

**A Never-Ending Love Story: A Narrative Exploration
into the Experiences of Men who Provide
Care in the Context of Dementia**

A thesis presented to the University of Dublin, Trinity College Dublin,
for the Degree of Doctor of Philosophy

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Declaration

I hereby declare that this thesis has not been submitted as an exercise for a degree at this or any other University and that it is entirely my own work.

I agree that Trinity College Dublin Library may lend or copy this thesis upon request.

Ann Stokes

July 16, 2015

Thesis Summary

Background

Men represent a growing minority of the overall population of informal carers with their requirement to provide care increasing as changes in traditional family structures take place and the focus of Government policy on community based care intensifies. The number of people with dementia in Ireland is predicted to increase threefold between 2021 and 2041. At the same time, Ireland is set to have the largest growth in the older population across the EU and the number of people with dementia is predicted to dramatically intensify (Trepel 2011). A major void exists in relation to research on male caring in Ireland and it was envisaged that through listening to the stories of a sample of male carers, useful insights into their experiences of providing care to a loved one or close relative with dementia would be provided.

Research Aim, Objectives and Question

The aim of this qualitative study was to explore and give an initial understanding of the experiences of men who were providing care to a loved one or close relative with dementia from a narrative perspective. The proposed objectives were to:

- Explore the meaning of the caring experience for male carers
- Explore how men view themselves in the caring role
- Explore how wider society impacts on men's identities as carers

The following research question informed the study: *How do male carers perceive their own experience of providing care to their loved one or close relative with dementia?*

Methodological Approach and Research Paradigm

An explorative narrative approach was employed. Underpinning my methodological approach was the idea that everyone has a story to tell, and telling that story provides potential to learn about personal meaning and experience, as well as understanding more about one's self-identity. In framing my work within social construction, the narratives gathered could be understood as ways in which male caregivers construct meaning through social interaction, specific to a particular time and place.

Data Collection

Ethical approval was granted by the Faculty of Health Sciences Ethics Committee, Trinity College Dublin. Through convenience sampling, sixteen men disclosed their personal caring experiences in the context of dementia through narrative in-depth individual interviews. According to Holloway & Freshwater (2007a, p. 12) 'The narrative (interview) is a journey or pathway through time which is told by its author, who tells the listener what happens on the way'. I adapted the three elements of the narrative interview outlined by

Flick (2009) to guide the flow of conversation, while also considering the work of other experienced narrative researchers such as Elliott (2005), Maple *et al.* (2010), Moen (2006) and Riessman (2008). Rigour was maintained by following the 'trustworthiness' criteria proposed by Lincoln & Guba (1985).

Data Analysis

All interviews were recorded and transcribed. With no single analytical technique dominant, I examined each of the men's stories through structural, thematic and dialogic/performance analysis. This allowed me to examine in-depth from a narrative perspective, interpretation in their caring experiences, examining the content, structure, function and context of stories. Computer software (Nvivo) assisted the process.

Key Findings

While each story is unique, the multi-layered approach to analysis revealed six key patterns of meaning across men's stories in which they described their caring experience in the context of dementia, namely the all-consuming nature of caring, determination and pride, loss and sadness, admiration and respect, intimacy and closeness, and future. Multi-layered dimensions exist within each pattern of meaning. Taken together, these patterns of meaning represent a complex patchwork of how the men in my study experience caring and demonstrate that they were making sense of their caring experiences in very complex ways, involving a multitude of emotions. Men's all-encompassing love for the person with dementia permeates across the patterns, holding together both their stories and so too their experiences of caring. The multi-dimensionality of this love is the key to understanding how and why the sample of men continued to care – despite constant and always evolving challenges. I use the symbol of a rose to discuss how it mirrors the interconnectedness between the six patterns of meaning and the central feature of love in men's caring stories.

Conclusion

In listening to the stories of sixteen men, I addressed gaps in literature on male caring in Ireland, specifically in the context of dementia. From a social constructionist lens and using a narrative methodological approach, the men's stories of caring have been co-constructed within interpersonal, sociocultural and historical processes. They are not a transparent window into men's caring experiences (Phoenix *et al.* 2010). Instead, they constitute an aspect of a socially constructed reality that is in constant flux. Implications and recommendations for policy and practice are proposed based on recognition of the centrality of the relationship between male carers and the care recipient.

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Chapter 1: Introduction

Introduction

This chapter will set the scene for the reader by introducing my study. In so doing, it will describe the background and reasons as to why I decided to undertake this study, the research question and methodological approach I took, and the research paradigm and theoretical framework that guided my work. The potential contribution of my research will also be outlined.

Background

Traditionally, informal caring has been linked primarily to women and in Ireland it has largely existed in the private sphere of the family home. However, men now represent a growing minority of the overall population of informal carers with their requirement to provide care increasing as changes in traditional family structures take place and the focus of Government policy on community based care intensifies¹. Thirty nine percent of carers (72,999 individuals) identified in the 2011 Census were male² (CSO 2012). In addition, the number of people with dementia in Ireland is predicted to increase threefold between 2021 and 2041, with Ireland set to have the largest growth in the older population across the EU (Trepel 2011). Baker & Robertson (2008) note that as demographics of the population continue to change, men are assuming increasingly important roles as caregivers.

Until recently a major void in relation to research on male carers existed, although, according to Fisher (1994), male carers have been 'discovered' and information has been gathered in an area once neglected. While the numerical predominance of female caregivers cannot be ignored, diversity among male caregivers has been overlooked in the literature (Campbell 2010). This has led to what Thompson (2002) has called the 'gender comparative' approach, in which there is a tendency to compare men's caregiving against an implicit female norm. Men as carers in many instances have to make the difficult transition from work in the public arena to the private, largely invisible world of family care (Russell 2007a). They have been found to go through transitions in their gender identity while adjusting to caring for their wives (Ribeiro *et al.* 2007; Black *et al.* 2008; Sanders & Power 2009; Eriksson & Sandberg 2008).

¹ For example, the Government's National *Primary Care Strategy*.

² In total 182,884 people identified themselves as carers (4.1% of the population and 114,111 females) (CSO 2012).

The timing of this study is key with the family as a caring unit in Irish society currently in a period of uncertain change due to factors such as changing demographics and family formations, women's labour force participation and the recent economic slowdown. Additionally, given the preference of older people to be cared for at home when dying (Weafer *et al.* 2004, as cited by O'Shea *et al.* 2008), it is crucial that informal carers are given a choice and offered the adequate support necessary to assist them in providing care in the home. According to The Report on End of Life Care for Older People in Acute and Long-Stay Care Settings in Ireland (2008, p. 30) 'As people are living longer they are suffering from diseases that have a longer and less predictable care trajectory'³. The Government's Chronic Disease Policy Framework *Tackling Chronic Disease* (2008) recognises the burden placed on families and carers of individuals with chronic disease, and the importance of reducing such responsibilities. Additionally, from a policy perspective the publication of the first ever National Carers Strategy in 2012 (DOH 2012a), along with a commitment to publish a National Dementia Strategy under the current Programme for Government (Department of Taoiseach 2006) are significant milestones in the area of informal caring in the context of dementia in Ireland.

Ultimately, with the requirement for men's availability to provide informal care set to intensify over the coming years, there is an urgent need to increase understanding and knowledge of the specific experiences of male carers⁴. It was envisaged that through listening to the stories of a sample of male carers, useful insights into their experiences of providing care to a loved one or close relative with dementia would be provided.

My Story

According to Andrews (2007, p. 27) 'Most often, the questions which guide our research originate from deep within ourselves. We care about the topics we explore.' My time in university first at undergraduate level studying social science, and then as a master's student of social policy, reading literature on men and masculinities, made me aware of the complexities of masculinities and lack of understanding of what it means to be a man in current society. After completing my master's degree in 2005, I gained a range of experience

³ Chronic illnesses common among older people are heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia.

⁴ Further detail is presented on the policy context in Chapter 2.

across public, university and voluntary sectors, in conducting research and policy development with various sectors of society that were experiencing marginalisation and inequality. I subsequently began working on various research projects on informal caregiving, firstly within a university setting, and then with a non-governmental organisation, both in Ireland and at an EU level. Also as a young mother and in a co-habiting relationship at the time, I had seen first-hand both loved ones who had required assistance due to chronic illness and close relatives who were providing care as a consequence of disability and illness. Together these experiences evoked curiosity about the changing social and political contexts in which informal caregiving was taking place. Significantly, I began to query in what direction was it heading in the future. Ultimately, this led me to begin to question how men were experiencing providing care to a loved one or close relative.

I was first introduced to narrative research by my PhD supervisors as I began to prepare my proposal and encouraged to consider it as an approach for my study. Previous to this PhD, I had conducted numerous qualitative individual and group interviews in various contexts simply because I am interested in other people's stories. I have also been attracted by the empowering potential that letting people speak about their situation in their own words can have in gathering evidence-based research. Thus, I have listened to many different stories since embarking on my academic career. However, I was privileged and honoured to be allowed access to the very personal stories of men providing care in the context of dementia. I believe that both my personal and previous work experiences gave me a reasonable degree of self-awareness and strength and I envisage including my own story as an integral part of this thesis. Indeed, I view my own life so far as a story - I too have been on a journey and I understand that the realm of relationships and my interaction with others in the context of informal caring has been central to my own sense of identity, knowledge and meaning making as I embarked on this thesis. Like other narrative researchers such as Lau & Van Niekrek (2011), approaching my thesis with this mindset is reflected in the conceptual and theoretical underpinnings I adopted.

Research Aim

The aim of this study was to explore and give an initial understanding of the experiences of men who were providing care to a loved one or close relative with dementia from a narrative perspective. For the purposes of this research, male carers are defined as individuals who provide physical and/or social care to a loved one or close relative with dementia in the home⁵.

The proposed objectives of this study were to:

- Explore the meaning of the caring experience for male carers
- Explore how men view themselves in the caring role
- Explore how wider society impacts on men's identities as carers

Research Question

The research question that informed the study was as follows: *How do male carers perceive their own experience of providing care to their loved one or close relative with dementia?* As outlined in detail over the following two chapters, an extensive review and analysis of both the socio-historical context of male carers and existing literature on male caregiving allowed me to limit the scope of my research question.

Narrative Methodology and Qualitative Research Design

According to Giacomini (2010, p. 129) 'Methodologies offer frameworks of logically related means and ends to guide empirical research design, while methods more commonly refer to specific research procedures and techniques to implement the methodology'⁶. An explorative narrative approach using qualitative methods was employed.

Narrative inquiry allows for the exploration of research activity itself as a story (Cortazzi & Jin, 2006). While various definitions of narrative have been offered across different schools of thought, Lieblich and colleagues (1998) define narrative research as '...any study that uses or analyses narrative materials' (p. 2). Narrative materials include 'naturally occurring' narratives

⁵ In addition, I acknowledged that care provided by men could be shared with other family members. The full inclusion and exclusion criteria are outlined in the Methodology chapter.

⁶ While I give a brief outline of both the methodological approach and research procedures I used here, the Methodology chapter provides a deep understanding of these.

such as conversations, life stories or written narratives from diaries, letters and policy documents (Griffin & May 2012, p. 442). According to Stephens (2011, p. 73): 'The very word narrative suggests spoken and written stories.' Narrative research explores how people experience the world through collecting stories about their experiences (Moen 2006).

Everybody has a unique story to tell. Atkinson (2002, p. 124) is of the view that 'If we want to know the unique perspective of an individual, there is no better way to get this than in that person's own voice.' In giving participants the opportunity to 'tell it as it was' the researcher is able to gain an understanding of the richness of a personal event and factors surrounding it (Jack 2010). The stories revealed through narrative can also enable individuals to make sense of their lives (Clandinin & Connelly 2007, Daiute & Lightfoot 2004, Holstein & Gubrium 2000). Narratives are not simply reports of 'the facts' of experiences (Schneider 2007). Jerome Bruner (1986), a key figure in the narrative movement, argued that narrative thinking is an important means for discovering how we construct our lives. Narratives also have the potential to give meaning to events that have disrupted and changed a person's life (Hydén 1997), such as men undertaking a caring role in the context of dementia.

In addition, narratives allow individuals to present their self/ selves (Miller 2005). Through a process of continuous narrative construction and reconstruction, an individual maintains a sense of personal identity (Murray 2000). Specifically in times of change and uncertainty, narration helps individuals to construct and reinforce their identity, repairing any damage and normality (Frank 1995). Thus, within a narrative approach, identities do not remain the same and are always in transition (Wiest 2013, Yuval-Davis 2006, Georgakopoulou 2008).

This study involved a series of qualitative in-depth personal interviews with sixteen male carers, focusing on their experiences and perceptions of providing care to a loved one or close relative with dementia. At the root of in-depth interviewing is an interest in understanding the lived experience of other people and the meaning they make of that experience (Seidman 2013, p. 9). Wiest (2013) contends that our 'interview society' means that people have become accustomed to telling 'their story' to an interviewer. My role as a narrative researcher was to invite men to tell their 'specific' stories rather than in the 'generalities' that they frequently speak about their experiences (Chase 2005). I decided to adapt the three elements of the narrative interview as outlined by Flick (2009) to use to guide the flow of conversation. I also considered the work of narrative researchers such as Elliott (2005), Maple *et al.* (2010), Moen (2006) and Riessman (2008). While a loose structure

guided each interview, I invited each man to 'tell their story' of caring. Through in-depth interviews, participants are able to express what they want to say rather than what the researcher wants to hear (Frank 1995).

Although asking men about their personal experiences, I understand that as a researcher, I was an active participant (Riessman 2011) and had an impact on each stage within the research process. The stories told were co-constructed (Mishler 1986). It is a 'complex' path that has led to the final production of this thesis, but in spite of the challenges I have faced, I believe that I have followed my instincts – the voices of men's caring stories in dementia. There have been times when I felt that I was going down the 'wrong' path, so used to writing in traditional ways and so instead, I had to learn to allow the real experiences of men to be heard.

Why Narrative?

Narrative research is grounded in storytelling. In my study, I envisaged that storytelling would allow for better understanding and provide coherence to men's caring experiences (Lieblich *et al.* 1998). Thus, the idea underpinning my methodological approach was that everyone has a story to tell, and telling that story provides the potential to learn about personal meaning and experience, as well as self-identity⁷. According to Hydén & Antelius (2010, p. 588) 'Telling and listening to stories is one of the most powerful instruments we have for sharing experiences and knowledge.'

However, there were a number of other important factors that led me to choose a narrative approach, namely how stories provide meaning of wider social change (Squire *et al.* 2013). There is a multidimensionality associated with people's individual stories (Cortazzi & Jin 2006). Narratives are integrally linked to the context and the web of social relationships which a person fits themselves – social, cultural and institutional contexts all have a role to play (Moen 2006). People's stories thus tell us not just about them but about our world, and about our society. They are never individual – they tell us about the culture in which a story is produced. Stories are 'located' in time and space, and within social history and social geography (Goodson 2013). Narrative research is 'embedded in and shaped by broad social and historical currents' (Chase 2008, p. 82). In taking a narrative approach, men's stories of

⁷ I return to discuss why I chose a narrative approach to explore men's caring experiences in further detail in the Methodology Chapter.

caring may therefore provide an indication of the wider experiences of male carers and where they are positioned and situated in society. Each story had the potential to tell a lot about societal expectations, gender roles and men as carers in Ireland. These wider narratives also have an influence on how we behave and act and construct meaning (Ricoeur 1991). Narrative materials are forms of social action (Atkinson & Delamont 2009). I was therefore drawn to the dialogic potential that narrative research held (Squire *et al.* 2013). However, the stories told are constantly changing and narratives are part of an on-going and constitutive part of reality (Phoenix *et al.* 2010). Narratives are therefore social encounters on a number of levels – this is why it is important to allow people the opportunity to tell their stories.

My decision to undertake a narrative methodological approach was ultimately reached following a deep examination of my ontological and epistemological assumptions. The following section of this chapter will therefore outline the philosophical and conceptual framework that underlies my study. There is no doubt that the interrelationship between what I thought could be researched (my ontological position), linking it to what we can know about it (my epistemological position), and how to go about acquiring it (my methodological approach) could not be ignored (Grix 2004, p. 66).

Development of Theoretical Framework – Influence of Philosophical Ideas

This section will now discuss the various philosophies that have influenced me on my intellectual journey as I undertook this thesis, and describe how my narrative study is situated conceptually within a research paradigm. An interpretive stance and key ideas associated with social constructionist thinking regarding the nature of knowledge and reality provided me with a framework to explore men's experiences of caring in the context of dementia, using a narrative approach. I believe that my way of thinking how knowledge is created fits best with theories associated with a constructionist ontology (the structure of reality) and the certain way of understanding what it means to know (epistemology) of interpretivism⁸. I will now outline how I went about answering such philosophical questions in the process of conducting this study. However, I will return to these ideas throughout the course of this thesis, in illustrating how they applied in practice, and how they influenced my work. I believe that in fact these ideas continued to develop and there were times I questioned such philosophical

⁸ Crotty (1998, p. 10) has argued that '...each theoretical perspective embodies a certain way of understanding what is (ontology) as well as a certain way of understanding what it means to know (epistemology).'

issues as I immersed myself further in my PhD. Like Witkin (2012) posited, no one learns about social construction, or any other framework in a vacuum.

