, you can't do it, so that's why I try and sneak out and I've been caught a few times*

Daniel did not elaborate on the consequences of 'being caught' but did say of his employers:

> *They just want people there to work, work, work, work, work and do overtime and weekends, and that's all they're interested in; they're not interested in me if I don't want to be there just get somebody else as simple as that.*

Daniel went on to explained that undertaking carer tasks whilst at his employment caused him anxiety because he could not focus completely on supporting junior colleagues:

> *I've got quite a responsible job being an engineer and I have to look after a lot of the other guys as well being an inspector, they're saying ' oh come on look I've done this job, you got to come and inspect this, and what do you want me to do next', and I'm going, I haven't ordered them pills, oh my god.*

Whilst Daniel experienced competing demands at work, Charles appeared more laissez-faire in his approach to undertaking carer tasks whilst at work, 'I want to speak to my sister and I don't want me mum to hear what I'm saying, just do it from work'. It may be that work environment influenced the ease with which participants could combine carer and employee roles. Daniel worked within industry on the workshop floor with several other people around him, whereas Charles and John worked in offices where their managers knew of their carer responsibilities.

John talked of being physically disturbed during his working day by phone calls from his wife, who experienced mental health problems. He explained he wanted to manage her intrusions. One way he did this was by using a private telephone rather than calls going through the company switchboard. On other occasions he took direct action to place boundaries around how paid work time was used:

> *If she is in a right angry state I can't get her off the phone…she's been on there so long; I've said 'I've got to get on', and I put the phone down*

However, this action does not always end the interruption and John then experiences conflict between responsibilities:

> *Then she'll ring back; yeah, some days you cannot get rid of her, and obviously I've got to do a day's work*

When carer tasks impinged into employment time participants frequently experienced conflict in their obligations, recognising they had responsibilities in the workplace, but being unable to relinquish their carer responsibilities. Whilst for some carers tasks and concern for their relative spilled into paid work time, others were more effectively able to separate the role of carer and employee. This separation occurred when they

perceived the alternative care provided as being of a high standard. Those participants who were able to hand over responsibility of their carer role viewed paid work in a positive way, rather than as another thing that had to be fitted into limited time.

There were patterns between the type of employment undertaken and the ease with which participants could combine paid work with caregiving. As only seven participants' were in employment findings remain tentative however, those who were able to be self-directive at work appeared to combine the two activities most successfully. Several participants expressed opinions on which types of employment could best be managed alongside being a carer.

Contracted time - Making time for paid work

Participants explained they thought some types of employment were easier to combine with caregiving than other types. Those who were self-employed had more flexibility about the hours they worked than those who worked for larger private companies. Philip expressed the opinion that voluntary sector employers were more flexible in meeting the needs of carers than private organisations. He explained this perception would influence any future employment he applied for:

> *I'm in a charity now and, and to be fair they do allow a bit of flexibility here… that's the reason why I've ruled out, maybe wrongly, but the private sector they wouldn't have the empathy or anything like that*

John did not express strong opinions either way about whether his workplace was supportive of his carer role, but did indicate that if he was unable to go to work because of his wife's condition he could telephone and use holiday leave without any repercussions.

Some participants described how flexible working times enabled them continue in paid employment. An employer may sanction flexi-time, as with Charles who shifted his working hours to start at eleven and finish at seven, enabling him to assist his mother in the morning. For three men being self-employed offered flexibility in their hours of employment.

Andrew and George worked from home experiencing paid work as an activity they could fit around their caregiving tasks.

Working and living in the same physical space enabled them to move between carer and worker roles, meaning they could undertake paid activities outside of standard working hours:

> *Do a few hours and go to make some tea, and I work in the evenings, I just work round and she's got the buzzer bell, she can ring me if she wants to (Andrew)*

Although being in the same physical space for paid work and care work led to an overlap of responsibility, they did not identify any difficulties with this situation.

Another factor that made it easier to undertake paid work was physical accessibility to the job. Philip found a long journey to a previous employment setting exhausting. He explained:

> *My last job, I had a lot of driving and to be fair that was just absolutely wearing me, I didn't realise the impact, but it meant that I had to leave the house earlier*

Further, his long journey times meant that other tasks could not be accomplished:

> *Often I didn't have time in the morning to make sandwiches and things, where as now I have that time, I can put on the washing machine on whatever*

Reduced travel time meant he could meet his domestic responsibilities before starting paid work, leading him to report that he felt more in control of the situation. Daniel also had long journey times to his employment and he described how the routines he completed to ensure he could leave the house on time in the morning cut into evening leisure time.

Daniel explained:

> *As soon as I'm home I've got to rush around, get a shower, make my lunch for tomorrow because I don't fancy making my lunch at half past five in the mornings*

Some participants found that they could not manage paid work within set time periods and they cited it as a reason for leaving employment:

> *Wasn't a straight nine-to-five job, I mean we had to be there to open up in the mornings at eight, the shop didn't shut till nine at night, we were constantly on call (Peter)*

176

If work patterns were not sufficiently flexible to enable participants to combine caregiving and employment, they either left employment, or made changes to their job. Whilst several participants found time to access employment, it was harder to find time to access activities that were purely for their own pleasure.

Free Time - Finding time for self

Participants tried to find ways of doing things that enhanced their sense of self as a person not just a carer. Some activities they did with their relative and they both drew pleasure from these and other activities they did by themselves. These activities gave them time away from being a carer. However, some participants found themselves engulfed within their carer role with little time for anything else. This affected their physical and mental well-being.

The concept of time for self is discussed under two headings:

⇒ Time for being other than a carer

⇒ Engulfed by being a carer

Time for being other than a carer

All participants spoke of trying to find small amounts of time to do activities not purely related to practical caregiving or employment. Samuel and Peter's wives were physically quite mobile and this enabled them to do things together which reaffirmed their husband and wife roles rather than carer and care-receiver roles. Samuel described how he and his wife had joined a gym together and used the time since he had left employment to go for walks and holidays together. Peter reinforced the concept of caregiving providing more time as a couple, saying that since his wife's illness they had both left employment and now they had time as a couple, 'time's our own when we can get on and do what we want so, it's certainly got its benefits on that sort of score'. For other participants though, the level of disability experienced by their relative meant they could no longer undertake activities together.

These participants used time away from their relative in a range of ways, but in each case they used the time in an activity which gave them pleasure and created a sense of well-being.

Martin captured this, firstly explaining the need to have time away:

> *I think I'd go absolutely nuts if I didn't get a chance to get out of this market town*

Then he explained the pleasure he derived from a simple activity and time way from his home:

> *I go down to beach, take a bottle of water and a sandwich and a book, and go and sit on the beach for two or three hours which is brilliant*

He reinforced the feeling of being free from his responsibilities of being a carer:

> *It's the freedom of knowing that she's looked after and I can just go off and do my own thing is really, really good*

Martin also spoke of the potential consequences of not having time for himself:

> *If you're at home caring all the time, you've got to have time out otherwise you'd, you know, you'd be jumping off the River Bridge*

The benefit of time away from being a carer and the potential consequences of not having this time were reiterated in most narratives. For example, Jack explained the need for short segments of time when he could relax from his carer role,

> *If you don't have that five, ten minutes then I believe the overflow would happen and it just becomes what's the point of living, sort of thing, if this is all there is, if the overflow did happen, what's the purpose of life*

Jack also explained that he feels his 'stress' building up before he accesses his regular respite holiday break, emphasising how this regular break helped him remain in his carer role.

Whilst other participants did not make explicit reference to their own mental health, they did comment on how they could understand why people cracked under the burden of caregiving. Bill said, 'I can see that one of these days something will go wrong and people will just take the disabled person down to the social services and say, you look after him'. All explained that time away from the carer role was essential for their sense of being able to cope with their roles. John captured this when he described how he took time away from his wife:

> *Quite often I would escape down to there (his son's home) sometime I'd have a weekend with him, but no end of times I just went out there and I got a key for his house…I know it was just place where I could go and chill out for a day and a half*

They used time away from their carer role in a variety of ways, either to develop social networks with others or in activities that are more solitary.

178

Bert used respite time to remain engaged with friends, thereby enhancing his support network. Percy used the time to work on his racing car; this formed part of his social network at weekends. Andrew and George used the time to take part in sports with others. John explained that he considered attending the carer support group, as his time stating, 'it's my time, it's the only time I switch my mobile phone off', indicating that for that that one hour he is not available to his wife or his employer. Others used time away for their relative in solitary activities.

Martin described how he liked to get away by himself out of his home town to explore other towns or the beach. John used weekends away from his wife as a means of coping with her mental illness. Jack relaxed not by leaving his home, but rather by findings small segments of time to do activities which gave him enjoyment:

> *In a twenty-four hour day I would say I am caring for twenty–three hours and just a bit lackadaisical for one hour…so for one hour laziness or non-caring role…you switch your mind off, perhaps listening to music for five minutes, on the computer for five minutes, another five minutes and it all adds up.*

Daniel was the only participant who did not talk of having an opportunity to undertake activities which he enjoyed and which might have enhanced his well-being. During his first interview he explained what he would like to do:

> *I don't get any time for myself, I like to play snooker or golf, or go for a ride on my motorbike, or go for a walk, or go to the pub with the lads, can't do it*

By the second interview Daniel had placed his wife in residential-care explaining that he could not find the time to be both a carer and an employee, 'you just can't live with it, everything going on'. Daniel also captured the importance of small periods of time by indicating that if he could gain twenty minutes in the evening that would be 'a huge amount'.

When participants had too little free time to undertake activities which gave them pleasure they appeared to experience caregiving as activity which engulfed them.

Engulfed by being a carer

Participants had a number of specific demands and obligations placed on their time. They did not always have a choice over how they used their time and frequently they put the needs of the care-receiver before their own. The restrictions and demands on their time affected them both physically and emotionally.

Physically every participant spoke of experiencing tiredness. Martin said:

> *I'm so bloody knackered looking after her all day*

Daniel also felt 'knackered' and expressed a sense of the feeling never ending:

> *Knackered is the word … it just doesn't go away, and I don't think it ever will, I've just got to try and cope with it*

Bert explained how even when physically exhausted he still had to keep on being a carer:

> *I feel absolutely cream crackered but I've still got to give you a cup of tea I've still got to do*

Percy spoke of the consequences of constantly being physically tired:

> *You do get very tired and I think where you pay is you get what most people consider to be a minor ailment and it tends to drag you down because you're already down and run down*

These four quotes captured how participants experienced being physically worn out. However, as Martin explained there was not only physical exhaustion but also mental exhaustion, because of having to think 'for someone else all the time'. Thinking for another person changed the ways in which some participants perceived their self. They described how they had become 'bossy'. This finding is discussed further through the theme of 'self as carer' in the following chapter.

For most participants their relative's condition continued to deteriorate, meaning no matter how much time they devoted to being a carer there would never be an improvement.

Jack, explaining how his disabled daughter did not respond to stimulation, captured this sense of caregiving being an endless task:

> *Day after day after day you do that and you don't get anything back, it cracks you up, that's what I mean by sanity, cracking you up*

Others experienced being constantly responsible for the welfare of another person and talked about this leading to a situation where a carer might not be able to cope, although no participant stated they personally felt like this.

Mentally caregiving was also a full-time activity because of having sole responsibility for the well-being of the care-receiver:

> *It's twenty-four seven, you're thinking not only what am I going to do, but what is she doing…I'm actually thinking for her all the time now. (Samuel)*

Even when the care-receiver was in day care participants did not experience time as being under their own direction; there was still the need to be available in case of an emergency. Jack explained, 'I've still got to be accessible while she's in day services, because they could ring me up and say, oh she's now had a big fit seizure can you come and get her'. The majority of participants expressed the need to always be available to respond to emergencies.

Participants experienced being a carer as a full-time role encompassing a twenty-four hour day. Whilst some were able to find windows of time to undertake activities which enhanced their well-being, others found their time engulfed by the role.

Summary

All these male carers found their use of time constricted and constrained by a number of factors including the demands of their employment, and the needs of the care-receiver and health and social care providers. They used a number of strategies to enable them to manage their time and so discharge their obligations effectively, thereby promoting their physical and mental well-being. They used time in discrete segments and developed routines to enable achievement of caregiving and employment tasks. Some allocated time to undertake activities which enhanced their own well-being, even if this meant rising earlier in the mornings. However, not all were able to take control of how their time was used and here an image emerged of these men being engulfed by their carer role and frequently also by their employment responsibilities.

Findings within this chapter have raised four points which will be discussed further in Chapter Eleven. First, there is the theoretical consideration of what time means to male carers. Time was an important issue for them and frequently participants' stories made reference to how time was used and whose needs were predominantly met within specific time periods. The concept of obligated time resonates with the earlier concept of caregiving being an obligated commitment discussed in the findings about why these men undertook caregiving. A person may become a carer through a feeling of obligation toward the care-receiver, and then once in the role the obligation continues as time becomes committed and structured to meet their needs. There are consequences linked

with time being obligated, for example difficulty in balancing one's own needs against those of the care-receiver, as a result employment opportunities may become restricted.

A second area for discussion concerns the structure of employment, as some employment structures appeared to make it easier to combine caregiving with employment. Employment that enabled flexible use of time, such as self-employment and working at home, enabled participants to move relatively easily between the dual activities. However, where employment times were rigidly set and travel to work engulfed hours in the day participants found it considerably harder to combine the two activities. Recognising the employment structures which support carers may be important with the current government imitative to support carers' access to employment.

Thirdly, participants highlighted how the preset structures of health and social care providers placed restrictions on how they used their time. For some, health and social care services enabled them to maintain employment, but for others the late pick-up times and early finish of day care services inhibited employment.

Fourthly, participants' narratives drew attention to the time it took to physically undertake caregiving tasks, such as getting a care-receiver up and dressed in the morning. The findings highlighted the physical intensity of caregiving and the resulting feelings of exhaustion experienced by all participants. Recognising the ways in which carers maintain their own well-being may help in developing initiatives which enable them to continue in their role whilst 'having a life of their own' (DH, 2008). The consequence of not having time for themselves led to an experience of being engulfed by the role. The concept of being engulfed by the role and losing one's own identity is discussed further in the next chapter.

Chapter 9 Self as carer-reworking identities

Introduction

Through exploring the roles and identities participants developed as working-age male carers, it emerged that their previous roles as husbands, fathers and sons were maintained, but the range of activities encompassed within these roles changed as an increasing number of novel responsibilities fell on them. This led several of them to feel that their identities were being subsumed within the carer role. Accepting identity to be an external or social description of the self, developed through roles, relationships and values (Christiansen, 1999), it became evident that participants faced new challenges keeping their identity as an employed man, particularly as the value they gave to paid employment changed in distinctive ways when they became carers. They no longer experienced employment predominantly as a career. They now talked of it as an alternative form of respite or simply a way of ensuring financial security. Findings suggested that the range of diverse activities participants undertook as family man, carer and employee constituted the roles they fulfilled. They referred to an internal unease between the roles of being a husband and being a carer, particularly when being a carer meant they had to become more direct in the way they related to their relative, thereby changing previous relationships. In retaining the identity of being a husband, participants talked of how the activities they undertook extended into roles previously undertaken by their wives, such as managing the home. Similarly with participants who were son carers there was a change in previous relationships as they provided increasing care to their mother. Having sole responsibility for the practical management of the home and the frequently complex management of their relative's care meant that all participants were fulfilling the role of carer even if they did not attribute this label to their activities.

When talking about employment, participants reported a loss of former roles when they made decisions to leave or reduced paid work. Some talked about how others perceived them as not achieving their full potential, or saw them as lazy men because they were not fulfilling the paid work roles attributed to them. When participants left employment there was the potential for their identity as working men to have been lost. However, it emerged that they experienced caregiving as a form of unpaid work and therefore retained the identity of being a working man. Participants also reworked their identities

and new identities were embedded within their experience of being a carer, so they described themselves as professional carers and expert carers.

Discussing these findings through four emergent categories made it possible to understand how participants struggled to retain their identity and the sense of self they had before becoming a carer. Also there was evidence of how the experience of being a carer changed the meaning of being in a spousal relationship and being an employee thus leading to a restating of who they were.

The family self: Participants referred to their relationship with the care-receiver and discussed shifts in responsibilities and roles between their self as a husband, father or son and their self as carer. Further, the changing relationship in spousal couples resulted in the experience of losing the reciprocal nature of the relationship. Participants spoke of their relative's disease as a third element in their relationship.

The lost self: Here participants described the ways in which being a carer seemed to wholly subsume their lives. Being a carer meant making changes to their future plans, often leading to a loss of expected life trajectories.

The employed self: Some participants were able to remain in employment and maintain their identity of employed man. However, others left employment, developing an identity as a working man through experiencing caregiving as their employment. At times the identity of being an employed man was linked with their sense of possessing what they perceived as characteristics of being a working man. They discussed reworking their identities to accommodate changing roles, changing relationships and changing employment status in terms of it resulting in a distinctive change in their sense of self, of who they were, leading to a fourth theme discussed as:

The reworked self : Here new identities were described as being formed. Frequently these identities were seen to reinforce the role of carer, with participants explaining that they were now a resilient man and an expert carer.

The chapter closes by drawing together the findings to discuss how caregiving changed participants' relationships with their relative and led to uneasiness with their sense of self. This was particularly evident in spousal caregiving relationships, where participants experienced a change in the roles they undertook and they talked of this leading to a change in their sense of who they were and what they did in the relationship. Most found their previous identities, perhaps breadwinners, perhaps

sportsman, were lost but they strove to rework new identities. There is discussion of how these new identities, such as expert carer, may have helped increase self-esteem.

The family self

All participants were caring for a relative. Throughout the interviews there were times when participants referred to themselves as a husband, son or father and other times when they referred to themselves as a carer. When they talked about their reason for undertaking care of their relative, they usually referred to themselves in their family role. For example, Jack said, 'I look upon myself as a father looking after his daughter'. Daniel went further stating, 'I don't think I am a carer, I just think I am my wife's husband'. Daniel described the characteristics of a carer, indicating he did not meet the criteria, 'I was at work and I thought, well, carers are probably a bit more full-time'. This comment suggested he had preconceived ideas of who can and cannot take the label of carer.

Nonetheless most participants did, at some stage in their interview, refer to themselves as a carer, although this may have been due to the information they received before participating in this study. Participant information leaflets raised awareness about the study aims, namely to explore the experience of male carers. When they used the word carer it was often accompanied by a phrase which placed limits on such an identity, suggesting a desire that their relationship not be turned into one of carer and cared-for. Peter illustrated this most effectively when through his narrative he continually referred to himself as a carer, whilst repeatedly situating his caregiving within the marital relationship.

Peter said 'that was my decision to become a carer', yet his narrative highlighted unease between carer and husband roles. First, he talked about telling his wife 'I'm here to look after you and that's what I'm going to do'. Then he spoke of becoming frustrated, as he did not feel able to fulfil the role, 'I give up work to be a carer for her and she doesn't allow me to do that role'. This comment suggested that roles might need to be formed in collaboration with others in the social setting. There was evidence Peter and his wife had both made a readjustment to their roles when he left work to become her full-time carer. He explained they had to 'work at it', but from the perspective of being a married couple, 'as if you're married husband and wife, rather than a carer and cared-for'. He went on to describe why it was important for him to retain the relationship of husband and wife, saying if you did not then 'you start looking at it purely as a job, rather than

being part and parcel of being married'. This explanation suggested that for him, it was important that he provided care not as a job but through a marriage obligation.

In several participants' narratives it was unclear at what stage in their carer career they start to think of themselves as carers, however John was explicit about the time he recognised himself as a carer. He had provided support to his wife who had had mental health problems since their marriage thirty years ago, yet it was only recently he experienced others calling him a carer and thereafter recognised his activities as caregiving. He explained he was, 'just her husband who went along to appointments'. It was health care professionals who informed him that as a 'carer' he could access support groups. He described how the label of being 'officially a carer' enabled him to access support and improved employment rights. There were benefits to accepting this label but his self-acceptance of the carer role was not immediate. In the second interview John explained he now felt more of a carer as he could instigate tangible activities to support his wife. In the first interview he was merely taking steps to protect himself from her mental health problems; by the second interview they were both attending therapy and he was able to help her do specific exercises, thereby offering endorsed practical help.

Most participants only referred to themselves as a carer at the beginning of the interview when they were outlining their caregiving role and activities. After this most talked about their roles either without referring to any specific identity or activity they undertook in order to support a relative, through love for their relative Although participants tended not to refer to themselves as a carer, through their conversations it became evident that their identity of husband, father or son was becoming lost within the work of being carers, as they spoke more of the tasks they had to undertake to support their relative than of the ways in which they retained their relationship. Recognising changes in their relationships, they explained how activities that previously defined their relationship with their relative had now been lost.

Loss of their wife

All participants who were caring for their wives specifically referred to changes leading to loss of the type of relationship they previously had with their wife. Nonetheless whilst the dynamics of, and roles within, their relationship were changing, their sense of self was embedded within the more expected roles they undertook as husband and provider to the family.

Percy described himself fulfilling a traditional role of husband:

> *Ours was an ordinary marriage and I went to work all day and she was housewife all day so it never occurred to me to learn how to iron a shirt or how to turn a washing machine on or, you know, any of the other jobs that women just take for granted*

In four cases the participant's wife had worked alongside him in paid employment contributing to both the domestic and employed work of the family. Consequently as her condition deteriorated participants explained how they experienced the loss of their wife's input into their employment as well as her management of the home. Samuel captured this significant loss and the impact it had on him:

> *She did quite a lot of work within the business, so over time she couldn't do so much in the business so that was sort of shelved to me and then she wasn't able, to do the house so then that came onto me as well*

Participants talked not only of the loss of the practical input of their relatives but also of how the company and emotional sustenance they previously drew from their wife were also lost. When the care-receiver's illness affected their communication and cognitive skills it affected the participants' experience of being a carer. For some the loss of conversation increased feelings of being alone. Bert captured this, saying, 'there's a lot of loneliness now because my wife can't reply'. As his wife's illness deteriorated he described 'losing contact with each other'. Whilst for some the sharing, communicative relationship they had previously had with the care-receiver was lost, a few participants described the pleasure they got from the smallest indication that their relative was responding to them. Bert described his wife's smile, her only means of communication, as being 'worth a million dollars'. Percy also sought signs of his wife responding to him, 'she'll give me a bit of a funny look now and again just to let me know there's still something going on upstairs'. However, he was also aware of the inevitable decline in her condition, 'but I suppose eventually that will disappear altogether', instilling a sense of complete loss of his wife. Bert explained that being unable to communicate effectively with his wife created more distress than providing physical care:

> *Well mentally…it's harder and harder when you can't talk to her, certainly can't communicate back, that's the hardest part, the physical side of it there's no problem*

When the care-receiver's communication skills were not affected, the caregiving relationship created an opportunity to increase communication and togetherness. Peter, whose wife experienced a physical disability rather than a degenerative disease, left employment to care for her and they now spent more time together than before her

disability. Peter explained they 'do a lot more things together again now'. Andrew, however, captured the reality for most other husband participants when he explained how the sense of being alone went further than just conversation. His wife's illness meant he now had sole responsibility for all activities and decisions undertaken in their marriage. He described this as:

> *It's like being single again, but it is actually worse than being single because not only do you do it for you you're doing it for someone else as well, so you're doing it for both*

He explained that not only did he have to manage the house he also had to be thinking about his wife's needs. He went on to express how his life differed from his peers:

> *Sometimes I look at other people my age who are married, and people we know and their wives, and you know, they do things we just can't do, we can't even think of doing*

Participants changed their perception of themselves as the nature of the family relationships changed. Samuel explained a marriage should be about equal partners 'in a marriage you would expect it to be sort of like fifty-fifty'. Now that he did all the organising he described how his personality had changed. He described himself as 'being a bit dictatorial and bossy'. He did not perceive these as positive characteristics but explained he had to take on this character if any activity was to be achieved.

The concept of marriage as a partnership was found in several of the participants. Peter explained how he and his wife supported each other:

> *I'll try and help and give her the support the same as she does for me, even you know, considering that she is the cared-for, it's just a fifty-fifty.*

However, whilst he said it is 'fifty-fifty' he still defined their roles as carer and cared-for. Throughout his narrative he moved between expressing his role as that of husband whilst in the same sentence referring to himself as carer. It may be that these two roles were synonymous for him. Alternatively it may have been that he needed to find a defined role as carer to justify his decision to leave work whilst in his forties.

The experience of being a family man was changed because a member of the family had experienced either a disease or a trauma resulting in them requiring care. Some participants made explicit reference to their relative's disease, suggesting that they too were living with the disease.

'Us' and the disease

Where the health condition had not impaired the care-receiver's ability to communicate there was evidence of the couple joining forces against the disease. There was talk of laughing together and of accepting the changes that were happening. Philip described it as, 'the two of us and the MS which is impacting…coming into the circle of the relationship'. For John, an improvement in his wife's condition between interviews led to him saying that he can now see a future, 'where it is not always illness, illness, illness'.

For others, however their relative's illness was always present and this led to a sense of uncertainty. George, whose wife had experienced a couple of traumatic hospital admissions, explained:

> *It leaves you with that feeling of uncertainty all the time, I mean it seems stable at the moment, things go on, but I mean it could change at any moment and without any warning.*

The effect of this uncertainty was captured by Jack, 'it's at the back of my mind all the time…So it cuts back on the relaxation', illustrating the way in which participants experienced being a carer even when they were not physically doing any caregiving activity.

Whilst those participants who were husbands experienced a significant change, specifically in the dynamics of their marriage, in a more general way all participants found that being a carer became a role in which they became immersed. Sometimes such change led to positive outcomes but more frequently less positive consequences were experienced.

The lost self

Previous identities of husband, father and son became lost within the roles participants now took in providing care. For most being a carer became all-consuming and their sense of self outside the relationship was lost, including the social self. Several also experienced a loss of what 'might have been' due to a change in their previous life trajectories.

Carer – an all-subsuming identity

To some extent all participants said that their life now revolved around the care-receiver irrespective of their relative's level of disability and support needs. For some this meant placing their needs at a lower priority then their relatives:

> *I eat when I feel I need to knowing that I can't eat when she'll got to be eating hers (Jack)*

For John the mental health problems of his wife meant that his evening activities were curtailed:

> *I can't put the TV on, I can't cook anything until she goes to bed (John).*

Whilst John was specific in what he could not do, Philip was less specific, but provided a picture of all his whole life changing because of his wife's illness:

> *You try to live your life around it, but it does slow you down put obstacles in your way (Philip)*

Participants expressed both positive and negative feelings about the experience of having personal needs subsumed by the care-receiver's needs. Bill, whilst acknowledging that his life was 'governed' by the needs of his son, explained that being a carer gave purpose to his life. He said his son was his social life, and keeping active caring for his son meant he had not had time to become depressed following the death of his wife and his subsequent exit from employment.