Constructionist View on the Nature of the World

In undertaking this study and embarking on my PhD, I had to first consider and examine fundamental theories that address the essential nature of things and in so doing, allowing the system of ideas and theories to assist me in collecting and analysing information, make sense of it, and transform it into usable knowledge (Giacomini 2010, p. 128). According to Grix (2004, p. 59) 'Ontology is the starting point of all research, after which one's epistemological and methodological positions logically follow.' Researchers then build the *methodologies* that guide empirical research upon such philosophical foundations (Giacomini 2010, p. 129).

Ontologies are beliefs about the basis of entities that make up reality (Giacomini 2010, p. 128)⁹. I found myself aligned to the ontological position of constructionism. Gergen (2009, p. 2) warns that '...constructionist ideas will challenge long honoured words like 'truth', objectivity', 'reason' and 'knowledge''. For Bryman (2008, p. 366) 'An ontological position described as constructionist implies that social properties are outcomes of the interactions between individuals rather than phenomena 'out there' and separate those involved in its construction'. Within this viewpoint, meaning (or truth) can never be described as either 'objective' or 'subjective', it is always constructed, and in so doing brings objectivity and subjectivity together (Crotty 1998, p. 43). It also implies that social phenomena and categories are not only produced through social interaction, they are in a 'constant state of revision' (Bryman 2008). Qualitative research in general can be seen as aligned to '...the belief that all depictions of reality are socially constructed' (Brophy 2009, p. 17)¹⁰. The ontology of constructionism and in particular how its ideas have influenced my own study in

⁹ Giacomini (2010) highlights 'further that: 'The ontology of *realism* holds that the world (social or natural) possesses qualities both independent of our ideas and empirically accessible to us as such. This leads to faith that, with the right methodology, one's data would correspond directly to these things without bias created by one's perspective, values, and so forth. *Idealism*, by contrast, holds that we have direct access only to our ideas and subjective experiences, and no empirical access to the world beyond, except through these ideas. It follows that when researchers study the world they necessarily examine only their mental constructs of it. Data do not correspond directly with reality; they are researcher's representations' (p. 131).

¹⁰ However, within this standpoint, many different scholarly traditions exist and are embedded in fundamentally different cultural contexts (Grix 2004, p. 59).

the development of my research paradigm will be discussed in further detail in the following section.

Interpretivist Stance to Knowledge Gathering

It is only after ontological assumptions are identified that one can discuss what it is that we can know about the social and political reality that is thought to exist (Grix 2004). So the next stage for me in my intellectual journey was to determine my epistemological position.

According to Giacomini (2010, p. 129) '*epistemologies* suggest how researchers can empirically access phenomena (given the ontological assumptions about what phenomena are).' The term epistemology is derived from the Greek words *episteme* (knowledge) and *logos* (reason), and focuses on the knowledge-gathering process (Grix 2004, p. 63). Knowledge, and the ways of discovering it are not static, and new theories of knowledge are constantly being developed that compete with existing models (Grix 2004, p. 63)¹¹.

Topping (2010) highlights that philosophically, quantitative research is underpinned by *positivism*, and according to this tradition scientific truths or laws exist. Positivism is often associated with realism (Flick 2009). A positivist approach may be used when there is knowledge of a phenomenon and a theory to be tested (Willis 2007). In contrast to positivism, within the interpretivist epistemological position 'stress is on the understanding of the social world through examination of the interpretation of that world by its participants' (Bryman 2008, p. 14). Topping (2010, p. 130) argues that qualitative research '...fits more clearly within an *interpretivist* tradition which is based on assumptions that in order to make sense of the world, human behaviour should be should be interpreted by taking account of interactions between people in natural settings.' The interpretative stance also proposes that there is no single interpretation, truth of meaning, and just as human beings are different, so too are the societies and cultures in which they live (Topping, 2010, p. 130). Hammersley (2013) contends that from the interpretivist point of view: 'any attempt to find universal causal relationships grounded in some fixed human nature or form of society is futile. Instead, the

¹¹ Two different standpoints exist – namely positivist and relativist in such theories of knowledge (Brophy 2009). Other authors refer to the two contrasting epistemological positions within the research paradigm, namely 'positivism' and 'interpretivism' (Grix 2004, p. 63). In other work, Crotty (1998) proposed three epistemological stances, namely objectivism, constructivism and subjectivism. Giacomini (2010) also proposes a third epistemological strand, *Pragmatic* epistemology which he believes occupies a middle ground between realist and idealist ontology.

primary focus must be on trying to understand particular people and event in specific socio-historical circumstances' (p. 27).

Research Paradigm of Social Construction

Having made choices surrounding the philosophical assumptions of my study – namely ontology and epistemology – I then shaped my qualitative piece of research further 'by bringing to the inquiry paradigms or world-views' (Creswell 2007, p. 19). According to Guba (1990, p. 17), a paradigm or worldview is 'a basic set of beliefs that guide action'¹². Similarly, Munhall (2012) argues that a paradigm is a philosophy: conceptualising fundamental beliefs (p. 41). I would therefore now like to introduce the specific theories and key ideas associated with social construction and how as a body of theory and practice (Burr 2003), it has guided my thesis. Taken together, I believe that ideas associated with interpretivism, social construction and narrative thinking are the key theoretical perspectives that have influenced how and why I conducted this study, and particularly the way I approached it using qualitative research methods. According to Munhall (2012, p. 61) qualitative '...methods offer ways to approach individuals in experiences, to encourage them to give voice to their experiencing, and to care enough to search for meaning within the experience'. While I acknowledge that there are differences in the philosophical ideas proposed by interpretivism and constructionism, there is also significant overlapping, '...at least in recommending the careful documentation of how particular social phenomena are culturally or interactionally constructed in particular places at particular times...' (Hammersley 2013, p. 45).

The development of social construction could be considered part of the post-modernist movement as it developed in the period following World War II (Witkin 2012). While social constructionism may be viewed as a specific outcome of postmodernism, Gergen (2009) believes that it has grown as a dialogue, shifting the balance of ways of thinking from critique to creativity (p. 14). The term 'constructionism' particularly 'social constructionism' derives largely from the work of Karl Mannheim (1893-1947) and from Berger and Luckmann's *The*

¹² Paradigms used by qualitative researchers vary according to the set of beliefs they bring to research. In addition, the types of paradigms continually evolve over time (Creswell 2007). For example, three other worldviews proposed in earlier work by Creswell (2003) are post positivism, advocacy/ participatory and pragmatism.

Social Construction of Reality (1967) (Crotty 1998)¹³. Peter L. Berger and Thomas Luckmann (1967) argued that although the social world appears to human beings as an objective reality, it is in fact constituted through human action and interaction and is not independent of it. People continuously create and recreate social reality and in turn are shaped by it in a dialectical process: 'Society is a human product. Society is an objective reality. Man is a social product' (Berger & Luckmann 1967, p. 61). Berger & Luckmann proposed in their 1966 volume of *The Social Construction of Reality* the following: '...we are socialized into *plausibility structures*, that is, conceptual understandings of the world and rational supports for these understandings'. We develop a natural attitude as we come to rely on these plausibility structures, that is, a sense of natural, taken-for-granted reality (as cited by Gergen 2009). To illustrate, they gave the example in which the clock (an eighteenth-century invention) now orders how we experience time (Gergen 2009, p. 23). Gergen & Gergen (2008, p.160) therefore contend that: '*Social construction* typically refers to a tradition of scholarship that traces the origin of knowledge, meaning, or understanding to human relationships'¹⁴. In the constructionist view, meaning is not discovered but constructed. It claims that meanings are constructed by human beings as they engage with the world they are interpreting (Crotty 1998, p. 43). Thus, in following this standpoint and applying it to my own work, and following other researchers who had previously explored the narratives of male carers from a social constructionist view of reality (Kirsi *et al.* 2004), I believe that the key determinant of meaning of men's caring experiences is their contextuality. For instance, Kirsi and colleagues (2004, p. 162) argue that: 'Meanings are not regarded as inner states of the subject's mind, but as intersubjective artefacts of social interaction constructed by language use'. Thus, from the social constructionist perspective, facts may be discursively constructed, but there is a recognition that such construction arises from an intimate

¹³ However, while the ensuing development took the form of 'sociology of knowledge', the idea of social construction had already had a long history when Mannheim, Berger and Luckmann took it up as it can be found in both the ideas of G.W.F. Hegel and Karl Marx (Crotty 1998, p. 59).

¹⁴ While it is recognised that there is no one feature that identifies a social constructionist position, Gergen (2009) identified five central assumptions: 1) The way in which we understand the world is not required by 'what there is', 2) The ways in which we describe and explain the world are the outcomes of relationship, 3) Constructions gain their significance from their social utility, 4) As we describe and explain, so do we fashion our future, and 5) Reflection on our-taken-for-granted world is vital to our future well-being (p. 5-12).

dialogical relationship between our embodied being in the world and how we discursively make sense of that embodied being and give it meaning. This is where the work of Mikhail Bakhtin (1986) is useful. Bakhtin and Vygotsky's ideas have much in common, such as the importance of language in shaping how we see and interpret the world around us. In Bakhtin's view, relationships are never static; they are dynamic and either being made or unmade. This is why Bakhtin's views have been summarised as dialogism. Meaning comes from the ongoing intersubjective dialogue that occurs in a dynamic relationship (Loftus & Higgs 2010, p. 381). There is also a relativism that exists within social constructionism. As Crotty (1998, p. 64) highlights that '...description and narration can no longer be seen as straightforwardly representational of reality.....even in telling our very own story, it is (again in the normal course of events) the voice of our culture – its many voices – in fact, that is heard in what we say'.

According to the perspective of social construction, reality does not exist prior to communicating about it but '...comes into existence through communication. In other words, reality depends on communication in order to become 'real'' (Foss *et al.* 2013, p. 32). In line with this view, our reality is shaped by shared social constructions. However, instead of an objective reality which is true throughout time for all human beings, a social constructionist perspective proposes that '...groups of people create their own realities based on their own interpretations and their sharing of those interpretations through communication' (Foss *et al.* 2013, p. 50). Foss and colleagues (2013) also contend that according to this standpoint, through communication, individuals have the capacity to change entrenched social patterns and structures (p. 50).

How Does the Paradigm of Social Construction Relate to My Study?

Social construction provided me with a conceptual framework for exploring the experiences of male carers within a narrative perspective. In practical terms, how does the paradigm of constructionism relate to my research? This study was interested in getting an insight into men's experiences of providing care to a loved one or close relative in chronic illness from a narrative perspective and also how wider society impacts on their identities as male carer, that is, how they view themselves in the caregiving role. As a consequence, the narratives gathered in this study cannot be understood as a transparent window into male caregivers' lives (Phoenix *et al.* 2010), but instead as ways in which they construct meaning through social interaction, specific to a particular time and place. According to Russell (2001, p.353) 'the experience of older male caregivers offers an exciting realm in which to examine the

social construction of late-life masculinity'. Gender was therefore an important focus of my study and ideas surrounding men and masculinities and where they are situated within a social constructionist perspective are discussed in the following chapter.

Following the social constructionist paradigm, I believe that identities should be viewed as constructions and social processes, whereby people are continuously creating and recreating their social reality in dialogue with others, at any given moment. As Foss *et al.* (2013, p. 12) point out: 'Identity is a social phenomenon, which means that your sense of self, like your gender story, has developed as a result of your interactions with other people and with social institutions'. As a consequence, men's caring experiences and thus their identities cannot be viewed in abstraction from concrete social interaction and practices and applying a narrative stance in my methodology was best suited to exploring such experiences a specific point in time. Ultimately, I strongly believe that social constructionism as a conceptual framework fits best with the narrative approach I applied to my study.

Consistent with a constructionist ideas, I believe that the powerful social and cultural attitudes that shape the context in which men become caregivers in Ireland provides a challenging backdrop against which to make sense of and narrate their experiences. At the same time, men's stories about their caring experiences are partial and positioned. Both their telling as well as my listening and interpretation are influenced by wider culture, as well as values and beliefs – men and myself are both socially and culturally positioned. I understand that there is no such thing as impartial telling nor is there no unbiased listening. Social constructions create social realities, truths and understandings. In so doing, social constructed meanings may cause tension and conflict, such as men contesting normative ideas or gender expectations through caring. Social 'assumptions' mean that certain things can seem impossible to overcome due to deep social conditioning, for example men being seen as capable of caring. Social constructs serve the purpose of 'control', they provide power and can disempower too, such as through exploiting certain individuals. I will develop these ideas throughout. Ultimately I believe that a conceptual framework comprising of the theories and perspectives regarding the wider social construction of masculinities have informed the design and execution of my study. The social construction of masculinities is discussed in the next chapter.

Potential Contribution of My Research

According to Kenedy (2012), the 'lived male experience' is under-researched. My study therefore attempted to contribute towards a better understanding of the lived experiences of a specific group of men, namely to give voice and tell the story of men providing care to their loved one or close relative with dementia.

In so doing, I envisaged that the men's stories would also provide evidence on:

- Male Carers' experience of providing care
- Male Carers' perceptions of the caring role
- Coping mechanisms employed among male carers
- The impact of caring on male carers' health and wellbeing
- Male carers needs in relation to providing care
- How societal attitudes impact on the male carer experience
- Recommendations for the future development of policies and services specifically targeted to male carers

Sharing stories of caring may make men's experiences more visible to wider society and help understanding of current discourses around the role of men in caring. The evidence gathered could be used for advocating for male carers and addressing the valuable role they play in society. I envisaged that this research would provide vital information to a range of key stakeholders such as policy makers, service providers, health professionals and academics on the possible future development of policies and services specifically targeted towards male carers providing care to a loved one or close relative with dementia. This is a particularly pertinent point especially given the climate where the activities of policymakers and policymaking are in potential conflict with one another, in a time of restricted budgetary constraints.

It is important to note that where informal carers are provided with adequate support, caring for a loved one may be an enriching and rewarding experience. There is a growing body of literature that recognises the possible positive aspects associated with providing care (Baronet 2003, Edwall & Hallberg 2007, Ribeiro & Paúl 2008). This is a very important point especially given both the focus of early discharge and self-management programmes

currently promoted at government level and the general preference of many individuals with chronic illness to be cared for at home where possible. It is therefore imperative that the needs of informal carers are adequately identified and addressed so as excessive demands are not placed on them. Ultimately, this research study would provide the School of Nursing and Midwifery, Trinity College Dublin with narrative data on the male informal carer experience in chronic illness and point to possible future areas of research focus. As a member of the academic community, my study findings would be of importance to the larger research activities currently taking place in Trinity College Dublin, such as the Irish Longitudinal Study on Ageing (TILDA) study, the evaluation of the Genio Dementia Programme and the De-Stress Study. Therefore, I believed that through a deep exploration of the specific experiences of male carers in the context of dementia, I could provide narrative evidence to add to this debate.

Conclusion

By applying a narrative methodological approach and listening to the stories of sixteen male carers, I will be providing useful insights into their experiences. This research has aimed to allow men tell their own story (as far as possible) of their caregiving experiences in the context of wider societal attitudes surrounding men's role in providing care. In addition, in framing my work within social construction, the narratives gathered cannot be understood as a transparent window into male caregivers' lives in dementia, but instead as ways in which they construct meaning through social interaction, specific to a particular time and place.

This thesis will unfold in the following chapters. Policy developments and debates surrounding informal care and male carers in Ireland will first be outlined and this will frame the basis for my study - set within larger political, social, theoretical and practical domains. The specific policy context surrounding dementia will also be discussed. Theoretical perspectives on conceptions of gender identity and notions of masculinity will be outlined as the basis for understanding how male carers are currently positioned in wider society.

In the literature review, existing literature on male caring is critically examined in order to gain a deeper understanding of knowledge that exists on how men experience and perceive caring.

In the methodology chapter, the narrative methodological approach adopted for the empirical study and data collection methods used are outlined and the rationale for using such an approach is articulated in further detail.

The analysis of the data gathered and the findings are presented over three chapters. Chapter 5 presents the narrative framework that I developed to analyse men's stories. I chose to apply a multitude of approaches, incorporating structural, thematic performative and dialogic analysis in order to answer the what, how, why, where and when of each man's story of providing care in the context of dementia.

Chapter 6 presents key segments from the narrative summaries of four men's stories as well as a long excerpt from the transcript of one man's story in order to allow the reader to understand how I interpreted the men's stories as well as providing details on the particular context.

Chapter 7 presents the patterns of meaning that emerged across the men's stories following my multi-layered approach to analysis, demonstrating the narrative underpinning through which men's stories of caring may be interpreted.

The discussion chapter reviews the findings under several key strands including the relationship of the narrative underpinning of men's caring experiences with the image of a rose, a conceptual model of dementia care and male carer literature, and how the narrative methodological approach and research paradigm of social construction guided my study.

The conclusion chapter will bring my story of conducting this narrative study to a close.

Chapter 2: Study Background: An Exploration of the Political, Social, Theoretical and Practical Domains

Introduction

The aim of this chapter is to provide a detailed background of the setting of my study. I will first provide an understanding of developments and current debates surrounding informal care in Ireland. In so doing, the policy context for male carers will be outlined as well as the factors which influence both men's current and future requirement to provide care. Men will be required to provide increasing levels of informal care specifically in the context of dementia over the coming years. The section which follows will therefore provide an overview of the specific policy context as well as future predictions surrounding dementia and the requirement for informal carers to provide care in Ireland.

Theoretical perspectives on conceptions of gender identity and notions of masculinity will then be discussed as a basis for understanding how male carers are currently positioned in wider society. I will present this chapter throughout in line with my alliance to social construction as proposed in the introductory chapter, and how I believe that meaning is ultimately gained through experience. I also recognise that the social world is in constant flux and always changing. I therefore understand that the context of my study is set within a specific time and place.

Informal Caring

Caring for people we love is part of what makes us human (Carers UK 2013). According to Kittay *et al.* (2005, p. 1) 'People need to be cared for and nurtured throughout their lives by other people, at some times more urgently and more completely than at other times'. For Zarit & Edwards (2008), a caregiving relationship emerges when a person becomes dependent on another's assistance to complete tasks. Caregivers may have a gradual transition into their role, where they increasingly provide help to the care recipient; however, some caregivers may experience an abrupt entry (Gaugler *et al.* 2003). Hennings and colleagues (2013, p. 684) contend that 'Love and other emotions contribute to why people care and their experience of caring'.

However, definitions of caring tend to be ambiguous (Twigg 1989). In the context of palliative care, family caregivers have been referred to as informal, unpaid, lay or untrained carers (Smith 2001). Family caregiver is a term used interchangeably with informal caregiver and

can include family, friends or neighbours (Pierce & Lutz, 2009). While the term ‘informal carer’ is used widely, it may be somewhat problematic as many individuals may say that there is nothing informal about the care they provide (Care Alliance Ireland 2013a). Informal carers are people who provide assistance to individuals with activities of daily living in the home on an unpaid basis. According to the OECD (2005, p. 17) activities of daily living are ‘self-care activities that a person must perform every day, such as bathing, dressing, eating, getting in and out of bed, moving around, using the toilet’. Ultimately, the roles and responsibilities assumed by informal carers differ depending on the condition of the person being cared for; as his or her situation changes, so too will the care provided (Arksey & Corden 2009). Caring may also be described in a number of ways, such as hours per week spent, types of activities performed or duration of the care period (Stokes 2009). The 2011 Census of the Irish population defines a ‘carer’ as someone who provides regular, unpaid personal help for a friend or family member with a long-term illness, health problem or disability (including problems with are due to old age). Personal help includes help with basic tasks such as feeding and dressing (CSO 2011).

The 2011 Census shows that 182,884 people provided regular unpaid care to a friend or family member in April 2011. This figure represents 4.1% of the total population (CSO 2012). Significantly, the 2011 figure also represents a 13.7% increase in the number of individuals providing unpaid care in Ireland, when compared with figures from the previous Census in 2006 which identified 160,917 individuals providing unpaid care. While spouses and partners may generally be the first involved in care, a large number of grown-up children are engaged in the provision of care (Dahlberg *et al.* 2007). Findings from Wave 2 of the Irish Longitudinal Study on Ageing (TILDA)¹⁵ found that overall 10% of participants provided care to their parents in the past two years (Nolan *et al.* 2014). In addition, there is a growing ‘sandwich generation’ of carers, namely people with potentially competing responsibilities towards family members as well as looking after their own children (Glendinning *et al.* 2009). In other circumstances, individuals may share caring responsibilities and a growing body of research has begun to acknowledge the importance of studying caregiving provided by multiple siblings (Tolkacheva *et al.* 2014). However, it must also be acknowledged that many

¹⁵ TILDA is a large-scale, nationally representative, longitudinal study on ageing in Ireland, collecting information on all circumstances from people aged 50 and over. Data was collected from Wave 2 during April 2012 – January 2013.

individuals who provide care may not identify themselves as 'carers', rather viewing their caring activities as a central aspect of their family role such as spouse or parent (Hynes *et al.* 2008, Ribeiro *et al.* 2008). Thus, 'carer' or 'caregiver' may be ascribed terms, not identified with by carers themselves (Smith 2001, Ribeiro *et al.* 2007).

The Policy Context of Informal Caring in Ireland

Caregiving always takes place in an interpersonal context. Informal caring has been traditionally linked to women and in Ireland caregiving has largely existed in the private sphere of the family home. Indeed, the Irish Constitution reflects the social constraints on the roles of women in late nineteenth and early twentieth century Irish society (Hantrais 1997). LeRoux (2008) points out that in state policies and public discourse, the word 'family' has often been synonymous with 'mother' and/or 'woman' whenever questions concerning informal caregiving are addressed. Until recently and reflecting other areas of social policy, there was an assumption by the Irish State, community services, carers themselves and extended family members that the onus *is* and *should be* on close relatives, particularly women, to take responsibility for caring in the home (Timonen & McMEnamin 2002). This view contributed to the invisibility and undervaluation of family caring (Baker *et al.* 2004, Lynch 2007). According to Garey and colleagues (2002), it was only in the 1980's that interest in informal caring emerged from practical considerations relating to care and kinship, and in relation to care as a challenge in society (as cited by Daly *et al.* 2013).

Men now represent a growing minority of the overall population of informal carers in Ireland with their requirement to provide care increasing as changes in traditional family structures take place and the focus of government policy on community based care and support intensifies as outlined in detail in the sections below. Baker & Robertson (2008) note that as demographics of the population continue to change, men are assuming increasingly important roles as caregivers. According to Thompson (2002, p 23) 'the pool of potential informal caregivers is shrinking, it is thus predictable that women who need care will be looking to other men to provide care. Men, too, will be looking to other men to provide care'. As such changes take place, it is vital that we learn to understand the dynamics and changing nature of informal caring (Sandberg & Eriksson 2007).

While figures from Census 2011 show that female carers continue to outnumber their male counterparts (114,113 and 72,999 respectively), there was a larger increase among male

carers when compared with figures five years previously¹⁶. For instance, 61% of carers in Census 2011 were women and 39% were men, and this represented a 16.8% increase in the numbers of male carers since 2006. In comparison, the gender balance for carers in Census 2006 data was 62.3% female and 37.7% male. The Central Statistics Office also included a special module on carers in the Quarterly National Household Survey in quarter three of 2009 (CSO 2010). They identified a higher prevalence of carers than found in 2006 Census data (8% rather than 4.6%), and of the 2009 sample, 10% of women and 6% of men identified themselves as carers. This could be explained by a broader definition of caring used in this survey. The Department of Health's *National Men's Health Policy 2008 - 2013* acknowledged that one in three carers in Ireland is male (DoHC 2008).

International statistics also show a steady increase in the numbers of men providing care. In the UK, the 2001 Census was the first time a question on carers was included in the UK context. The 2011 Census therefore provided the first ever opportunity for comparative data on changes in the caring population over a 10 year period in the UK. Figures on the gender profile of carers in the 2011 Census found that the gender ratio remained the same as in 2001, and in England and Wales 58% of carers were women and 42% were men. One in four women and one in six men aged 50-64 was found to have caring responsibilities for older or disabled loved ones in 2011 (Carers UK 2013). In Northern Ireland, according to figures from the Northern Ireland Census 2011, 64% of carers were women, while 36% of carers were men (NISRA 2014). As part of a study on long-term care across 16 OECD countries, the OECD (2011) found that carers are more likely to be female but significantly, more males were found to become carers at older ages. For instance, relatively more males were found to be carers among the 75 years old and above category - in two thirds of the countries, a similar or higher percentage of male carers than female carers was observed. However, the OECD (2011) also point out that there is a lack of comprehensive or comparable international evidence on carers and the definition and measurement of unpaid care presents significant challenges.

There is no doubt that informal care is now a major global issue as questions of who does the caring, and under what conditions interconnect with a series of complex social problems relating to care migration, labour market supply, gender equality, and social justice in general

¹⁶ Overall, in Ireland the statistical profile highlights that the majority of carers are female and the peak age for caring amongst women is 45-49 with 11.2% of women in this age group providing unpaid care (CSO 2012).

(Zimmerman *et al.* 2006, Hochschild *et al.* 2000, as cited by Hanlon 2012, p 2). From an Irish perspective, the timing of this study takes place against the backdrop of the recent publication of a National Carers Strategy in Ireland. The first ever National Carers Strategy was published in the summer of 2012 (DOH 2012a). The strategy sets out a future road map for better recognition and support for family carers across Ireland into the future. It marks a significant milestone in the advocacy and for the recognition of the enormous contribution made by family carers in Ireland (Care Alliance Ireland 2012). At the same time, the economic value of informal caring activities is not officially captured and those family carers who are not in paid employment are registered in national statistics as being economically inactive (Care Alliance Ireland 2013a). However, it has been estimated that the value of informal caring activities is in the region of €4 billion per year. This figure, calculated from Census 2011 data, has increased significantly from the 2006 estimate of €2.5 billion (Carers Association of Ireland 2012). The huge contribution played by informal carers in the community thus minimizes the cost to the exchequer (O'Shea 2004). Indeed, at international level and including Ireland, the OECD has commented on the potential collision course whereby at one end, Governments are driving informal caring. At the same time, they are pulling back on incentives for informal caring (OECD 2011).

Additionally, there is no denying that family as a caring unit in Irish society is currently in a period of uncertain alteration due to a range of factors such as changing demographics and family formations, women's labour force participation and the economic slowdown. The Working Group on Long Term Care (2008) recognises that as the proportion of women in the paid labour force increases and family sizes are smaller, it is expected that less informal family care will be available for older people in the future, and that the state will need to provide more support in this area. In relation to changing demographics, Ireland's population is ageing at a rapid rate. It is estimated that the proportion of older people in the Irish population is due to increase dramatically over the coming years, and at the same time there is set to be an increase in their life expectancy. Census 2011 showed that there were 535,393 people aged 65 and over in Ireland, accounting for almost 12% of the population. People aged 80 and over accounted for 24% of those aged over 65, with more women than men in these old age groups (CSO 2012). The CSO forecasts that the share of the population aged over 65 years will rise to almost one-fifth by 2036 (18.4% or 1.24 million individuals) from 2006 (when the same figure stood at 11% or 462,000 individuals) (CSO 2008). Hoffman & Rodrigues (2010), while referring to similar changes taking place across Europe, point out

that given the prospect of a potentially reduced number of informal carers of working age, spouses may find themselves as the main carers over the coming years. However, they warn that this depends on the future living arrangements of older people, as well as on their health status.

At the same time, the projected demand for informal carers is significantly determined by the future population of those living with a disability that are resident at home (Care Alliance Ireland 2013a). For instance, Yumiko and colleagues (2012) completed a profile of community dwelling older people with a disability and their caregivers in Ireland as part of the Irish Longitudinal Study on Ageing (TILDA). This study identified that amongst community-dwelling older people in Ireland, 11% of men and 14% of women aged 50 or over had at least one limitation in daily activities. This translates into 164,000 older adults with care and support needs living in communities across Ireland. Wren and colleagues (2012) undertook a study to develop a predictive model of future long-term care demand in the Republic of Ireland and Northern Ireland. Among their findings, they found that by 2021, demand for all-day and daily informal home care by people aged 65 years and over will expand by 23,500 in the Republic of Ireland, representing a 57% increase in demand.

In addition, recent economic changes in Irish society such as high unemployment rates and reductions in social welfare payments have also had an impact on the lives of informal carers in Ireland (Carers Association 2010). It has been recognised that the economic climate therefore places increased financial demands on families and they will thus find it increasingly difficult to afford to provide care in the home (Ageing Well Network 2012). The period since I began my PhD has been a time of significant social and economic change as a consequence of the most severe financial and economic crisis faced by the state since World War II (Fitzgerald *et al.* 2013). While the Irish economy has shown positive signs in recent months, by the time of speaking with men in my study (during 2011 and 2012), the economic downturn had already been well established. Undeniably, we face very serious long-term indebtedness in the country as a whole, and in the context of fragile and limited growth internationally (McGreevy 2014). As a consequence, we could only very slowly begin to restore what has been taken from health and social services in a series of austerity budgets. Therefore, it is in this context that the men's stories of caring are set.

Home-based social care has received renewed attention in recent years as policy makers have sought to avoid the need for older people to move into institutional settings when in

need of care (Pierce 2006). From a policy context, the government's national *Primary Care Strategy* (2001) emphasises a shift away from hospital to community-based care. Ultimately, it documents how the focus of government policy in Ireland is the provision of care in the home for as long as possible. The combination of health policy trends towards home care, as well as advances in treatment to support people with advanced chronic illnesses, mean that more people with debilitating illnesses are living longer with increased dependency (DOHC 2008). According to *The Report on End of Life Care for Older People in Acute and Long-Stay Care Settings in Ireland* (2008, p.30): 'As people are living longer they are suffering from diseases that have a longer and less predictable care trajectory'. Chronic conditions such as diabetes, respiratory diseases, cancer, cardiovascular problems and dementia are far more common among older adults than among their younger counterparts (Stephens & Franks 2009, p. 62). The Government's *Chronic Disease Policy Framework - Tackling Chronic Disease* (2008), recognises both the burden placed on families and carers of individuals with chronic disease, and the importance of reducing such responsibilities. However, since the specialist support services for these chronic illnesses are usually hospital-based, family carers for these patients receive little support in the community (McCarron *et al.* 2011, p. 12). In 2012, the Department of Health published *Future Health: A Strategic Framework for Reform of the Health Service 2012-2015*. In this document, they acknowledge that the major challenges to the current health services in Ireland such are scarce financial resources, an ageing population and an increase in the number of people with chronic illness (DoH 2012b). Another factor which must be considered is evidence gathered from Irish research regarding the preference of older people themselves to be cared for at home when dying (Weafer *et al.* 2004, as cited by O'Shea *et al.* 2008). While a large majority (between 67-80%) of the older population want to die in their own home, in reality only 26% does so (Murray *et al.* 2013). McCarron and colleagues (2011, p.14) highlight 'The key policy challenge in the Irish context (as is true in many other countries) is the expectation that families will take on the bulk of care in the home... This model assumes that the State 'steps in' when all else fails'. Speaking from an international context, Hoffman & Rodrigues (2010) argue that it is crucial that public policies learn to adapt to the changing caring conditions, and do not try to 'crystallise' current informal care arrangements (p. 14). Community care policies assume that individuals will be willing, and able, to provide appropriate levels of support for people with long-term care needs (Edgell 2012). One thing is certain: home-based care is financially cost effective for the healthcare system (Pierce & Lutz 2009).

The factors outlined above which detail the policy context of informal care in Ireland highlight the importance and timeliness of conducting this research focusing on the experiences of male carers in Ireland. Men will be required to provide care in the future whether they want to or not. Ultimately, as Pierce & Lutz (2009) point out, caregiving experiences incorporate societal values and are shaped by governmental policy (p. 197).

Support Entitlements for Informal Carers in Ireland

The state supports informal carers in Ireland in different ways, with the Department of Social Protection assuming a lead responsibility. Carers Allowance is a weekly means-tested payment to people on low incomes who are looking after a person who needs support because of age, disability or illness. The maximum weekly rate is €204 for a carer aged less than 66 years of age, caring for one person. Individuals who are in receipt of another social welfare payment may be entitled to a Half-Rate Carers Allowance. Carers Benefit is made to insured people who leave the workforce to care for a person(s) in need of full-time care and attention. It can be claimed for a total period of 104 weeks for each person being cared for. The maximum weekly rate is €205 (Citizens Information 2015). However, as the weekly Carer's Allowance and Carer's Benefit payments are both means-tested, many Family Carers in Ireland do not receive regular financial support in their caring role (Care Alliance Ireland 2013a). All full-time informal carers are eligible to receive a Respite Care Grant. A Respite Care Grant of €1,375 is paid once each year and it is not taxable (Citizens Information 2015). However, the Respite Care Grant was cut by 19% in 2013. For many full-time informal carers, the Respite Care Grant is the only direct financial support they can receive from the state for caring for their dependent family member (Care Alliance Ireland 2013). In 2013, 57,136 individuals were in receipt of the Carers Allowance, while 24,940 received the Half-Rate Carers Allowance. 1,598 individuals received Carers Benefit, while 58,758 individuals received the Respite Care Grant (Department of Social Protection 2014).

Formal care in Ireland consists of home help and home care packages. They are delivered mainly by the HSE, but also increasingly by voluntary and private for-profit organisations (Care Alliance Ireland 2013). However, there is no legal obligation on the HSE to provide a home help service, nor is there a set home care package (Care Alliance Ireland 2014a). Care Alliance Ireland (2014) notes that this is a resounding weakness of the Irish home care system that these services are not underpinned by legislation and are not provided on a statutory basis. The Law Reform Commission (2012) has also previously pointed to the absence of a proper regulatory structure for the delivery of professional care in the home.

Dementia

Dementia is a progressive condition, with deterioration likely to occur in all domains (Cahill *et al.* 2012). Dementia is primarily a disease associated with old age, mainly affecting people aged 65 years and over (WHO 2006). It is an umbrella term used to describe a range of conditions and commonly cited definitions of dementia highlight its construction as a biomedical disease, for example the Alzheimer's Society (2006) point out that:

The term 'dementia' is used to describe the symptoms that occur when the brain is affected by specific diseases and conditions, including Alzheimer's disease, stroke and many other rarer conditions. Symptoms of dementia include loss of memory, confusion and problems with speech and understanding (as cited by Innes 2009, p. 4).