For other participants the experience was not as positive, especially as their ability to maintain alternative identities was affected by the care needs of their relative. Daniel explained how his opportunity to undertake hobbies had been lost, however he holds on to the hope that he will be able to resume them:

> *I'm still thinking about selling my motorbike because I don't use it, I don't get a chance to go out on it on a weekend go to Yarmouth with the lads, just not the time to do it…I'm just hanging on and hanging on to it just in case one day I get a window of opportunity to go for a ride for a couple of hours down to anywhere*

It may be that through holding on to his bike he was trying to hold on to a past self when he was a man with the freedom to join friends and ride motorbikes.

Philip also described how his wife's needs subsumed his own. She had Multiple Sclerosis and continued to work full-time with adaptations to the workplace. He explained that he 'revolves' his life around hers. However, here it was the demands of her employment coupled with her disability which constrained his activities, 'in essence

her job tends to over-arch everything, because of her condition, if she didn't have the condition she has with MS, she would be able to do it all a lot quicker'. This highlighted the complexity of relationships, raising awareness that it is not always just the illness which caused changes to the relationship.

Participants expressed frustration when their personal needs were continuously subsumed by the needs of the care-receiver. John said he thought his wife should have supported him when he went for a monitoring visit following his cancer treatment, but she did not fulfil his expectation. He said:

> *On my special days it still revolves around her rather than being my day, you do feel angry, because I think those days she should be supporting me not the other way round.*

This extract illustrated the change in the nature of the marriage relationship. Whilst some participants had cited reciprocity within their marriage as a reason for undertaking the role of carer, in John's case, and others, the balance in the relationship had changed with some participants no longer experiencing a reciprocal relationship. Not only did participants talk of changes in the nature of their relationship with their relative, there was also talk about the experience of living within a world where the disease changed the abilities of their relative.

There was an overriding sense of loss within participants' narratives. There was the evident loss of employment, loss of their relative's skills but also a loss of potential opportunities and future plans.

Changes to expected life trajectories

All of the participants spoke about their life not being what they had expected it to be. For example, Daniel explained how he and his wife had planned that she would find a job and they would build a family home. However, her illness had stopped this happening. Linked with roles and identities, several participants spoke of a sense of losing their shared identity of husband and wife, particularly as the needs of the care-receiver increased. Percy captured the change in his life trajectory explaining he and his wife had planned to retire and travel but now 'you can't make plans, plans I had all went out the window, so I don't bother any more'.

The participants who were not spousal carers spoke of the loss of their expected life trajectory in different ways. Bill and Jack, carers for their adult children, described the loss of hopes they had held for their children. This was expressed in different ways to

the loss of partnership experienced by the spousal carers. Bill explained that prior to his traffic accident, his son had held a good career but following his accident he had experienced brain damage. Bill described it as 'like training a baby that was twenty years old'. However, caring for his son provided a role for him since the death of his wife and on reaching retirement age:

> *I've seen people when they retire they just sit back in the chair and don't do anything, but with my son I have to have him up in the morning*

And there was also an element of companionship in their relationship, suggesting a degree of reciprocity:

> *I enjoy his company and he enjoys going, and he sees a lot of people up there that he knows so it's quite enjoyable for both of us really*

However, the situation was different for Jack whose daughter has been profoundly disabled since birth. He had no expectation that her condition would improve and there appeared to be very limited communication or personal benefit from providing care. Rather, Jack appeared to accept this was the decision he had made and now he just had to get on with it, 'just do it, it's routine, don't think about it, got to be done, just do it'. Yet there was a degree of recognition that this is not a usual type of father daughter relationship: 'it's not what should be happening'. Jack went on to describe how there was little reciprocity in the relationship and providing care became a source of stress, 'you're doing it all and the stress is added to, not her fault, I know it's not her fault but you don't get that back, you don't get that back from her, it's not her fault I know it sounded, perhaps sounded greedy'. This comment captured the complexity of emotions experienced by participants who became increasingly burdened by the demands of caregiving yet who understood their relative did not chose to place such obligations on them.

Martin and Charles cared for their elderly mothers, and neither of them referred to loss of companionship, although Charles had been living with his mother for some time before she became ill. Rather their loss was expressed through the loss of opportunity to do things in their life. Martin explained his social life had been curtailed by his carer role; Charles left employment between interviews in order to provide a higher level of care for his mother.

Even when participants provided similar levels of care to their relative it appeared that participants who were spousal carers experienced greater life changes and loss of companionship. It might be that the meaning participants attributed to caregiving were

influenced by their relationship to the care-receiver. Within the home participants experienced a variety of roles and identities: they were husbands, sons and fathers, yet they also spoke of being carers. The time demands of fulfilling their carer roles meant that frequently they did not have the opportunity to undertake other activities which had previously shaped their identities, such as sport and employment.

The employed self

The employed self was illustrated in two ways. Firstly, those participants in employment had an identity as being an employed man, evidenced through the ways in which they drew their paid work into their narratives. Secondly, full-time carers created an identity of a working man through the way in which they spoke about their caregiving roles and activities. A masculine identity appeared to be linked with being in work.

Merging the employed and carer self

Whilst some participants experienced an overlap in the workplace of carer and employee responsibilities, the meanings they attributed to being an employed man went deeper than the practicalities of managing caregiving activities within a limited time. There emerged an experience of having dual identities, with occasions when the responsibilities of one identity shaped the experience of the other.

Sometimes the dual identities were experienced on a pragmatic level, such as when they talked of using skills from their employment in their carer role. For example Andrew talked about how his engineering skills had enabled him to adapt equipment for his wife. However, being a carer also influenced the experience of being an employed man on a more conceptual level, affecting participants' sense of self as an employed man. They no longer experienced employment as a career, rather it became a means of providing financial income or a form of respite from caregiving. Philip captured the way in which employment was no longer a career when he discussed how he changed his employment to enable him to manage his carer responsibilities.

Philip had changed jobs twice over the past few years and he spoke at length about the nature of the work he now undertook and the sense of self he had within this job. He moved from a senior teaching job to working for a charity, explaining his priority had been to seek a job with regular hours and limited travelling. Such employment enabled him to undertake household tasks before leaving in the morning and to return home in

the evening in a less than exhausted state. Yet changing jobs to ease the strain of being a carer changed the meaning of work for him. He described his current employment as being operative level rather than managerial. He repeatedly stated that he could work at a more demanding level, but he also recognised that more demanding work would have consequences on his role as carer,

> *I feel I could be doing more but if I do, something would give, it would either be my health or her health, her job role or my job role or whatever, something would go*

It appeared the nature of employment had changed for Philip. He captured the fact that employment occurred within the present time and he gave little thought of long-term career plans. He described how he was 'treading water', experiencing this employment 'as a job versus a career'.

Although other participants did not explore the nature of their employment in such detail as Philip, they still explained the well-being of their relative was more important than their paid work. Percy said, 'she comes first, I mean if I was at work and something happened I'd just shut up'. Whilst participants spoke of the daily challenges of accessing employment, none refer to their employment as a career, rather paid work was an activity undertaken to ensure financial security, a sense of achievement or respite from caregiving.

The 'breadwinner'

When asked why they worked, participants said they worked for the money. Most had mortgage commitments and one man spoke of having debts to pay off. Daniel explained that because of his wife's illness she could no longer contribute to the monthly income:

> *I thought it was going to be okay even if I paid the mortgage, two thirds perhaps and my wife paid one third when she was working I thought we'd become quite comfortable, but no we haven't been comfortable at all, it's just me.*

Again this extract captures the sense of being alone and solely responsible for the welfare of the family.

Percy differed from other participants; he worked part-time time, employing private carers for his wife and as a result did not derive financial gain for being in employment. Nevertheless he experienced different rewards from employment, rewards intrinsically linked with maintaining a self away from being a carer.

Employment for respite

Whilst a few participants spoke of the benefits they gained from being in employment such as contact with other people and financial income, Percy was the only one who explicitly stated that he undertook employment as a break from being a carer:

> *I've got to work, I actually lose money going to work, but you've got to put some value on your sanity, I couldn't sit in here twenty-four hours a day, seven days a week, I'd be up the wall, so this is as much for therapeutic reasons as financial gain*

Whilst there were challenges involved in combining caregiving with employment, such as balancing responsibilities and managing both activities within the time available, there were benefits to being in employment. These benefits were financial and less tangible in that being in employment provided an alternative identity to being a carer. This was captured by George who, when asked how he would describe himself, replied 'I'd say I own a shop and that's all'. Those participants who had left employment maintained an identity of a working man through constructing the caregiving experience as a form of unpaid work.

Caregiving as unpaid work

Participants experienced work, both paid employment and unpaid caregiving, as integral to defining who they were. Participants who had left paid employment, whilst still describing the employment they had previously undertaken, also reworked their identity as a working man through giving status to activities they now undertook in their carer role. They developed self-identities that highlighted the managerial aspects of their care work, rather than the more feminine, emotional and intimate personal care aspects of the work, describing themselves as a home manager and professional carer. In doing this they appeared to link their role and work to managerial and expert occupations within the health and social care sector.

Martin captured this reworking of identity when he described himself as 'self-employed in that I'm running a nursing home with one resident'. He made a direct link with paid employment through being self-employed and highlighted the management role of running a nursing home. Samuel gave status to the role of carer explaining he told people he was leaving work to become 'a professional carer'.

Yet Samuel expressed tension between the roles of carer and husband:

> *Professional's not really the right word is it? Because a profession is something you do as a job, and I don't do it as a job I do it because I want to do it, I need to do it*

This quote confirmed the finding that participants undertook care out of a duty to their relative, but the committed obligated nature of the role could lead to them experiencing caregiving as a job. Several participants spoke of their caregiving activities in ways that mirrored the language of paid employment. They spoke of having days off, of having to learn new skills with this job and of taking on new roles such as 'cook, nurse and hairdresser'.

The importance of both paid employment and unpaid care work to shaping their self-identity was reinforced when participants spoke of their work identities both in current and past employment situations.

A man at work: a masculine self linked with employed man

For all participants it appeared that paid employment provided them with a masculine self whether this was a man amongst other men, or a man providing for the family. When they left paid employment there were consequences for this masculine self.

Participants who left work spoke of their previous employed identity. They provided examples of how their current activities as a full-time carer mirrored those they had undertaken in employment. Bert explained:

> *Before I go to bed I put all my bits and pieces there… before we go out I tidy everything up so when we come back home everything is spick and span, but I was like that at work all through my working life*

Martin explained how he made lists of things to achieve in his day, describing how in employment he had, 'always been quite organised … I worked in a small team and everybody used to say you drive us all nuts because you're so organised'.

This suggested that their sense of self remained embedded in past routines rather than current roles. Beyond the mirroring of employment attributes to carer activities, all the participants who were full-time carers spoke about aspects of paid employment they missed. They missed the camaraderie, the opportunity to talk about football, the responsibility and status which had been embedded within their employed roles. Bert spoke about his identity at work, describing himself as a 'man's man' who misses 'being with men at work'. He went on to talk about the responsibility he had for junior

colleagues. Nonetheless he appeared to have added to his identity, as he now described himself as a 'domesticated man'. Whilst none of the participants explicitly spoke of feeling less of a man now they were in the carer role, several did provide narratives which suggested their sense of self was challenged by being a carer.

Peter, who became a full-time carer in his forties, explained that being out of paid work impacted on his responsibilities as a man to support his family. Peter captured this when he talked about living on social security benefits:

> *She has to initially apply for all the benefits and everything, I ain't going to say that's make you feel second-class, but, you sort of do sometimes feel, really that was supposed to be that's my job to provide and, sometimes that can get you down a little bit*

Later he again referred to living on benefits, this time stating that he had to 'go cap in hand' to charities for help. Although this image captured a disempowered man, other aspects of his narrative suggested Peter was reworking a masculine identity. He spoke of himself as a provider, 'if she needs anything to be done and I can sort of do it' and took this further, explaining, 'my legs become her legs'. He also acted in a controlling way when she tried to be independent, 'I'm afraid I do have to keep telling her about it because she keeps trying'. The two participants who left employment near to retirement age did not refer to receiving benefits in the same way as Peter, rather they explained they had worked and paid taxes and were now accessing what was due to them. Nonetheless they still had financial concerns due to a reduced income.

Of all the participants Jack appeared to have experienced most comment from others about his role as a full-time carer. Jack's narrative developed the concept of what is an acceptable role for a man when he explained:

> *In today's world a lot of people they just look upon it as it's not a man's job. I feel they think it's strange that a father should look after his daughter you know … I get the impression that they think it's wrong and I shouldn't be doing it because I am a father looking after her daughter*

On being prompted about why he had such an impression he replied, 'Why, the lack of respect they seem to have for me'. With further probing Jack explained he perceived people expected him to be in employment rather than being a full-time carer, suggesting the issue was not completely related to his being his daughter's carer rather to his not being in employment. He developed this further, saying he believed other people thought he was lazy because he was not in employment, 'like my sister, I believe, she believes I should go out to work'. However, another layer of meaning could be seen

within this extract because Jack does not say that his sister has ever said he should go out to work, rather this is what he feels she thinks. The importance lies in the meaning that Jack gives to his sister's responses, whether this is her meaning or not.

Philip also described how his family disapproved of his choice to care for his wife explaining:

> *My mother thinks I should certainly be doing something different in terms of like if I didn't have a wife to care for I would be in a better job in a different place, so in some ways I think she thinks that my wife has held me back, right across the career spectrum*

As with Jack it was only possible to capture Philip's perception of his mother's opinions, but again there appeared to be an expectation by others that he should be in a certain type of employment.

Percy did not say that he had received comments from other people but he did perceive himself as different to other men although he had a more positive view of how he differed.

Percy spoke with pride:

> *Apparently I'm quite rare, I think I was the only one who's round here that's ever took anybody out of care, most blokes are able to leave their wives here and go out and enjoy themselves but I couldn't do it, so they thought it was a bit rare when I said I was taking her home*

The development of a masculine self appeared embedded within the nature of work undertaken by the participants. Being in employment provided opportunities to fulfil the breadwinner role and to create an identity separate from carer. After becoming full-time carers these men still spoke of who they had been in employment and referred to the skills they had transferred from employment to caregiving. Further, they spoke of caregiving as work and created an employed identity for themselves. Being a carer, whether in or out of employment, also created the opportunity to rework identities other than employed man.

The reworked self

Through being a carer participants appeared to develop new identities. Talking of themselves as resilient men and expert carers enabled a positive image to be presented to others.

The resilient self

The resilient self appeared through participants' attitudes to coping with the carer role. George explained how he just had to get on with the role:

> *Some people seem to make, a real trial of it, but you know, it's something that you need to do, no good whinging about it [laughter], get on with it*

Whilst several stopped to question why this life-changing event had happened to them and their relative they appeared to accept their situation and seemed determined to manage it the best way they could, making decisions which suited them and the needs of the care-receiver at that time. They appeared to do the job without stopping to reflect on the choices they had made and consequences to them of being a carer. It may be that this unquestioning acceptance was a defence mechanism. Percy explained that sometimes he thought:

> *Why me and why her and in time that just passed to well, you've got to get on with it you can't do anything about it, so just do it the best you can and look after her the best you can*

With the acceptance of their roles there came a desire to be good at this new activity and a few participants described how they learned new skills and now considered themselves expert carers.

The expert carer

The expert carer identity emerged when participants talked about how they learned new skills, the level of expertise they had in providing care and in how as experts they offering advice to other carers. Most participants explained they had learned how to manage domestic tasks such as cooking and cleaning. Whilst some were reticent about their ability others took pride in their achievement. Bert took pride in his ability to provide not just for him and his wife but also for others:

> *I can rustle up a meal, what we've got in the freezer or in the cupboard, say like a friend can come down for the day, I mean, I could give us a meal*

There were several occasions where participants spoke of the support they offered neighbours and other family members, suggesting that they remained aware of responsibilities to others.

The sense of self-belief in their abilities was also evident when participants talked of being able to provide better care for their relative than a nursing home could. Martin

described how in a nursing home his mother would be 'one of many and her needs would not be met'. He said he could care for her 'better than anyone else'.

Other participants focused on specific skills. For example, Jack said he always put his daughter's spinal brace on so that he then knows it has been done correctly. Andrew explained how his way of moving his wife was preferable to the method suggested by health professionals:

> They have their techniques and I started their ways and I thought no some of these are not as good as we could get so we have our own techniques how we do it

For a few of the participants, specifically those who accessed carer support groups, there was an opportunity to share their expert knowledge and skills. Within this setting new identities were formed. Peter took on the role of chairman of a carer support group, explaining how he was able to share experiences through this work. Percy referred to himself as an 'expert carer', describing the unique understanding he had gained caring for his wife with early onset dementia. Martin undertook paid voluntary work, running drama workshops for carers, enabling him to combine former employment skills with his developed carer knowledge and skills.

In creating new identities participants focused on their strengths and previous employment skills. When talking about their caregiving they exposed positive character traits, such as resilience, coping and expert knowledge.

Summary

These findings illustrate how participants experienced at times unease and discontinuity between their identity as father, son or husband and carer. For example, as a husband they described that they should be providing for their wife, but being out of employment they were reliant on her benefits. The role of carer could become all-consuming leaving space for no other identity. Nonetheless some embraced the identity of carer and developed new identities within carer support groups. Others accepted they were carers, but still felt uneasy with this new identity and the way in which being a carer affected their relationship with their wife. Employment provided a defined identity of a man who could provide financially for his relative. However, concessions were made about the type of employment which could be undertaken, and these impacted on the participant's sense of being a man with a career. Those carers who had left employment spoke of caregiving as a form of work and constructed an identity of a carer at work. It appeared

that the perceptions of others had limited impact on the participant's sense of self and most participants were able to rework identities and present an identity of being a resilient, expert carer. These findings raise three points to be discussed further in Chapter Eleven.

First, the uneasiness participants experienced between roles may have resonance with the decisions they made to undertake the care of their relative. If, as suggested in the findings related to 'Being a carer' in Chapter Seven, the role of carer was undertaken out of obligation linked with marriage vows, then when a substantive change happens in the relationship the man may have to rework his identity and re-justify his decision to remain a carer.

Secondly, findings highlight the importance of work, both paid and unpaid, in the construction of identity for these men. There is little current empirical literature which explores the way in which male carers construct caregiving as an alternative form of work. Further exploration of this concept may increase understanding of how male carers give meaning to the phenomenon of caregiving.

Thirdly, taking the identity of carer has been seen to enable these participants to rework new identities which increase their sense of self-esteem, through becoming an expert carer and a man who can cope with the carer role.

Accepting that findings within a hermeneutic phenomenology study are interpreted and so cannot be held up as an absolute objective truth the following chapter offers a reflective account of how the design and implementation of the study provides a context within which to generate new understandings of the experience of being a male carer.

Chapter 10 Reflecting on the study

Introduction

Throughout this study a reflexive stance was adopted, enabling recognition of personal subjectivities and conscious awareness of how the design has impacted on the knowledge claims which may be made. This was especially important in that as a woman who was not carrying these types of caregiving responsibilities, I would need to take particular care to address and not impose the different experiences and assumptions I might be bringing to the research and to my encounters with male carers. Such a reflexive stance is congruent with hermeneutic phenomenology where the researcher is an integral tool in the data collection and analysis (Holstein and Gubrium, 2003). A number of strategies have enhanced reflexivity, including use of a research journal, sharing stages of the study with a panel of experts, and sharing aspects of the study with the wider academic and care community.

Procedural decisions and also personal insights, particularly during data analyses, were recorded in a research journal, encouraging an open and questioning stance. This enabled recognition of new and alternative meanings (Finlay, 2003). Referring my work to a panel of seven experts, including a member who was a male carer, a nurse working with carers and academics from social care, occupational therapy, physiotherapy and sociological professions, provided the opportunity for drawing on diverse perspectives to probe and offer challenges to reflect over the whole research process on decisions and problems encountered through the study. Aspects of the study, including my use of narrative summaries and findings relating to support networks and care as an alternative to paid work, were subject to peer and lay review at a number of conferences. The responses from these audiences helped build a sense of the validity of this work and of findings having resonance with others' experiences.

This process of continual challenging helped ensure I remained alert to the strengths and limitations of the study. Critiquing the study provides an epistemological context for claims to be made within the discussion chapter.

The strengths and limitations of this study are discussed under the following headings.

⇒ **Obtaining and using a purposeful sample**: The effectiveness of recruitment procedures are discussed, including reflection on how the diverse characteristics of the participants added to the transferability of claims.

⇒ **Collecting phenomenological experiences**: Using the narrative summary presented methodological challenges and there is a critique of how those challenges were mitigated. The methodological rationale for using follow-up interviews is justified in terms of the way in which the stories that participants told became more experiential, adding to an understanding of the phenomenon.

Obtaining and using a purposeful sample

The methodological aim of recruitment was to capture the experiences of male carers in a variety of caregiving situations, as to do so would strengthen claims that essential themes may be transferable to other male carers. Male carers, both known and unknown to statutory services, were recruited as it has been proposed that those men who access services may constitute a unique group who are either comfortable seeking help or who experience greater strain than their counterparts (Bookwala et al., 2002). Men in a range of relationships with the care-receiver were recruited, as there was evidence that the relationship of the male carer to the care-receiver may influence the nature of such experience (Harris, 2002). Sampling also took place across the characteristics of the care-receivers' illnesses, as the majority of studies exploring the experiences of male carers have recruited men caring for relatives with dementia. Those few who have recruited from younger men whose relatives have physical disabilities, rather than dementia, suggest that there might be differing experiences (Parker, 1993). To capture such a diverse range of experiences, several recruitment methods were used with varying success.

Using recruitment emails through employers was an innovative method designed to capture hidden carers and specifically male carers in employment, but only one participant was recruited using this method. Within the confines of this study, only one employer provided access to their central staff email and others placed flyers in staff rooms and published the study in internal magazines. There was reluctance amongst employers approached to participate in the study, with many stating that none of their male staff were carers. Recruitment letters sent via Crossroads for Carers were the most successful recruitment method. These participants had varying levels of support from

two hours a week provided by Crossroads to five days a week day-care for their relative. Nevertheless, there emerged similar descriptive categories in all interviews, suggesting that the findings may be transferable to male carers who are both known and unknown to statutory bodies. Whilst recruitment through employers was limited in this study, if future research is to capture the experiences of hidden carers it remains important to consider alternatives to participant introductions through carer support services.

The findings captured only the experiences of those who came forward for the study; one cannot know the stories of those who chose not to participate. Further, one cannot know the motivations of those who self-selected to take part, and it may be that they had a distinctive story to tell (Karnieli-Miller et al., 2009). It is acknowledged that the homogenous racial or ethnic nature of the sample, all white British, may make these findings difficult to generalise to culturally different male carer populations, specifically as studies recruiting from ethnically diverse groups have found that black and minority ethnic carers may well have different experiences grounded within differing cultural expectations (Katbamna et al., 2004). Although purposeful variation sampling (Patton, 2002) ensured that a range of caregiving experiences were captured the findings may not be representative of all male carers. However, findings do illustrate individual experiences within a broad social phenomenon and, through reference to empirical literature, Chapter Eleven further explores the resemblances of findings from this study with those of the larger caregiving populations, providing the opportunity for others to 'judge the soundness of the generalisation claim' made in the conclusions (Kvale and Brinkmann, 2009:263). Sampling in future studies should aim to include younger employed men from a wider range of employment situations to explore whether similar themes arise. It may also be that men who care for a relative with an acute illness experience caregiving in different ways to those whose relatives require intensive caregiving over substantial periods of time.

A strength of this study is that all participants were the primary carer who lived alone with the care-receiver. This is a strength as their caregiving was unsupported by wives, daughters or siblings, therefore they experienced quite minimal levels of informal support. This may be important because other studies have found that son carers in particular will draw a high level of support from their wives (Horowitz, 1985; McFarland and Sanders, 1999; Gerstal and Gallagher, 2001), thereby potentially changing the nature of caregiving they undertake and the subsequent meaning they give to their experiences.

Collecting phenomenological experiences

To address the possible limitations of single interviews, namely difficulty with recall, articulation and uneasiness with the researcher within the interview process (Seidman, 2006), the decision was made to interview each participant twice. Using sequenced interviews prolonged engagement with participants which helped to increase trust and rapport. However, sequenced interviews alone may not have actively involved participants in sharing meanings, therefore the narrative summary was provided before the second interview. The narrative summary aimed to engage participants in further reflection and this coupled with the follow-up interview enabled the meanings of being a male carer to be explored in greater depth as participants had time to reflect on and added to earlier responses. Nonetheless, using narrative summaries presented ethical and methodological challenges. There was the ethical concern of returning raw data to participants, as this might result in concerns about the information they had shared and the ways in which they had presented themselves (Forbat and Henderson, 2005). The methodological challenge reflected the nature of knowledge, namely would the meaning of experiences change over time and if they did, was this still congruent with the phenomenological stance that people give meaning to phenomenon in a pre-reflective way. Two examples are drawn on to critically examine how far narrative summaries and follow-up interviews may have enhanced the methodological aims of this study. There then follows a discussion of how this innovative methodology remained congruent with the philosophical position of the study.

Using the narrative summaries

Narrative summaries appeared to provide an effective method for developing rapport and trust with the participants, as they were able to see how their data had been interpreted and whether their accounts were sensitively handled. They also offered the opportunity for prolonged engagement and the observation of caregiving over time, as there was at least a four-month time lapse between the first interview and the follow-up interview. This time lapse meant that participants could see that I had maintained commitment to them as members of the research project, helping to build trust between us. This time lapse also meant I could begin to find meaning in the individual accounts in preparation for deeper exploration of the phenomenon in the second interview. Participants' comments also helped illustrate how using narrative summaries, as a method, appeared to help in the building of relationships with participants and the

collection of richer phenomenological data, thereby enhancing the credibility of the findings. There is discussion of how the male carers found their narrative summary both empowering and challenging, highlighting the potential ethical issues of using this method.

Increasing rapport — increasing experiential data

A methodological purpose of the narrative summary and follow-up interview was to enable a developed rapport with participants, which might enhance the communication between participants and myself leading to more multi-layered, experiential data in the second interview. The developed rapport and trust could be seen by the differing stories I heard in the first and follow-up interviews. The first interviews tended to offer a story of 'doing': for example descriptions of the activities participants undertook, the routine of their day and also much description about the care required by the care-receiver and the services who delivered this care.

An example of the 'doing' story is illustrated by an extract from Andrew's first interview. He is a full-time carer for his wife and during the first interview he told a detailed story of 'doing', of being occupied rather than emotionally experiencing being a carer:

> *I'll get up first and wash and dress and probably go and get the papers and then I'll go back and I'll get my wife up, that probably takes twenty minutes, half an hour by the time we've got her up …I empty the catheter, … and so I sort of undress her, clean her up if she needs cleaning, I'll dress her on the bed itself (Andrew first interview)*

This extract was typical of the data obtained in the first interview, providing a story of the activities and the adaptations made to the home. Whilst I tried to use questions to explore emotional responses, I was unable to capture the emotional experience of being a carer. However, in Andrew's second interview the conversation quite quickly moved from a description of activities to a rich, emotional tale of what his lived experiences were like:

> *I think the problem is, it's not so much what, how do you feel about cooking, it's how do you feel about doing them all…and that's the problem, yes it is, it is wearing on you because you, you're going to do everything, everything, nothing happens unless you do it… it's all down to you, whereas with other people it's husband and wife and you work together. I said it's like being single again but it's actually worse than being single because not only you do it for you, you're doing it for someone else as well, so you're having to do both (Andrew second interview)*

Using a methodology that incorporates follow-up second interviews has strengthened the study design. Personal experiential data were collected during the second interview and I suggest that the use of the narrative summary enabled participants to reflect on their experiences. This reflection alongside developed rapport appears to have facilitated the sharing of more concrete experiential data, thereby ensuring that findings could be grounded within an extensive data set.

Mis-capturing meanings - sharing meanings

Whilst the majority of participants stated that the narrative summary captured their life, one stated that he could not recognise his life in the account. Although my initial reaction was to be concerned by this response, the opportunity of the follow-up interview enabled me to explore this apparent mis-capturing of his meanings with this participant, which led to him dropping his initially presented 'coping' persona.

Percy did not recognise himself in the narrative summary from the first interview from which I had made interpretations which conveyed a sense of him having a 'coping' narrative; he got on and did the job. On discussing his concern that he could not recognise his lived experiences in this summary it became apparent that he had, perhaps unconsciously, told a 'sanitised' version of his experiences in the first interview. He stated that he didn't like to complain and just tried to make the most of his lot: *'I don't anyway sit there saying how hard it is, what you can and can't do because of it'*. An example of his increased confidence in managing the research interview was suggested by the fact that he had invited his statutory carer (whom he spoke of as a friend) to be present during the second interview. This person became a prompt for him to talk more deeply about his experiences, as she encouraged him to expand further on what his experiences were like. An example of how the description of his lived experiences developed could be seen when in the first interview he stated quite simply that when his wife was asleep he had time to do his hobbies: '*I do DIY when I get the chance, usually when she's asleep'*. His description had been interpreted as finding time for his own activities, but when we discussed it further in the second interview a different story emerged.

His lived experience was one of constant concern for his wife with snatched time:

> *I don't begrudge it, it's frustrating sometimes if I want to do something outside and you have to keep stopping I have to keep wary …check that she's alright, it can be very frustrating even if you've got some time outside…I couldn't live with myself if something happened because I was out there messing about instead of keeping an eye on her*

In the second interview part of his reticence to talk about emotional aspects was removed and he added to his experiences, thereby providing deeper insights into his lived experience. Although, these two participants provided the most distinctive stories of the emotional aspects of being a carer, additive data was provided in the majority of second interviews, frequently offered with direct reference to the narrative summary. Such consistent evidence suggests that the narrative summary and second interview achieved the phenomenologically-relevant aims of increasing rapport and adding richer experiential data to the study.

Empowering participants

One unexpected consequence of introducing the narrative summaries was that they empowered some participants to take ownership of their data and use it in a variety of ways. For some, the summary provided them with the opportunity to reflect on their life and feelings and enabled them to seek to make changes. For others it captured their life and enabled them to share their lived experiences with others.

Philip explained how reading his story made him realise how negative he had become and stated that he intends to make changes to increase the amount of support he gets with domestic tasks, such as gardening and cleaning *'it made me re-evaluate it…now I've seen it written down'*. He said he had not shared the narrative with anyone else. Bill described how the narrative so effectively captured the reality of his son's disabilities that he has shown it to his son's care workers as a means of helping them to improve their care.

Bert also shared it with his family, so that they could better understand his experiences. For Jack it was the means of showing his statutory carer how hurtful her passing comments had been to him. He explained why he showed her the narrative summary:

> *I just done it to put across how I was; how I had spoke to you and how you'd put it back into writing, and because that's not the thoughts that I would get out often and open, not being an open person so there are probably a few different thoughts in there she hadn't realised or hadn't heard of before*

These different reactions help to show the transformative nature of being involved in research and increased my awareness of ethical responsibilities not to cause harm to the participant (Elliott, 2005). Creating and deploying narrative summaries as a method not only engaged participants in the research process, thereby increasing the development of trust and rapport, but also provided a document which some participants chose to use to consider changes to their lives, or to share their experiences with others. I suggest this may go some way to providing participants with some immediate outcome from the research they freely give their time to.

It was evident that, for some of the participants, reading the narrative summary also had a transforming effect on the way in which they were conceptualising their caregiving roles. It needed to be acknowledged that this could impact on the stories shared in the second interview.

Using narrative summaries and follow-up interviews within a hermeneutic phenomenological study

Returning a narrative summary to participants stepped outside the research design common to many phenomenological studies. Phenomenological research seeks to capture a person's reflected thoughts on the pre-reflective experience. However, it may be countered that no experience is ever pre-reflective because to describe the 'now' of an event means that the 'now' is no longer there (van Manen, 1990). For example, to describe the frustration of being woken from sleep you have to reduce the emotion of frustration to find and use words with which to describe the event.

Also, to meet research ethical requirements, participants were provided with some detailed information about their role in the research and the purpose of the study, and they may have started to reflect on areas of their experience they wished to discuss. The fact that I as a researcher was interested in their everyday experiences might have led participants to consider their activities in a different way. Certainly, during interviews it appeared as if a new way of understanding was taking place when the men reflected and reconsidered past events and stated, *'you know different things crop up, don't they, when you start talking'* (Martin first interview). Accepting that knowledge was not concrete and static waiting to be collected from participants, rather it was a dynamic concept, and by actively seeking to share knowledge construction with participants through a hermeneutic analysis, I engaged with the epistemological challenge of the changing nature of data.

A modified phenomenological methodology strengthened the study by enabling the capture of the lived experience of male carers whilst also recognising that the 'now' of the moment will have already been tempered by the need to put experience into words (Kahn, 2000b). So while it is acknowledged that returning narratives prior to the second interview may have enabled participants to reflect on past events, it is argued that, through the use of phenomenological questioning in the second interview, participants were facilitated to provide descriptions of their lived experiences in enough detail to enable an understanding of the phenomenon.

Sequencing interviews strengthened the analytical process, as this enabled questioning about aspects of the first interview transcript. Moving on from the first interview to also produce the narrative summaries set up the first stage of interpretation, which was then developed by seeking and examining concrete examples of experiences in the second interview. Producing narratives within this analytical framework can be seen to facilitate the development of contextualised understandings of the meaning participants gave to their lived experiences, and the second interview may have enabled the collection of further data and prompted reflection on shared meanings.

Summary

Particular strengths of this study's design and implementation can be seen in the purposeful sampling of men with a variety of caregiving experiences to produce findings which may therefore be transferable to other male carers. The innovative use of narrative summaries and follow-up interviews resulted in additive data and phenomenological data, with the participants expressing their emotional 'being' in their life world, rather than simply 'doing' the role. Achieving this may have been expected to be particularly challenging for male carers, for whom the value they gave to their own autonomy and competence as workers and care workers was highlighted repeatedly in this study. Taking a reflexive approach enabled the recognition and management of differing interpretations of caregiving and employment, which were acknowledged in the earlier discussion in Chapter Six on trustworthiness.

A limitation of the study lies with the fact that the majority of the sample have had contact with support services and as such may have had distinctly different experiences to those whose caregiving remains outside the involvement of statutory and voluntary organisations. It was a challenge for this research, and remains a challenge for researchers, to find ways of recruiting those carers who remain hidden, either because of

their lack of contact with support services or because they do not name what they do as caring. Within this study I started to explore different ways of recruiting, such as email, but this remains an area which would benefit from further exploration.

The knowledge developed through this study is not represented here as an absolute truth, rather as a tentative interpretation. Nonetheless, it is an interpretation developed through a framework of reflexivity, questioning and justifications. In the next chapter I discuss the ways in which the data may enable the development of new understanding about the meaning of caregiving and specifically the ways in which male caregiving may be conceptualised as a form of work informed by these male carers' history.

Chapter 11 The meanings of being a male carer: discussion of the findings

Introduction

This study sought to explore how men experienced being a carer and an employee, including the meanings they gave to the activity of caregiving. The literature review helped delineate four areas where further understanding of male carers experiences remained to be developed. There was a lack of empirical evidence about the dynamics between employment and beginning caregiving. Studies exploring ways in which male carers undertake employment alongside caregiving had subsumed male carers experiences within those of female carers. Despite some evidence that men undertook caregiving in task-based ways there was a lack of understanding about how they conceptualised their caregiving, including their perception of identity. Although it had been identified that male carers may drawn on support from family, friends and work colleagues, whether their relationships with others changed over time was little investigated. The literature review also yielded three conceptual themes: the changing of meanings over time, the ways in which relationships shaped meanings and the shifting ways in which male carers shaped their identities. All these themes are used here to ground the discussion within a phenomenological paradigm to identify the meanings which participants shared and the interpretations dynamically shaped by past and present experiences, developing over time as experiences and relationships change.

The findings presented in Chapters Seven, Eight and Nine are therefore now discussed under the headings of: Becoming a carer: an obligated choice, Being a carer in employment, Caregiving as work and Seeking support-changing relationships.

Becoming a carer: an obligated choice -presents participants' choices as influenced by: perceived responsibilities, relationship and obligations to the care-receiver; attitudes to alternative care provision and the ability to undertake employment alongside caregiving. The procedural decisions made had resonance with the concept of differing and negotiated levels of familial obligations illustrated through sociological and caregiving literature (Finch and Mason, 1993; Twigg and Atkin, 1994; Coleman and Ganong, 2004; Campbell and Carroll, 2007). It was evident that participants did not become a carer at a single point in time; rather a sequence of events and corresponding decisions led to them increasingly defining themselves as committing to undertaking the

role. This has provided novel insights into the ways in which men become carers, specifically the choices they make over whether to stay in or to leave paid employment.

Being a carer in employment - highlights the specific employment structures which may be congruent with discharging dual carer and employee responsibilities. These add to the understandings of the experiences of working-age male carers

Caregiving as work - was emphasised in exploring the meaning male carers gave to their experiences enabling the conceptualisation of men's responses to their involvement in caregiving as a form of purposeful occupation from which new identities may emerge. Here occupation refers to the many activities which people do in their daily lives, such as caring for themselves and others, undertaking employment, leisure activities and community activities (Wilcock, 1999). Occupations and a person's identity are intrinsically linked (Laliberte–Rusman, 2002; Christianson, 2004; Phelan and Kinsella, 2009). Adopting this enhanced understanding of how male carers find meaning in caregiving offers an alternative lens through which to explore the experiences of male carers, supporting insights into the ways though which these participants could come to experienced caregiving as an acceptable alternative form of work.

Seeking support: changing relationships-with others during the caregiving experience, showed how support networks other than family, friends or colleagues were used. Evidencing participants' use of non-traditional support structures, specifically paid social care workers, provides new insights into the ways in which professional paid and informal unpaid carer roles may themselves cross formal employment boundaries.

It has been clearly acknowledged and emphasised that the knowledge generated through this study is interpreted and selectively captures the experiences of a distinct group of thirteen men, at a specific time in their lives. However, also throughout the study a reflexive approach was used to ensure researcher presuppositions and subjectivities are meditated. A variety of validation strategies have suggested that these interpretations of the data have resonance with the wider carer community. To increase the credibility of this discussion empirical evidence has been retrospectively explored to illustrate where interpretations are congruent with previous studies and where interpretations tentatively add new understandings. An aim within this discussion is to present conceptual ideas which may be used by others to continue to add to the understanding of the experiences of working-age male carers.

Becoming a carer: an obligated choice

Becoming a carer emerged here as a two stage process, with participants firstly expressing some duty or desire to support their relative and then, secondly, realising the consequences of that choice for their capacity to continue in employment. Six of the men made the choice to leave employment to become full-time carers. The wealth of literature pertaining to the inherent obligation individuals experience to provide care and support to others has embraced both male and female carers, but distinct within this study has been the opportunity to explore the decisions of working-age men and to compare and contrast them with the empirical literature, drawing conclusions about the lived and changing experiences which come to shape the choices made by male carers.

To map the findings in the empirical literature meant having to define the concept of obligation, which is a complex concept capturing both internal duty and external expectations. Whether one does or does not experience being obligated to undertake an activity may be influenced by the social and cultural context in which such an obligation occurs. In caregiving the obligation to provide care traditionally falls on family members and more traditionally female members of the family (Twigg and Atkin, 1994; Szinovacz and Davey, 2008). Within everyday language the concept of obligation more readily transposes to the language of duty; certainly definitions of obligation suggest that if one is obligated one has a duty to fulfil specific responsibilities. A recurrent theme within caregiving literature is that carers perceive they have a duty to provide care to a family member (Horowitz, 1985; Twigg and Atkin, 1994; Harris, 2002). Nevertheless a number of studies suggest that obligation is not absolute, rather procedural decisions are made which influence the decisions people make when faced with scenarios where others require support and care (Qureshi and Walker, 1989; Finch and Mason 1993; George et al., 1998; Daatland and Herlofson, 2003; Mosher and Danoff-Burg, 2004).

A duty to provide care

Acknowledging that there are family obligations to provide care to relatives, findings from this study confirm that men in diverse family relationships experience obligations to provide care. There was evidence to support the earlier empirical findings that obligation is inherent within expectations of the marital responsibilities of marriage (Parker, 1993; Harris, 1993; Boeije et al., 2003). The two participants who provided care to their mother experienced a sense of duty to care for elderly parents especially

where there are no other available siblings. This confirms the findings of studies by Horowitz (1985) and Harris (1998). The two participants caring for adult children also spoke of their duty to look after their child, adding to the understanding of fathers' experience of caring for adult children with learning disabilities (MacDonald et al., 2006).

There was evidence that the internal obligation experienced by participants to provide care for their relative at home was not always acknowledged and supported by other family members, suggesting the expectation that men should provide care to wives, mothers and children is not absolute. Whilst evidence indicated that participants experienced fulfilling a duty and doing the best thing for their relative, there were occasions where this was seen as causing conflict with other family members and health professionals, both of whom suggested that their relative could be placed in alternative care. Recognising this conflict over carers' experienced sense of obligation and others' expectations of who may be the best provider of care for the care-receiver raises interesting insights into the conflicting expectations between the primary carers and others who are on the boundaries of dyadic caregiving relationships.

The concept of who holds the power and the ultimate decision over where, how and by whom care is delivered remains at the centre of disability literature which argues that legislative actions whilst enhancing the rights of carers may have reduced the position of disabled people (Morris, 1997; Parker and Clarke, 2002). Certainly within this study it was striking that at no point did these male carers directly talk about involving the care-receiver in any decisions about where they would be cared for and whether the participant should leave employment to provide the care. Such an observation may be seen to fit with the value these carers seemed to give to presenting themselves as competent workers and care workers, even when, as with Daniel, they later admitted to not feeling as though they were uniformly coping.

It may not be a single experienced obligation which leads men to become carers, rather a number of factors might need to be in place to enable the caregiving to commence and then be continued. Understanding that carers give meaning and justification to their obligation to provide care may be important, as Simoni and Trifletti (2004) suggest that, certainly in southern European families, providing care purely because of family obligation may lead the carer to feel that they are making a sacrifice, leading to increased feelings of burden. Therefore, if carers are able to perceive their obligation to provide care not in terms of duty, expectation and obligation, but instead in terms of

having made a reasoned and balanced decision to do this role they may experience the activity in more positive ways. One of the reasons cited by several participants for providing care was that the care-receiver had previously contributed to the relationship and provided for the participant.

Obligation tempered by reciprocity in past relationships

Reciprocity may be found in any relationship, but is perhaps most regularly observed and formally endorsed in that of a marriage partnership (Neufeld and Harrison, 1998). However, the two participants who were son carers also spoke of caregiving because they wanted to pay back the care and support they had received from their parent as a child mirroring the findings from other studies which have recruited son carers (Parsons, 1997; Harris, 1998; Campbell and Carroll, 2007). Whilst there may have been a previous reciprocal relationship prior to the caregiving event, the level of dependency of the majority of care-receivers in this study meant that such reciprocal relationships appeared to be completely lost with the care-receiver not being seen as contributing to finances, practical activities or in some cases even to communication within the relationship. This raised serious questions about what factors were sustaining the participants in the caregiving relationship.

There was evidence that participants may have been constructing a degree of reciprocity, as the data illustrated the subtle ways in which they were holding on to essential personal features of their relative as they had been before their illness. Often it was small indistinguishable movements by the care-receiver which participants elaborated on to construct as communication between the care-receiver and them. This may be a strategy which enables the continuance of caregiving to a largely uncommunicative, unresponsive person. Construct reciprocity is a concept identified by Neufeld and Harrison (1998:962), in their study exploring the influence of reciprocity in older spousal male carers. They identified that current reciprocity may be 'waived' if there has previously been a positive relationship (1998:961). Neufeld and Harrison (1998) recruited mainly from older spousal male carers, therefore the evidence from this study indicating that younger spousal carers also appear to experience both waived and construct reciprocity adds to the understanding of male carers' reciprocity.

Linked with the concept of reciprocity is the procedural decision some participants made about whether their relative was deserving of care.

Obligation moderated by views of care-receiver as 'deserving of care'

The importance of past experiences in shaping current meanings was illustrated in the ways in which many participants' spoke of their relative being 'deserving of care'. Here participants' narratives drew on characteristics the care-receiver had previously displayed rather than their present being. The concept of the care-receiver being deserving of care was seen to be expressed in the ways in which familial obligations were mediated by considerations of how much the person requiring support brought the situation on themselves (Finch and Mason, 1993).

Finch and Mason (1993) used the term 'procedural decisions' to capture the complex decisions made when their respondents faced questions about whether they would offer support to family. In their sociological study, they found people applied criteria to enable them to decide whether or not to help the other person. Respondents considered whether they felt the care-recipient was deserving of help. They also considered the impact that providing care and support would have on their personal lives, for example whether the family member would need to move into their home and how much time or money it would cost them (Finch and Mason, 1993). Expressing decisions in terms of whether someone is deserving of care also embeds such decisions within some concept of justice. Gilligan (1982) described how men might care through a natural principle of justice, in contrast to having an innate ethic of care which she proposed is found in many women.

Within the findings participants' appeared to focus on the blamelessness of their relative, suggesting they were invoking a natural form of justice in that they were now willing to give up aspects of their life, such as employment and leisure pursuits, in order to care for their relative. The idea that judgements are being made about the worthiness of another person has resonance with the findings of George et al. (1998), who found that support was offered to friends who had tried to help themselves, suggesting that procedural decisions occur beyond family obligations.

Caution needs to be applied to this interpretation as some participants had been caring for several years and it may be that the meanings they gave to becoming a carer had changed over time. Zarit et al. (1986) argue that carers develop coping skills over time. One of the coping tactics used by carers may be conceptualising that the care-receiver is not to blame for their illness (Nolan et al., 2003a). Participants could now be using the

blamelessness of their relative as a means of coping with an obligated activity. Nonetheless, there did appear to be benefits to becoming a carer which might also have mitigated against the burden experienced by participants.

Employment or caregiving: conflicting obligations

This study was distinctive in that it sought the experiences of working-age male carers. Whilst the body of literature exploring male carers continues to grow, the majority of studies exploring why men undertake caregiving have predominantly recruited from post-retirement men. Such men may be in more traditional roles where they are starting to renegotiate relationships and responsibilities for tasks within the home with their wives (Barnes and Parry, 2004; Russell, 2007). There remains limited understanding about the distinct experiences of men who face the potentially conflicting obligations of being in employment, thereby providing financial income to the family, whilst also fulfilling familial obligations to care for a relative. Although obligations remain embedded within family values and societal expectations that family will undertake the care of dependent relatives (Daly and Lewis, 2000; Daatland and Herlofson, 2003; DH, 2008), there emerged evidence that for these participants caregiving was a choice which may lead to them leaving employment. Leaving employment may place male carers in a non-normative role, as despite changing family demographics men are still predominantly perceived as a breadwinner rather than the nurturer within European societies (Holter, 2007). These dual obligations presented distinctive challenges for participants.

Understanding how these male carers rationalised leaving employment to fulfil what they experienced as a greater obligation to ensure the safety of their relative may increase knowledge about the ways in which male carers mediate these obligations. Decisions over whether the primary obligation is to provide for the family through monetary rewards derived from employment, or through direct personal care, are decisions that many carers have to make if and when it becomes apparent they can no longer combine caregiving and employment.

Deciding to leave employment appeared to have been a gradual process for many participants. Very few left employment immediately their relative became ill, suggesting there was a gradual realisation, perhaps resisted initially, that it would not be possible to maintain the dual role of carer and employee. As Boeije et al. (2003) found frequently people drift into the carer role and it may be that on reaching a crisis point,

such as a decline in the health of the care-receiver, it becomes extremely difficult to then shy away from the carer role. Therefore, the obligation to provide care becomes more absolute as the care needs of the care-receiver increase.

In this study nearly all of the men had been in full-time employment before taking on the carer role. Further, they had frequently been in marriages where the wife played an active role within their employment, such as working alongside them in shops or providing administrative support in businesses. Therefore, it may be that in undertaking the carer role they had more to lose than older spousal carers in terms of occupation identity, roles within families and financial reward. It may be because of their experience of having so much to lose and the potential for a dramatic change in roles that participants gave stories of making considered decisions. They described sitting down to work out the finances, talking it through with families, or firstly trying residential care before making the choice to become a carer. Yet recognising that for choice to take place, there must be at least two alternatives, it was not readily evident in their narratives what would have happened if they had not chosen to provide the care, particularly as many explained that they would not consider alternative care, such as a residential home, due to their perception of this type of care being of poor quality.

Whilst there is evidence that men feel one of their responsibilities is to provide for the family (Simon, 1995), the inability to provide a financial income from employment appeared not to be of great concern to participants. Those who left employment justified their reduced financial contribution to the family by explaining they had previously paid taxes and made national insurance contributions and that they were now drawing on these. Further, some made reference to how much carers saved the government, suggesting that they experienced caregiving as a valued activity. However, this meaning may have been derived from repeated media presentations of how carers save the government £57 billion a year (Lloyd, 2006). Nonetheless, it was evident that leaving work to become a carer led to a reworking of their identity as employed men, this reworking still enabled them to give value to their occupational activities.

Although participants experienced leaving employment as a positive step in that they were replacing work with another socially productive activity, namely caregiving, there was not a general acceptance from others that this was a natural role for men, leading two participants to describe the unease their relatives had with the choices they had made to undertake the caregiving. This has resonance with the wider concept of who within society may be acceptable to provide care to others, suggesting that experiences

may be shaped by relationships with others and cultural norms. Bagilhole and Cross (2010) described how men in non-traditional gender roles sometimes experience resistance from others. Further, there is empirical evidence that male carers may receive different services from their female counterparts, in part based upon assumptions of what they can and cannot do as carers (Bywaters and Harris, 1998). Recognising that these assumptions reflect cultural preconceptions may be a step towards recognising the needs of individual carers, rather than grouping carers' needs into specific groups divided by gender.

Participants appeared to make a number of negotiated decisions when deciding how to discharge their responsibilities and there emerged evidence of new understandings that becoming a carer was not undertaken purely out of duty, but also because of the possibility to personally benefit from being a carer. For some becoming a carer provided a positive way out of employment.

Benefits of exiting employment

Whilst becoming a carer is often portrayed as an altruistic action there was evidence that the obligation to provide care moved along a line from absolute obligation to negotiated obligation; from purely altruistic to self-rewarding. The types of benefits participants got from caregiving were varied, including having more time to spend with the care-receiver, have a legitimate reason to leave employment and developing a sense of self-achievement.

Being in employment has recognised benefits including financial reward, social support and increased self-esteem (Black, 2008). However, carers in employment might experience poorer health and poorer financial well-being than their non-caregiving counterparts (Yeandle et al., 2007) and combining the dual activities may increase the burden experienced by carers (Carmichael et al., 2008), reducing the time available to undertake care work. Therefore there may be distinct benefits in becoming a carer and exiting employment, but no literature was identified which explicitly explored the benefits of leaving employment to undertake full-time caregiving. Nonetheless, evidence from this study did highlight participants seeing themselves as benefiting from more time to discharge their care responsibilities, more time with the care-receiver and the opportunity to undertake a new role when choosing to exit unsatisfactory employment situations. Whilst caregiving did consume and structure the time available to participants, a few who had left employment experienced more time with their

220

relatives which they discussed as a positive consequence of leaving employment. They made use of the time away from contracted employment to pursue interests and take holidays with their relative. They used respite care to pursue their personal leisure interests. This use of time and activities appeared to have enhanced their sense of well-being

Another benefit to undertaking the full-time carer role was that it provided an acceptable route out of an employment situation they may have been experiencing as detrimental. They moved from employed man to carer, rather than employed man to unemployed man. Being a carer may be a more socially valued role than becoming unemployed. Further, it may be that by constructing caregiving as a socially acceptable and productive role, participants were mitigating the inevitability of having to leave employment when it became apparent that their greater obligation could be seen to meet the needs of their relative than their employment.

Caregiving is often presented as a burdensome self-sacrificing activity, but there may be positive rewards within the carer role (Grant et al., 1998; Nolan et al., 2003b). Certainly the stories heard in this study frequently highlighted the sense of achievement and pride gained through learning new skills such as cooking, cleaning and feeling that a good job had been done in providing aspects of care to their relative. This finding has congruence with the suggestion that male carers may have higher levels of self-belief in their ability to undertake caregiving than their female counterparts (Hagedoorn et al., 2002), suggesting they actively recognise the achievements they have made in the carer role.

Whilst this study found evidence of distinct benefits to being a carer, such as increased time with relatives, the opportunity to develop new skills, a sense of fulfilling obligations and giving back previously received care to relatives, there was also evidence of participants expressing concerns that they did not have choice over whether or not they provided care and subsequently whether or not they left employment.

Is there real choice about fulfilling obligations?

Although participants talked about making a decision to take on the carer role, deeper exploration of the data for the degree of congruence showed that often the decision was not made as freely as perhaps first suggested. Frequently a number of distinct explanations were offered, with many participants providing detailed justifications of why they became a carer. Ultimately it became evident that they had little choice but to accept the role or walk away from the relationship.

Lack of acceptable alternatives

For choice to take place people need to have at least two acceptable options (Arksey and Glendinning, 2007), but data suggested that participants did not have an acceptable alternative as residential care was considered by most to be unacceptable, either because of perceived poor quality or because accepting such care might indicate their own failure to fulfil their familial obligations.