Impairment of these functions impacts on all aspects of the person's life and close relationships (Evans & Lee 2014). The course of the illness in dementia may be gradual and, sometimes, subtly, as in the case of Alzheimer's disease. However, it may be more abrupt and can often be characterised by sudden episodes of deterioration as the case in Vascular Dementia, also known as Multi-Infarct Dementia. In Lewy Body Dementia, the course of the illness may be punctuated by episodes of confusion, hallucinations and delusions and in fronto-temporal dementia by insidious personal or behavioural changes (Cahill *et al.* 2012). Ultimately, the gradual loss of cognitive function associated with dementia progressively diminishes a person's ability to perform everyday activities (Eriksson *et al.* 2013a). To date, Dementia has no single cause and no cure (Cahill *et al.* 2012).

Demographic ageing is a worldwide phenomenon and many people are now living longer and healthier lives than before (Alzheimer's Disease International 2009). However, with increased life expectancy and survival from previously untreatable diseases, the prevalence of dementia has increased (Alzheimer's disease International 2008). Worldwide, it is estimated that there are 35 million people living with dementia and this is expected to double by 2030 and more than triple by 2050 to 115 million (Prince *et al.* 2014). According to the WHO (2003), dementia contributes to more years lived with a disability in people aged over 60 years (11.2%), than stroke (9.5%), cardiovascular disease (8.9%), all forms of cancer (2.4%) or musculoskeletal disorders (8.9%). However, while, the economic burden of dementia ranks higher than stroke, heart disease and cancer combined (Lowin *et al.* 2001, as cited by Trepel 2011), health care allocations for dementia continue to be substantially lower than each of these individual disease groups (Trepel 2011). In addition, while dementia is a major cause of

disability in the elderly, leading to loss of independence; there are also other associated issues such as the increasing costs to society and high strain placed on caregivers (Jönsson & Wimo 2009). One thing is certain, dementia is a global health issue that poses significant challenges to 'people, society and the economy' (Moniz-Cook 2011, p. 283).

Globally, costs for people with dementia amount to more than 1% of gross domestic product (GDP) (Wimo & Prince 2010). Wimo and colleagues (2011), upon examining the economic impact of dementia in Europe, found that the total cost of dementia disorders was in the region of €160 billion, 56% of which was attributable to the costs of informal care. However, dementia remains a hugely neglected, underfunded and under-prioritised health issue in Ireland and lessons could be learnt from the experiences of other countries in the development of dementia policy (Cahill *et al.* 2012). A major increase in the number of people with dementia in Ireland is likely to occur after the year 2021, with numbers growing to between 141,000 and 147,000 by 2041, depending on assumptions about migration and fertility. In line with the projected growth in the number of the oldest old population, the most marked increase in the numbers with dementia in Ireland will be amongst people aged 85 years and over (Cahill *et al.* 2012). In real terms, this population is predicted to increase threefold in Ireland and with this so will the demand for dementia specific services (Trepel 2011). Unfortunately, there is no population-based study on the prevalence of dementia in Ireland. Connelly and colleagues (2014), in their study of estimating the economic and social costs of dementia in Ireland in 2010, derived an estimate of the number of people with dementia by applying age/gender dementia specific prevalence rates from the European Collaboration on Dementia to the most recent population estimates for Ireland. This gives an estimate of 41,740 people with dementia, of whom 3,583 are aged less than 65. In addition, the majority of people with dementia in Ireland live in the community. Estimates of the number of people living in the community with dementia for this study were derived by applying age specific dementia rates for those aged 65 and over (Lawlor *et al.* 1994) to available population estimates from the Census of Population. They also found that there are a total of 26,104 people with dementia estimated to be living in the community in Ireland (Connelly *et al.* 2014).

A growing awareness of the prevalence of dementia has also resulted in an increased interest in those expected to provide care (Quinn *et al.* 2012). Recent demographic, social and policy developments across Europe have raised the question of whether 'care gaps' are increasingly likely to occur as informal care may become less available, which in turn could lead to an increase in demand for formal long-term care. In particular, as outlined above, the

numbers of people with dementia is set to dramatically increase in the coming years due to an increasing ageing population and this will therefore have consequent implications for care provision, care burden and public expenditure (Cahill *et al.* 2012). In such an increasingly ageing society, there is a growing need for informal caregivers to help support an older person in the community, particularly when that person has dementia (Quinn *et al.* 2013). For example, as a consequence of future prognosis of dementia combined with predicted economic impacts, the World Health Organisation (WHO) (2008) specified that a key priority for dementia is targeted interventions focusing on the carer.

In Ireland, the stated objective of public policy for patients with dementia as documented in *The Years Ahead: a Policy for the Elderly* (1998) is to encourage and assist continued living at home for as long as it is feasible and practical. Family carers are therefore the cornerstone of support for many individuals with dementia in Ireland (O'Connor 2011). Similarly, in the UK, informal carers are recognised as 'the most important resource available for people with dementia' (Department of Health, UK 2009, p. 4). However, Cahill and colleagues (2012) point out that while informal care from family and friends provided to people with dementia is generally free of charge, this does not mean that it is without value (p. 51). For instance, Connelly and colleagues (2014) estimate that a total of 81 million hours of care is provided by family and friends each year in Ireland. Informal care for those with dementia in Ireland is also estimated to be €807 million (Connelly *et al.* 2014). Another Irish survey of carers providing care to an individual with dementia found that while 63% of respondents were below retirement age, as a result of caregiving, half stopped working to care; of those in full-time employment, 61% reduced working hours, and 71% of carers in part-time employment reduced to below 20 hours per week (Trepel 2011). This research also notes that such levels of carer burden are avoidable, through appropriate services and intervention (Trepel 2011). Indeed, Cahill and colleagues (2012) warn that without adequate support and the development of community based services; continued reliance on informal care in Ireland may be unsustainable in the longer term. Insufficient funding is ultimately resulting in carer burnout and greater demand for long-term care (p. 46). Important issues relating to Family Carers are therefore highlighted in their 2012 research review for Ireland's National Dementia Strategy entitled *Creating excellence in Dementia care: A Research Review for Ireland's National Dementia Strategy*. It is envisaged that the findings of this vital piece of research will ultimately form the basis for the creation of a National Dementia Strategy which is yet to be

published¹⁷. The Alzheimer's Society of Ireland (2012) has argued that the National Dementia Strategy, combined with the National Positive Ageing Strategy and the National Carers Strategy, has the potential for Ireland to have world-class services and supports for those living with dementia (Alzheimer's Society of Ireland 2012). Thus, dementia in Ireland is very slowly moving to being seen as a key health and social care issue.

Informal Caring in Dementia

The increasing prevalence of dementia means that many people are taking on a caring role for someone with dementia in the home. Early work on informal caring found that caregiving limited caregivers' lives (Twigg & Atkin 1994). Existing research has shown that caregiving in the context of dementia can be burdensome and stressful to family members and contribute to the high prevalence of anxiety and depression among this population (Joling *et al.* 2010, Pearlin *et al.* 1990, Schulz *et al.* 2004). Individuals providing care in dementia have also been found to face unique challenges not posed in other physical health caring situations due to the nature of the illness. They have reported greater emotional strain due to changes in cognition, mood and behaviour of the individual with dementia (Ory *et al.* 2000). According to Daly and colleagues (2013, p.502) 'As the impacts of dementia are progressive and multiple, informal carers can encounter changes in all domains of their lives'. In addition to physical health conditions and functional impairments, dementia caregivers often need to deal with symptoms related to dementia including compromised memory, judgment, orientation, communication, as well as problematic behaviours (Schulz & Martire 2004).

In particular, spouse carers of people with dementia face unique challenges as they adapt to the demands of caring whilst experiencing significant losses in their couple relationship (O'Shaughnessy *et al.* 2010, p. 237). Baikie (2002) contends the couple relationship in dementia is an intimate relationship that potentially faces major intrapersonal and interpersonal stresses. In addition, pre-caregiving and current relationship quality appear to have an impact on carers' wellbeing and the carers' perception of relationship quality is influenced by the care-recipient's needs for help with activities of daily living and level of behavioural problems (Quinn *et al.* 2009). According to de la Cuesta-Benjumea (2011), the losses that caregivers of people living with dementia experience has been voiced in the literature since early days (citing the work of Farran *et al.* 1991 as an example). de la Cuesta-

¹⁷ The Irish Government gave a commitment in the Programme for Government 2011-2016 to develop and implement a strategy for dementia for Ireland (Department of the Taoiseach 2011).

Benjumea (2011) notes that of significance is the loss of self resulting from the constrictions of normal activities; and the carer becomes engulfed by care-giving activities as originally proposed by Skaff & Pearlin (1992). Several studies have examined the nature and trajectory of anticipatory grief among carers of individuals with dementia (for example Garand *et al.* 2012, Meuser & Marwit 2001). Other forms of media have also examined the concept of pre-death grief such as in the book *The Long Goodbye* (Davis 2004) and the movie *Iris* (Eyre 2001).

According to Peacock and colleagues (2010, p. 642) 'Although much of the literature on caregiving to persons with dementia refers to the care as burdensome or stressful, caregiving has been described as having both positive and negative aspects'. However, they note that to view caregiving as a source of opportunities has not been commonly considered within the current literature (Peacock *et al.* 2010). Similarly, Carbonneau and colleagues (2010) highlight that the positive aspects of caregiving need to be further developed within research. There is the potential to learn valuable strategies from caregivers who report positive experiences (Shim *et al.* 2012). Existing literature shows the importance of the positive aspects of caregiving for the carers' physical and mental health (for example in the work of Pinquart & Sörensen 2004, Cohen *et al.* 1994, as cited by Carbonneau *et al.* 2010). Researchers have also demonstrated that the positive aspects of caregiving are not at the opposite end of a continuum from burden, and instead these aspects reflect a separate dimension of the caregiving experience (as evident in the findings of Boerner *et al.* 2004, Cafferata & Stone 1989, Kramer 1997, as cited by Carbonneau *et al.* 2010).

Another branch of research within dementia caregiving has focused on preserving the personhood (self) of the individual with dementia (for example as evident in the work of Hellström *et al.* 2005, Perry & O'Connor 2002, as cited by Shim *et al.* 2012). For Hellström and colleagues (2005), maintaining the dignity, autonomy and sense of self of the individual with dementia was found not only to be beneficial for that person, but also for the carer, and for the relationship between the two people. Perry & O'Connor (2002) introduced preserving personhood as an essential principle that guides spousal caregiving in their study of husband and wife carers of individuals with dementia. The spousal caregivers in their study used four strategies to operationalise the principle of preserving personhood: maintaining continuity, supporting competence, protecting from incompetence, and strategising encounters. They concluded that from a social constructionist perspective, the focus on preserving the personhood of the partner with dementia promoted more holistic, person-centred care but

also preserved their own identities as husbands and wives. However, when examined independently, each of the strategies used to achieve this goal presented both challenges and opportunities for the spouse caregiver (Perry & O'Connor 2002).

In other work, Hellström and colleagues expanded the ideas they had developed in 2005 further in 2007 to explore strategies for maintaining the 'couplehood' between caregiver and spouse in dementia. Strategies for a positive caregiving experience identified included talking things through, being affectionate and appreciative, making the best of things, keeping the peace, maintaining involvement and moving on (Hellström *et al.* 2007). However, Shim and colleagues (2012) argue that whether the focus is on caregivers' finding meaning or preserving the personhood of the individual with dementia, existing research suggests that positive caregiving experiences stem mainly from the dynamic between the caregiver and the care recipient (p. 222). Indeed, spousal caregivers of people with dementia in their own study who described positive caring experiences described both their past and present relationship with the care recipient in loving terms. Other research has found that through the various tasks of daily care, including GP visits, paying bills, managing medications, dressing and bathing, talking, spouse carers in dementia co-construct a new identity and way of relating (Gardner, 2008). This new identity comes to embody a sense of couplehood for both members of the couple (Kaplan 2001, as cited by McGovern 2011). Defined by a feeling of *we-ness*, couplehood describes the relationship between two committed individuals who share a sense of identity, commitment, and purpose, as suggested by Kaplan (2001) in her typology of relationships in dementia-affected couples (as cited by McGovern 2011). McGovern (2011) proposes that when viewed through the lens of couplehood, the experience of caring in dementia can be interpreted beyond burden and burnout, and instead understood as meaning making processes in support of the inter-subjective self co-constructed in the context of couplehood (p. 680).

Early Conceptions of Gender Identity

The theoretical domains in which male caring is situated in society will now be examined through providing an outline of relevant conceptions of gender identity and notions of masculinity within the literature. Gender identity is a complex aspect of the self and the theoretical literature on gender has evolved over the past twenty five years (McNeill 2007). Foss and colleagues (2013) propose that there are three different ways that scholars have

conceptualized gender: first, in viewing gender as equivalent to sex; a second view that gender is separate from sex and thirdly, viewing gender as the assignment of meaning to bodies (p. 6). Gender was firstly conceptualised within the literature as part of the essentialist perspective. Within this tradition, gender was believed to exist within individuals as a quality or trait, separate from the interactions of daily life (Bohan 1993, as cited by McNeill 2007). This perspective also assumed that men and women have distinct biological roles, because they have evolved over thousands of years to have sex-specific characteristics and traits (Eagly & Wood 1999, as cited by McNeill 2007). However, this approach to understanding gender received criticism for its highly reductive generalisations about 'masculine' and 'feminine' characteristics and potential influences on gender such as social class, race, education, sexual orientation, age and socio-economic status were ignored (McNeill 2007, p. 411).

Social Construction of Gender

Rather than viewing gender as a static entity, theorists later became interested in the ways that gender is constructed and evolves over time (McNeill 2007). Social constructionist theorists took a critical stance toward essentialist conceptualisations of the categories *man* and *woman*, instead viewing gender and gender roles as the result of the normative prescriptions of masculinity and femininity and circulating in a particular point in time (Burr 2003, as cited by Ussher *et al.* 2013, p. 911). Thus according to this view, while assigned gender is a construct based on human chromosomes, man and woman, masculine and feminine are instead social constructs and culturally determined at a specific moment in time (Foss *et al.* 2013, p. 8). People are viewed as gendered individuals that have been socially constructed in which their behaviour is not an inborn part of them (Foss *et al.* 2013, p. 8). According to this perspective, through social interaction, individuals learn what is expected, see what is expected, act and react in expected ways, and thus simultaneously construct and maintain the gender order (Lorber 2009). The social context in which gender identity is immersed is now recognised as an important influence in shaping gender (McNeill 2007).

Butler (1990) highlights that in this process, gender is thus a 'complex cultural construction' (p36) and 'not biology, but culture, becomes destiny' (p. 8)¹⁸. Gender is viewed as a performed social identity (Harris, 2013). For Kimmel & Messner (2013a, xvi) this perspective

¹⁸ Connell (2000) explains gender as active identities, traits, and values culturally and historically associated with men and women.

is ‘...both *historical* and *comparative*’. The social construction of gender also demonstrates that assumptions about what is appropriate for women and for men within the culture of a society can shape and influence a person’s identity, as well as the scope which individuals have for deciding both ‘who we are’ and ‘who we want to be’ (Woodward 2000, p. 22).

Social ‘assumptions’ about gender identity mean that certain roles can seem impossible to overcome due to deep social conditioning (Seidman 2010), for example such as men being viewed as capable of caring. Butler (1991) argues that as individuals conform to gender norms, others are likely to interpret their behaviour as expressing a core gendered identity. However, Butler (1991) suggests that there is no core gender identity that drives a person’s behaviour. Rather than viewing our gender performances as expressing an inner gender identity, Butler contends that these behaviours are modeled after images of what it means to be a woman or man that we learn from our families and other institutions (as cited by Seidman 2010, p. 37). People therefore often adopt certain behaviours assumed as masculine or feminine to form and fit with the identities that they construct (Gove & Watt 2004)¹⁹. Campbell & Carroll (2007) highlight that central to the ‘doing gender’ approach proposed by Butler (1990) and earlier by West & Zimmerman (1987) ‘...is the idea that what doing gender means can vary not just across cultures or across historical periods but also from situation to situation within the same culture’ (p. 492). Through performance, certain aspects of gendered identity become normalized and legitimized (West & Zimmerman 1987). Pullen & Simpson (2009, p. 567) proposed that ‘A focus on doing and undoing difference supports the notion of gender as social practice’. Thus, they highlight that in this respect, gender and identity are conceived as emergent and incomplete, rather than a product that can be achieved (Pullen & Simpson 2009, p. 567).

Following on from the social construction of gender, post-structural ideas have recently suggested that gender is discursively constructed through language (Perry *et al.* 1992), not only within conversation but it is constructed through written text, institutional practice, media and the law (Butler 1990). While the post-structural paradigm may overlap with social constructionist ideas on gender, Payne and colleagues (2008) note that post-structural accounts of gender permit greater recognition of the ways in which there are competing and contradictory ways of ‘doing gender’ within normative boundaries, using the notion of

¹⁹ According to Gove & Watt (2004, p.53) ‘Identity is not just something we achieve, not something that is just thrust upon us; it has elements of both’.

hegemonic gender to allow for the greater acceptability and higher status of certain gender practices (p. 27). For instance, 'hegemonic masculinity' has become increasingly used to refer to 'the most honored or desired' form of masculinity within a society (Connell 2000). At this point, discussion will now turn to the development of such ideas specifically relating to understanding men and masculinities.