Whilst the government points to its efforts to provide alternative care to enable carers to have time away from caregiving, in this study all participants described the care they provided as superior to that provided by statutory services. Most perceived the quality of residential care to be poor, irrespective of whether they had direct experience of such care. There may be a number of reasons why alternative care was perceived as poor quality. Firstly, participants spoke of not wanting to place their relative in residential care and that their relative would be dead if had they used such care. This perception may have developed from media stories of poor residential care and abuse within social care systems which taint the public perception of residential care (Kirkman, 2006).

Another reason for describing alternative care as poor quality may lie with the participant's wish to be perceived as being a good carer fulfilling his obligations. Through identifying alternative care as a poor substitute for family care, a situation was created where participants could justify that they were offering superior care and therefore successfully performing the carer role. Also identifying alternative care to be of a poor quality may be a means of justifying the decision they have made to undertake the carer role, particularly if they chose unpaid caregiving over paid employment.

Where statutory services were used by participants to provide short respite periods, they experienced a lack of choice over when and how these services supported them. At times such services were seen as adding to the burden of being a carer, as the expected substitute care was not delivered and because time was also taken with organising and managing such care provision. This finding has resonance with the review undertaken by Sedden et al. (2010) which highlighted that carer assessments do not always result in carers' needs being met.

Negotiating support to enable access to employment

Health and social care providers offered services directed at the care-receiver, such as day centres, alongside services directed at the carer, such as respite care. Findings from this study confirm other reports that services may be inflexible in their approach to

support working carers (Philips et al., 2002; Pickard, 2004a; Arksey and Glendinning, 2008). Participants appeared to have little negotiation over when services were offered. Services were not perceived as enabling participants to access employment. There was also concern that they needed to be available in case the care-receiver was ill, or the day service closed. Understanding this raises questions about whether it is care services or employers who need to develop more flexibility, consistency and receptiveness to enable all types of carers to re-enter the workplace.

Choice over whether to remain in employment

Those who chose to remain in employment alongside caregiving were able to because of flexibility of work and acceptable sources of alternative support. The absence of those resources resulted in participants having to leave employment. It appears that their responsibility to their relative was a greater obligation than their obligation to be in employment. Flexibility of employment has been cited as one reason why men experience being able to undertake caregiving (Hequembourg and Brallier, 2005). However, male carers in Hequembourg and Brallier's study had other relatives who could provide care, therefore they had more choice about where their greater obligation lay. In this study participants did not appear to have family who could undertake the caregiving and they experienced obligation to undertake care and they were willing to sacrifice employment to do this. Flexibility of employment enabled these participants to stay in paid work, but it did not appear to influence their decision to become a carer. Therefore, it may be that the sense of natural justice and the desire to give back to those who have previously supported them have more influence over whether or not participants become carers than the nature of their employment.

In summary, evidence from this study is congruent with empirical evidence that male carers may provide care for relatives through a sense of obligation. However, by considering the changing experiences of participants' across time it became apparent that this obligation was not absolute, rather it was negotiated and levels of obligation might change over time. The meaning participants gave to becoming a carer was one of obligation, an expected duty. Yet this duty was tempered with a range of other factors, including how deserving of care the relative was, whether there were alternative care options, and the costs and benefits to them. Therefore, there was not an innate obligation to provide care, and where obligation was mediated by the concept of reciprocity caregiving may be experienced as a more positive occupation.

The study has therefore added to the understanding that becoming a carer may provide a route out of an unsatisfactory employment. The social expectation in the UK that adults will be economically active (Lewis, 2002) may make it harder for men to chose to opt out of paid employment, but becoming a carer can provide a potentially socially legitimate reason for leaving employment. Having become a carer either through considered decisions or through a lack of alternative choices, the reality of undertaking the daily activities of caregiving were seen to begin to shape participants' meaning of the lived experiences of being a carer in identifiable ways, as a distinctive form of work. When the work of care was undertaken alongside paid employment there were distinct features of the workplace which either enhanced or inhibited male carers opportunities to undertake these dual activities.

Being a carer in employment

The literature review identified that few studies on carers' employment practices had specifically explored the experiences of male carers helping affirm a key research objective in this study to develop an understanding of the meaning male carers find in the activity of being a carer and being in employment. This data suggested that the meaning of work changed for those participants who combined caregiving with employment. They described the pragmatic ways in which they managed these dual roles, highlighting factors such as flexible working hours, job location and supportive employers which helped them fulfil dual roles, but they also spoke of how the importance of employment had changed. For some it was no longer a career, but now a source of respite. The data evidenced that some employment practices could enhance the opportunities for men to combine paid work with caregiving while other practices limited opportunities.

Employment practices which enhance male carers' access

It emerged that three styles of employment were particularly congruent with undertaking paid work alongside being a carer: employment in the same physical space as caregiving, negotiable work times, and the containment of employed work within working hours.

Firstly, employment which occurred within the same physical space as the care work, such as being self-employed or managing a shop with integral living accommodation, enabled flexibility in employment practices. Dual responsibilities could be more easily managed within the same physical space, and participants described being able to move

between carer and employee tasks. Being self-employed meant that they could control the hours of their working day and leave if an emergency happened, enabling a balance between carer and employee responsibilities.

Secondly, employment where flexible start and finish hours could be negotiated appeared to support the combining of caregiving and employment. Flexible hours have been highlighted as a facilitator in increasing the ability of caregiving employees to remain in the workplace (Arksey 2002; Philips at al., 2002; Pickard, 2004a; Yeandle et al., 2007; Arksey and Glendinning, 2008).

Thirdly, if employed work tasks could be achieved within employment hours participants identified this as empowering them to manage both roles. Where there was a higher level of autonomy over when and how work tasks were achieved, employment was experienced as a positive addition to their life. However, where there was little autonomy and restrictive set-time working practices, employment was perceived as adding to the burden of caregiving. This had congruence with studies exploring the types of workplace which increase well-being in employees (Waddell and Burton, 2006).

Employment practices which hinder carers' access

Whilst employment for carers may have the beneficial effect of increasing financial security, enhancing social support and increasing self-esteem (Arksey, 2002; Philips et al., 2002; Arksey and Glendinning, 2008), there are also employment situations which have negative effects on employees' well-being. Evidence from this study indicated that employment which had clocking-in and-out times, short lunch breaks, frequent changes of work colleagues, high levels of responsibilities and frequent requests to undertake overtime, all led to employment being experienced as an additional burden and was not conducive to combining carer and employee roles. The nature of the workplace was perceived as either accommodating or constricting even when participants had not tried to negotiate help or support for their carer role.

Understanding how the types of employment might enhance their resources to undertake the dual roles of carer and employee may help in the structuring of employment practices to support carers, particularly as the Work and Families Act 2008 begins to impact on employers' actions.

Whilst it may be that lack of flexibility in employment led to participants leaving employment there was also a sense of competing responsibilities and, for a few,

uncertainty as to whom were they were most obligated to. Certainly there was an obligation to ensure that the care-receiver was safe, but this obligation could be deferred to others perceived as being suitable care providers. An alternative explanation lay not in the responsibility to the care-receiver, but in the sense of responsibility to the potential employer. Data suggested that participants did not perceive that it was fair to the employer if they frequently needed to take time off work. This suggested that there may be a work ethic (Meriac et al., 2009) to do the best in paid employment which was preventing some men from considering reduced or flexible employment patterns. Instead they preferred to opt out of employment rather than not be able to fulfil their perceived obligation to the employer.

The pragmatic ways in which these participants managed their employment were very similar to those found in other studies (Arksey, 2002; Philips et al., 2002; Pickard, 2004a; Arksey et al., 2005; Yeandle et al., 2007; Arksey and Glendinning, 2008; Vickerstaff et al., 2009), but a key finding to emerge from this study was the way in which the meaning of being in employment appeared to have shifted as these men became carers. Employment changed from being a way of developing a career to being a way of seeking respite from being a carer. Whereas employment has been held as 'good' for people in general, in that employment will provide extra finance income and perhaps social support and self-esteem (Black, 2008), findings in this study suggested that employment for carers served other purposes and had a different meaning: it was no longer a career, rather it became a form of respite from caregiving.

Employment as a form of physical and mental respite

Employment was seen to be experienced as a form of respite when participants enjoyed their work, got a sense of achievement from their role and were able to create a mental divide between being a carer and being a paid worker. Respite was not directly linked with time away from the care-receiver, but rather in the ability to mentally turn off from the care responsibilities and to tune completely into an occupation which was enjoyed and creative, reinforcing the concept that through being engaged in a purposeful occupation, carers may achieve better mental well-being (Reid, 2008). Understanding that employment *per se* did not equate to respite, led to a deeper exploration of what specific facets of employment led to some participants appearing to benefit from their employment whilst others found it burdensome. These included the perceived quality of respite care, employment being seen as purposeful, and whether employed work fits with self-definition.

226

The substitute care provided to the care-receiver had to be perceived as good quality, to encourage confidence in the employed carer that their relative would not come to harm when they were at work. This was one of the reasons why day care did not always help participants access employment. Having good respite care in place, coupled with the flexibility to leave work if an emergency occurred, appeared to lead to employment being experienced as a positive respite activity which did not appear to cause extra burden.

Employment was spoken of as enhancing well-being when it provided a purposeful activity which was enjoyed. Participants offered a sense of pride in their work. As well as creating a source of self-esteem, employment could be seen to provide an identity different from that of carer. Whether employed work was experienced as worthwhile appeared to be mediated by whether such work was part of how they defined themselves.

The finding that two participants left employment to become carers because of dissatisfaction with their employment indicated that being in employment *per se* may not always have beneficial effects on carers' experiences. Rather the nature of the employment must also be perceived as worthwhile if the carer is to experience paid work as offering respite from caregiving.

Employment as a 'job rather than a career'

Employment was seen to take on different meanings now participants were carers; the focus on career which might be expected in male employees (Kimmel, 2008) appeared to have diminished and rather they talked of 'treading water' with regard to their career, although it was not clear from their accounts when and if they would be able to re-establish a career. Nonetheless, tangible benefits to being in employment were seen if the employment structure was supportive.

The known benefits of employment for carers, such as increased financial security, developed self-esteem and respite, were evidenced in the data. However this study, unlike other studies (Arksey, 2002), did not find that employment provided a support structure to the carer. Whether because these men chose not to tell colleagues, or because colleagues did not understand their circumstances, work colleagues were not identified as offering support to them in their carer role. There is evidence to confirm that many carers keep their role hidden in the workplace, either through fear of repercussions, or in an effort to have separate identities and gain respite from the carer

role through paid employment (Hirsch, 1996; Harris, 1998). Nevertheless it is difficult to draw firm conclusions here as the study sample included only seven men in employment, three of whom were self-employed and working in rather isolated employment structures.

Work, whether paid or unpaid, was a concept which was integral to the stories told by these male carers. Whilst care has historically been linked with the concept of work, in this study participants appeared to give meaning to their experiences through defining and describing their activity as carers as a form of work.

Caregiving as work

The literature review highlighted that male carers appeared to undertake caregiving in task-orientated ways, but did not provide understanding of what meaning they might be giving to their experiences as carers. The themes which emerged from the scoping review underlined that early caregiving literature had began to conceptualise caregiving as a form of unpaid work (Finch and Groves, 1983), but this theoretical thread had tended to become subsumed within literature exploring gender divisions of caregiving labour (Stoller, 2002). Nonetheless, there is growing debate about how the concept of care as work may inform social policy, specifically relating to the concept of dual full-time worker families (Daly and Lewis, 2000; Land, 2002; Lewis and Giullari, 2005). There was evidence that male carers developed meanings related to their carer roles and identities based on their personal histories (Hirsch, 1996). Applying the conceptually-developed lens of 'work' to the findings made it apparent that many participants were describing caregiving in terms more readily associated with paid employment. Further reflection and exploration of literature within the fields of sociology and occupational science helped outline the tentative theory that male carers appear to be experiencing caregiving as an acceptable alternative to paid employment while drawing on their previous employment histories to experience caregiving as 'alternative work'. Whilst it is argued in this thesis that care may be conceptualised as a form of work, here work has been explored more in terms of a purposeful occupation rather than as a basic component of economic capital.

Exploring the components parts of work generally, and reflecting on these from the perspective of both paid employment and unpaid caregiving, prompts the emergence of several similarities. Participants' narratives suggested that as an employee they had responsibilities to attend the place of employment for a set number of hours, to be active

in undertaking employment activities, and to be accountable for the end product resulting from the job. Similarly as a carer they had responsibility to undertake a set of activities which supported the care-receiver, to be available in the place of caregiving for extensive hours and if in contact with social services to show evidence of sufficient industry to maintain the well-being of the care-receiver. In both employment and caregiving there were socially embedded responsibilities: a 'good' employee attends work regularly and ensures they are industrious in the workplace, whilst a 'good' carer ensures the care-receiver is healthy and stimulated. The 'good' employee is available when his manager wishes to see him, whilst the 'good' carer ensures he and the care-receiver are available to meet with statutory service providers at times specified by the service providers. Examining this evidence in this way led to a re-exploration of the theoretical conceptualisation of what work is and the part work might play in the experiences of these working-age male carers.

Defining the concept of work

Within western culture the word work has become synonymous with paid employment (Ross, 2007). The concept of what activities constitute work is socially determined and when asked to talk about work most people will talk about their paid employment. Yet work is undertaken in a variety of settings and for a variety of purposes (Pahl, 1988; Poland, 1991; Muirhead, 2004). Work provides 'plurality of functions and rewards, including purposeful activity, sociability, status and material gain' (Barnes and Parry, 2004:218). For many people work is a social activity, occurring outside the home and enabling the construction of a distinct worker identity (Sayers, 1988), enabling the development of self-respect (Ronco and Peattie, 1988). Yet, work may place obligated demands on people, specifically over how they use time (Hearn and Michelson, 2006). Whilst work may be beneficial for well-being (Waddell and Burton, 2006; Black, 2008), the activity undertaken needs to be experienced as meaningful if it is to enhance well-being (Wilcock, 1999). Accepting that work may define who one is, examination of the data exposed the ways in which these male carers were experiencing their caregiving activities as a form of purposeful work. Their work was not paid but was obligated, required physical and mental activity, it structured their time, provided some new social networks, required the mastery of new skills and provided a reworked sense of identity.

Conceptualising care as work, in the sense that these men recognised work in their personal histories, made it possible to understand that these participants were occupied beings actively undertaking both physical and mental activity, using the activities of

caregiving to create a recognisable structure and purpose to their day. The comparisons between paid work and care work were evident through each theme of the data. In the chapter 'Being a male carer' (Chapter Seven), caregiving was seen to be experienced as both a physical and mental activity which provided the opportunity to learn new skills and through which new social networks were made. Through the study theme of 'Obligated time' (Chapter Eight), both caregiving and employment could be seen to provide structure and purpose to time. Through the third study theme 'Self as carer - reworking identities' (Chapter Nine), work was discussed in terms of how self-identity was reworked when participants left paid work to undertake unpaid caregiving.

Work was presented as a key feature in all participants' lives. They brought in existing work skills and developed new skills within their work as carers and their self-belief in their abilities to undertake the work of carer, as work, may have buffered them against the burden of caregiving which many carers experience. However, caregiving may also be experienced as a form of 'bad' work. Waddell and Burton (2006) argue that whilst work is generally good for both physical and mental health and well-being, there are employment environments and practices which are detrimental leading to poor health and increased mental health problems. Care work may be constituted as a form of 'bad' work if it occurs within the private home sometimes with scant regard to a carer's health and safety. There is often little opportunity for leisure and the physical and emotional demands of undertaking the obligated responsibility of providing sole care for a relative may be extremely demanding, leaving the carer seeking new sources of support.

To understand how carers came to experience caregiving as a form of work it was necessary to explore the theoretical constructs which may have led to this meaning. Reviewing literature generated within occupational science, and drawing on theories from occupational therapy and the social sciences, may provide some useful insights here in thinking about people as 'occupational beings acting, interacting and reacting with objects and others within and on environments and contexts' (Lentin, 2005:191). This study had found that participants were concerned with remaining meaningfully occupied and through reacting to and interacting with their social contexts they had created meanings. If activity is an 'observable unit of behaviour' (Christiansen and Townsend, 2004:275), then the act of feeding the care-receiver would be one activity among several activities which may be undertaken as part of the occupation of caregiving, where an occupation is defined as 'engagement or participation in a recognisable life endeavour' (Christiansen and Townsend, 2004:278).

Participants were engaged in being a carer and for some in also being an employee. It is through engaging in occupations that identity may be shaped (Huot and Laliberte-Rudman, 2010). If it is accepted that what you do is a 'defining statement of who one is and one's relative value' (Unrah, 2004:290), then in sharing their stories of 'doing' participants were seen to be seeking to present themselves as having an identity as a working carer. This analogy is strengthened through exploring how, particularly for those six who had left employment, caregiving became an acceptable alternative form of work. Caregiving was work from which new identities could be developed. Full-time carers who reworked an identity as a working man may have been creating an internal sense of self which buffered them against some of the burden of being a carer and also created an identity which could be valued by society.

Through understanding how participants experienced caregiving as an alternative form of work, it became possible to understand the value of caregiving and the ways in which a positive self-identity may be developed by those who have relinquished the breadwinner role and the identity of being the traditional, employed man. Such an understanding may help to initiate policies which are sensitive to the choices carers make, rather than considering paid employment as the ideal situation in every case. While accepting the tentativeness with which such a theory can be presented here, based on a sample which included only six men who had left paid employment, some justification can be provided for the argument that caregiving may be experienced as work, in mapping the findings about meanings of caregiving on to key concepts of work. The component parts of care work for these men are now sought through an exploration of how the home became their workplace and the ways in which care work provided a purposeful structure to their day. Experiencing care as a form of work appeared to enable these male carers to rework their identity and in part to have created a buffer against the recognised burdens associated with caregiving. However, care work may not always be 'good' work. These conceptual propositions are examined in turn.

Home as the workplace

Becoming a carer was seen to entail change in a whole spectrum of areas. These may include physical changes to the house to provide the equipment needed for the care of the relative. There may be changes to the structure of the day, with the care-receiver requiring treatments and medications at certain times. There may be changes in the type of employment undertaken by both the carer and the care-receiver, with carers employment outside the home reducing or ceasing.

As the care-receiver's condition deteriorated, in many ways the home became the participant's workplace. It was the place where carers undertook the practical care of their relatives and there were numerous visible signs of the caregiving work, even when the care-receiver was not present. Whilst only a few participants specifically said 'I work from home', the concept of the home as the workplace was seen in more subtle ways. The raised seat, the hoist, the incontinence pads were constant visible reminders of the activities they were required to undertake. Several participants were eager to provide tours of bedrooms and bathrooms, which had been adapted with equipment to enable care work to take place, evidencing the significance of the equipment to the meaning they gave their experience. The equipment appeared to represent the tools of their work and as such there was talk of how they were the most skilful in using particular equipment. Frequently skills from previous employment were drawn on to refine and adapt equipment to better meet their and the care-receiver's needs. Unlike paid employment where the tools of work may be left behind, with care work the tools were ever present, perhaps resulting in the loss of the distinction between being at paid work and being at home.

Alongside using the skills they had developed in paid employment there was a requirement to develop new work skills, for example maintaining a house and here participants drew pride from their achievements. The everyday activities of maintaining the home tend not to be highlighted in female carers' narratives because women may more readily assimilate such work into their homemaker role (Heenan, 2000). However, these male carers drew attention to this aspect of their role, talking with a sense of pride about how they had learned and mastered such skills. This suggests the possibility that housework may be a valued form of work for some carers, including rather than excluding male carers.

Whilst male carers may undertake the same work as female carers they may experience this work in different ways. Here participants placed value on domestic work and highlighted the managerial skills they used. For example they spoke of seeking additional services to support their relative and organising and managing activities to keep their relative occupied. In focusing on managerial tasks participants may have been reinforcing historically masculine attributes (Moynihan, 1998).

This concept of the home as a care workplace resonates with literature exploring how the privacy of the family home may be changed and lost when caregiving takes place within it (Twigg, 1999b). However, no studies have been identified which specifically

explore how the home becomes the workplace for the carer and the consequent implications of not only being constantly with the care-receiver, but also being in a place which may have been adapted to meet the needs of only one half of a couple. The home of a person with long-term care needs is no longer a private space; other people regularly enter the home to provide specialist help (Blaxter and Poland, 2002). Just as in a place of employment these people do not always need the front door opening, rather they come with cheery hello into the private home, therefore the privacy of both carer and care-receiver may be compromised. As for any workplace the equipment takes up space and the environment must be cleaned and dusted. However, unlike the employer workplace there is not the option of clocking off and moving to a different stimulating environment. For carers the home and the workplace become one with no physical separation. Even if the care-receiver does not require twenty-four hour practical hands-on care, the carer would always be in the workplace unless provided with short periods of respite care. The concept of having time away from home, the care workplace, was evident with explanations of how these male carers used 'time off' when their relative was in alternative care to get away from home and the visible signs of their work. While other studies have identified that being at home all day may lead to depression and ill health (Lewis and Sloggett, 1998; Mathers and Schofield, 1998), participants in this study strove to remain purposively occupied and developed routines which provided structure to their working day. The different way in which they experienced being out of paid employment may be because of how they structured and gave meaning to their time, to create a working day which they could recognise.

Providing purposeful structure and activity to the working day

In this study there was evidence that participants appeared to use the activities and responsibilities of being a carer to create structure and organisation in their day. They discussed their personal need to be occupied and some also spoke of the wish to ensure their relative was purposefully occupied. Undertaking activities which have a purpose or use and which encourage a sense of achievement (Wilcock, 1999) has been identified as one of the benefits of paid employment (Waddell and Burton, 2006; Black, 2008). Employment also provides structure to the day and people who are unemployed may find that they lack purpose and activity leading to depression and withdrawal (Jakobsen, 2001). It emerged that these male carers took distinctive actions to reduce the monotony of their day and to some extent that of the person they were caring for as well.

Strategies used to develop structure and purpose to care work included breaking caregiving tasks into smaller segments and planning when these could be achieved, thereby creating opportunities to feel a sense of achievement at the end of the day. This evidence of forward planning mirrors coping strategies used by carers of people with dementia (Nolan et al., 2003a). Evidence that male carers in a variety of caregiving scenarios coped by creating discrete attainable tasks throughout their day increased understanding of the ways in which carers may introduce coping strategies, thereby reducing possible carer burden.

As with paid employment, participants' time was seen to be obligated. Specific activities had to completed otherwise responsibilities to others could not be fulfilled. For example, caregiving activities had to be undertaken by a certain time if the care-receiver was to be able to access day care. The obligated nature of caregiving meant that they appeared to have to fulfil care work before accessing either paid employment or leisure activities. Parallels may be drawn between these participants' care work obligations and the more general obligation to fulfil employment responsibilities before undertaking leisure pursuits, thereby reinforcing the argument that male carers may experience caregiving as a form of work. If the demands of care work were too great then leisure activities were dropped, just as an employee may sacrifice an evening out to complete a business report.

Other parallels between care work and paid work were observed in the language participants used to describe the discharging of their carer responsibilities. They talked of *managing* their relative's care, of *working* twenty-four hours a day; of ensuring they and their relative were *occupied*. This language suggests a purposeful engagement with the work of being a carer. Therefore, unlike workless people who might experience negative health impacts (Black, 2008), even though participants were not economically active they could be seen as being purposefully occupied in doing unpaid care work and they did not appear to experience negative consequences on their health. Rather, some felt their well-being had increased since leaving employment.

Throughout this thesis there has been discussion of the nature of being-in-the world; in this case existing in the world of male caregiving. At first it appeared the data had not captured the essential experiences of being a male carer, but further reflection and interpretation suggested that in talking of doing care participants were providing stories of being, or existing, as occupied people. This understanding illustrated that in the doing of care these men were giving meaning to being a carer, and the work and occupation

involved in doing care was creating opportunities for them to rework their identities (Christiansen, 1999; Abrahams, 2008).

Caregiving as work: providing a re-worked identity

Participants presented themselves as 'occupied beings' undertaking a range of activities within the roles of husbands, sons, fathers, carers and employees. There was a sense that they were actively managing their roles and creating structures and meanings by linking the activities of caregiving with activities undertaken in paid employment. Leaving employment meant they risked the loss of the identity and status inherent in being an employed man. The identity of being an employed man has been linked with the ways in which men construct a masculine self (Beagan and Saunders, 2005; Kimmel, 2008). Therefore, it may be that on leaving employment to undertake a traditionally feminine nurturing role male carers may experience a sense of loss of their masculine self. Certainly work by Hequembourg and Brallier (2005) illustrated the efforts male carers made to retain a distinct masculine self by keeping up their male social networks and hobbies. Keeping up 'male' hobbies was not evident in this study, rather it emerged that participants experienced caregiving as a meaningful valued activity, which in itself was used to promote a sense of self-esteem and mastery of skills.

Just as employment may shape the roles people undertake and the identities they assimilated (Jakobsen, 2001; Beagan and Saunders, 2005), so being a carer changed the ways in which these participants named themselves. People construct labels for themselves and develop status within their communities based on the roles and work they undertake (Barnes and Parry, 2004). Work forms the foundations of one's self-identity (Ross, 2007). This is particularly so for men where a masculine identity is frequently intertwined with their employment (Goodwin, 2002; Haywood and Mac An Ghaill, 2003; Abrahamson, 2004; Connell, 2005). Many of these participants chose to leave paid employment well before the statutory age of retirement, explaining they found it impossible to combine the two activities. Many of the participants who left employed work to become a full-time carer were exiting predominantly male workplaces, such as shipyards, the building trade and electrical engineering. Within their narratives it was possible to understand the similarities and differences in the identities participants embodied both within their paid employment and within their care work. When they lost the identity of employed man, it became important for them to rework their identity, especially as they were forsaking their breadwinner role and entering an alternative form of work predominantly linked with feminine characteristics.

These male carers were seen to rework their identity in a number of ways: internally through valuing the activities they undertook in the home and externally through the voluntary work they undertook. They developed self-identities which highlighted the managerial aspects of their care work rather than the more feminine emotional and intimate personal care aspects of the work. They spoke of themselves as a home manager, professional carer and nurse. In doing this they linked their role and work to managerial and expert occupations within the health and social care sector. Through presenting themselves as professionals and managers of care, participants mirrored patterns of employment observed when men enter traditionally female occupations. Men who enter health and social care professions tend to migrate quickly to management or highly skilled positions (McLean, 2003). Few men remain as care assistants undertaking high levels of intimate personal care, with this type of work generally perceived as women's work (Twigg, 2002). Such reinforcement of masculine employment traits has been identified in other studies which have interviewed men working in caregiving and other traditional female professions (Simpson, 2004; Ribeiro et al., 2007; Russell, 2007), suggesting that the transference of masculine employment traits may be commonplace in both male paid and unpaid carers. By reinforcing masculine aspects of the caregiving role and creating professional self-identities, participants who were full-time carers may have been compensating for the loss of their employed identity and consequently buffering themselves against some of the burden associated with caregiving.

Buffering against burden

There was evidence that these male carers constructed care as a form of physical and managerial work, thereby appearing to recreate a work environment which mirrored the one they may have experienced in employment. When they talked about the emotional aspects of care it was to talk of their feeling rather than of providing emotional support to the care-receiver. They more usually talked of the physical activities of caregiving, gaining a sense of satisfaction when activities were successfully completed. These male carers described a care work environment in which the activities they undertook were measurable and frequently had a distinct end product and as such were similar to the paid employment settings they had exited. Although they were sometimes self-effacing about their skills in domestic activities, participants expressed a sense of pride and achievement in the new skills they had developed. They all stated that they were the best person to care for their relative. Through recognising their skills and valuing their

work as carer, participants may have increased their sense of self-efficacy. Hagedoorn et al. (2002) identified that when carers had a developed sense of their ability to be a good carer they experienced less stress. By concentrating on those activities of caregiving which were familiar to them from their employed work, such as management and practical activities, participants may have limited some of the negative consequences of caregiving.

Nonetheless, such findings need to be interpreted with caution for it may be that the participants experienced high levels of emotional distress and provided high levels of emotional support for their relative, but chose not to discuss this within their interview. This may be because of not feeling safe enough to disclose personal aspects of their relationships, or because they wished to focus on more masculine aspects of care work.

Good work or bad work

Being 'out at work' can provide a distinctive place where the concerns of home may be held in abeyance. Although some participants did not physically leave the home to engage in work there was evidence that they were, at times, able to create a degree of emotional detachment which in part may be due to the specific ways in which they experienced, or at least presented, caregiving as a form of work. Nonetheless, not all work provides the benefits of increased self-esteem, social support and financial reward and there may be work which can cause harm to people.

Being a carer has aspects of activity which if not carefully managed or monitored have the potential to lead to a harmful situation either for the carer or for the care-receiver. For example, the physical aspect of being a carer, which includes the moving and handling of the care receiver. In this study, multiple tales were offered of how these male carers did not use the lifting equipment provided as they found it quicker and 'easier' to undertake manual handling. Another potentially negative aspect of caregiving is when the carer receives insufficient support and feels physically and mentally subsumed by the role, leading to depression and feeling of burden. This situation may potentially lead to abusive or neglectful behaviour toward the care-receiver. Recognising the ways in which caregiving may be detrimental to the carer may enable support services to target those care relationships where there are heavy work demands placed on the carer and little time for time away from work, either physically or mentally.

It is also important not to dismiss those few occasions when participants spoke of weeping as they helplessly observed the relentless decline in the health of their relative. Whilst their stories focused on the management of caregiving and the experience of care as an alternative form of work, there was also evidence of some men seeking support.

Seeking support: changing relationships

The experiences of participants appeared to be shaped by the relationships they had with others including family, friends and health and social are workers. Support networks were important to the participants, but the networks of family, friends and colleagues, which had perhaps supported them before undertaking the carer role, frequently shrank. Providing care may create the need for increased support structures because carers are facing new challenges and may be losing communication with the care-receiver (Nolan and Keady, 2001; Ray and Street, 2005). Social support is the emotional and physical help and information provided by others (Hibbard et al., 1996). Such support may be provided by 'multiple, inter-related sources of support that can include family members, friends, self-help groups and professionals' (Carpentier and Ducharme, 2003:518). In this study, support needs were identified as needing someone to talk to, having someone to call on if not able to be in the home, and having others who could offer advice and information on specific caregiving tasks.

Support may be drawn from family and friends where these are contactable and accessible (Blaxter et al., 2001). However, data from this study illustrated how support from these traditional networks may be limited due to conflicts about care decisions, levels of obligation and uneasiness when faced by the illness of another person. Nonetheless, support was seen to be drawn from other sources specifically linked with the activity of being a carer, such as carer support groups and through developed relationships with paid social care workers. Whilst social care workers provided the support these male carers needed, including empathic listening and credible information on how to undertake caregiving, examples were also given of where the boundaries between professional and friendship appeared to have been crossed, producing relationships which had the potential to be abusive to both participants and social care worker.

Reducing support networks

The presence of social networks was not in itself indicative of supportive interactions. Exploring why support networks had contracted for these participants pointed up a

number of reasons evidenced within the data. Frequently, as the caregiving episode developed, there was a reduction in contact with family and friends. Occasionally there was a withdrawal of support from family, particularly if there was disagreement about the most appropriate way to care for their relative. There was not an absolute obligation for other relatives to support the carer, rather participants were starting to experience the negotiated nature of family obligation as observed by Finch and Mason (1993). As the time available to maintain a social life reduced, relationships with friends changed. Work colleagues were not seen as providing support, although frequently participants had not exposed their carer role to others in the workplace.

These proposed reasons had resonance with previous studies which found that male carers may shy away from exposing their carer role (Kaye and Applegate, 1990; Hequemborg and Braillier, 2005). A reduction in carers' social networks has been observed in other studies (Archer and MacLean, 1993; Neufeld and Harrison, 1998; Sanders, 2007; Neufeld and Kusher, 2009). Further, it is known that men tend to have smaller social support networks than women (Ray and Street, 2005). This may disadvantage male carers, however Kirk et al. (2002) found that caregiving husbands received more emotional support from friends than non-caregiving husbands. However, small sample size and limited presentation of findings make it hard to discern why this may be. The absence of anticipated support from family may be an additional cause of distress to the carer (Archer and Maclean, 1993; Neufeld and Harrison, 1998; Ray and Street, 2005), which might go towards explaining the stance that many participants took, that they did not expect family to help.

Recognising the reasons why social support networks may have reduced may help to increase understanding of how male carers might be experiencing some types of support as more appropriate than others. Friendships are usually based on a reciprocal relationship, but the obligated nature of time means that there were reduced opportunities to maintain such friendships. Another reason why these male carers may have been reluctant to talk to colleagues and friends about their experience of caregiving was that they wished to retain the identity of the care-receiver intact as a wife or mother, rather than as a dependent adult (Lawrence et al., 2008; Sandberg and Eriksson, 2008). Certainly within the data participants frequently spoke of the skills and positive attributes of their wives, perhaps as a way of presenting her as unique valued person, rather than someone with complex needs dependent on them for care. With a lack of undemanding, understanding support from previous support networks, new

support structures were sought from trusted, empathetic and often more easily accessible sources, namely carer support groups and the paid social care worker. By understanding the experience of using these alternative support networks it becomes possible to conceptualise support structures which may more effectively help male carers.

Using carer support groups

Those participants who attended support groups found this social network extremely beneficial, not only in providing practical and emotional advice but also in creating an alternative identity. Through accessing the group new roles were developed which went some way to replacing the diminished role of employee. Whilst previous studies have described the effective support carers may find in carer support groups (McFarland and Sanders, 1999; Carpentier and Duchrame, 2003), in this study male carers who could attend support groups appeared to find a degree of appreciation for their role which was not evident when they spoke of interactions with their family members. Whilst the gender composition of groups has been cited as prohibiting male carers access to this type of support (McFarland and Sanders, 1999), in this study the difficulty of accessing groups whilst in employment was a reason offered for not using carer support groups. It appeared that for those participants who had left employment, the roles they undertook in the group provided opportunities to rework their identity.

Creating a reworked identity through carer support groups

Russell (2007) has described how post-retirement male carers draw on employment skills to manage their caregiving and a similar concept was seen in this study, both in the ways in which participants took on leader roles in care support groups where the majority of other members were females, and in the ways in which they managed the support of the care-receiver. Accepting that identity may, in part, be formed through the role individuals take and the way in which those roles are perceived by others (Kroger, 2007), carer support groups were playing an important part in the reworking of a purposeful male identity. These male carers were no longer an employee, but now a chairman, or treasurer or an expert in a carer support group. To lead a group or provide expert advice is within the normative roles of some men (Kimmel, 2008). Therefore the roles undertaken within carer support groups might have helped these participants reaffirm some of their masculine identity. This concept is support by empirical literature

suggesting that male carers draw on social networks and sporting clubs to reaffirm an identity other than carer (Hequemborg and Braillier, 2005).

Learning about caregiving through accessing a support group has been found to be a way of helping carers understand the meaning of their new experiences, roles and responsibilities (Chien et al., 2004). But if men are to understand the specific role of being a male carer, then support groups which are tailored to address the key concerns of male carers, which may be more practical and information-driven than emotional (Pierce and Steiner, 2004), could more effectively support male carers, but at times and venues and through media which are effective for men.

Support from social care workers

Whilst it was not surprising that carers formed a rapport with the paid social care worker who entered their homes to tend to the care-receiver, the level of support participants drew on from social care workers was unexpected. They drew primarily on social care workers for emotional and practical support and at times the relationships morphed from one of client and professional to that of friends (Pahl and Spencer, 2001; McGhee and Atkinson, 2010). Friendship was suggested by the degree of reciprocal concern participants felt for the social care worker. Through recognising that carers may keep their roles and responsibilities hidden from others, it becomes possible to understand why social care workers are perceived as a 'safe' support network. Social care workers are 'safe' in that they understand the experience of the carer, yet also have a degree of emotional distance from the carer and care-receiver relationship. They are not as emotionally involved as family and friends. They understand the practicalities of caregiving in ways that friends and work colleagues may not.

Why access support from social care workers

There were a number of reasons why social care workers were perceived as a valued source of support, based upon the frequent access that they had to the carer, and the fact that the social care worker was an insider in the care relationship, knowing both the care needs of the care-receiver and also being witness to the burden experienced by the carer.

Firstly, social care workers were in a unique position seeing the carer every day in the home. Social care workers remain predominantly female and there is evidence that male carers perceive women to be effective emphatic listeners (Campbell and Carroll, 2007). Therefore, it perhaps expected that friendships form between the carer and social care worker. This is particularly so if it is accepted that male carers' willingness to initiate

support from formal services is linked with their acknowledgment of the need for help (Coe and Neufeld, 1999) and the evidence that they may wish to keep aspects of the caregiving relationship hidden (Kaye and Applegate, 1990; Lawrence et al., 2008). It may be easier to draw support from someone who is already known to them and is involved intimately in the home (McGhee and Atkinson, 2010). With such a person it may be easier to let the persona of a 'normal couple' drop, enabling a more open relationship. Further, the social care worker also experiences the challenges of caring for someone with physical and behavioural difficulties and can empathise with the carer's concerns around physical care and handling difficult behaviour. The social care worker becomes someone in whom carers can confide and someone who can recognise the increasing carer burden. There is evidence that such mutual understanding is beneficial for a support network to develop (Sandberg and Eriksson, 2009). The social care worker who knows about the unique situation of the male carer, may reaffirm his skills, empathise with his challenges, legitimise his requests for additional support, and develop a rapport, leading to an effective support relationship.

Whilst social care workers could be a source of support there were also occasions in the data when there appeared to be a blurring of the distinction between worker role and friend. Carpentier and Ducharme (2003) highlighted the need for further investigation into the relationship which develops between the caregiver and professionals, yet there still remains an absence of studies exploring this relationship and specifically the effect the relationship may have at different stages of the care-receiver's illness. Certainly, data from this study suggested that the social care workers might be being placed in a potentially abusive position.

Blurring the boundaries

Whilst social care workers may be ideally placed to offer support to carers there are risks inherent within this role and this study found occasions where the boundaries between worker and client had been blurred, with potentially compromising consequences. Twigg (2002) discussed the experiences of social care workers who enter the private home of carers and care-receivers; theirs was a position of trust but also a position of potential abuse. Stacey (2005) and Baines (2006), exploring the experiences of paid social care workers, highlighted the relatively common practices of unpaid overtime and supplementing agency resources with personal resources, concluding that this blurring of boundaries may be detrimental to the social care worker. This study supports these earlier works, as there were examples of unregulated financial

242

agreements and the blurring of friendship-paid worker boundaries. Within caregiving relationships, the roles of paid and unpaid care worker may become blurred, however recognising and supporting both carers and paid social care workers in these relationships may help to prevent them becoming potentially abusive.

In summary, these male carers drew on a variety of diverse support systems but within each structure there appeared to be aspects of negotiated support. There were differing expectations of whether family should be responsible for supporting them in the delivery of care to the care-receiver. There were concerns about being unable to fulfil the reciprocity they appeared to hold inherent in friendships and the consequent reduction in friendships. Whilst accessing carer support groups was effective for some, others felt that obligations to their paid employment and their relative meant that they did not have the time or opportunity to access this type of support. Although access to emotional and practical support from paid social care workers was frequently observed as beneficial for these male carers, the responsibilities and obligations of each role and the types of support which could reasonably be expected was not always clear and there was a blurring of boundaries between paid worker and friend.

Taking the findings into practice

Whilst acknowledging the interpreted nature of the findings and discussion in this study, the degree of resonance of experiences, evident when findings were shared with carers and health and social care practitioners, suggested that findings may have relevance to the practice of those supporting working-age male carers. This study has added to the knowledge of the experiences of working age male carers in four distinct areas: the complex decisions made about undertaking caregiving and relinquishing employment at different stages in the carer career; the types of employment practices which support carers; the ways in which male carers may experience caregiving as an acceptable alternative to paid work; the changing nature of social support. These illustrate ways in which health and social care practice may be developed in light of these new understandings.

Firstly, male carers may make complex decisions about whether to undertake the responsibilities of being the carer and then whether to relinquish paid employment were made at different stages. Recognising the complexity of rationalising choices made by male carers and how, when and why choices are being made may enable practitioners, such as job centre staff and social workers to provide appropriate information at

appropriate stages in the caregiving career. For example, being able to easily access information on entitlement to financial benefits and the opportunities for flexible working may facilitate carers in employment to fully appreciate the financial consequences of leaving employment and consider the option of altering employment patterns rather than exiting employment, thereby increasing carer choice.

Secondly, appreciating the employment practices which enable male carers to remain in paid work: flexibility, geographical position and limited additional expectations, may help employers develop sensitivity to the needs of carers in their workforce. However it is recognised that many carers chose not to expose their caregiving commitment to their employers and work colleagues and a safe culture of disclosure needs to be developed alongside more flexible employment practices.

Thirdly, understanding the ways in which male carers may experience caregiving as an acceptable alternative to paid work, may enable practitioners such as social workers and nurses to explore and reinforce the benefits of being a carer, rather than attempting to mitigate the consequences. By experiencing care as work, participants appeared to have a developed their sense of self-worth and value in their contributions not only to their relative, but also to others, such as contributing to support groups. A more developed sense of self and self-empowerment may enable carers to more effectively develop partnerships with care assessment and provision agencies

Fourthly, whilst concerns have been raised in social care literature about the power dynamics in a relationship where boundaries are blurred, it may be that any social network has the potential to be destructive or abusive therefore to over-regulate friendships which may be formed between carers and social care workers could negate a valuable source of social support. A more productive way of managing the situation would be by recognising the relationship between carer and social care worker as a potential support network. This would help social care workers to develop ways to support the carer whilst still maintaining their professional responsibilities. Service providers might recognise that the same teams of workers entering the carer's home may be more supportive than continually changing employees. Nonetheless, as a supportive friendship may develop there must also be strategies for disengagement when the working relationship has to change, for example following the care-receiver's death or a move to full-time residential care.

Summary

This thesis has provided a range of evidence to show that care work undertaken by men and their employed work are not necessarily separate domains of experience, but will be intertwined and can purposefully inform each other. Using a hermeneutic phenomenological approach has helped sensitise the study to how male carers do not separate parts of their life world and that they develop meanings of their care work through the historicity of their whole experience and not simply in isolation. The experiences of being a carer and being an employee can be seen to be intertwined; particularly when there is a cultural expectation for men that employment is a normative activity. Care, as a particular type of work may be a model which applies even more to those carers who have previously identified themselves primarily as workers rather than retired or unemployed or stay-at-home. Viewing care as work enabled most of the male carers in this study to make the invisible work of caregiving both visible as work and as purposeful work. For these men conceptualising and performing care as work helped them to raise the status of the activity, placing value on it as a commodity which had to be learned, in which they were experts.

By conceptualising care as a form of alternative work, it becomes possible to move the discussion about male carers' experience beyond a simple gender debate into a discussion about the very nature of what work is and specifically what care work is. However it must be emphasised that the theoretical reflections advanced within this chapter are based on the experiences of only thirteen male carers and therefore conclusions cannot be drawn on how working-age women experience caregiving. Nonetheless when presenting the findings at a carer's support group a number of people did state that working age women who had been in full-time employment had similar views as these participants on leaving work to provide full-time care for a relative. Caregiving may be experienced as 'alternative work' in a number of ways. Firstly, caregiving activities can be organised to give structure and purpose to the carer's day. Secondly, male carers may gain a sense of achievement from learning new skills, leading them to value the domestic work they are obligated to undertake. Doing these tasks, which female carers frequently assimilate into their homemaker role, becomes a distinct part of their work as a carer. Thirdly, experiencing care as work enables the construction of a reworked self-identity; male carers may move beyond being a carer to becoming a care manager and a care professional, bringing them a degree of status as an occupationally competent man. Fourthly, the new networks which become available on

becoming a carer offer the possibilities of being used in similar ways to the networks inherent within employment, namely to seek useful contacts, expert advice and support and to undertake roles and activities which in themselves confer status within the network. Finally, experiencing care as a form of work may enable carers to create some distance from the emotional labour of caregiving and in so doing they may have created a buffer against the negative impacts of caregiving.

By conceptualising care as work that men can identify with, a deeper understanding becomes possible of how men may make the transition from employee to carer whilst still maintaining a self-identity they find acceptable. The transfer of management and practical skills from employment into the work as carers enables the utilisation of skills developed in paid work. Making this visible may therefore support male carers to see some direct transference of skills between workplaces, instilling a sense of greater expertise in their new care work. Through understanding the ways in which men experience care as work, service providers may be better equipped to support pre-retirement men as they undertake the new job of carer.

It may therefore be recommended that service providers supporting men who are making the decision to become carers encourage them to see the transferable skills they can take from paid work to unpaid care work. Through increasing self-belief in the ability to undertake care work, feelings of stress may be decreased. If male carers can share perceptions of experiencing care work as a valued form of work it may mean male carers can exit employment seeing it not as an end of employment, but more as a change of career, thereby enhancing their identity of a working man.

Chapter 12 Conclusions

This thesis has added to knowledge of the caregiving experiences of working-age male family carers in the UK, particularly in relation to the meaning men give to caregiving when of an age for paid work to be part, or all, of what they do. Whilst initially the specific research focus was on how male carers might experience caregiving alongside employment, it emerged that the meanings participants gave to their experiences could be seen to be intricately bounded and shaped by their personal history, both their relationship with the person they were caring for, also their previous experiences of work and their desire to retain the identity of a 'working man' even when not in paid employment. Caregiving was, for these men, an acceptable alternative to paid employment; a way in which they re-worked their identities whilst fulfilling their perceived obligation to support a relative. Although participants detailed choices they had made in becoming carers citing gains in reciprocity, duty and personal gain in the carer role they also faced the confines of obligated time. Their activities, both paid and unpaid were shaped and pressured by external and internal drivers. The activity of being a carer, as they described it, affected the ways which they experienced the phenomenon of caregiving, suggesting that the meanings they gave to caregiving as work were grounded within past experiences of structured and task-focused employment.

The four key findings from the research objectives of deepening understanding male carers' experiences, particularly in relation to why they move from employment into full-time caregiving and their roles as carer and employee, are:

⇒ Internally and externally imposed obligations and personal incentives arise at different stages of the carer career and have to be negotiated for care work to be experienced as manageable.

⇒ How men perceive caregiving as work, based on their personal histories, goes on to enable them to rework and sustain their identity as working men.

⇒ Perceived and structural disincentives to disclose their caregiver identity and obligations in employment constrained male carers' abilities to combine caregiving with employment.

⇒ Male carers largely did not draw on family and friends and other informal structures for support, perhaps reinforcing their identity as autonomous care workers and care managers.

Key findings

Challenges to the credibility of the findings arose from the self-disclosing participant group and the interpretive nature of the findings. These were addressed by purposeful sampling strategies which ensured that the variation of carer characteristics was captured and validation strategies which helped ensure that research interpretations remained grounded in the lived experiences of participants. Consequently findings from this study may have applications to the wider caregiving community.

The key findings help deepen understanding of experiences of a relatively under-explored group of carers and offer the potential to inform the practice of health and social care workers supporting male carers and carer employment.

These findings have helped trace the complex decisions made by working-age male carers when deciding to take on the carer role and particularly when making the decision to leave or remain in employment. Participants did not become carers overnight but over a period of time, increasing caregiving activities and reducing contact with paid employment. Decisions to undertake care work were grounded within men's roles as fathers, sons and husbands, conditioning their sense of obligated commitment based upon reciprocity and the person being deserving of care. Yet it was also evident that when becoming a carer, participants frequently gave consideration to the way in which this might negatively or positively affect them. However, during this period they found it difficult to access information on benefits and rights to flexible employment as many sources of information, such as Citizen's Advice Bureau and carers' groups were only available during standard employment times. Increasing knowledge about this may enable service provider to ensure that access to information and support is provided at more appropriate times and through appropriate media. Appreciating that caregiving may be an acceptable alternative to paid employment should help to ensure that carers are truly provided with choice: whether to undertake care and whether to combine this with paid work. Whilst government policy initiatives seek to enable carers to access paid employment this study has highlighted the possibility of sustaining and refashioning a working identity, to find a developed sense of self esteem within alternative forms of work.

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Secondly, this research has specifically added to the understanding of the experiences of working-aged men who have left employment. The six men who had left employment drew on personal work histories, mirroring working practices within their occupation as a carer. They created structure and meaningful occupation within their days and this appeared to increase self-esteem and coping abilities. A few transferred skills from their paid work to benefit both them and the care-receiver. Where a developed work ethic had been embedded within their previous employment histories, there appeared to be a conflict of obligation, for some the greater obligation lay in their familial obligation and therefore they could not fulfil obligations to an employer. Employment advisors, such as Job Centre Plus, may need to recognise and explicitly discuss with carers their concerns that if they cannot do a full-time working day, then how feasible is it to enter the employment arena. As full-time carers care work became the occupation through which they reworked an identity as a working man. Recognising the value these men gave to their occupation as carer adds to the body of research which explores of how identities as carers may be constructed. Reflections on how care was experienced as an acceptable form of work suggested that this may be a coping strategy. Evidence from other empirical studies indicates that men and women may well experience carer burden in different ways (Almberg et al., 1998; Pinquart and Sorensen, 2006); findings in this study have pointed to some reasons linked to the distinctive ways in which male carers may experience and organise their caring. However, further research with both male and female working-age carers would be required to explore this proposition.

Thirdly, this research study has added to the growing body of research exploring carers' employment practices, by identifying types of employment which these men found enabled them to fulfil their dual commitments. Their ability to remain in employment was supported by flexible working times, commutable distances and the ability to differentiate and allocate activities into employment and carer time. However, whilst government policy may encourage active support for carers in the workplace this study has found that to access employment participants need to have confidence in the alternative care provided to their relative. Therefore, organisations such as Job Centre Plus and social care organisations will need to continue to work in collaboration to enable carers to become partners in organising good quality care which provides them with both confidence and opportunities to return to employment if they wish.

The study also highlighted the perceived and structural disincentives for participants in disclosing their carer identity. Findings suggested a need for employers to be more

active in encouraging carers' visibility, as support and flexible employment practices cannot be offered to those who remain hidden in the workforce. Being a carer and employee did, for some, create distinctive respite from both the physical and mental activity of caregiving. However, for others the dual roles equated to increased burden. Individual circumstances and choice will need to be considered during carer's assessments otherwise the risk remains that working-age carers will face unfeasible competing demands on their time to fulfil both contracts to employers and familial commitments to ill or disabled relatives.

Finally, this research has highlighted the important role paid social care workers play in providing a range of support for carers, opening up a relatively under-explored aspect of caregiving. Family friends and informal support structures were not heavily drawn on by these male carers, rather they appeared to take on a 'lone worker' role as 'manager' of the care work. Access to carer support groups was restricted by their perceptions of who such groups were aimed at, so whilst those few participants who accessed carers' support groups found them to be extremely useful in providing practical and emotional support and enabling them to value the care work they did others had tried support groups but ceased attending them. If service providers wish to increase working –age male carers access to support groups they may need to remove organisational barriers, such as groups taking place during standard employment hour. Further, ensuring that care-receivers are either actively involved in the group or that good quality alternative care is provided will enable men to have free time to attend.

Rather than family and carers groups providing support the key person who provided both emotional and practical support was the paid social care worker. This may have been expected, as they are the person making frequent visits to the carer's home and as such they had intimate knowledge of the carer's and the care-receiver's needs. However, the boundaries between the carer and social care worker's roles were blurred. There appeared to be the potential for the relationship to became symbiotic, with each providing additional services or support to the other, but there is the possibility for such relationships to become abusive. If service providers understand the complex relationship which may develop between the carer and paid social care worker they can develop strategies which both support the beneficial aspects of this relationship whilst limiting potentially abusive aspects.

The thesis not only provides findings related to practice but also provides an insight into the use of qualitative research methods, specifically in the context of increasing participants' involvement in the co-constitution of interpretations.

Developing qualitative research methods to address shared meanings

This study sought to develop knowledge of an area of men's experience that may have been difficult for them to reflect on and share, which raised methodological challenges which have been addressed in novel ways. The methodological approach developed for this study to meet those challenges may add to qualitative methodology in ways having wider relevance, as its innovative use of narrative summaries and follow-up interviews actively engaged participants in sharing meaning. The research design enabled reflection on both raw data and early analytical decisions, offering participants the opportunity to actively engage in the making of meanings. Interpretations were seen to be shared and opportunities were created for additive, more experiential-grounded data, which in turn have increased the credibility of the findings. Whilst accepting that second interviews alone may add to the qualitative data set, the use of the narrative summary to develop and link the process helped change the nature of the data produced, enabling those who chose, to share more personal emotional experiences. at the follow-up interview. Those who commented that they found their presentation of self challenging in the narrative summary did not disclose new data in the second interview, suggesting the narrative summary was, at least in part, the tool which could help generate additive data. This research method could be further developed and refined to increase participant reflection and rapport building where there is the potential for unease and reticence between participants and the researcher. It is a method particularly appropriate to hermeneutic phenomenology as it brings the participant, the person experiencing the phenomenon, into the interpretative cycle.

A personal narrative may also be a tool to help practitioners working with carers. Within this study participants shared their narratives with others as a means of sharing experiences they could not normally verbalise; perhaps the written words removed some of the personal confrontation in telling relatives or a friend how their comments were affecting them. Others were able to use their written narrative as a tool to instigate change such as seeking more support. There may be the potential for narrative to be developed in non-research contexts and used to structure conversations about caregiving situations perhaps during assessments.

Building understanding of male caregiving experiences

The findings from this thesis have identified the importance of recognising the obligated nature of responsibilities, the support structures drawn on and the meaning given to care work in the experience of working-age male carers. Three areas for further research were identified which may further increase understandings of carers' experiences. Further research would be valuable in increasing understanding about how choices are made at different stages of a carer career; about the nature of support carers may draw on and about the ways in which carers may experience caregiving as an alternative to employment.