The Social Construction of Masculinities

The theoretical field of men and masculinities is complex and diverse (Featherstone *et al.* 2007). The concept of masculinity is a fairly recent historical product (Connell 1995). Indeed, Kimmel (2001, p. 273) has argued that masculinity 'historically and developmentally ... (has been) the flight from women'. While the biological sex of individuals is visible, the ways in which the complex social meaning attached to biological sex in men's lives, namely gender, is less understood (Kimmel & Messner 2013, p. xi). According to Robertson (2007, p. 27) 'At its most basic level, masculinity can be understood as the outward expression of being biologically male'. Kimmel & Messner (2013a) contend that to be a man according to the social construction perspective: '...is to participate in social life as a man, as a gendered being. Men are not born; they are made. And men make themselves, actively constructing their masculinities within a social and historical context' (p. xvi). The specific contribution of Raewyn W. Connell to the perspective of viewing masculinity as socially constructed, produced and reproduced will be outlined in the following paragraphs. There is no doubt that Connell has been one of the most influential writers within men and masculinities studies since the 1980's.

'Gender-as-performance' investigators such as West & Zimmerman (1987) and Butler (1991) appreciated that within a single culture and across various cultures and environments, diverse masculinities as well as femininities co-exist (Campbell & Carroll 2007). Age, cohort, class position, ethnicity, and even disability status were seen to contribute to the differential experience and expression of masculinity among men (Connell *et al.* 2005, Thompson 2006). However, such divergent masculinities and femininities fitted into a hierarchy (Campbell & Carroll 2007). In this regard, some masculinities become dominant within social contexts – the main ways of being a man in society, or what as Connell (1995) called *hegemonic masculinity*. Other masculinities (which Connell (1995) called subordinated) can be very different, for instance through emphasising femininity, or homosexuality, or being highly resistant to gender (Macionis & Plummer 2008). Carrigan, Connell and Lee (1985) firstly argued for an understanding of masculinity based on the recognised dominant interpretations

and definitions of masculinity as embedded in and sustained by a range of male-dominated institutions such as the state, education, family, and the workplace. Drawing on the work of Italian Marxist Gramsci on 'hegemony'²⁰, Carrigan *et al.* (1985) argued that there was a dominant form of masculinity called 'hegemonic masculinity' (as cited by Featherstone *et al.* 2007, p. 14).

Following the work of Carrigan and colleagues, Connell developed the analysis of hegemonic masculinity further in 1995, defining masculinity as 'simultaneously a place in gender relations, the practices through which men and women engage that place in gender, and the effects of these practices in bodily experience, personality and culture' (p. 71). Connell (1995) believed that the relational patterning of masculinities in current Western gender order consists of hegemonic, subordinated, marginalised and complicity masculinities. In later work, Connell (2000) added more masculinities, namely frontier, gay, military, protest and transnational business masculinities, arguing that such masculinities begin to proliferate as 'types of men', through occupation or socio-economic status, orientation or ideology. Connell (1995, p. 76) also believed that masculinities develop not as isolated acts but as actions configured in larger units that may be referred to as '*configurations of gender practice*'. In turn, these configurations also interact with other areas of social practice such as race, class, sexuality and disability. Connell (1995, p. 77) defined hegemonic masculinity as 'the configuration of gender practice which embodies the currently accepted answer to the problem of the legitimacy of patriarchy, which guarantees (or is taken to guarantee) the dominant position of men and the subordination of women'. However, Connell & Messerschmidt (2005) suggested that only a small percentage of men actually measure up to a hegemonic version of masculinity²¹. Instead, they proposed that the relational nature of

²⁰ Atkinson (2010, p. 30-31) outlines in detail Gramsci's (1971) notion of *hegemony*. For him, socially legitimate and enduring power is established and maintained through subtle inter-institutional and cultural means: a process of hegemony. Hegemony is political, ideological, social and cultural power that flows from intellectual and moral leadership within a society. A ruling class forms and maintains its hegemony in civil society by creating and enforcing its norms, values and statues that are, in turn, promulgated and normalised through political parties, schools, media, the church, and other voluntary associations.

²¹ Reeser (2010) also notes that the study of masculinity should not assume that all men have power or hegemony at all times, pointing to the work of French sociologist Pierre Bourdieu (2000, p. 69) in *Masculine Domination*, who talked about how men are 'dominated by their domination', essentially how masculinity can cause internal problems for men who deploy it for various ends.

different masculinities means that other men locate themselves in the context of the hegemonic ideal. Evans and colleagues (2011) point to other work that suggests that maintaining hegemonic masculine identities can be challenging for men given that identity is performatively constituted (for example citing Berger *et al.* 1995).

While the concept of hegemonic masculinity is clearly the most popular and influential element of Connell's theory of masculinity, it has also attracted the most criticism (Wedgewood 2009). Synnott (2009) points out that while variations exist within masculinities, and men may resist particular ideals, the fundamental difference between these masculinities is not always clear. More recently, masculinities theorists have urged the expansion of the concept of hegemonic masculinity, such as Hearn (2004) (as cited by McGinley 2011). Hearn (2004) argued that because masculinity is fluid, relational, and context dependent, notions of masculinity change constantly through interaction (as cited by McGinley 2011). For Coles (2009), the concept of hegemonic masculinity as the descriptor of the culturally dominant ideal only takes into consideration dominant and subordinate/ marginalised masculinities at the structural level. It does not take into account men's lived realities of their own masculinities as dominant in relation to other men, despite being subordinate in relation to the cultural ideal (Coles 2009, p. 30).

Another model for studying men and masculinities has since emerged within the social constructionist perspective, namely the life course perspective which has been championed by Kimmel and colleagues (2007, 2013). Scholars who examine masculinities within this approach share with the social constructionist perspective a view that gender is a performed social identity, and while multiple masculinities exist and take place within sociocultural contexts, some are prioritised and situated as dominant above others (Harris 2013). According to Kimmel & Messner (2013a, p. xvii) 'The issues confronting a man about proving himself and feeling successful and the social institutions in which he will attempt to enact his definitions of masculinity will change throughout his life'. In this view, because gender is a performed social identity, the ways in which individuals conceptualise and express masculinities change as men 'grow and mature' (Kimmel & Messner 2007, p. xxii). Similarly, Calasanti (2010, p. 721) recognises that 'Ideals and enactments of gender identities change over the life course, both in response to historical and life-stage changes but also to age-based changes – not only just physically or as bodies change but also as our age statuses

change'. 'Key' transitional moments in men's lives can encompass first entering employment, career progression, and retirement, through to becoming or being single, divorced or separated, becoming a couple or having a family (Robinson 2014, p. 158). Coles (2009) highlights that the fluidity of masculinity is rarely given critical consideration in the context of men's lives. Ultimately, Kimmel & Messner (2013a) believe that this perspective which still stresses the importance of social construction of masculinities, but over a life course, allows for a more comprehensive understanding of men's lives.

Gender Ideologies are Constantly Changing and Challenged

One thing is certain among the divergence in ideas: 'Gendered roles change' (Lorber 2009, p. 113). Broad generalisations may not be helpful as there are multiple masculinities and much diversity among men (Ridge *et al.* 2011). Thus, masculinity is not static but rather fluid and subject to change, with men more likely to be enacting multiple and competing masculinities (Connell & Messerschmidt 2005). Areas of the labour market and of domestic work, including unpaid caring work within the home, had until recent years been seen as 'men's work' or 'women's work'. The former was seen as masculine and the latter as feminine. This was enacted in most Western societies through the notion of a male breadwinner which was primary to a man's identity, whereas women's work was seen as an extension of their roles as wives and mothers and thus as a secondary activity (Woodward 2000, p. 21). Cultural meanings about what is considered masculine and feminine and what is not also vary from one society to another and from one historical period to another. This is all part of a gender order, which refers to the ways in which societies shape notions of masculinity and femininity into power relationships (Macionis & Plummer 2008).

Therefore, as Aboim (2010) points out that in today's Western societies, changes to the earlier 'modern family' have had serious implications for masculinities in so far as new models of 'being a man' are being created. Men are, to some extent, expected to embrace new expressive roles within an intimate private sphere, beyond the traditional model of the authoritarian provider. As partners and fathers they are dealing with new expectations generated by the widespread acceptance of companionship-based and egalitarian ideals (Morgan 1996, as cited by Aboim 2010). Additionally, the ideal of the male carer - a nurturing figure capable of expressiveness and intimate involvement, which was traditionally a stereotypical feature of femininity, has been gaining strength. However, it is also true that, rather than setting up a dominant model, gendered developments have been displaying multiple, sometimes even contradictory aspects which bring a degree of haziness into the

making of masculinities (Aboim 2010, p. 161). According Aboim (2010, p. 161): 'In this sense, men are plural not only because the ideological codes of masculinity have also multiplied, but because they use them in more individualised ways'. Aboim (2010) also contends that social individualisation, as put forward by a number of authors such as Elias (1978, 1991), Beck & Beck-Gernsheim, (2002) and Bauman (2004), has had an indelible impact upon gender relations and identities (p.161).

In Ireland, men as gendered subjects have remained largely outside the gaze of critical inquiry, and academic research in this area is limited. Traditional masculinity in Ireland has been constructed in terms of the 'hard working man' and 'good provider'. However, there is increasing recognition of the impact of the climate of rapid social change upon men (Hearn *et al.* 2006). This study therefore attempts to explore as specific area of social change for men, namely informal caring in the context of dementia.

Masculinity, Paid Work and Retirement

Paid work has been recognised within the literature as a chief source for masculine identity and power (Collinson & Hearn 2001). According to Connell (1995, p. 33), the 'cultural function of masculine identity is to motivate men to work'. Edwards (2006) argues that historically, successful masculinity has been directly equated with success at work. Men's sense of who they are is constantly re-affirmed at work, but also open to scrutiny and question (Robinson *et al.* 2011, Robinson & Hockey 2011). For instance, Kimmel & Messner (2013b) note that men have experienced dramatic shifts in the quality of their work experiences due to a number of factors such as women's continued movement into the paid labour force, higher levels of unemployment and the rise of a more service-oriented economy. Working in a female dominated occupation upsets a traditional gendered division of labour (Williams 1995). This often does not allow men to easily confirm hegemonic masculinity, with men at risk of being both feminised and stigmatised as a consequence (Lupton 2000).

In the context of the non-traditional career, specifically nursing and primary school teaching, Pullen & Simpson (2009) explored how men manage difference at work, and highlighted the partial and fragmented nature of masculine identities. This qualitative study of twenty five men explored the process of doing gender as a social and discursive practice, and the findings illustrate the complex ways in which men manage difference and transcend 'Otherness', by doing masculinity and appropriating femininity so that masculinity is partially

subverted and partly maintained at the same time (p. 561)²². Broadbridge & Simpson (2011) comment that this work, along with other previous research such as Pringle's (2008) study of lesbian managers, complicates the binary divide of male/ female and masculine/feminine to incorporate complexities of difference as well as how gendered norms may be contested and experienced (p. 475).

Milligan *et al.* (2013) point out that while hegemonic masculinity valorizes physical dominance, emotional control and achievement through paid work, in post-retirement, this 'ideal' may be difficult for older men to maintain (p. 6). Kilmartin (2007) highlighted that men in the Western world buy into masculine workplace norms through defining themselves according to their jobs and evaluating their worth across public and private, paid and unpaid work boundaries. Transition to retirement can therefore lead to older men's estrangement from the masculine man-as-breadwinner associations with paid work (Buchbinder 2002). Brown (2006) notes that retirement can cause an identity crisis when work has been a man's primary source of affirmation and accomplishment. Retirement may bring with it a sense of loss of identity, status, income and friendships as the lives of many older men, including their social networks, are shaped by work (Williamson 2011, as cited by Milligan *et al.* 2013). Men have also been found to experience isolation in post-retirement (Hall *et al.* 2007). Oliffe and colleagues (2013) explored the connections between thirty older Canadian-based men who experienced depression with masculinities, work and retirement. Work provided the men in this study with a place to perform and reinforce masculine workman ideals. Retirement was seen as a threat when men's identity was bound to their work life and tested their capacity to manage their depression. A sense of unfinished business, loss of routine and erosion of important purpose were viewed as key challenges (Oliffe *et al.* 2013).

However, Oliffe *et al.* (2013) also found that men's ability to reconstruct gendered identities was critical for the transition to successful retirement. They comment that idealized masculine activities may be expanded in retirement into alternative avenues that could ease the burden experienced. These include men's involvement in volunteer community ventures, the development of meaningful hobbies and attending to the relational needs of the family (Oliffe *et al.* 2013). While volunteering may be a socially acceptable 'replacement' role for men in

²² In focusing on the negotiation of gender identity by men in terms of 'Otherness', Pullen & Simpson (2009) follow on from the work of Hearn (1996) who proposed that an understanding of masculinity and masculine identity practices can be gained by focusing on contexts where men as 'the One' become 'the Other' (p. 562).

retirement, Milligan and colleagues (2013) point out that it tends to appeal more to older men who are relatively affluent and middle class, rather than more deprived working class men (p.6). Milligan *et al.* (2013) conducted a systematic review of the effect of Men's Sheds and other gendered interventions on older men's physical and mental health and social wellbeing. Significantly, the authors found that such interventions create and foster social interaction and connections, and a sense of camaraderie for older men (Milligan *et al.* 2013, p. 6).

Gender and Male Caring

The cultural positioning of caring has situated caring as an activity that is expected of women and of women as 'natural' carers (O'Grady 2005, as cited by Ussher *et al.* 2013), and as women better suited to caring (Collins & Jones 1997, as cited by Ussher *et al.* 2013). Moreover, feminist approaches to studying how care is constructed demonstrated that care has been socially constructed as a gendered concept, reflecting a specifically 'feminine' expression of society that is built around notions of familial ties and obligations (Milligan 2009, p. 9-10). From a social constructionist perspective, Ussher *et al.* (2013) demonstrated in their qualitative study with fifty three informal cancer carers (34 women and 19 men) that cancer caring is not a gender-neutral experience. It is closely tied to gendered constructed expectations of being 'woman' or 'man', which has considerable implications for psychological well-being and coping (p. 911). As outlined earlier, both in Ireland and internationally, more men are assuming an informal caring role and their requirement to do so is set to continue to increase over the coming years, specifically in the context of dementia. At the same time, the increasing care gap in Irish society has heightened the roles, rights and responsibilities of men to share caring on an equal basis with women (Fanning & Rush 2006). Thus, men's involvement in informal caring is one area in which they are participating in non-traditional 'masculine' areas. It may also be fair to suggest that in so doing, men assume a paradigm shift in their gender identity. Pringle (1995) has argued that caring for an old and frail spouse may potentially present alternative ways of being a man.

Studying men's involvement in informal caring may therefore have the potential to provide important insights into wider notions of masculinities in society. According to Hanlon (2012, p. 6) care relations have the potential to '...expose important contradictions and tensions in men's lives: between the hegemonic dictates of masculinities and the intimate, compassionate and empathetic experience of our inherent human vulnerability'. Indeed, the 'subversive performance' of undertaking caring activities has the potential to generate new understandings of masculinity that are not necessarily intentionally organised by men

(Eriksson *et al.* 2013b, p. 244). Following qualitative work focusing on the experiences of daughters whose fathers were caring for their spouse, Eriksson and colleagues (2013b) argue that even where the choices and practices of the men in their study may be influenced by 'hegemonic' understandings of masculinity, the outcome of their practices may not reinforce such understandings (p. 244). In other work, Eriksson and colleagues (2013a, p. 160) referred to the idea of 'situatedness' as proposed by Haraway (2008). Given that the positions of men and women in society are always gendered and connected to power structures, Haraway (2008) suggested that both physical and social embodiment of knowledge can be understood with respect to 'situatedness', the lens through which one encounters and interprets the world²³.

Conclusion

This chapter has framed the basis for my study within larger political, social, theoretical and practical domains. It has provided a crucial starting point for developing the significance of my study and also for the literature review chapter which follows, illustrating that research evidence shows that male caregiving occurs within an evolving social context and considers caregiving to be a gendered activity. The social construction of masculinities emphasises the influence of social interactions, social structures and social contexts in producing and reinforcing so called normative expectations of masculine behavior. With cultural and society shifts in attitudes on men, new theories of masculinities are constantly emerging – men undertaking informal caring may thus be one such example. Such changes therefore provide me with a base for exploring the male caring experience in dementia from a narrative framework. An understanding of the experiences of male carers in the context of dementia is vital, particularly as their requirement to be involved is set to increase dramatically over the coming years, as documented in the first half of this chapter. In the chapters that follow I will also show how a narrative approach compliments and strengthens the philosophical underpinnings of my study.

²³ This lens is shaped by one's values and ideals as well as personal experiences; any experiences of gender oppression and discrimination impacts on one's sense of identity and social position, and thus one's situatedness (Haraway 2008, as cited by Eriksson *et al.* 2013a, p. 160).

Chapter 3: Male Caregiving: A Review of Existing Literature

Introduction

The previous chapters have conceptualised male caregiving by providing an understanding of the developments and current debates on informal care and dementia as a basis for understanding how male carers are positioned. Based on the contextual and theoretical foundations laid out in the last chapter, the aim in conducting my literature review was to gain a deeper understanding from existing literature of the knowledge that exists on how men experience and perceive caring. The focus of this review was on the generic experiences of men who provide care. It became clear that much of the existing work carried out to date is indeed focused on male carers in the context of dementia. It was envisaged that such a review of existing knowledge in this area would also assist me in formulating my own research question. Ultimately, it would provide me with a justification of my study which aimed to make sense of and narrate the experiences of a sample of male carers in the context of dementia.