This study captured participants at two points in their carer career, approximately four months apart; yet even in this short period substantial changes had occurred for two men: one had placed his wife in residential care and the other had left employment to undertake full-time care. Undertaking a longitudinal study of caregiving dyads from the point the care-receiver enters the medical system may help to deconstruct the complex decisions that are made by carers. Such work may also illuminate whether decisions are made in consultation or led by the carer. In this study participants made little reference to involving the care-receiver in their decisions making and understanding this decision-making process more deeply may empower both the carer and the care-receiver to make informed choices.

Through the data it emerged that these men were using support systems in distinctive and unexpected ways. The presumed support from family and friends was not evident. Rather support was drawn from carer support groups and by relationships formed with paid social care workers. Within the structure of this design it was not possible to explore the carer and paid social care worker relationship further, but as it appears that such relationships may potentially be both beneficial and abusive to all parties, it is suggested that further research in this area is appropriate. Understanding the characteristics of this type support could be further developed through undertaking ethnographic research centred in carers' homes, or focusing on the professional and personal relationships formed by social care workers in the course of their employment.

Finally, the participants' stories encapsulated the experience of undertaking employment alongside caregiving whilst also representing the experiences of being a full-time carer making meaning of a distinctly different life world through experiencing the activity of caregiving as work. Understanding how working-age carers may

experience caregiving as work facilitates the reinvestigation of key theories about carers' experiences from new angles. For example, there is evidence that carers may experience burden associated with their role and that men frequently appear to experience less burden than their female counterparts. It is tentatively suggested that this may, in part, be because of the meaning they derive from caregiving as a purposeful activity rather than an extension to their domestic roles. Exploring caregiving as work may change the focus of studies recruiting working-age carers and provide an alternative insight into their experiences, as they become people engaged in caregiving activity, rather than people who have left employment. Acknowledging that within this study there has not been the opportunity to further refine or validate the concept of care as an acceptable alternative to paid work, it is suggested that further studies, particularly those within the grounded theory paradigm, may either dismiss or develop the early conceptualisations made in this thesis.

In conclusion this thesis began with a definition of caregiving as a phenomenon consisting of feelings of affection and responsibility, activities including physical and emotional care and providing direct services (Cancian and Oliker, 2000:2). However, the vividly-lived stories shared by the study group of working-age male carers provided new insights into the experience of caregiving, which offered the potential to reframe caregiving as a phenomenon going beyond task- based activities. The meaning of the act of caregiving, instead, is seen to be shaped by the personal histories of those who undertake it.

Being a carer may well require affection and responsibility but these qualities do not only shape the act, they also underpin decisions to undertake caregiving, sometimes overriding the obligation to be in paid employment. It emerged here that male carers' own understandings, and consequently wider conceptualisations, also needed to take into account a complex web of obligations and identity negotiations. These were seen to shape men's decisions to become caregivers and how they then came to take on this challenging work. Many had made personal decisions to leave paid work and gained positively-experienced incentives of securing more time with their relative, enabling them to discharge their sense of responsibility.

Definitions of caregiving frequently focus on a list of task-based activities such as bathing, feeding, and preparing medications, but the findings of this study illustrated that the meanings of caregiving and of being a carer, went beyond pragmatic activities. For these male carers, caregiving was a recognisable form of work, carried out within

the confines of obligated time. They saw themselves as managers of the care, fulfilling responsibilities to ensure the well-being of others. However, the ways through which they discharged these responsibilities enabled them to shape the activity as an acceptable alternative to paid employment.

Caregiving was not a set of task-based activities rather it involved discharging obligated commitments to others within a changing lived world. Being a carer was grounded within the decision to accept the responsibility, leading to experiences being situated within obligated commitments and obligated time; relationships changed as families and friends withdrew and social care workers often became a source of support. Within this changing lived world working-age male carers faced additional challenges accessing paid employment or reworking their identities as full-time carers.

Finally, undertaking this study using a phenomenological approach has displayed the ways in which the phenomenon of caregiving is not merely an activity to be divided into tasks to be managed and achieved, but an experience that is lived through with its meaning being shaped by the competing obligations to be both a carer and an employee for working- aged male carers.

Appendices

Appendix 1   Example of literature search strategy

Table provides example of search terms and results using ASSIA database. Peer-reviewed journal articles from earliest – 2008

Keywords	Sourced peer reviewed articles	Number meeting inclusion criteria
Care*	78556	Not reviewed
Caregiving	1551	Not reviewed
Caregiving + male	44	Not reviewed
Caregiving + male + employment	2	0
Caregiving + employment	65	Not reviewed
Caregiving +unpaid employment	8	0
Caregiving + employment + men	11	2
Caregiving + work	227	Not reviewed
Caregiving + work + male	3	1
Caregiving + work +men	20	2
Caregiving + obligation	20	3
Caregiving + choice	22	1
Male care	1	0
Family care	243	Not reviewed
Family carer + male	4	0
Informal care	343	Not reviewed
Informal care + male	6	1
Informal care + men	10	1
Informal care + choice	7	0
Informal care + obligation	4	0
Informal care + employment	30	Not reviewed
Informal care + employment +men	5	5
Informal care + employment + male	1	1

Appendix 2   *Review of literature*

Review of literature adding to understanding of working –age male carers experiences of caregiving.

Authors	Study design	Key findings	Methodological issues
Almberg et al. 1998 Sweden	Aim: Explore differences in carer burden across genders and carers and non-carers. Method: Used burden questionnaire and self reported measures during face to face interview. Sample: Caregivers 52 of which 15 males age 42-88. Non caregivers n=66 , 23 men age 37-92 Analysis: correlation and regression analysis.	*Male carers experienced less strain* than female carers. *Male carers experienced less conflict* with other family members. *Male carers experienced limited* social support and lacked a positive outlook when compared to non-caregiving men.	Personal contact during data collection may have improved response to questions. Difficult to identify where age may have been a variable. Little reference to employment characteristics and whether this was a variable of the experience.

Authors	Study design	Key findings	Methodological issues
Archer and McClean 1993 Canada	**Aim**: To explore the meaning men give to caregiving. **Method:** In-depth open end interviews. **Sample:** 3 husband and 3 son carers: age range 52 71 **Analysis:** Thematic analysis.	Three themes: *Importance of outside interests* in helping with coping. Ensured they got respite *Relationship changes* felt abandoned and neglected by family and friends. Experienced social stigma related to care-receivers illness. *Personal emotional gratification* suggested they received gratification from role. Undertook caregiving not from duty but motivation more readily linked with reciprocity. They felt that they provided a high standard of care.	Participants had high level of engagement with social support services, which may have changed the meaning they gave to caregiving. Only 1 participant in employment, hence no details on how employment impacted on caregiving. Does provide a good range of illustrative quotes to strengthen the findings.

Authors	Study design	Key findings	Methodological issues
Arksey, 2002 UK	**Aim**: Explore the impact of employment for working age carers. **Method:** Each participant interviewed twice. **Sample:** 12 employed of which 2 were men. **Analysis:** Thematic analysis.	*Conflicting demands* of care and work leading to ill-health. *Needed time off work* sometimes difficult to access at short notice *Found friendship from colleagues*. *Lack of support* for some from flexible employment practices. *Balanced competing* demands by: reducing travel time. Reducing working hours, using lunch breaks.	Very few men in sample but able to pull out their illustrative quotes. Not clear on method of analysis, appeared to be both inductive and deductive. Smaller study within part of funded study exploring how workplaces support carers. Indicated employers actions and carers needs not always reconciled.
Campbell and Carroll, 2007 Canada	**Aim:** To explore the fit between masculine traits participants assign to themselves and the traits of hegemonic ideal male. **Method:** Single interviews using guided conversation. **Sample**: Purposive sample58 sons age range 35-75 mean 57 years **Analysis:** Coding of data leading to themes.	Little or no reluctance to undertake the carer role. *Displayed masculine traits* I the 'just-do-it approach and a taking charge. *Willing to take on the gender activity* of housework Spoke of undertaking caregiving motivated by reciprocity. *Willing to expose their emotions* but still held that females were more intuitive carers.	Sample included 34 male carers in some form of employment, but the impact of being in employment on the meaning they give to caregiving not explored. Sample included both married and single men thereby removing some of the potential for experiences to be moderated by female support.

Authors	Study design	Key findings	Methodological issues
Gerstal and Gallagher 2001 USA	**Aim:** To test if women spend more time caregiving than men. To see if family structure and employment patters alter level of male caregiving, specifically do men change level of caregiving if wife employed and does flexibility of their employment increase their caregiving. To explore if gender ideology affects caregiving **Method:** Structured interviews undertake separately with spouses. **Sample:** random sample of 94 married couples, median age 41 years. **Analysis:** Focused on amount of time caregiving and types of caregiving activities.	*'Hierarchy of care'* more likely to help kin than friends. *Men spent less time caregiving* and less likely to complete feminine tasks than wives. *Family characteristics* rather than employment characteristics influence male caregiving. *Wives and sisters* appeared to draw men into caregiving as men did caregiving activities to help women rather than to help care-receivers. *Gender ideology* has little impact on caregiving behaviours.	In sample 88% of men employed, but lacking details on nature of employment. Likert scale to measure gender ideology did not appear to be validated. Adds to understanding of tasks male carer may undertake and the ways in which caregiving may be led by women. Does not add to understanding about the meaning men find in their caregiving. Little discussion of the impact of employment on male caregiving.

Authors	Study design	Key findings	Methodological issues
Hagedoorn et al, 2002 The Netherlands	**Aim:** To explore why there are reported differences in carer psychological distress based on gender **Method:** Cross sectional design using a range of validated measurement scales to measure self efficacy, personal accomplishment, supportive unsupportive behaviour, distress. **Sample:** 32 female and 36 male partners of people suffering form cancer. Mean age 54 years 63.9% men in employment. **Analysis:** Regression analysis.	*On average female carers* reported more distress than male carers, but if they felt good about their caregiving performance reported the same lower levels of distress as male carers. *Proposed that increase self- efficacy* amongst male carers may have resulted in lower levels of distress.	Whilst proposing one explanation for the evidence that male carers experience less distress than female carers study concentrates on self reported responses. Relatively small sample size with limited response rates. Does not attempt to make links between levels of distress and variables such as employment length of time as a couple.

Authors	Study design	Key findings	Methodological issues
Harris, 1998 USA	**Aim:** To develop understanding and provide perspective on son carers. **Method:** In- depth interviews with topic guide. **Sample:** 30 sons caring for parent with dementia mean age 50 range 32-71 years **Analysis:** Content analysis leading to themes, undertaken with co researcher.	Themes: *Duty as a motivation* to care. *Taking Charge* –one of the roles was to push family to make decisions. Common emotions -*Expressed felling of love, pain, anguish, anger, guilt, resentment, sadness and compassion. Some expressed carer burden.* *Work Flexibility*- enabled sons to undertake caregiving. *Loss* – loss of the character of the care-receiver and loss of their personal time and space. *Sibling relationships*- majority became closer to siblings and increased contact. *Reversing roles*- difficulty to take charge of parent and reduce their independence. *Coping strategies* – used problem solving, immersion in work, confiding in wives and finding solace in religion to help them cope with role. *Positive outcomes* chance to give back to parent.	Meaning of experiences may have been affected by the fact that majority of sample heavily used social support services. Some care-receivers had died previous to the study so participants recollection of experiences may have changed. Unclear who in sample was primary care and who cared alongside wife. Did provide understanding of meaning of caregiving.

Authors	Study design	Key findings	Methodological issues
Hequembourg and Brallier 2005 USA	**Aim:** To explore whether siblings use gender as a criterion for dividing caregiving tasks. **Method:** In-depth interviews with sibling pairs. **Sample:** 8 pairs of male/female siblings providing care to parent. Majority in employment mean age 47.1 years. **Analysis:** Grounded theory.	Defined two types of help provided by brothers Helper-brothers *Where caregiving led by the sister with brothers undertaking more traditional male task e.g garden maintenance.* Co-provider brothers *Actively involved in care. Flexible work schedules and family obligations encouraged higher levels of caregiving.* *Division of care* not explicitly planned. Few acknowledged gender influenced decisions.	None of sample lived with parent which perhaps suggest lower levels of caregiving. Did not mention if saturation achieved with only 8 interviews. Unclear if married brothers drew on their wives as a source of support or if their wife's undertook caregiving alongside the female sibling. Limited characteristics differences in sample.

Authors	Study design	Key findings	Methodological issues
Hirsch 1996 USA	**Aim:** To explore personal meaning of caregiving to male carers including internalisation of gender typed attitudes and psychological processes used to resolve cognitive dissonance. **Method:** Interviews and Bem Sex Role inventory. **Sample:** Purposeful sampling 32 chief male caregivers, 21-79 mean age 52.75 **Analysis:** Scores from Bem sex role inventory used to allocate to gendered personality traits.	*Personal ideologies* based within family histories, religious ideologies may enable masculine gender-typed men to undertake caregiving. *Filial obligation and affection* for relative were motivators to care for men with androgyny as an ideology. They also spoke of needed a spiritual belief. Disavow carer role in case people think him less of a man. *Different roles* in different social arenas to maintain masculine self.	Unclear on how much of interview was narrative and how much guided by the gender role inventory. Sample appeared to be largely representative of wider male population.

Authors	Study design	Key findings	Methodological issues
Horowitz 1985 USA	**Aim:** To explore under what conditions do sons take on care of parent; do sons and daughters undertake care in different ways; do they differ in perception of social and emotional consequences of caregiving. **Method:** Structured interviews with pre-set scales. **Sample:** 32 sons – 99 daughters **Analysis:** Quantitative analysis of scale points and summary of interview responses.	*Few differences between sons* and daughters around levels of contact and shared living accommodation. *Daughters significantly* more likely to provide 'hands on ' care e.g. personal care meal preparation. *No significant difference* between sons and daughters for tasks such as financial management, managing services or providing emotional support to parents. *Men significantly more likely* to be involved in caregiving if wives were also providing care. *Sons experienced less stress* as result of caregiving than daughters, many men drew on wives for support.	Difficult to draw conclusions on motivations to undertake care as 88% of sons in the sample were either only children, had only male siblings or where the only geographical available child. Adds to understanding of tasks male carers may be more likely to undertake. Limited details on employment patterns of sample and length of time they had been caregiving.

Authors	Study design	Key findings	Methodological issues
Mays and Lund 1999 USA	**Aim:** To explore lived experiences of male caregivers to people with mental ill health. **Method:** In-depth interviews with topic guide. **Sample**: Purposeful sample5 husbands 5 fathers, - 6 male carers aged below 60 years 3 in employment. **Analysis:** Content analysis.	Expressions of burden- *Carer burden influenced by understanding of the illness, length of time carer and ability to continue own life, psychosocial impact of mental illness.* Duration and depth of commitment-*Became more resigned to role as length of time caregiving increased, leading to lower levels of stress.* Sense of obligation Role affirmation- *Took on role even when others offered help experienced sense of duty. Pride in accomplishment of role.* *Psychosocial impact*- need for adjustment in their life. *Financial impact* – effects on employment status. Cost of care led to financial burden. Crisis management concerns *Actions to maintain control and used support services to manage crisis.*	Whilst majority of sample aged below 60 only 3 remained in employment, unclear why left work. Used a range of validation techniques but limited description of sample characteristics.

Authors	Study design	Key findings	Methodological issues
Parsons 1997 Canada	**Aim:** To explore the meaning inherent in their lived experiences. **Method**: 2 in-depth unstructured interviews. **Sample:** 5 husbands 3 sons primary care to person with Alzheimer's disease. **Analysis:** Thematic analysis.	Themes: *Enduring* – endlessness of caregiving undertook role because love, lack of alternative, felt best able to cope. *Vigilance* – watching out for and keeping care-receiver safe. *A sense of loss* –loss of person as they had known them. Loss of relationships with care-receiver and others. *Aloneness and loneliness* – separated from siblings needing to make decisions alone. *Taking away* –independence of care-receiver. *Searching to discover* –find out about disease. *Need for assistance* – formal and informal support. *Reciprocity* – caregiving led to role reversal. *Overstepping boundaries* – sons unease with providing mothers with personal care.	Few details about the sample so unclear on age or employment characteristics of the cohort. Thematic analysis provides a good description of the meaning of caregiving.

Appendix 3   Recruitment email

Subject line: Research with men involved in looking after partners,
            family or friends

Body of email:

I am a postgraduate research student carrying out research on the
experiences of men who look after their partner, family member,
friend, or neighbour for more than 10 hours a week.

I am particularly interested in finding out the experiences of men who
combine paid work with their caring role.

I am based in the University of East Anglia and supervised by staff in
the School of Allied Health Professionals.

Your company have agreed to send this email to all employees', but
they are not involved in the study in any other way. Any contact with
you will remain confidential.

I have attached an information sheet with details of my study.

If you would like to find out more about this study please contact me
at:

linda.birt@uea.ac.uk or 01603 593094, there is an answering machine so
if you wish to leave your number I will phone you back.

Thank you for taking the time to read this and I look forward to
hearing from you.

Linda Birt

Postgraduate Research Student

The Queen's Building

UEA, Norwich, NR4 7TJ

Tel: 01603 593094

Appendix 4   Recruitment letter

UEA
University of East Anglia

Faculty of Health
School of Allied Health Professions

University of East Anglia
Norwich NR4 7TJ
United Kingdom

Email:Linda.birt@uea.ac.uk
Tel: +44 (0) 1603 593094

The Crossroads office has kindly sent this letter to men who receive a care package from Crossroads. I have not had access to your personal details.

The research study.

I am completing a research project exploring what it is like to be a man who looks after a partner, family member, friend or neighbour. I am particularly interested in talking to men who are less than 65 years and who combine paid work with caring; or who have made the decision to leave work in order to look after somebody else.

I have included an information sheet which gives you more details about the study.

I realise that it can be difficult to find the time to commit to other activities; therefore it may be possible to provide some financial support for you to employ a Crossroads carer whilst you are completing the research interviews.

Your decision on whether or not you join the study will remain confidential and will not affect your relationship with Crossroads, or any services you currently receive.

Crossroads are not part of the study and if you require more information or decide to participate **please contact Linda Birt** at the above address, or email linda.birt@uea.ac.uk, or telephone 01603 593094, there is an answering machine so if you wish to leave your number I will call you back.

Thank you for taking the time to read this letter and I look forward to hearing from you.

Yours faithfully,

Linda Birt   Dr Fiona Poland Dr Margaret McArthur
Postgraduate Research Student   Research Supervisors

Version 1
5.10.07

268

Appendix 5   Participant Information Sheet

Research title: **An exploration of the lived experiences of being a male informal carer.**

You are being invited to take part in a research project. Before you decide it is important for you to understand why this project is being done. Please take time to read the following information and discuss with others if you wish. Please contact me if there is anything you would like more information on. Take time to decide whether or not you wish to take part. Thank you for reading this.

2   What is the purpose of the project?

A lot of research has shown us that carers may experience different problems to those people who are not carers. This study is trying to find out what it is like to be a man who is providing care for a partner, family, friend or neighbour. It is known that many men combine work and caring and this can be both beneficial and challenging. In this study I would like to talk to men about their experience of working and providing care.

3   Why have I been chosen?

You are being considered for this study because you have indicated that you are a man who is providing at least 10 hours a week unpaid care to another person. You have a range of experiences that will help me to understand the research question.

4   Do I have to take part?

It is up to you whether or not to take part. Refusing to take part will not lead to any penalty or loss of service you already receive. If you decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without penalty, and without reason.

5   What will happen to me if I do take part?

If you do decide to take part you will be asked a number of preliminary questions about who you care for, how long you have been a carer and whether or not you work. These questions help me make sure that I interview men with a variety of experiences.

If you are selected for the study you will be contacted by telephone or letter within a month to arrange for the first interview. This interview will last up to one hour. Approximately 4 months after the first interview I will send you a summary of the interview. I will then arrange a time for the second interview.

The second interview will be an opportunity to discuss the ideas that were covered in the first interview and to discuss how your caregiving role has developed. It is expected that the second interview will last about an hour. After a few months when I have analysed all the interviews I will send you a summary of the issues arising from all the interviews, giving you an opportunity to comment if you wish.

I am hoping that more people will join the study that I can accommodate. If you are not selected for the study I will send you a letter and delete any information I hold about you. Thank you for your time

6   What do I have to do?

You have to be available for two interviews in your home, or another mutually convenient venue. There is the possibility of financial support to pay a formal carer to support the person you care for. Travelling expenses can be paid for journeys to alternative venues. You will also be asked to read an interview summary that I will return to you before the second interview.

7   What are the possible disadvantages and risks of taking part?

I do not foresee any disadvantages to taking part in this study. If you do become distressed when talking about your experiences I can advise you of where to access additional support.

8   What are the possible benefits of taking part?

Whilst there are no immediate benefits to you in taking part in this study, it is hoped that this work will inform those who work with male carers.

9   Will my taking part in the project be kept confidential?

All information collected about you during the course of this research will be kept strictly confidential. Names and identifying details will be changed. Paper records will be kept in a locked drawer in the School of Allied Health Professions at the University of East Anglia. Digital recordings will be erased at the end of the research. Any information held on computer is password protected and will be deleted at the end of the study.

Confidentially <u>will</u> be broken if the researcher feels that you or anyone else are at risk of serious harm.

10   What will happen to the results of the research project?

Results from this study will be shared in a number of ways: through seminars, published papers, visits to carers support services. If you wish for a copy of the report please let me know when I visit or in writing by July 2009.

11   Who is organising and funding the research?

The project is being completed as part of a higher degree programme for the principal researcher. The funding of the degree and costs of the study are being met by a grant through the University of East Anglia.

12   Who has reviewed the project?

The study was reviewed by the Faculty of Health Ethics Committee at the University of East Anglia.

13   Contact for further information

Principal Researcher: **Linda Birt** Postgraduate Research Student

Linda.birt@uea.ac.uk or **01603 593094,** there is an answering machine so if you wish to leave your number I will call you back.

The Queen's Building, UEA, Norwich. NR4 7TJ

In the event of any complaint please contact my supervisors:
Dr Fiona Poland 01603 593630 or Dr Margaret McArthur 01603 593299
The Queen's Building, UEA, Norwich. NR4 7TJ

Appendix 6   Recruitment poster

School of Allied Health Professions

Are you a man looking after a family member, friend or neighbour?

Would you like to be part of a project exploring the experiences of informal carers?

What do I have to do?
⇨   Be available for two interviews
⇨   Comment on summaries of your interviews
⇨   Comment on the findings

What are the benefits of this study?
⇨   Hopefully this work will help with understanding the needs of male carers

Will anyone know if I take part?
⇨   No ... all interviews and information will be anonymised and kept strictly confidential

Who do I contact for more information?
⇨   **Linda Birt** Research Student

at Linda.Birt@uea.ac.uk or
01603 593094, if no reply leave a message and I will call back

School of Allied Health Professions
The Queens Building, University of East Anglia
Norwich. NR4 7TJ

UEA
University of East Anglia

Appendix 7   Non-inclusion in study letter

UEA

University of East Anglia

Faculty of Health

School of Allied Health Professions

University of East Anglia
Norwich NR4 7TJ
United Kingdom

Email:Linda.birt@uea.ac.uk
Tel: +44 (0) 1603 593094

Dear

Thank you for expressing an interest in taking part in the study 'Exploring the lived experience of male informal carers'. Due to the unexpectedly high level of interest shown in the study, I will unfortunately not need to interview you.

The personal information I collected will now be deleted.

Thank you for your interest and I wish you all the best.

Yours sincerely,

Linda Birt
Postgraduate Research Student
University of East Anglia
Tel: 01603 593094

Version 1
5.10.07

Appendix 8 Interview topic guide

Introduction

Thank you for agreeing to talk to me about what it is like to look after your _…_. I would like you to tell me what your experiences are. We have up to an hour to talk and I will let you know when we are getting near the end in case there is anything else you want to tell me.

Warm up questions:

How long have you been looking after _…_?

What type of job do you do?

Do you mind telling me your age?

Possible questions:

Perhaps you could tell me about how you came to be looking after _…_.

How do you describe yourself to other people?

What's it like to go to work and also look after _…_.?

How do you feel when you are at work?

How does your employer support you?

Do you tell others you are looking after _…_?

How do you feel about being a person who is looking after someone else?

Does anyone else get involved in helping you look after _…_.?

Where do you see yourself in the future?

Topic areas:

Employment: have you told work colleagues, balance of commitments, support, tensions, benefits.

Male identity: how describe self, male or female role, views of others.

Family roles: have roles changed, how feel about current roles, change in relationships.

Care career: How started, where feel going.

Support: family, friends, community, professionals.

Prompt and probing questions:

You mentioned that you feel like _…_ when that happens can you tell me a bit more about that?

You started to tell me about _…_ but then we moved on to another topic please can you tell me more about that now.

It would help me to understand more about what it is like to work and look after someone if you could explain a little more about _…_.

Appendix 9   Process of producing narrative summary

This appendix provides an example of the narrative summary which was produced from the transcript. There is then an example of the questions used in the follow-up interview to illustrate how interpretations were developed and shared through the summaries and the second interviews.

The interview transcript has been lightly edited to remove the researchers 'ums' and 'yeahs' which were used to encourage the participants.

Martin's Interview

Interview undertake with Martin 50 year old full-time carer for his mother.

LB First of all thank you for agreeing to talk to me again we've had the chance to go through the consent form so what I want to talk about today is to give you the opportunity to talk about your experiences looking after your mother so can you tell me about your typical day?