Search Strategy

Several search strategies were applied during the process of this literature review. While I took the decision to commence my review at the beginning of my study, in practice it grew and developed throughout the lifetime of my PhD as I constantly revised and updated data sources.

Literature searches were conducted within the following electronic databases: CINAHL, EMBASE, Google Scholar, JSTOR, PsycINFO, and Science Direct. In addition, a variety of other potential sources of information were searched both electronically and manually when appropriate, including books, unpublished theses, conference presentations, discussion papers and policy documents. Such searches included a review of documents from the Department of Social Protection and the Department of Health, as well as an examination of the database of existing research on family caregiving which is maintained by Care Alliance Ireland. Key search terms were also inputted into Lenus (the Irish health repository), and EThOS (the Electronic Thesis Online Service managed through the British Library). The references cited within journal articles, books, theses, policy papers and research reports also proved important in obtaining further possible sources²⁴.

²⁴ This information was also important in laying out the introduction and setting the context for my study.

The titles and abstract of the above potential sources were searched using a variety and combination of the following search terms: 'male carers', 'male caregiving', 'experiences of male carers', 'male informal carer' and 'men caring for family member'. As a consequence of the potential generation of an excessive amount of literature to review, I decided to limit my review to exclude the following: foreign language papers; studies from developing countries and studies that only had female participants.

I recognise that there may be potential limitations to my literature review. For instance, the discussion in this review is based on the areas of research and the papers that were deemed most important. Given limitations I faced both in terms of time and space and the aim of this review to contribute to an understanding of the male caregiving experience, there is potential for further future work to be undertaken. This may include a more in-depth focus on the strengths and weaknesses of research conducted to date, particularly in the context of dementia, in addition to a critical appraisal of male caregiving literature through a systematic review.

Presentation of Literature Review

The findings of my literature review will be evaluated and critiqued under the following areas, reflecting key themes that emerged during the process²⁵:

1. Development of research on male caregiving – discusses early work on male caregiving that largely focused on gender difference and the gaps highlighted within this initial phase
2. Becoming a male carer – outlines the circumstances in which men become carers, motivating factors and their feelings upon embarking on providing care
3. Being a male carer – discusses the roles and responsibilities associated with male caring, adaptations they make, their style of caring, and applying experience gained from working life to caring
4. The meaning of caring experience for men – examines the stresses and losses experienced in providing care as well as rewards and gains. This section is further divided under a number of sub-headings: burden, isolation, worries and strains, intimacy and closeness

²⁵ In addition, Appendix 1 provides an overview studies that I reviewed as part of my literature search.

5. Emerging body of work within male caregiving literature – discusses recent developments, specifically focusing on how men conceptualise their identity in caring and the impact of normative constructions of gender on how they experience caring.

Development of Research on Male Caregiving

The traditional discourse of informal care has been a focus on burden and duty, with carers being discussed in a unified manner and disconnected from the person to whom they are providing care (Ray 2006). The dominant assumption has been that caring is a woman's activity (Baker & Robertson 2008, Neno 2004). However, over the last three decades, demographic changes have meant that in particular older men have assumed caregiving roles (Baker *et al.* 2010). The previous chapter demonstrated that the number of male caregivers both in Ireland and internationally is rapidly increasing and there are a number of interlinked factors at play.

The emergence of research on male carers was mainly as a by-product of work on redundancy and retirement (for example Bytheway 1987, as cited by Neno 2004). Kramer (2002) points out that in the mid-1980's, caregiver research began to discuss the importance of men as caregivers (for example as evident in the work of Stone *et al.* 1987, Tennestdt *et al.* 1989). However, male carers' experiences were largely marginalised and diminished in importance within the literature during this early period (Kramer 2002). During the 1990s caregiving literature began to recognise that men were providing more care than in the past (Russell 2007b). However, despite an acknowledgement of men's numeric presence within the literature, care work continued to be associated with an almost exclusive female activity, and this research also continued to attribute caring with traditional gender roles and expectations (for example as evident in the work of Hooyman & Gonyea 1995, Hochschild 1990, as cited by Russell 2007b). The long-standing cultural ideology of separate spheres and the gendered division of labour also meant that men were portrayed within the family as providing only minimal assistance (Russell 2007b, p. 3). In light of this, Thompson (2002, p. 21) points out that 'the adjective 'male' announces a predisposition to reframe caregiving to something different... generally something less... when caregivers are men'. According to this view, even when men are caregivers, 'conventional wisdom and stereotypical thinking' led to the assumption that they 'lack the inclination and capacity to meet the physical and emotional needs of another person' (Kaye & Applegate 1994, p. 218-219). Male caregivers within the research literature were depicted as in conflict with 'norms of masculinity' according to Arber & Gilbert (1989, p. 80 as cited by Russell 2007a). Thus, the cultural positioning of

caring located it as an activity expected of women and of women as 'natural' carers (O'Grady 2005, as cited by Ussher & Sandoval 2008, p. 957), and as women better suited to caring (Collins & Jones 1997, as cited by Ussher & Sandoval 2008, p. 957).

Indeed, much of the early work on male carers focused on comparing gender differences rather than examining how carers' constructions of their gender interact with their constructions of caring (Baker *et al.* 2010). This led to what Thompson (2002) has called the 'gender comparative' approach (p. 21). Such a focus within the literature has since been highly criticised in recent years. 'Internalist' explanations of female predominance within caregiving suggested that as a consequence of early childhood experiences, women are more likely than men to acquire personality traits that predispose them to caregiving (Campbell 2010, p. 73). Russell (2001) drew attention to this categorisation of men as ineffective and unreliable caregivers that stemmed primarily from the view that the average male's socialisation predisposes him to providing a less satisfactory level of care. Campbell (2010) acknowledged that internalist arguments have increasingly gone out of fashion. Researchers have since developed what might be called 'externalist' explanations in understanding female predominance (Campbell 2010, p. 74). Such explanations emphasise the structural conditions external to an individual that push or pull women or men into caregiving. This view holds that men, while capable of becoming satisfactory caregivers, differ in qualitative aspects from the accepted female standard (Russell 2001). However, Campbell (2010) argued that such explanations reduce individuals involved to passive agents and their subjective understanding of caregiving over time is thus ignored.

In addition, much of the research that compares men's caregiving experience and style to that of women has tended to ignore both the force of gender relations, as well as the importance of the type of relationship between primary caregiver and care receiver (Calasanti & Bowen 2006, p. 253). Ducharme *et al.* (2007a, p. 5) argued that research on male caregiving conducted from the theoretical perspective of gender socialisation such as that of Crocker Houde (2002) and Miller & Cafasso (1992) has had a limited scope, as they overlooked variations that can occur among men with respect to the phenomenon of caregiving due to the fact that they have been based on a stereotyped concept of gender roles. For instance, within the literature gender appears as lists of traits, learned through socialisation (Calasanti 2010). A number of commentators have critiqued the gender-based literature on caregiving on the basis that it enforces a simplistic dichotomy between men and women (for example Walker 1992, Opie 1994, Fisher 1994, as cited by Ray 2006, p. 138).

Ray (2006, p. 138) contends 'Not all women provide care in the same way, and men may provide care in ways more typically associated with female caring'. Instead, Calasanti (2010) has called for a focus with caregiving literature on 'gender repertoires' and on the '...sets of skills and resources learned over the life course that affirms gender identities formed in the context of inequality' (p. 726). Studying gender and caregiving in this way allows for explanation for how men and women construct and experience caregiving (Calasanti 2010)²⁶.

Early work conducted on the gender difference in caregiving found that in general, women who care for a person with a chronic illness were more burdened by their caregiving than men, reporting a more dramatic effect on their health and well-being than their male counterparts (Barusch & Spaid 1989, DeVries *et al.* 1997, Robinson 1988, as cited by Boeije & Doorne-Huiskes 2003, p. 224). In a study of young couples in which one partner was disabled, Parker (1993) found that women had more difficulty than men in putting their own needs first. Female caregivers of spouses with dementia were found to be more attentive to their spouse's needs than male caregivers in an earlier study by Miller (1990). Male caregivers in this study were also found to be more in control and better able to distance themselves emotionally (as cited by Boeije & Doorne-Huiskes 2003, p. 224). Boeije & Doorne-Huiskes (2003) highlight that Miller's (1990) findings correspond with the results of Twigg & Atkin (1994), who typified in their own work the responses of some female caregivers to their caregiving role as engulfment. In contrast, male carers in their study were more capable of setting boundaries and balancing their own interests with those of the person they supported (as cited by Boeije & Doorne-Huiskes 2003, p. 225).

More recent work on gender differences in caregiving has found that women have higher perceived caregiver overload, burden and more depression than men (Cohen *et al.* 2007, Pinquart & Sorensen, 2007). While women caregivers reported greater physical and emotional vulnerability than men in Ekwall and Hallberg's (2007) study, men caregivers were found to be more satisfied than women. In addition, men's coping skills were found to widen their horizons and help them grow as persons (Ekwall & Hallberg, 2007). The lifelong expectations to provide family care that underpin women's roles do not underpin men's. As a

²⁶ However, Calasanti (2010) also warned that this approach to caregiving research takes for granted the ways that heterosexuality shapes gender repertoires by assuming a marital relationship with different roles for husbands and wives. For example, Connidis (2010) pointed out that unique challenges are faced in same-sex caring relationships, not posed by poor health among heterosexual, particularly married couples.

consequence, Milne & Hatzidimitriadou (2003, p. 403) contend that men's ability to manage caring tasks and cope with caring demands more effectively than women reflects their different motivation to care as well as their capacity to adopt an instrumental approach to caring.

Several qualitative studies conducted in the 1980s and 1990s did focus specifically on male caregivers (for example Harris, 1993, 1995, Hirsch 1996, Motenko 1998, Parsons 1997, Siriopoulos *et al.* 1999). Ducharme *et al.* (2007a) note that in general, this work documented that older male carers defined themselves less in terms of polarised gender roles or of a stereotyped image and more in terms of the feminine and masculine dimensions of their identities. In 2001, Pearlin *et al.* found in their study that men's ability to adjust to work demands, concerns about household finances, and the number of roles, predicted their providing of care and not gender. Sanders *et al.* (2003) highlighted that these findings validate the earlier qualitative findings of Harris (1998) who found that work flexibility directly affected men's choice to provide care for a parent. Only a few encouraging examples of research on male caregiving in the 1990's specifically examined the health of male caregivers without seeking to compare it against that of their female counterparts (for example Fuller-Jonap & Haley 1995, Kaye & Applegate 1990, Kramer & Lambert 1999 as cited by Ducharme *et al.* 2007a).

However, Ribeiro & Paúl (2008) note that more recent studies of male carers have begun to support an emergent perspective that men are capable, nurturing and innovative in their caring role. As a consequence, men's representation has begun to change from being seen as 'ineffective or inconsequential' to 'capable and competent' carers. The reasons as to why men are beginning to be seen in a different light within caregiving literature will be outlined in the sections that follow.

Becoming a Male Carer

This section of the review will focus on findings within the male caregiving literature on men's motivating factors for providing care as well as their feelings upon embarking on the role of carer.

In terms of motivations to care, early studies found that men's desire to provide care was associated with viewing it as the right thing to do (Horowitz 1985, Harris 1998, Mays & Lund 1999). Harris (1993) identified four types of male caregiver: the worker, labour of love, sense of duty and at the crossroads. Overall, findings from Harris' (1993, 1998) studies suggested

that many men perceive their caring role as a duty or as a 'labour of love'. A religious belief that caring was the right thing to do was important for some male carers in Hirsch's (1996) study. In terms of sons caring for a parent with Alzheimer's disease, Sanders & McFarland (2002) found that the eighteen men in their study who were providing care to their parent, shared a 'do what you have to do attitude', which they applied to their commitment to care.

The framework of marriage has been found to act as a specific motivation for older husbands to care (Thompson 1993). Spouse care is unlike other caring relationships, tending to be regarded both by the carer and care recipient as an extension of the intimacy and companionship that characterises marriage (Milne & Hatzidimitriadou 2003). A strong and entrenched sense of commitment and purpose was the hallmark feature of interviews that Russell (2001) conducted as part of his US qualitative study with 14 elderly male caregivers to their wives with dementia. While the men in this study also expressed feelings of sadness, even resignation about their caregiving duties, none verbalized resentment toward the care receiver. Indeed, many men framed the meaning of commitment in terms of "paying back" their spouse for having cared for them during past illness, although none described it as their primary reason for caring. A "just do it" approach to commitment and responsibility of caregiving was found to characterise the narratives of many of the men. The findings of Russell's (2001) study are particularly significant as they support the perspective that men are capable, nurturing, and innovative carers. While men may experience isolation and feelings of doing "invisible" care work, they exhibit powerful feelings of commitment as well as immense adaptability and resilience (p. 364). Similarly, Ribeiro & Paúl (2008) found that husbands' positive features of their caregiving experiences were all associated with a sense of commitment and duty. They conducted in-depth personal interviews with fifty three elderly men who were caring for their chronically ill wives. According to Ribeiro & Paúl (2008, p. 170) 'Clear evidence of acting out of love or reciprocity was found in many of their expressions, but satisfaction was most often expressed spontaneously when the men talked about their obligations as husbands'.

Other work has demonstrated the link between reciprocity and a motivation to care. For example, spousal male care partners and their wives with dementia in Atta-Konadu *et al.* (2011) study expressed a moral obligation to reciprocate the nurturance that they had received from their partners during their marriage. This study explored the experiences of nine male care partners and their wives as they adjusted to food roles previously performed by their wives. They found that such a desire to pick up food roles was an appreciation for all

the years that their wives had looked after their needs. Through food roles, the men were able to show love, care and affection as well as support for their spouses (Atta-Konadu *et al.* 2011). Similarly, Eriksson & Sandberg (2008) found that the guiding ethic that shaped men providing care to their wives in their study was based on a mutual agreement they had shared before the onset of illness, as lover with equal status (p. 134). Campbell & Carroll (2007) found in their study of sons providing care that a sense of reciprocity was an important motivation in their decision to care for their parent. Spouse caregivers of individuals with multiple sclerosis in Boeije & Van Doorne-Huiskes (2003) study expressed an obligation to provide care with a strong reference placed on marriage vows. However, the male carers in this study also felt obliged to give care, followed by becoming resigned to it. Most of the men gradually grew into the caregiving role. Indeed, some of the spouse carers in their study had taken on caregiving as a matter of course and had taken it for granted as part of their marriage (Boeije & Van Doorne-Huiskes 2003).

Reciprocity was found to be a motivation for men to provide care in early work (for example Parsons 1997). However, Neufeld & Harrison (1998) found that the motivations of husbands in their study in providing care changed as the caring period lengthened, as a feeling of reciprocity adapted to viewing caring as an obligation. Emerging into the caring role rather than making an active choice to provide care was highlighted by the husband and son caregivers of individuals with a mental health problem in Mays & Lund's (1999) study. Having no alternative option was found to be yet another motivating factor in providing care for men in other work (for example Gerstel & Gallagher 2001, Hequembourg & Brallier 2005).

Following analysis of narrative interviews with three older husband carers, two main categories emerged for Sandberg & Eriksson (2007) - taking on a new and unfamiliar role, and learning to live with the new role. Taking on the role as a carer was found to be a difficult experience for the men in this study. The men felt that they were put in a difficult situation when they suddenly had to become a caregiver to their spouse, as a consequence of the lack of continuity in men's experiences of caregiving activities over the life span (Sandberg & Eriksson 2007). Similarly, Kirsi *et al.* (2004) reported that many of the husbands in their study felt that they were 'one step behind' upon embarking on the caregiving process (p. 163). However, Atta-Konadu *et al.* (2011) found that while men undertook a dynamic and complex process of re-negotiating role changes while caring for their wives with dementia, at a certain stage in caregiving, this ceased to occur.

Issues surrounding gender expectations and stereotypical ideals and practices associated with masculinity have also been found to impact on men's feelings of undertaking caring. Men may feel uncomfortable in caring roles because they contradict dominant ideals and practices of masculinity that imply that men are biologically ill suited to the emotional tasks of caring (Fraser & Warr 2009, p. 137). Gender ideologies specific to caring may also have an influence. For instance, Atta-Konadu *et al.* (2011) comment that in the context of dementia, the ability of male care partners and their wives to adapt or cope specifically with food-related role changes will depend on their gender ideologies and their perception about the gender construction of food-related housework. For example, a spousal male care partner who views food-related tasks as 'women's work' may be reluctant to assist with or take up such tasks. In contrast, male carers in a study by Hirsch (1996) recalled how prior experience and role models in their childhood made them view caregiving as an appropriate male role.

Being a Male Carer

This section of the review will discuss findings within the literature on what being a male carer entails, namely the feelings that they experience as a consequence of the roles and responsibilities associated with caring; men's coping mechanisms and experiences of support; men's 'style' of caring, and how men apply experiences from working life to caring, as well as the specific experiences of sons who provide care.

Isolation in the caring role has been expressed by men in several key studies. For example, feelings of social isolation were apparent for the male carers in studies by both Harris (1993) and Carpenter & Miller's (2002). Sandberg & Eriksson (2007) found in their study that male neighbours and friends did not understand their role as carers, and as a consequence social isolation was common, with men receiving little support or understanding for their new role (p. 12). Ducharme *et al.* (2006) also found that men experienced social isolation and diminished contact when caring for their ill wives. The new role of carer was characterised as a lonely journey for men in Sandberg & Eriksson's (2007) study, despite the fact that the men still lived together with their wives. Sandberg & Eriksson (2007, p. 9) highlight that for the men in their study 'Loneliness was expressed as living together, but moving from a mutual relationship to a one-way caring relationship'. In later work, Eriksson & Sandberg (2008) found that the physical and social responsibility of providing care to their ill spouses led some men to experience both isolation from as well as attachment to their wives (p. 134). Black *et al.* (2008) found that for elderly husband carers of spouses with dementia, keeping a link with the 'outside' was important, giving them a sense of control over their lives (p. 189).

The men in Russell's (2001) study also spoke about a sense of isolation in their caring role, as well as a feeling that their caring work was invisible to others, especially family members. Russell (2001) conducted in-depth open-ended interviews with fourteen elderly male caregivers for their wives with dementia. However, these men also exhibited powerful feelings of commitment as well as immense adaptability and resilience. The use of outside assistance and respite supported many of the men in their caring role, as well as maintaining outside activities and interests. Russell (2001, p. 364) therefore concluded that this study of elderly men caregivers '...supports the emerging perspective that men are capable, nurturing, and innovative carers'. Boylstein & Hayes (2012, p. 586) upon commenting on the findings of both Harris (1993) and Russell's (2001) work note that 'In this sense, caregiving shifts from a burdensome and socially isolating experience to a world in which men have pride in the care they continue to provide for their wives'.

However, research has shown that men find particular aspects of the new roles and associated responsibilities as a consequence of providing care challenging. For instance, Harris (2009) found that for some husbands, the intimate role associated with caring in dementia was a challenge within their marriage, requiring them to learn new skills. Men also spoke of role reversal when they began caring for their wives in a qualitative study by Russell (2007b). Thirty elderly male caregivers participated in in-depth, open-ended interviews. Men's wives had previously taken on the majority of the household tasks and the transition into the previously concealed world of home-based care work was difficult to adapt to; men struggled with the demands associated with gender norms (Russell, 2007b, p. 1). Similarly, Sandberg & Eriksson (2007) found that taking on the role of being responsible for the household and personal care was a difficult and challenging task for men. Feelings of guilt were expressed by some men in Sanders & Power's (2009) study for the lack of assistance they had given to their wives previously. However, there was a sense of pride expressed in trying to maintain the standards set by their wives. Despite such feelings, men faced a continuous struggle between "how things were" and "how things are now" as their roles, responsibilities, and the relationship they had shared with their wives continued to change (Sanders & Power 2009, p. 50). As part of the adoption of the caregiver role, Kirsi *et al.* (2004) found that most of the husbands in their study had to rethink accustomed patterns of the gendered division of labour in their family (p. 174). Housework and especially cooking was the domain of caregiving in which the husbands portrayed themselves as most skillful and competent (Kirsi *et al.* 2004, p. 177). At this point, it is important to note that role reversal has also been discussed in other

caregiving contexts such as in the older daughter caregiver literature. Upon assuming the caregiving role, adult daughters must adjust their lives to accommodate the additional responsibilities (Bachner *et al.* 2009, Stephens *et al.* 2001). Bastawrous *et al.* (2014) found that daughters felt 'parent' and 'child' roles were reversed as a consequence of the types of caregiving tasks performed.

In terms of men's coping mechanisms, learning to cope with the unexpected has been found to be important for husbands caring for their wives with memory loss and other chronic health conditions in work carried out by Sanders & Power (2009). Husbands felt that their wives had been one of their primary sources of support, serving as a crucial element in their ability to cope with aversive situations (Sanders & Power 2009, p. 48)²⁷. Many husbands also indicated that although they had not been patient in the past, it was crucial for them to identify new ways of coping that promoted a sense of tolerance and patience, particularly as a consequence of the personality changes of their wives due to their chronic illness (Sanders & Power 2009, p. 48). The male carers in Sandberg & Eriksson's (2007) study also sought to maintain continuity in their relationships with their wives. For example, they used the past to cope with the future, in that they still viewed their earlier life and their marriage as important.

As part of a literature review undertaken for their own study, Sanders & McFarland (2002) highlighted that other research has shown that the utilisation of outside resources assisted male carers in coping. In particular, they pointed to the work of Coe & Neufeld (1999) and Kaye & Applegate (1990) who found that male caregivers had an initial reluctance in accessing outside services. Neufeld and Harrison's (1998) study provided evidence that male caregivers prefer to use formal services rather than seeking help from informal services. Brown *et al.* (2007) undertook a qualitative study to gain an understanding of the help-seeking process of nine older husbands who were caring for their wives with dementia. Using a grounded theory approach, they found that the availability of willing informal sources of help, positive past experiences with both informal and formal resources, and availability of gender-specific education programs in personal care and household management and respite care programmes assisted the help-seeking process for husband caregivers. However, role expectations, negative previous experiences with informal and formal

²⁷ It was among several categories that emerged following analysis of seventeen qualitative interviews with husbands who had to learn how to form new types of relationships with their ailing wives.

resources, cost, inadequate information, and lack of knowledge all impeded on the help-seeking process for husband caregivers.

Sanders & McFarland (2002) highlighted that support groups have specifically been found to be an important service in existing literature through assisting male caregivers to cope (for example citing Davies *et al.* 1986, Kaye & Applegate, 1990, Kosberg & Kaye, 1997, McFarland and Sanders 2000). However, in a more recent review of existing literature, Pretorius and colleagues (2009) noted that support groups have been found to rarely attract male participants (for example citing Cahill 2000, Fromme *et al.* 2005), while they have been viewed as potential support mechanism for female caregivers (for example citing Mittelman *et al.* 1995). Pretorius *et al.* (2009) pointed out that such gender-specific idiosyncrasies in support utilization have most often been attributed to socialization and gender identity variables. Sibley and colleagues (2012) undertook a quantitative study investigating the perception of support for adults with MS and of men caring for them. Thirty four percent of the 231 men who completed the questionnaire had not tried to access advice or information about support and services. While most men spoke of largely positive experiences of support and services, those men who were still working reported significantly more dissatisfaction than retired men. In addition, younger men repeatedly differed in their perceptions of support compared with older men, suggesting that they either had higher expectations, greater need or both (Sibley *et al.* 2012). Munro & Edward (2010) found that gay male carers in their study who were caring for men living with HIV/AIDs faced additional barriers in their support-seeking efforts as a consequence of their sexual orientation. In particular, a significant barrier identified by the participants was related to stigma and that the people living with HIV/AIDs often wanted their partners to provide all the care, thus limiting opportunities for respite and sharing the caring role (Munro & Edward 2010).

In terms of informal support, Russell (2001) found that male caregivers in his study felt guilty about asking informal support networks for assistance due to their other career and family obligation. In addition, the men were made to feel guilty by their informal support networks for accessing formal assistance. In 2007, Sanders examined the experience of rural male caregivers with their informal support networks. The twenty men that participated in this qualitative study were found to have unique relationships with their informal support networks, dictated by their perceptions of the informal supports' willingness to provide assistance, as well as their own willingness to ask for help (Sanders 2007). Ducharme *et al.* (2006) believe that male carers have a tendency to minimize their needs given their own findings on male

carers' low levels of service utilisation and their perceived utility²⁸. Pretorius *et al.* (2009) found that support from their daughters facilitated male caregiver coping. Cahill (2000) also found that elderly husbands (n=26) who were caring for their wives with Alzheimer's disease were inclined to depend upon the support of their daughters.

Findings from existing research have also provided important evidence on men's 'style' of caring. It has been described by Russell (2001, p. 360) as 'a model of caring that blends management with nurturing'. In so doing, men frame the 'work' of caregiving as being partially organisational in nature, resulting in a managerial or professional 'style' of caregiving. Men have also been found to lend traditional workplace values with emotional and nurturing provision of care in a number of studies. For example, Ribeiro *et al.* (2007) found that being in charge of the situation, including the organization of services and care, was congruent with work and, in some cases, family roles of authority. A managerial perspective has also been found to fit with men's sense of masculinity and as a way of exerting control in an unpredictable situation (Neufeld & Kushner 2009). Male spouses caring for their wife with dementia (n=10) in a study by Pretorius *et al.* (2009) adopted an approach to caring that was task-oriented and focused on problem-solving, through the effective use of available resources while also maintaining meaning and satisfaction in their role. Similarly, Sandberg & Eriksson (2007) found that the men in their study attempted to relate their new caregiving role which they had been unfamiliar with, to their earlier working life, with a clear set of goals to fulfil. In addition, Black *et al.* (2008) found from their analysis of the narratives of four elderly husband carers in the context of dementia, that they treated caring like any labour-intensive task; continually appraising their role and feeling positive when they performed duties well, and dejected when they perceived they did not. Thus, there was a parallel in how the men in this study talked about prior careers and care work. However, Russell (2007a) points out that caregiving husbands' may struggle with the fact that their work goes largely unseen after lifetimes of recognition for work in the public marketplace, representing an immense cognitive and psychological shift (p. 303). In the UK, Milligan & Morbey (2013) gathered narrative accounts from fifteen older men about their experiences of caring for their wives or partners. They found that older men in their study drew on previous experiences or skills to provide

²⁸ Gender expectations are also suggested by Ducharme *et al.* (2006) to influence men in their caring experiences in that they place a high value on self-reliance, exert pressure to show they are competent in unfamiliar situations, and lack experience in dealing with social and welfare services. Specific challenges highlighted by men with reference to their sense of gender identity are discussed in a later section of this chapter.

coping strategies in their caring role. A theme that emerged from men's narratives focused on practical solutions to managing the challenges of caring (Milligan & Morbey 2013).

Sons as Carers

The vast majority of research in relation to male caregivers has focused on spousal carers (Neufeld and Kushner 2009). However, there is a smaller body of work that has examined the experiences of adult sons who provide care to their parents. For instance, Campbell (2010) has undertaken some interesting qualitative work focused on understanding the diversity of male caregiving, specifically in the context of adult sons who provide care to their parent. Following a series of intensive interviews, participants (n=48) were found to fall into two clusters. The first cluster involved sons who were married, employed or retired, and living apart from their parent. These men tended to be committed to care, but often in more limited or traditional ways (assisting with finances or paying bills, providing transport, helping with shopping or providing emotional support through visits or phone calls). The second cluster included sons who were never married and often co-resided with their older parent. These men, particularly those who were not employed, tended to be much more intensely involved in all aspects of care, including 'non-traditional' domestic and personal care. Campbell (2010) notes that the never-married sons may be a particularly 'at risk' group (socially and financially) because of their role in care or more likely, due to their social and structural circumstances before and during care. Similarly in earlier work, Martin-Matthews and Campbell (1995) found that sons who acted as primary caregivers were likely to be only children, to have no sisters or to have sisters living far away from the parent, and to be working-class (as cited by Connidis 2010). In a later study, Martin-Matthews (2007) found that sons helped their parents more in areas that were traditionally classified as masculine, such as through financial support and home maintenance. While son carers were more likely to express stress and burden than spousal carers, the participants in Harris's (2002) study were also more likely to set boundaries.

Connidis (2010) contends that a gender bias exists within research suggesting that parents must 'make do' with sons as caregivers and they are at risk of receiving inferior aid. Yet when sons take on primary caregiving responsibilities, Connidis (2010) argues that their commitment has been found in previous studies to be as stable as that of daughters, and the patterns of involvement become quite similar for sons and daughters (for example, Martin-Matthews & Campbell 1995, Stoller 1990). From an Irish context, McDonnell & Ryan (2013b) recently undertook a qualitative study to explore the experiences of sons caring for a parent

with dementia. Individual, semi-structured interviews were conducted with a purposeful sample of sons (n=13) in a rural part of Ireland. Key themes that emerged following analysis were 'the parental bond', 'a binding role', 'coordinating care and support', and a 'getting on with it' approach to care. Mc Donnell and Ryan (2013b) note their study highlights the commitment of sons to their caregiving role and the strong sense of duty that motivated them to provide care.

The Meaning of the Caring Experience for Men

This section of the literature review will discuss key findings from existing research on the meaning of the caring experience for men: namely burdens and stresses as well as rewards and gains they experience. Men's experiences of loss, intimacy and closeness while providing care will also be explored.

As previously outlined, much of the early work on male caregiving compared their experiences with that of their female counterparts, and in general, men were found to fare better. In their own review of existing literature, Sanders & Power (2009) pointed out that several researchers concluded that male caregivers experience less stress, burden, anxiety, and depression when compared with female caregivers, as well as less interpersonal conflict (for example citing Hibbard *et al.* 1996, Kramer & Kipnis 1995, Thompson *et al.* 2004). However, according to Baker and Robertson (2008, p. 413) 'While research has described sex differences in caregiving and psychological outcomes, there appears to be little understanding of varying ways men may cope with the strains of caregiving'.

Pearlin's model of carers' stress (1990) applied through the work of Ducharme and colleagues (2007a), enabled important analysis of why some men relinquish caregiving and decide to institutionalise their wives. It was the first time that this model was used specifically with a male cohort of caregivers²⁹. Three hundred and twenty three older husband caregivers participated in this study across four regions of Quebec, Canada and various measures were tested through a standardised interview. Ducharme *et al.* (2007) identified primary and secondary stressors associated with the health of older husband caregivers (p. 25). For

²⁹ Pearlin *et al.* (1990) proposed an original conceptualisation of caregiving that rested on the notion of stress proliferation. This model distinguished three constellations of stressors: background-contextual variables, primary objective and subjective stressors, and secondary stressors. Pearlin *et al.* (1990) considered caregiver resources (such as social support) as mediating conditions that influence the impact of stressors on caregiver health (as cited by Ducharme *et al.* 2007a, p. 6).

instance, subjective stressors were found to be associated with outcomes. Role overload was linked to psychological distress and the intention to end home caregiving. The likelihood of ceasing home caregiving increased when caregivers reported high relational deprivation. The quality of prior husband-wife relationships, frequency of disruptive behaviours, family conflicts and self-efficacy were all associated with levels of psychological distress. Self-efficacy was found to have a mediating effect between subjective stressors and psychological distress, whereas the number of services received had a moderating effect on the intention to end home caregiving among husbands with high role captivity (Ducharme *et al.* 2007a, p. 3-4). The findings thus demonstrate how subjective stressors, rather than objective stressors and caregiver resources were significant predictors of caregiving outcomes (Ducharme *et al.* 2007b).

Baker & Robertson (2008) cited the work of Ducharme *et al.* (2007a) as part their own literature review in discussing how they considered whether masculine and feminine traits, as measured by the Bem Sex Role Inventory (Bem 1974), of male carers were important as background contextual factors in stress in their work. They found that femininity was not a significant factor associated with any measure of psychological distress, self-perceived health, or the intention to institutionalise their spouse as an outcome of caregiving (Ducharme *et al.* 2007a as cited by Baker & Robertson 2008). Baker & Robertson (2008, p. 414) believe that these are interesting findings when contrasted with previous research that found that male caregivers who rate themselves as high on feminine traits reporting lower levels of burden and greater sense of competence (for example, Kaye & Applegate 1990).

In earlier work conducted in 1997, Parsons tried to explicate through in-depth interviews, the meaning of men's lived experiences as they cared for a parent or spouse with Alzheimer's. Eight interrelated themes were identified following analysis: enduring, vigilance, sense of loss, aloneness and loneliness, taking away, searching to discover, the need for assistance and reciprocity (Parsons 1997). Kirsi *et al.* (2004) have highlighted that Parsons' (1997) analysis challenged the notion of a 'caregiving burden' as the predominant aspect of caregiving and identified the complexity of the caregiving phenomenon: a 'mosaic of care', summarising her findings with reference to Gubrium's concepts (1991).

Loss, at many levels, has been documented as a theme within the literature of the male caring experience. For example, in a study of seventy one male caregivers caring for a loved one with Alzheimer's disease, Sanders and colleagues (2003) examined their expressions of

grief and loss. They found that male caregivers in their study, regardless of whether they did or did not identify themselves as grieving, expressed feelings of loss. Multiple losses were identified such as loss of communication, loss of intimacy, loss of activities, loss of relationships, loss of social interaction, loss of physical health, loss of mental health, loss of friends and loss of self (Sanders *et al.* 2003, p. 12-13). Male carers in Harris's (2002) study expressed a loss of their manliness, despite the fact that taking charge of caregiving came naturally to them as they felt that taking control was part of their male role in society. Sandberg and Eriksson (2007) found that illness changed the mutual relationship to a one-way relationship for husbands and wives' in their study. Male carers suffered the loss of their past mutual relationship and the things that they had planned to do together in the future with their wives. In a qualitative study of both husband and wife caregivers of spouses with Alzheimer's disease, Boylstein & Hayes (2012) found that feelings of loss such as no longer being able to hold a conversation with their spouse, or go out together and have fun, or share true physical intimacy were among the factors which led caregivers to see their spouse as a different person (p. 596). Similarly, male carers in Milligan and Morbey's (2013) study expressed loss in many areas of their lives and experiences, such as loss of futures, plans relationships and friends³⁰.

However, research has also shown that men appear able to cope with the losses associated with caregiving. Existing work has demonstrated how men experience their caregiving role as an extension of their work and provider roles (for example Calasanti & King 2007, Harris 1997, Russell 2007, as cited by Boylstein & Hayes 2012). As Boylstein & Hayes (2012) comment, men in the context of spousal care, may be able to alleviate the losses they experience as the 'new' entry into the traditionally woman's world of caregiving. It may provide them with opportunities for interpersonal interaction and emotional connectedness. In addition, Boylstein & Hayes (2012, p. 24) point out that: '...men were more likely to see their role of a caregiver as a 'helper' to their wife compared with women who were more likely to view caregiving as taking over their lives'.