R3 Right well unfortunately most days are very similar so like a Monday is like a Thursday is like a Sunday it starts it normally if you start it if you think about midnight as the start of the day it starts during the night, because my mother has her commode next to her bed because she's unable really to sort herself out with the loo during the night.   So it means that very often in the night she'll call me because she needs to go to the loo, so I get broken sleep, very occasionally we'll sleep right through but that often means that mum's you know wet herself…And you know it's changing her and sheets and things like that but very often she'll get me up in the night to use the commode… so that's the start of the day really in the morning because I don't work any more the day will start when it starts it could start at seven it could start at eight it could start at nine, if I've slept well I'll get up earlier and come down here and do a few jobs before getting mum up if it starts later because I've got up a couple of times in the night then it doesn't matter normally it starts with me getting out of bed and getting her back on the commode again and I'll take her a cup of tea she'll drink that and then I'll get her dressed and bring her down stairs and she'll sit in here and have breakfast which is normally slice of wholemeal bread with jam or marmalade and then she'll have some porridge and then after breakfast I take her to the loo she'll brush her teeth oh she's taking something and after her breakfast she'll take medication as well and then after

274

we'll go to the loo, brush her teeth go to the loo again brush her teeth wash her face and then I will then get her sitting in the armchair in the living-room which is you know but you know but quite well supported I've got one of those big cushions and everything she uses and she walks 'round the house with a Zimmer frame as well…And although she can walk on her own she's very slow and yet I really have to stand behind her because she's had a few falls and and by it's it's for I mean from our point of view we've had breakfast but for most people's point of view it's nearly lunchtime because it's about eleven half past eleven before we've done all that

And then that's uh she'll then sleep guaranteed because the medication she takes and the exertion of getting up getting dressed having her breakfast and washing really does knock her out so this so I know then that if I need to go to the supermarket or go to the post office or run round and do a few chores that's an opportunity for me to do that so she'll be asleep probably anything between half an hour an hour, she has got a community alarm

Uh that she that's connected to district council and all the neighbours are on the loop and my mobile is as well so if there was a problem and if she remembered to press the button it would go through to my mobile and then lots of the neighbours around here are retired fortunately so they're on they're numbers are on it as well so there's about three or four chances of if there was an emergency …And they've all got keys obviously to get in

R3 So I can go off and do a few things then I'll come back and by then mum will have woken up a bit so I then make we'll probably make her a cup of coffee and when she's had that and she's feeling a bit more with it I'll probably I'll take her to the loo again and then you know the normal routine back into the living room and then it's probably and it and it sounds sounds crazy but it's probably nearly lunchtime then it's probably nearly about half past one two 'o clock by then so we'll I'll make her a sandwich and then she'll have another cup of tea and then it's it's sort of broken up between trips to the loo and you know making sure and eh it's not only the loo it's also a bit of exercise otherwise she could just spend too long in that chair so every at least every hour hour and a half she needs to get up and walk about do you know for exercise for much as anything…But obviously in the summer you know we can sit out in the garden which is quite nice but in the wintertime she can't

really sit outside at the moment, one afternoon she has a lady from crossroads who comes and sits with her

R3 Uh to give me a break so I can have an afternoon out and one day the routine is slightly different in that we start much earlier in the day because she goes to a day centre

And I get a whole day out to myself then so I and I'll take her to the day centre in the morning and then they bring her home in the afternoon so I get a sort of a day and a half uh a week out off off you know off yes

Well most people get like Saturday and Sunday mine's Tuesday afternoon and Friday

I'm also quite involved with Carers group I'm on different panel meetings and committees and I run a few workshops and things like that for the groups and everything so and they'll pay for respite care for me then so I do get other opportunities you know to go out and do other things

R3So that so come back to the routine so if it's a normal day and I'm not going out anywhere and it's not a Tuesday or a Friday and there's nothing else special happening that I can go out for so that mum gets respite we might you know she might watch a bit of telly in the afternoon and you know when I'm trying to do if it's in the summer I'll try and do the garden or cleaning or washing or ironing or preparing the dinner or you know all the things that everybody has to do because I you know and I do try and find chat chances to chat with her as well but sometimes the conversation is very one way.. Mum will never initiate conversation she'll rarely start one oh if I mention something that I've read in the paper or I've seen on the TV or I've listened to on the radio I she'll have a bit of a conversation with me but it's always very often the answer is well I don't know don't ask me so it's a bit frustrating that you can't really get a really good two way conversation going so the afternoon is a mixture really perhaps she'll watch a bit of telly she'll listen to the radio, drink cups of tea and I'll be in and out by doing other things as well and then we'll have dinner about six which I cook obviously because mum can't really do anything for herself can't really cook or clean uh make herself a cup of tea or anything I mean I do it all for her we'll have dinner about six and then that and also it takes mum much longer to everything I mean if she has her, if she has her dinner or lunch or breakfast I mean she could sit three quarters of an hour eating a

bowl of porridge…You know it's cold by the time she's got too into it [you know / huh] and then we'll have dinner about six and then it'll be back in the living room and I usually take her up uh to bed about nine nine fifteen because it takes a good the time I've sorted her our in the loo down here brushed her teeth and undressed and into bed it's very often a good anything between half an hour and an hour and at the end of the day I need a bit of down time [do you know what I mean / right] I need to put mum to bed and then I need I like to get her if I can get her done by ten 'o clock then I can watch sort of the ten 'o clock news or whatever do you know what I mean…I get a chance just to unwind and think you know another day over with so you know and whether I'm going to get a good night's sleep and all the rest of it you know

R3 But yeah so the days are you know and really again a Monday is I mean apart from the days when I go to the day mum goes to the day centre that that you know a Monday is like a Tuesday is like a Friday is like a Saturday or Sunday do you know what I mean that none of the days are that different…

I did have somebody that used to come and give mum a bath every week but she can't do that anymore and so I've got into a routine I mean because I deal with a lot of mum's care ending up bathing her feet and all sorts of things but so I give mum a bath once a week as well and she has a bed bath as well a couple of times a week so.. But yeah it's all routine routine is the thing that's the thing you know I try and think of different ways of breaking up the routine but there's not much you can do really. You know and also if I have a routine mum knows where she is as well 'Cause she keeps asking to be reminded of what she should do because although she hasn't got senile dementia or anything like that she does get a bit forgetful she's had a few little strokes which keep chipping away at memory and mobility and things like that so you know

LB So how long have you been looking after your mother?

R3 Uh well I was I would say it must be about three or four years now yeah

LB And what happened when you started?

R3 Well I was working for xxxxx and then went on to a training program I was two thirds through the training when mum's health really went down hill

she used to at that point she would have somebody come in and help her in the morning but during the day she was okay she could you know go to the loo without a problem make herself a sandwich and make herself a cup of tea you know and turn the telly on and off and would be okay but then it became quite obvious that she was deteriorating quite badly and she'd had a couple of those little TIAs you know the mini-strokes and at that point I realised that she couldn't really look after herself in other words she couldn't be left on her own during the day, so the training wasn't going as well as I I thought it would and so I had to make a I made the decision to, because I've got no brothers and sisters, and my father died many years ago there's no extended family within you know spitting distance sort of thing so it's really been all down to me so I had to make the decision that if I carried on with the training course to finish this training program for a year mum would have to go into residential care or I'd have to pay a fortune to have carers come in everyday which I didn't really want so I sat down and sort of literally got a bit of paper out and looked at the finances the mortgage is paid so that's alright you know looked at the finances and thought well I think I'm going to pack up the job and look after her myself

So sort of quite a cathartic moment really but I realised that that was the best thing to do really and I think although it was very frustrating to begin with and it's not I mean I'm not saying it's not frustrating now but it took a long while for it to get into into a bit of a routine and for my and for my sort of stress levels to come down because to begin with I would get really frustrated and angry and cross and loose it with mum I mean occasionally I still loose it now but in the main it's not too bad

But it takes a long time to really get into the routine and realise that one of the things you miss as well with the like packing up work is the social aspect of work

Because even if whether you like what you're doing or not if you uh if you don't have that social contact with people it's you know I can go a whole day with just me and mum I mean I've got my neighbours are quite good and I do you know obviously if I go out to the supermarket or whatever I end up talking to people that probably don't want to listen to me no I'm only joking but you know what I mean you end up sort of striking up conversations with all sorts of people for no apparent reason but there we go. But yeah the routine that's the routine really and then I just

go up to bed and I get this you know a you know bit of a bit of a window of opportunity for my self to unwind and then back to what happens next day

LB So you were saying that you felt your stress levels were less now?

R3 Yeah

LB How do you manage that then?

R3 Uh only well I think it's because when I first packed up work it was I it was the fact that it was such a momentous decision and I realised what I'd given up as well as not realising how much looking after mum full time twenty-four seven would take out of me and it takes a long while to get used to that

That's what I'm saying and I know talking to other carers that have done a similar thing uh mainly through Carers group that they feel exactly the same and it takes it takes a while to get sort of an equilibrium and an understanding of the whole the whole process of being a full time carer and what that really means because you are you know if I've got friends that say go away up to xxxx for the weekend I can't suddenly say oh I'll come with you because of mum you know I can't I haven't had a proper I used to go on holiday quite a lot at one time but I don't have holidays now

I mean my passport runs out soon so I will renew it but the chances of me using it for a while is probably out of the window I mean I do get respite I get an allowance through carers group f-for respite care

So I do have a few nights out I'm not stuck in all the time you know where's the violin you say you know but I do go I do get a chance to go out a few evenings through the year you know with friends or whatever for a meal or something and then a carer will come and sit with mum and put her to bed and everything so that does give me a break

LB Does that take planning then?

R3 Yeah well yeah because I have to book I have to book a carer in advance so if I wanted to go out say probably this week I'd if I was to go out at the end of this week I'd probably would ought to have booked a carer by last week so yeah you can't say I can't just suddenly say I'm going out for the evening if I'm going to go out it takes you know I need I need at least a week's notice

You know to book a carer either through carers group or you know Crossroads or one of the agencies I mean carers group use their own uh agency but yeah it does take a bit of planning yeah I couldn't suddenly say I'm going out tonight you know I mean early on I could have gone out before mum got really bad because a neighbour would have popped in just to check on her do you know what I mean but now it's just impossible without planning

LB And why has that change happened then?

R3 [Sighs] When well when I was when I before I packed up work completely oh even even shortly after packing up work when mum's health when she didn't need quite so much care because the need the care need is increased like just as you've saw as you came in

Previously mum would have able to go to the loo on her own and sort herself out and come back but she can't do that now unaided so to begin with I could have gone out for the evening and perhaps a neighbour might have popped in during the evening just to check on her but now that can't happen because she help with the loo and all the rest of it it's not fair on neighbours to ask them to do that

If I if I'm not here then I have to have a carer a trained you know a trained carer in with her

LB And so how do you feel about doing that personal care for your mum?

R3 Well years and years and years ago I worked in a hospital for a year so I'm not at all squeamish about bodily functions or all the rest of it so that's not a problem at all so it doesn't you know somebody else might find that really difficult but but I don't so and also it's my mum you know it's not sort of somebody that's not family or

Somebody different as I say I worked in a hospital about thirty years ago for a year so you know so that was okay I don't have a problem with that

LB Ok so when you made your decision to give up work and become a carer did you envisage you said it's change so did you envisage it would be like like how it is now when you gave up to something else?

R3 No I do I mean I know no I don't I do know I don't think unless you've made any sac I'm not saying it's a sacrifice because I love it to bits and I do it because I

love her I don't do it because I feel it's a sense of well it is a sense of duty because I suppose in a way I feel though as though she made a really good job of bringing me up or mum and dad made a really good job of bringing me up and all I'm doing now is is repaying her and it's I mean in this country I know you know it quite annoys me when you see people if you watch a TV program or you listen to somebody on the radio where they say oh yeah we had to just put our parents into a residential care home because I don't think people I I think people in this country can be quite selfish really I mean in the Mediterranean countries it's quite common for generate more than one generation two or three sometimes to live under the same roof you know you know parents they'll have children but they'll also have their own grand pare their own parents so you've got the three generations all living in under the they all sort of care for each other whereas here this country it's quite rare doesn't happen quite so much like that does it here generally speaking I know but I mean there probably are care homes abroad but it I think in the lots of Mediterranean countries they do tend to look after their own whereas here we tend to stick granny into an old people's home but you know if I I suppose it would help if I had brothers and sisters maybe because I you know you could share the load a bit But no doesn't happen it's not happened like that

Never mind does that answer your question, I tend to go off on a tangent sometimes

LB No that's fine

R3 do hold me back if I sort of start wandering

LB It's what you want to talk about as much as anything

R3 yeah I know but you know different things crop up don't they when you start talking about them yeah so no I don't think you can envisage how it is going to turn out it turns out how it turns out…I mean some people may start the caring role and after a year realise that they can't cope with it anymore and maybe they do have to put somebody into a residential care unit

And I think you've got to be a certain sort of person you know I mean I've always been in the sort of the caring professions if you like I mean I don't think couldn't be a plumber or an electrician do you know what I mean I couldn't be you know but or an estate agent or an insurance salesman or anything like that

I'm a people person

LB Yeah - I just you said you said that you do some of you get some respite from Carers groups to go and do groups there so what do you get out of that?]

R3 I do some workshops and I did one last week down at (town's name) and I mean I've got a couple more they want me to do and uh and there's the flexible respite project which they have which is uh giving finances to people for respite I'm on their panel and there's a couple of other panels that and committees that I'm on down there so I'm quite involved with carer group which is quite useful and again it's a it's a brilliant organisation you for the support that uh they give carers

LB So as an individual what do you get out of that?

R3 Well I get we have a in (market town) we have uh a monthly group which we meet every month and that's a support group and we have guest speakers and sometimes people from the group will bring you know will run the day as well and you get the chance to meet other carers that are doing the same as you and looking either looking after children or their parents or their or their partner so that's like a support group and again carers group I mean carers group quite obviously quite a big organisation… so yeah there is a support network think you know that there's someone there I mean if you really were need someone to talk to and it not just a friend but somebody in the profession to understand what you're going through there's somebody there to talk to

LB Oh can you give us is it an informal situation then the carers group and people to talk to

R3 Yeah I mean they have guest speakers they have we have a program that runs each year in fact we've just we've just been given the program for the next this coming year they paid for us to have a day at health club

LB Oh right

R3 So I had a massage and used the Jacuzzi and three a good three course lunch and uh and then a head massage during the afternoon I fell asleep during that but the girl said that's fine and people often do

Yeah so and like that was so that, we've got a talk with a member of staff from Carers group and then there's another lady coming from Carers group about the befriend they've got a befriending group there so that I think it's it's so that somebody that can ring say once a week to uh to somebody that is a carer that feels

282

a bit lonely or isolated and they'll phone them once a week to see how uh how they are

LB Is that something you would consider

R3 As a as some as a befriender or I mean I don't [no as the person] I don't think I don't think I need anybody to ring me once a week 'cause I'm okay well I think I am other people might disagree but I haven't really I haven't really thought about it from a personal point of view again it's how much time you feel you have to to phone someone once a week but I yeah I would be prepared to do that and then in April we've got somebody coming to talk to us about carers allowance which I get and most people unless you're retired when you're not entitled to it but that's another issue and that's it that's somebody's coming to talk to us about uh safety and emergency planning in may and then the rest of the year is not made up yet but

LB So it's a combination of the social group and the support group?

R3 Like for example in xxx we've just put tea and chat we haven't got anything to say so yeah it's a befriending group more than anything and we have a laugh and you know it's quite good fun really…but yeah so not everybody goes every month you know and it depends if you've got other problems or commitments or whatever but that's quite that's quite it's a support group really that's the idea

LB And you spoke about having time to yourself when your mother goes to [day centre and when your carers come in why's that important for you?

R3 Well I think I'd go absolutely nuts I feel as though I go nuts some of the time anyway but if I didn't get a chance to get out of market town I mean I've got myself I've got a car and I drive so you know I'll go I'll go down to town name or I'll go to town name or I'll go to town name or sometimes I'll go to town name I mean there's only a limit how far you can go in a few hours but yeah it's just a chance to get out and especially in the summer well if the weather's nice and mum's in the day centre I go down to beach you know take a you know bottle of water and a sandwich and a book and go and sit on the beach for two or three hours which is brilliant you know although if I didn't have those little windows those little pockets of time out to do my own thing I'd go I would go completely nuts I mean if you're totally housebound without anything going you know I mean if I had to stay in or around market town all of the time I'm you know I would go spare I think no I

think it it's really important if you are a carer to be able to have the opportunity to go and do other things meet other people annoy other people you know just to get out and about really yeah

LB So it's time just for you?

R3 Yeah that's what it is yeah and the centre name which is the day centre that mum goes to I mean they know that they know I mean like for example when we went to health club they I mean in order to make that a whole day   I needed to take mum into the day centre a bit earlier than normal and they said that was fine but yeah and you do need yeah I mean if you're here care if you're at home caring all the time you've got to have time out otherwise you'd you know you'd be jumping off the River Bridge wouldn't you you know

LB You've talked about caring being the time it takes to caring and having to do your jobs and your chores and things like that so would you say that on the days your mother doesn't go out that it completely fills your day or?

R3 Well it depends I mean like last summer or no was it probably about this time last year just as the nights were drawing out a bit I I wanted to decorate a couple of bedrooms upstairs and whereas normally you see if you say you're going to decorate a bedroom I mean it if you were working full-time you'd probably get all the gear in and everything you'd probably do it in the weekend wouldn't you you'd get it done well to do a bedroom in between looking after mum and find finding an odd half hour here odd half hour there it took me about two or three weeks just to decorate one bedroom so that gives you an idea of how much time you know I mean like for example we're here together for about an hour today I mean when you've gone I'll go and make mum another cup of tea and then I'll have to take her to the loo again you know so it will be you know you can't you have to it's almost like there's the little slots in the day of half an hour or an hour of when you do things to get you know in order to get things done everything just takes so much longer you knowI mean I'm a great list maker I'm always making lists of jobs that I need to do and quite often what what needs to be done

LB And do you get through your lists?

R3 Not always no I mean I always feel if I tick if I do a little list and I you know uh and it gets ticked at the end of the day then I feel as though I've had a successful

284

day but it ultimately if it doesn't get done it's not urgent you know it can yeah if it's obviously if it's something like a dental appointment I mean for example last week the optician came because I can't get mum to the opticians very easily we've got a wheelchair and everything but all the equipment is all really geared up for people who are quite able well not disabled not that she's really disabled but that she's quite frail and she can't really manoeuvre into position so the optician came and did a home visit which is I say he was more than prepared to do her into the dentist is a bit easier because you know into the dentist there's a ramp up and they'll actually look at her teeth while she's sitting in a [wheelchair so that's okay sorry I forgot what your question was see that's what I mean I keep going off at a tangent

LB [laughter] no what about the tiredness you've said sometimes you're up two or three times a night how do you feel about that

R3 If I can back if to if mum calls me and I get up and I sort her out and I and I and I then she goes back to bed and then I go back to bed and I go to sleep straight away that's not a problem it's when I don't go back to sleep and I I lay there for you know and I just drift off again and then she calls me again so uh I mean last night for example she didn't call me at all during the night but then I know that she'll although she wears a pad and all that sort of stuff I know that that'll all be soaking wet and her nighty will as well so 'cause she forgets I think or she falls asleep and she doesn't realise that you know that's she won't admit to being slightly incontinent but she is

LB So what's it like in the morning when you get up to her?

R3 Yeah us she'll well if I if she's not called me during the night then she will be sodden and uh will need changing and cleaning and you know whereas one time the washing machines only go on you know if I could help it once in a blue moon it goes on far more regularly now maybe that's a bloke thing I don't know you know but yeah the washing machine has to go on far more often I mean I've got Tena who are a company who do deliveries I don't know if you've heard of them but that they deliver pads and also sheets to go on the bed to protect otherwise you would literally have to change the bedding everyday well uh that's the last thing I really want to do you know so I do there is sort of protective stuff for the bed and for mum as well but you know but she'll have her vest and her nighty and that'll be all soaking wet so yeah into the washing machine

LB You've said the washing you've said about the housework and the chores and things was this something you did before you gave up work that your used to

R3 When I working full time I had a cleaner I've still got a chap who helps me in the garden in the summer he comes once a fortnight so I used to have a cleaner and I used to have when and I used to have a carer to help mum in the morning but now I do all I don't have a cleaner in fact the house is a bit too big really I could do with a little two bed apartment or something really but anyway that's for the future maybe so yeah no uh you just get on with it don't you I mean there's no dogs or children here so that does help a bit I think…I don't know whether you've got dogs or children, dogs and children would make the cleaning far worse so

LB And so you just get on with it

R3 Yeah you just get on with it and just fit it in amongst I mean it doesn't really get filthy this place as I say you know but I mean it does you know but I mean it does you know I think proximity to the road as well I don't know what a lot of the neighbours say they they hey they have you know they can they can just but the following day it's all back again but I don't find it quite as bad as that but yeah you just you know just yeah to get on with all those chores don't you

LB Just thinking about your neighbours and you've said that at the beginning they were quite you could call upon them and now you're talking about chatting

R3 Well one particular neighbour I used to be able to and she be very good with mum but that's before mum couldn't really sort herself out in the loo but now she needs helping what you know wiping her bum and all the rest of it she uh it's not fair to ask neighbours to do that so you know I'll get on and do that it's not a problem

LB But are they a form of support?

R3 no they were to begin with they're I mean they're still there I mean I can still chat and everything I mean I feel a bit I mean I haven't retired myself but my neighbours have you know she lost her husband recently unfortunately but she's retired and there's a couple in the in the big in the bungalow next door they've retired and yeah they they're you know they're not really there they were there they would there be there in an emergency you know for example if I if there was a major problem and I was out and mum was on her own and she remembered to

286

press the button which all goes through to a system and for some they couldn't get me on my mobile it would go through to the neighbours and they they've all got a key so if the emergency services need to come they would let them in do you know what I mean so they're there really as a backup in an emergency

LB Hmm rather than a more active support

R3 yeah yeah more of an active support yeah definitely yeah

LB and what about people from work do you keep in touch with any of them

R3 No No I did before I went into teaching I used to keep in contact with people from work but people move on don't they and some of the people I used to work with aren't there any more and and so there's no work connection at all really

LB And how do you feel about?

R3 Fine I don't know I don't know I mean a lot of the people I was very close to aren't living in I mean there was a girl that I worked with and she now lives up in with her husband and children they live up in county name now and you I just think you loose touch with people it's like anything you know when people first leave I mean you might keep up contact for a while but you sort of people drift drift off and I don't get a chance to socialise like I would normally so but I don't I don't that really I'm a bit of a I would like to say I mean I am quite a social person but I can be quite of a loner as well so I'm quite happy with my own company a lot of the time do you know what I mean a lot of the time I find other people annoy me [laughter] so it's often better but I don't mean that I don't mean that in a nasty way but do you know what I mean it's just I'm okay really about that

LB And just thinking perhaps on a slightly different theme you said the phrase I'm not retired myself and you talked about the future where do you think the future might take you?

R3 Well I don't know I mean at the moment I don't know at the moment mum seems okay and she might live a very very long time and she might not I mean I'm too young to retire well I'm fifty but I mean uh I would I think I would sell here and downsize definitely and I would go back to work I don't know what I would do I might just go back part time perhaps initially just to sort of have some social contact and also have a little bit of money coming in but other than that I haven't really thought about it…But haven't thought about it at all I'd probably have a I'd

probably have a year off make sure my stamp is paid but I'd probably have a year off and I've got some friends in county name and I'd probably go and visit a few people have a couple of holidays I'd I don't know don't know I don't think about it really because that's not on the horizon you know

LB So you just think day to day then?

R3 Yeah I do yeah yeah I just think about today you know what I needed to do this morning your visit this afternoon what we're going to have for dinner tonight and then oh and I'm a football fan you see my team versus another football team it's on telly tonight on Sky well I've got Sky so I shall watch that so that that's today taken care of you see and then tomorrow is another day. And I'll worry about tomorrow when it comes really

LB So do you think you miss work or not?

R3 Hmm no when I listen to the radio in the morning and there's those there's an accident at the road on the A** and there's a traffic queue or there's a problems on the A** or there's any traffic anywhere I just think I'm glad I'm not involved in all that because when I was at work I'd have to go over to town name quite a lot and that and then wherever the road is out to town name and you know that used to take over an hour to get there or a good hour to get there town name was about forty forty-five five minutes cross country so when you know when I hear on the radio in the morning that there's traffic queues here and traffic queues there and I'm just so gratefully that I'm not rushing around like a watsit you know trying to you know get through all the traffic so no I don't miss I don't miss the travelling because I used to have to drive quite a lot at one time don't miss the and you probably know that coming down from Norwich today you might have had a good run coming here but you know back might be more difficult [sighs] but no I don't miss that at all I don't really no I don't miss the fact that I needed to be somewhere by nine 'o clock or ten 'o clock or two 'o clock or whatever I   I feel I feel a bit like I'm self-employed in that I'm running a nursing home with one resident…And uh that's fine I'm working from home if you like I mean it is a full-time job but it's not a nine-to-five full-time job is it twenty-four-seven full-time job just as we're chatting I'm just going to put my head through the door just a minute

LB yeah do

R3 she probably dropped off hopefully she's dropped off to sleep pause while *(checks on mother)* no she's not nodding really so got the radio on in there don't know if she can hear it or not I don't know yeah sorry Linda

LB No that's okay so you said you feel that this is your job?

R3 Yeah well it uh is really I mean it's a full-time job as I say it's a twenty-four-seven it's not you know nine-to-five and then you know and but I wouldn't I wouldn't *(quiet thoughtful)* change it for the world really yeah although it's frustrating I do en I do get some sort of well I get a lot of pleasure out of looking after my mum yeah because I know that I can do it better than anyone else I don't mean that in a sort of supercilious sense but I mean in the sense that I feel if she was in a nursing home she'd just be one of a number and her needs would be met as and when whereas here I know that she's you know I mean she's got she has to have a quite a specific diet 'cause she's got diverticulitis so I can make sure that she eats properly and you know she's fed and not like a dog but you know that she's fed and watered and she's looked after and she's clean and I can wash her clothes and do you know what I mean I just uh I mean she did a couple of years ago she went into a nursing home for a week to give me a break and uh I know she didn't have a very good experience because a couple of neighbours popped in to see her while I was away I only went up to the coast for a few days and looked and stayed in a hotel but she picked up a chest got a terrible chest infection while she was in there and she was worse when she came out she needed medication now why they didn't pick that up while she was in there I don't know but she needed even more care when she came out so in the end I just thought oh it's just not worth it you know even to give me a break for mum to go into a residential care for a week uh I just I just you know and the organisation of all that as well is just too much I'd rather not bother

LB So this job as a full time carer has rewards and also disadvantages too?

R3 Oh yeah yeah no the rewards are that I know that I feel as though I'm doing a good job by my mum and disadvantages is you do miss out on a bit of a social life you know social life through a work environment as well as a social life through going out in the evening

R3 But I'm not a great big you know I mean if I go out with you know as I've got some friends from county name that come down occasionally and I'll go out for a meal with them and have a carer with mum and that's fine   but that's alright I don't

289

miss it really I know I quite like going out and about during the day 'cause I'm I don't miss going out not going out a night I mean even though I go out during those days where mum's at the day centre on a xxxxx and on a xxxxxx when she has somebody come and sit with her as well I go out and I get a lot of enjoyment you know going down to you know town name or say town name or wherever and you know wandering around the Charity shops and you know having a bit of lunch somewhere so I get a lot of pleasure out of that so that's okay

LB Just again pulling up on something you said earlier about the lack of conversation, difficulty you have getting a conversation going how do you feel about that?

R3 Well that is difficult it is frustrating because it's as I say it's nearly always me that will initiate a conversation sometimes you'll hear something on the radio and she might make sense of it and she might not and she might comment on it but it's quite rare you know it's always me that will say something yeah she won't she rare she would rarely start a conversation about something unless something pops into her head and then it's not necessarily connected with anything and she gets she does get a bit confused sometimes and she'll come out with very peculiar things as well which are I think are probably slightly to do with being the strokes I think make her a bit confused and her memory and you know something that she might have heard on the radio or something, she doesn't read so much now, something I might have read to her from the newspaper or something she might have seen on the television she'll get them all jumbled up or something that's connected to her past or either past in years ago or more recent past she'll get confused and then she'll talk about something as though it's something that's happened to her or do you know what I mean…Or something like that so yeah it takes a bit of unravelling sometimes she'll come out with something and you can't quite work what she's said and then it you realise it's something that we'd spoken about the week before

R3 Or that we was on the radio that morning or something that was two or three days ago on the telly or something you know uh yeah so it can be quite it can be quite funny as well I mean there's things like the other morning I was getting her dressed in the morning she used to go to a day a not only she goes to day centre but she used to go to a lunching club years ago before she was really poorly [sighs] and uh you know so there was something I was listening getting her dressed in the

morning and she there was something on the radio about India or somewhere or Brazil or India I can't remember where it was now and then she said oh I've been there and I know she hasn't and so I said oh when did you go there and she said oh I went there with my club [laughter] you know so there are little funny things I think there are other things as well which I can't recall now but there's lots of things she comes out with which are quite funny and I think that's a key key thing because when I first started to care full time for mum if she'd said that it would have it would have annoyed me you know and I would have got quite cross with her no mum that's not right don't be stupid you know blah blah blah blah and lost it a bit whereas now I'll just go with the flow and if she says that the you know the sky is green and the grass is blue whereas three or four years ago I'd have got quite angry about that I now I just go with it because if she thinks it is that's fine you know it's not doing anyone any harm is it you know and if she thinks that I think the other day there's something she said oh I can't remember what it was connected with now she's I was I was I was just taking her to the loo and I said are you alright mum and she said yeah I'm fine but I've got the little boys here with me now I don't know where that came from but no little boys here and I don't know you know I don't know where that came from something she'd heard are read ,or not read she doesn't read too much now, but do you know what I mean there was just look she'd come out with total things that are totally unconnected to the current event so but that's okay I don't mind

LB can you just accept that now

R3 yeah well I would say I have no I would say to her mum there's no little boys here and then she'd say she might stay quiet or she might say something you know you know I wouldn't get uptight about it do you know what I mean thing is do you know what I mean and she just says something that just doesn't annoy me or doesn't frustrate me or whatever then that's fine but I mean it if she came out with something that was you know totally way off I mean I wouldn't get upset or annoyed but I I would say no that's not you know that's not the there's no one here like here called that or whatever do you know what I mean sometimes she thinks there's people here in the house that aren't here…Don't know where she gets that from and I just say no it's just you and me mum and then she says oh you don't know what you're talking about [laughter] so I say okay that's fine you know and I believe it but you know

291

LB So just to help me get a better understanding can you give me some examples of things that are frustrating because you've talked a little bit about being frustrated

R3 gosh I don't know I think sometimes I mean sometimes mum can play up a bit when she's got other people in the house when there's other people in the house that you know getting her out of the chair is not too bad I mean sometimes if she's been asleep obviously I'll let her come to a bit before but sometimes when she has a carer arrive or if there's a visitor to the house or something and I'm trying to do something with her she make she's not as co-operative as she is as she can be if you get my drift she makes out that she's more needy than she really is she's quite she is very needy but like she'll try and get up out of the chair oh I can't do it and sit down again whereas I know that she can actually do it because when it's just her and I here she can do it but she does play up she can be a bit of an actress a little bit not in a nasty way not in a heavy way but just sometimes she she plays up a little bit you know and has or has a moan at me in ear shot of somebody else just I know it's not enough doesn't mean not in a nasty

LB so how do you feel then then

R3 well it is it is a bit frustrating I get annoyed though because she knows I do a darned good job and everybody knows that I you know friends family neighbours they all know they do a a good darn good job and I think she's just sort of this is her way of having a little go a dig do you know what I mean I don't think she deliberately does it in a nasty way but it can but sometimes it can be a bit hurtful you know I don't know if I can't really explain it's just some things she'll say or I mean she'll know she'll say if I'm going if it were a carer comes and I'm going out then she says oh bugger off then she'll say you know but then she'll turn to the carer oh I love him really you know but it's just little things and she just makes out that she can't do things and she'll have a moan at me in front of somebody else and I don't know where that comes from really but you know I'm not worried about it really yeah

LB That's been helpful you've talked about a lot of parts of your day and what it's like for you to be a carer which is the essence of what I'm trying to find within this research is there anything else within your care giving role that you'd like to talk about

R3 No Don't think so uh can't think of anything really the is the I mean the key thing really is routine 'cause there's an awful lot of routine there has to be routine because otherwise you know we've I wouldn't get anything done or we wouldn't be able to cope really and it suits mum to have a routine 'cause I think it helps her know where she is but she does rely on me an awful lot obviously you know she'll often say I'll say something to her like she you know she'll finish a meal or something and I'll say well should we go and sit we go and sit in the living room what do you want the loo and I'll say we'll go and sit in the living room we should get out of the door here and then she'll say well where are we going the loo or the living room where do I go what do I do now you know is what she says so that can be a bit frustrating really but no I mean we've covered most of it do you think so Linda or

LB yeah okay that's fine I'll turn the tape off now then if that's helpful

Martin's narrative summary

This narrative was returned prior to follow-up interview

I have been looking after Mum for three or four years. I was two thirds of the way through a training course when Mum's health really went down hill. At that point somebody come in and helped her in the morning, but during the day she was okay; then it became obvious that she was deteriorating quite badly. I realised that she couldn't really look after herself; she couldn't be left on her own during the day. I haven't any siblings, there's no extended family so it's all been down to me.

The training wasn't going as well as I thought it would and I had to make a decision. If I carried on with the training course Mum would have to go into residential care, or I'd have to pay a fortune to have carers come in, which I didn't really want. So I sat down, got a bit of paper out and looked at the finances and thought I'm going to pack up the training and look after her myself.

Leaving work was such a momentous decision, I realised what I'd given up and hadn't appreciated how much looking after Mum would take out of me. It takes a long while to get used to that. To begin with I would get really frustrated, angry, cross and lose it with Mum; it took a long while to get into a routine and for my stress levels to come down. I still occasionally lose it now, but in the main it's not too bad.

Other carers say they feel exactly the same, that it takes a while to get an equilibrium and an understanding of the whole process of being a full-time carer.

Unfortunately most days are very similar. During the night she'll call me so I get broken sleep. Very occasionally we'll sleep right through, but that often means wet beds and washing in the morning.

Because I don't work any more, the day can start later if I've been up a couple of times. If I've slept well I'll get up earlier and come down here and do a few jobs before getting Mum up. I get Mum up and give her breakfast. Although she can walk on her own she's very slow and I really have to stand behind her because she's had a few falls.

Once in the living room then she's guaranteed to sleep; that's an opportunity for me to go off to the shops. She has got a community alarm so if there was a problem, and she remembered to press the button, it would go through to my mobile. The neighbours are retired and they've all got keys to get in.

When I come back I will make drinks and lunch, then the day is sort of broken up between trips to the loo. It's not only the loo it's also a bit of exercise otherwise she could spend too long in that chair so she needs to get up and walk about for exercise.

294

If it's a normal day and there's nothing special happening that I can go out for, I just get on with chores, all the things everyone has to do. I try to chat with her, but sometimes the conversation is very one way. Mum will never initiate conversation; you can't really get a really good two-way conversation going. Mum can't really do anything for herself can't really cook or clean, make herself a cup of tea or anything I do it all for her. I've got into a routine, I deal with all of Mum's care.

At the end of the day I need a bit of down time. I put Mum to bed then I get a chance just to unwind and think another day over with and whether I'm going to get a good night's sleep and all the rest of it. None of the days for me are very different. That's the routine, I just go up to bed and I get this window of opportunity for myself to unwind. It's all routine, there's an awful lot of routine. I try and think of different ways of breaking up the routine but there's not much you can do.

There has to be routine otherwise I wouldn't get anything done or we wouldn't be able to cope. Also it suits Mum to have a routine because I think it helps her know where she is, but she does rely on me an awful lot. Mum's care needs have increased. At the beginning I could go out for an evening and neighbour would come in and check on her, now it's not fair to ask a neighbour to do that. If I go out I have to have a trained carer in with her.

One afternoon Crossroads lady comes to give me a break and I have an afternoon out. On Friday the routine is slightly different because Mum goes to a day centre and I get a whole day out to myself. I get a day and a half a week out off. Most people get Saturday and Sunday off mine's one afternoon and Friday.

I get an allowance through carers group for respite care so I get a chance to go out a few evenings when a carer will come in and that gives me a break. I have to book a carer in advance so I need at least a week's notice. I quite like going out and about during the day and I don't miss going out a night. I get a lot of enjoyment going down to local towns and wandering around the charity shops and having a bit of lunch somewhere, I get a lot of pleasure out of that.

It took me a long time to really get into the routine. I realise that I missed the social aspect of work. When people first leave you might keep up contact for a while but people drift off and you lose touch and I don't get a chance to socialise. I am quite a social person, but I can be quite of a loner as well; I'm quite happy with my own company a lot of the time. Often I find other people annoy me. However, I don't have social contact with people; I can go a whole day with just me and Mum. I've got my neighbours who are quite good and if I go out to shop I end up talking to people, you end up sort of striking up conversations with all sorts of people for no apparent reason.

I'm involved with the carer group which is a brilliant organisation. It's a support network if you need someone to talk to, not just a friend, but somebody in the profession to understand what you're going through. I'm on different panel meetings and committees. They asked me to do some workshops. They pay for respite care which enables me to run workshops for them, so I do get other opportunities to go out and do other things.

I don't think I've made a sacrifice because I love it to bits; I do it because I love her. I don't feel it's a sense of duty, although there is a sense of duty in that Mum made a really good job of bringing me up and all I'm doing now is repaying her. It annoys me when people say we had to put our parents into a residential care home; people in this country can be quite selfish. In Mediterranean countries they tend to look after their own, three generations under one roof, whereas here we tend to stick granny into an old people's home.

I think you've got to be a certain sort of person to be a carer; I've always been in the caring professions. I'm not at all squeamish about bodily functions and also it's my Mum. I couldn't an estate agent or anything like that, I'm a people person. I feel like I'm self-employed in that I'm running a nursing home with one resident and it is a full-time job, it is a 24/7 full-time job.

I wouldn't change it for the world, although it's frustrating I get a lot of pleasure out of looking after Mum, because I know that I can do it better than anyone else. If she was in a nursing home she'd just be one of a number and her needs would be not be met. When she went into a nursing home for a week to give me a break she didn't have a good experience. When she came out she need medication and even more care. I decided it's not worth her going into residential care, even to give me a break. What with the organisation of it I'd rather not bother. I don't have holidays now.

However it's important for me to get out and visit other places. I think I'd go absolutely nuts if I didn't get a chance to get out of this town. I've got a car and I drive although there's a limit how far you can go in a few hours. I go and sit on the beach for two or three hours which is brilliant. If I didn't have those little windows, those little pockets of time out to do my own thing I would go completely nuts. If I was totally housebound and had to stay in or around this town all of the time I would go spare. It's really important, if you are a carer, to have the opportunity to go and do other things, meet other people, annoy other people, just to get out and about. The day centre are flexible and when I went to the health club they took Mum a bit earlier. You've got to have time out otherwise you'd be jumping off the Bridge.

Sometimes Mum can play up a bit if there's a visitor to the house. I'll be trying to do something with her and she's not as co-operative as she can be; she makes out that

she's more needy than she really is. It is a bit frustrating and I get annoyed because she knows I do a darn good job and everybody, friends, family, neighbours they all know that I do a darn good job. I don't think she deliberately does it in a nasty way, but it can be a bit hurtful.

It can be hard to find the time to get everything done. It's almost like there are little slots in the day of half an hour or an hour when you can do things. I'm a great list maker, I'm always making lists of jobs I need to do, but I don't always get through the list. If it gets ticked at the end of the day I feel as though I've had a successful day, but ultimately if it doesn't get done it's not urgent.

At the moment Mum seems okay and she might live a very long time and she might not. I'm too young to retire, so I think I would sell here and downsize and go back to work, although I don't know what I would do. Initially I might go back part-time just to have some social contact and also have a little bit of money coming in. I could have a year off, make sure my stamp is paid, and then I'd probably go and visit a few people, have a couple of holidays. I don't think about it really because it's not on the horizon; I just think about today.

The rewards of looking after Mum are that I feel as though I'm doing a good job by my Mum and disadvantages are that you do miss out on a bit of a social life, social life through a work environment as well as a social life through going out in the evening.

Martin's follow-up questions

How did you feel reading your story?

Employment

- Thinking back to when you made the decision to leave your training course can you describe that process in more detail.

- What factors influenced our decision

- How did you feel when you left the course.

- You talk about not fully realising what caregiving was like. Can you give me an example of an event when you realised what you had taken on.

- What is your life like now compared to when you were working

- How do you feel being out of paid employment

Self

- You used the statement 'I'm a people person' can you explain a little more what you mean by that phrase

- You speak of being a self employed manager of a residential home –can you tell me a bit more about what makes you feel this way

Caregiving

- You spoke of being woken at night what does this feel like

- You talked about your mum playing up can you describe a specific occasion and how you felt.

- Can you describe a situation where you get frustrated and angry

- What do you get out of caring for your mother.

- You spoke of needing to get out of the house and away from the town can you discuss that a bit further.

Appendix 10   Examples of analysis

Care as Work

- **Learning new skill**
  - 'had to learn as I went along, nobody else was going to do it'

- **Manager of care**
  - 'I'm self employed, my full-time job like I run a nursing home with one resident'

- **Time off being a carer**
  - 'I get a sort of a day and a half a week off'.
  - 'I get six hours off the week'

- **Some payment attached**
  - 'I get carer's allowance but that's only about fifty pounds a week,'

- **The job**
  - 'it's a full time job, it's unpaid I work from home'
  - 'can be a full-time job'

- **Language of work**
  - 'with our job we work weekends'
  - 'it's hard work'

- **Provides new social networks**
  - 'chance to meet other carers'
  - 'they seconded me into the committee wanted a younger man the committee'

Appendix 11   Participant validation document

Validation document were prepared for both participants who were full-time carers and those who were in employment, as some different categories emerged during analysis. These appendices contain the document text, but not the participant-friendly formatting used in the original.

11a   Validation document for male carers in employment

Themes from the study
'Exploring the lived experience of being a male informal carer'

Thank you for taking the time to look at and review the emerging findings from the study you took part in last year.

Firstly, I have written a paragraph which describes your situation. This will be used in written documents to enable readers to understand your caregiving situation. Your age was the one I noted down when we started the study. I have changed your name to protect your anonymity.

Please can you check whether the information is accurate. Please let me know if you think you, or your relative, could be identified from this description. This will alert me to alter any detail that could identify you or your relative.

Description of caregiving situation

**, aged **, is employed as ……. He has been sole carer for his…….since XXX was recruited through Crossroads for Carers. The interviews took place in his home.

Secondly, I have developed findings from all of the interviews I have carried out with male carers in this study. These findings are written here as statements. Please will you read the statements overleaf and think about whether they capture your experiences.

If you have comments you wish to make please write alongside the text or in the open boxes. Your comments may help me understand the meaning you give to your experience.

Reasons some male carers give for staying in employment

There are a number of reasons why male carers continue paid employment whilst also providing care to a family member. These include:

 ⇒ Need to work for financial reasons

Some male carers state they have to work to pay the household bills.

 ⇒ Have not considered any other options

Some male carers may never have considered the option of leaving work and becoming a full-time carer.

⇒ Work provides a sense of achievement

Being at work and using valued skills, or interacting with others, provides some male carers with a sense of achievement. They may feel they have used their time productively.

⇒ Going to work can offer a break from being a carer

For some male carers when they are at work they are not responsible for their relative. Work can be a respite from caregiving.

Please feel free to provide written comments on any of these statements.

Factors which make being in paid employment easier

A number of things may make it easier to balance paid work with caregiving. These include:

⇒ Ease of travelling to work

It may be that going to work is easier if the journey to work is relatively quick and traffic free.

⇒ Flexibility in working hours

Some male carers have the opportunity to be flexible with their working hours and this makes combining employment and caregiving easier.

⇒ Understanding managers and colleagues

Some male carers say that if others in their work place understand that they may need to make telephone calls or leave work suddenly this helps them balance work with caregiving.

⇒ Being self employed

Many male carers explain that being self-employed, and so able to decide when they work and what they do at work, helps them balance caregiving with employment.

Please feel free to provide written comments on any of these statements.

Difficulties of balancing paid employment with caregiving

Some male carers experience difficulties with trying to balance employment with caregiving. These include:

⇒ Caregiving is emotional and physical work

Many male carers say that caregiving can be mentally as well as physically challenging. This can leave them exhausted in the workplace too.

⇒ Carer roles have to be done in work time

Some male carers say that they have to use some of their time at work to make phone calls and order medications.

⇒ Reluctant to tell others

Some male carers describe how they are reluctant to tell people at work about their carer role in case this leads to repercussions for them.

⇒ Managing the household as well as employment

Having done a day at work, male carers may have to come home and do the cooking and housework; some men find this difficult.

⇒ Balancing risks

Some male carers talk of having to balance risks from leaving the care-receiver alone with the need to go to work.

⇒ Putting their career on hold

Some male carers say that they have taken a less demanding job so that they can fulfil their carer roles.

Please feel free to provide written comments on any of these statements.

Self identity

Male carers may see themselves in various ways. These include:

⇒ Doing a good job

Some male carers get a sense of achievement from knowing that they give the best care they can to their relative.

⇒ Changed sense of self

Male carers may talk about how they are a different person to the one they were before they took on their carer role.

⇒ Carers' needs are taken over by those of care-receiver

Male carers often talk of how there is less time to meet their own needs and that their activities and wants come second to the needs of their relative.

⇒ Like being a single person again

Some male carers explain how they have to make all the decisions and that they are no longer able to talk issues through with their partner.

⇒ Men as different types of caregivers than women caregivers

Many people expect women to be carers, but male carers find themselves outside traditional gender roles.

Please feel free to provide written comments on any of these statements.

Appendix 11b

Validation document for male carers who had left employment

Themes from the study
'Exploring the lived experience of being a male informal carer'

Thank you for taking the time to look at and review the emerging findings from the study you took part in last year.

Firstly, I have written a paragraph which describes your situation. This will be used in written documents to enable readers to understand your caregiving situation. Your age was the one I noted down when we started the study. I have changed your name to protect your anonymity.

Please can you check whether the information is accurate. Please let me know if you think you, or your relative, could be identified from this description. This will alert me to alter any detail that could identify you or your relative

Description of caregiving situation

**, aged **, has been a full-time carer xxx years. xxx was recruited through Crossroads for Carers. The interviews took place in his home.

Secondly, I have developed findings from all of the interviews I have carried out with male carers in this study. These findings are written here as statements. Please will you read the statements overleaf and think about whether they capture your experiences.

If you have comments you wish to make please write alongside the text or in the open boxes. Your comments may help me understand the meaning you give to your experience.

Leaving paid employment

There are a number of reasons why male carers leave paid employment. These include:

⇒ A duty to provide care

This might be because of marriage vows or the expectations of others, including service providers or family.

⇒ Feeling that the care-receiver deserved to be cared for at home

This might be because the illness or accident was not their fault. It might also be because residential care was not perceived as good quality.

⇒ Financial benefits

Some male carers speak of feeling able to leave paid employment because there would still be sufficient money coming into the household.

⇒ Being worried about care-receiver's safety

Worry about the care-receiver alone at home may impact on the ability to undertake paid employment.

$\Rightarrow$ Caregiving is a positive alternative to paid employment

Some male carers find leaving paid employment a positive step and welcome the change.

$\Rightarrow$ Feeling there is no other option

Some male carers feel there is no choice and they have to become the carer.

Please feel free to provide written comments on these statements.

Consequences of leaving paid employment

A number of things may happen as a result of leaving work. These include:

$\Rightarrow$ Reduced financial income

There many be less money coming into the household and this restricts opportunities for social activities. Male carers may feel they are living off the benefits of the care-receiver.

$\Rightarrow$ Losing contact with work colleagues

Maintaining contact with friends from work maybe difficulty because of a lack of time, or because the subjects talked about at work are no longer relevant to life as a carer.

$\Rightarrow$ Have more freedom in how you manage your time

Some male carers welcome the unstructured day and use to time to plan activities both they and the care receiver enjoy.

$\Rightarrow$ New routines replace the ones of paid employment

Many male carers talk of having routines which give structure to their day. Achieving routine activities provides a sense of achievement.

Please feel free to provide written comments on these statements.

Caregiving is unpaid work

The activities and time needed for caregiving may mean that caregiving is unpaid work. These include:

$\Rightarrow$ Being a carer is a full time job

Male carers have to think about the needs of another person 24 hours a day.

$\Rightarrow$ Being a carer is a professional job

Some male carers describe being a carer as a new profession.

$\Rightarrow$ Being a carer means being devoted to the another person

Some male carers state than they care for a relative because of their love for that person

$\Rightarrow$ Personal time is constrained

Male carers might feel that they don't get much time off to spend on their own interests.

$\Rightarrow$ Caregiving is emotional and physical work

Male carers say that they become exhausted mentally as well as physically.

$\Rightarrow$ A carer is a manager

Male carers may need to manage household tasks and personal care activities for the care receiver. They may also need to manage relationships with social care services, family and friends.

$\Rightarrow$ Balancing risks

Some male carers talk of having to balance the risk of leaving the care-receiver alone in order to get time to do other tasks.

Please feel free to provide written comments on these statements.

Self identity

Male carers may see themselves in various ways. These include:

$\Rightarrow$ Doing a good job

Some male carers get a sense of achievement from knowing that they have given the best care they could to their relative.

$\Rightarrow$ Changed sense of self

Male carers may talk about how they are a different person to the one they were in paid employment.

$\Rightarrow$ Carers' needs are taken over by those of care-receiver

Male carers often talk of how there is no time to meet their own needs and that their activities and wants come second to the needs of their relative.

$\Rightarrow$ Making time for myself

Male carers talk of how they make time to be themselves, perhaps away for the caregiving situation and how this is important for their wellbeing.

$\Rightarrow$ Men as different types of caregivers than women caregivers

Many people expect women to be carers but male carers are outside the traditional gender role.

Please feel free to provide written comments on these statements.

Appendix 12   Carer group validation

Summary of comments from a presentation at carer support organisation illustrating that attendees agreed that findings from this study had resonance with their experiences. Event took place on 23.6.09 attended by twenty people one from job centre plus, two from local county council and the remainder from carer support organisation

After presenting my study findings I asked those present to make comments about whether my findings linked with their experiences and whether they had anything to add or suggest.

Summary of responses:

⇒ As condition of cared-for deteriorates the carer looses any social contact they had left with friends. This is for those that work a plus as they speak about 'general chat' with colleagues

⇒ I work with male carers from other cultures and they face many barriers and isolation is huge even within own community – stigma, honour etc especially around mental health

⇒ Male carers who work can't get typical info/service provision events as most, if not all, are held during work hours

⇒ Single dads who are parent carers balance work/caring and constant stream of people professionals coming in and out of the house

⇒ Male-hunter/provider-need to go out to work for sense of self worth

⇒ Male carers returning to work after being full time carer can feel 'lost' 'fearful' have been out of typical work environment

⇒ Male carers not always recognising they are carers or that they have carers rights

⇒ Respite available such as coffee mornings etc very female orientated barrier to getting employment/information

⇒ Men can find it more difficult to seek support for themselves e.g. support groups

⇒ When care worker helped a adolescent disabled girl with personal hygiene, single father had started to use care worker as a mother figure, over come by using two care workers.

⇒ The importance of employment depends on the stage of caring they are in e.g. 2, 10 years etc

⇒ Being able to offer solutions is hindered by knowledge and existing services imperatives

⇒ There is gulf between the aspirations of carers' legislation and the reality of statutory provision. Independence of service users is independence of family carers

⇒ Male carers may have more difficulty acknowledging their role and for others to do so too

⇒ Male carers have difficulties with giving personal care especially if this is to opposite gender
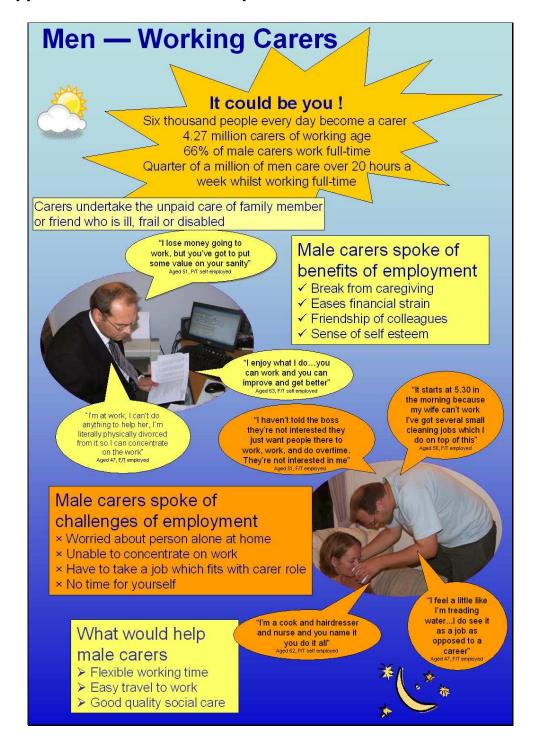
Appendix 13   Consent forms

Appendix13a: First interview consent form

Consent Form First Interview

Title: An exploration of the lived experience of being a male informal carer.

Researcher: Linda Birt

Please initial each box

1. I confirm that I have read and understand the information sheet dated 5th October 2007 for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I understand that the interview will be up to one hour, and that it will be recorded by a digital recorder.

4. I understand that I will be asked to read a summary of the first interview

5. I understand that I will be asked to take part in a second interview.

6. I understand that quotes may be used in future publication but that these will be anonymised.

7. I understand that the responses I give will not affect the support I receive from any statutory or voluntary agencies.

8. I agree to take part in the above study.

Name of Participant	Date	Signature

Researcher	Date	Signature

1 copy for participant 1 copy for researcher

Version 1
5.10.07

Appendix13b: Follow-up interview consent form

Consent Form Second interview

Title: An exploration of the lived experience of being a male informal carer.

Researcher: Linda Birt

Please initial each box

1. I confirm that I have read and understand the information sheet dated 11ᵗʰ October 2007 for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I understand that the interview will be up to one hour, and that it will be recorded by a digital recorder.

4. I understand that I will be asked to read a summary of the issues identified in the interviews.

5. I understand that quotes may be used in future publication but that these will be anonymised.

6. I understand that the responses I give will not affect the support I receive from any statutory or voluntary agencies.

7. I agree to take part in the above study.

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Researcher   Date   Signature

1 copy for participant 1 copy for researcher

Version 1
5.10.07

308

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