Recent conceptualisations of caregiving have begun to highlight that caring is more complex than the traditional association attributed to it being a feminine role. However, much work still focuses on the burdens of care (Ribeiro & Paúl 2008, p. 165). An emergent perspective has

³⁰ Specific references to loss of gender identity in the male caring experience within the literature will be explored further in the final section of this review.

begun to develop within the literature that men are capable, nurturing and innovative in the role; changing their representation from being 'ineffective or inconsequential' to 'capable and competent' carers (Russell 2001, as cited by Ribeiro & Paúl 2008). The findings of such research throws into question '... the skewed presumption and perception that the care-giving experience is wholly negative' (Ribeiro & Paúl, 2008, p. 180). Evidence gathered on the positive aspects of men's caring within the literature will now be discussed. For instance, Sandberg & Erikson (2007) point to early work which noted that although caring for an ill wife involved numerous difficulties and sacrifices for men, caring also encompassed feelings of pride, inner growth, satisfaction and self-esteem (for example Archer & MacLean 1993, Harris 1998, Kramer 1997, Matthew *et al.* 1990, Motenko 1988). Similarly, Kaye & Applegate (1990) found that the emotional support offered by men to their wives was not only an important aspect of care for them, but also the principal source of personal gratification. In a critical review of the psychosocial challenges and rewards to men in providing care, Carpenter and Miller (2002, p. 114) noted that much of the literature was descriptive in nature. An exception to the above was Kramer's (1997) cross-sectional quantitative study of the differential predictors of strains and gains among husbands who were caring for wives with dementia. This study revealed that positive aspects of caring were reported by those of lower education, who were healthier, had better social networks, or reported greater use of problem-focused coping. Baker & Robertson (2008) also note that husbands who use problem-focused coping strategies have been found to report positive caregiving experiences. For instance, male carers' in Calasanti and King's (2007) study evaluated their caregiving based on tasks performed successfully rather than on their notions of themselves as providing emotional support or making their wives happy when conflicts arise.

In a Portuguese study, Ribeiro & Paúl (2008) analysed the positive statements in the personal descriptions of the care-giving experience of fifty three elderly men who were caring for chronically ill wives, following a series of in-depth personal interviews. They also explored the differences between the positive references made by the men who were caring for a wife who had dementia and those made by men whose wives had physical impairments. Positive aspects were identified in thirty two of the 53 caregiving situations. The most prevalent themes were 'satisfaction' and 'perceived social honour' (Ribeiro & Paúl 2008, p. 165). The most frequently mentioned positive aspect of caring was the husbands' enjoyment of 'just being there' with their wives, keeping them company, while doing their marital duty as husbands who ought to care. Besides the perceived personal reward, these men believed

that the marital relationship was intrinsically rewarding. Choosing deliberately to care and maintain the relationship through sickness, despite its difficulties, provided the men with a sense of gratification (p. 171). Eleven of the 32 husbands in Ribeiro & Paúl's (2008) study were satisfied with doing care work, feeling that it had a special positive meaning in the couple's relationship. Learning how to undertake new tasks such as cooking not only promoted husband's sense of confidence and self-worth but also increased the couple's closeness and intimacy. Self-protectiveness, while less frequent, was cited as an expression of the positive returns in caring for some men, providing a defence against negative feelings such as the avoidance of grief in the future and of guilt in the present (Ribeiro & Paúl 2008, p. 172). A positive return was also expressed by some men in terms of other people's recognition of their involvement with care work. Interpersonal recognition occurred as a consequence of their wife's appreciation and from third parties through social recognition (p. 173). The findings of Ribeiro & Paúl's (2008) work also show that positive returns from the caring experience and role were strongly associated with previous good marital relationships and the husband's good self-rated health. Indeed, the particular form of meaning construct that husband carers develop was found to be very important. Two conceptualisations were prominent and distinguished the men who found positive aspects of caring from those who did not: situational constructs (associated with specific coping strategies) and global constructs (that gave a sense of purpose). Ribeiro & Paúl (2008) contend that further research about the meanings made of the caring situation for men as an expression of positive aspects of care would be particularly valuable (p. 179). The findings of their own research demonstrate such.

Existing literature has also found that many men assume a protective role in providing care. For Sanders & Power (2009), the husbands in their study expressed that protecting their wives was one of the most critical roles they played as caregiver. While they had always perceived themselves in a protective role, this role assumed new meaning as their wives' condition deteriorated (Sanders & Power 2009, p. 44). The husband's conceptualisation of a protector was associated with their desire to maintain their wives' self-esteem, dignity and personhood. Some men attributed their role as a protector in ensuring that their wives' self-esteem was not damaged in potentially embarrassing moments associated with their health condition, such as episodes of incontinence, not recognising or recalling people or places, or exhibiting potentially inappropriate social behaviour around others. For other men, the feelings of being a protector were linked with providing care at home, instead of in a long-

term care setting (Sanders & Power 2009, p. 45). Male caregivers in this study also maintained the idea of being a couple as being of utmost importance in the search for strength to continue as carers but also as partners to their wives (Sanders & Power 2009). These findings thus demonstrated caregiving as a process that built on the history of the relationship between the person in need of care and the caregiver (Sandberg & Eriksson 2007).

As highlighted above in relation to the protection of dignity, many men assume responsibility for the personal care needs of the individual they are providing care for. Despite the challenges faced, such responsibilities have been found to have the potential to assist in men's positive feelings of caring. Specifically referring to dementia, Kirsi *et al.* (2004) found that the further the person's condition advances, the focus of caring shifts gradually from activities directed to the patient's (and the carer's) environment towards activities directed to the patient. Kirsi *et al.* (2004) note that care directed to the patient's body – bodily care or bodywork (Twigg, 2000) – constitutes a particular type of providing personal care. Provider of personal care was seen as one of the new roles that husbands assumed in caring for their wives in Sanders & Power's work (2009). Thirteen of the 17 husbands in their study noted that not only had they never considered being a caregiver but they had not anticipated assisting with tasks, such as bathing, toileting, or dressing. Despite this, they learned strategies for how to provide personal care in a way that was acceptable to their wives and themselves (p. 45). A strong sense of pride emerged in relation to providing personal care to their wives. It was also a way in which some men could show commitment. However, the challenges in providing personal care were a reason why some men surrendered their caregiving responsibilities (Sander & Power 2009). For Eriksson & Sandberg (2008), the men in their study found caring tasks linked to the naked body as the most challenging to learn. This aspect of care also remained out of sight because it was something that they regarded as 'not spoken about'. While bodily care aspects were difficult, such intimate involvement appeared to give men a sense of meaning in this new phase of their lives (p. 134). Ensuring that spouses' appearances remained 'intact' by assuming personal hygiene responsibilities emerged following analysis of interviews with men and women caring for their spouses who were cognitively impaired for Calasanti & Bowen (2006, p. 259). Calasanti (2010) later commented that men in the 2006 study approached toileting as problems to be solved, while time consuming and sometimes distasteful but not impossible to deal with. For women, poor

toileting behaviours had more relational importance, as a symbol of the ends of marital relationships as well as rousing grief (as cited by Calasanti 2010, p.727).

For Hayes and colleagues (2009) in their study of spouses with Alzheimer's disease and related disorders, caregiving husbands did not stop seeing their wives as spouses, and they spoke of how they could still initiate sexual intimacy. In contrast to caregiving wives in this study, caregiving husbands were less bothered by their wives lack of emotional support such as love and compassion, and did not experience this as rejection. Hayes *et al.* (2009) explain that the differences between husband and wife caregivers' feelings on intimacy relate to gender relations³¹. Sanders & Power (2009) found that through caring for their wives, husbands developed a new type of intimacy and closeness. Transformations in the sexual connection with their wives led to a different type of dedication and devotion through the development of greater ways of emotional intimacy (Sanders & Power 2009, p. 47). Regardless of changes in their intimate relationship, the men in this study were committed to their wives and to care for them.

Boylstein & Hayes (2012) undertook qualitative work with a sample of men and women in order to explore how people caring for a spouse with Alzheimer's disease reconstructed the meaning of closeness within their marriage. They found that significant changes in the social identity of the impaired spouse had important implications for how caregivers viewed their marriage and their ability to re-establish a sense of marital closeness. The majority of caregivers in their study (13 = male, 15 = female) experienced substantial disruptions in their marriage as a result of their respective spouse's dementia. Boylstein & Hayes (2012) argue that an understanding of the ways marital closeness changes when a spouse is diagnosed with Alzheimer's disease is an important way in which marital closeness can be maintained or re-established so that caregivers feel they are partners with their spouse (p. 587). Findings from Atta-Konadu *et al.* (2011) study showed that through the process of sharing food roles with their spouses who had dementia, both male carers and their wives found new ways of honouring identity and remaining connected to each other. They also found that spousal

³¹ '(W)ives... often had less status and power relative to their husbands throughout their marriage, and this changed little after wives' diagnosis... In contrast, women caring for a cognitively impaired spouse were uncomfortable with continuing sexual relations when husbands' status changed from competent male provider to child-like and dependent. The identity of husbands receiving care was tarnished more by the illness' (Hayes *et al.* 2009, p. 55).

couples living with dementia continually strove to maintain and develop their marital relationship. Atta-Konadu and colleagues' (2011) work therefore points to the importance of recognising spousal couples as a dyadic unit, instead of individuals in providing a more comprehensive understanding of their experiences with dementia.

Men's sense of both hope and guilt has also been explored within the male caregiving literature as another important factor in continuing to provide care. For instance, in a qualitative study of eleven male spouses of women with breast cancer conducted in Canada by Duggleby and colleagues (2012), participants emphasised the importance and positive outcomes associated with engaging their hope, such as in being able to continue caring for their partner. Duggleby *et al.* (2014) undertook quantitative research to examine the relationship between the quality of life of male spouses of partners with breast cancer and a number of factors. Hope, self-efficacy, feelings of guilt, age, and their partners' quality of life were significantly related to the quality of life of the male spouses of women with breast cancer. At the same time, acceptance by men of what the ultimate consequence of caring for a spouse with a chronic health condition has been noted in work by Sanders & Power (2009). For instance, recognition of the finality of the relationship was among the categories that emerged for husbands in describing how to learn how to form new types of relationships with their ailing wives. Men expressed a sense of grief as they recognised the finality of their relationship. Feelings of sadness, anger, denial, guilt and resentment were all expressed. Despite such feelings, men understood that placing their wife in a long-term care facility may be their only future option (Sanders & Power 2009, p. 49).

Emerging Body of Work Focusing on Men's Caring Experiences in Relation to Gender Identity

While research has reported on men's relatively low levels of caregiver stress (for example Baker & Robertson 2008), what this means is unclear according to Calasanti (2010, p. 726). What has been largely absent from debates on both men and women's caregiving experiences is the force of gender relations. Calasanti (2010) has argued that:

...gender repertoires – sets of skills and resources learned over the life course that affirm gender identities formed in a context of inequality – influence how they approach care work, the stresses they encounter and how they cope with these, as well as the aspects that they find rewarding in order to demonstrate the links between gender and experiences of care work that research, policies, and interventions can address effectively and equitably (p. 726).

In 1999, Bowers explored the relationship between gender role identity and caregiving experience with a sample of elderly widowed men. Two hundred men were interviewed 12-16 months after the death of their wives. Male caregivers scored higher on the masculine dimension of the Bem Sex Role Inventory, with masculinity as a significant predictor of well-being for both caregivers and non-caregivers. Following a cognitive dissonance model (Hirsch, 1996), the results did not support the adoption of feminine or androgynous ideals as a way of coping. The findings of this early work instead gave weight to the idea of a masculine model of well-being (Bowers 1999, p. 645).

Carpenter & Miller (2002) undertook a critical review of existing literature between 1988 and 1999 on psychosocial challenges and rewards experienced by male carers. It revealed that gender as a contextual factor was only examined in terms of sex-roles, rather than through other interpretive frameworks such as feminist theory. Baker and colleagues (2010) have argued that while there is a general awareness that men experience care in a different way to women, there have been very few studies that have investigated how carers' constructions of their gender interact with their constructions of caring (p. 319). Other researchers have also argued for the need for more work to be undertaken in this area: 'Further understanding is much needed of how older men experience the process of caring for a spouse from a gender identity perspective' (Eriksson & Sandberg 2008, p. 131).

In light of the above, I will now evaluate encouraging steps that have been made to date with a specific body of work currently developing within male caregiving literature. This research has attempted to understand how men conceptualise their identity in caring. In so doing, it is also seeking to understand how normative constructions of gender may impact on caring for men and ultimately answer the question of what being a carer means to men³². According to Eriksson & Sandberg (2008, p. 132) 'Since masculinity and caring does not have that strong conceptual connection, there is an overall interest from a gender perspective to analyse men's experiences of caring, and the influence and impact such activities have both on men's identities and the conceptual understanding of the division of labour'. Eriksson & Sandberg (2008) highlighted the work of Connell (1995) who pointed out that to present other ways of being a man beyond traditional 'male activities' involves the re-construction of gender identities. Thus, to be held accountable for a caring relationship can, according to Connell

³² In so doing, I will also return to some key ideas surrounding the social construction of gender and masculinities that were discussed in setting the context for my study.

(2002, 2005), be a subversive experience in which there is a potential opportunity to redefine the conceptual meaning of masculinity. Furthermore, men's experiences of caring have, according to Connell (2000), relevance that is potentially subversive not only for the question of the division of labour, but also for the way men's gender identities are formed (as cited by Eriksson & Sandberg 2008, p. 132).

Empirical evidence gathered to date has documented that men do reconstruct their identities when providing care. For example, in their 2000 study, Kirsi and colleagues analysed the narratives of fifteen husband caregivers' and revealed four speech repertoires by which men signified their experiences of caring for their wives with dementia. By drawing upon factual, familistic, agency and destiny speech in varying context of narration, the men in their study adopted different subject positions that provided them with different identities as caregivers. These identities were of an observer and reporter, a responsible caregiver, an independent actor, and a victim or a drifter and highlighted the diversity of husbands' experiences of caregiving and the contextuality of the ways in which these experiences were talked about (Kirsi *et al.* 2000, p. 153).

Gollins (2001) attempted to add evidence to the assumption that there is an interaction between male carers' gendered understanding of themselves and personal notions of being a carer, given that it had not been researched in depth until that point. Gollins' (2001) qualitative study therefore considered the caring experiences of males pre- and post-retirement. He found that men saw themselves in a number of different ways (*a worker, a husband, a loving husband, Mr. Anyone*) but never primarily as carers. Gollins (2001) also found that they brought to caring an instrumental rationality approach by defining caring duties as work. Significantly, men avoided expressing emotional aspects of being a carer but easily spoke about the emotions felt as husbands or partners. Ribeiro *et al.* (2007) comment that according to Gollins (2001) findings, it appears that both notions of masculinity and notions of being a carer play an important part in men's gendered identity and in their performance of the caregiving role (p. 303).

The findings of Calasanti & Bowen's (2006) qualitative study of twenty two caregivers of spouses with Alzheimer's disease and related dementias reinforced the importance of gender as an essential factor in the experience of caregiving within late-life marriage. They provided evidence that both husbands and wives cross gender boundaries in performing the caring role and that in understanding such a path, caregivers sought to preserve care recipients'

sense of self as gendered beings. According to Calasanti & Bowen (2006, p. 253), caring therefore: '...involves more than simply performing tasks, it involves an implicit recognition of the other as a gender being and the importance of masculinity or femininity to personal identity'.

Campbell & Carroll (2007, p. 495) highlighted that there are now a number of studies that have assessed 'the meaning of masculinity' to male caregivers against the backdrop of Connell's (1987) work and other developments in feminist theory. For instance, they referred to the work of Russell (2001) and Kirsi *et al.* (2000). However, Campbell and Carroll (2007, p. 496) believe that '... the feminist revolution in the literature dealing with male caregivers is not so much 'missing' as is incomplete'. Therefore, they sought to contribute to this body of work by exploring the potential development of a new masculine self through providing care. In their qualitative study, Campbell & Carroll (2007) explored how fifty eight men caring for elderly parents, forty of whom were caring for their mother, conceptualised their gender and masculinity. They found that although adult sons saw themselves as male, the male caregivers in this study appeared to have a vision of masculinity that was in some ways quite different from the hegemonic ideal. They developed a vision of masculinity that de-emphasised or eliminated certain elements associated with hegemonic masculinity (such as not revealing emotions, avoiding housework). However, it also emphasized others (such as taking charge and 'male to male bonding' in the case of sons caring for their father). Simultaneously, they incorporated into their vision of 'being male' a generalised emphasis on abstract principles of reciprocity and fairness that distinguished (at least implicitly) their caregiving from the caregiving provided by women, which most of these men saw as deriving from a 'natural' predisposition. On the other hand, precisely because their vision of masculinity co-existed with a quite traditional view of gender, it was a vision of masculinity that did not threaten the hegemonic ideal (Campbell & Carroll 2007, p. 504). Whether caring for their mother or father, men felt comfortable with their identity and their role as a male carer. Campbell & Carroll (2007) contend that the evidence from their study is consistent with the conclusion reached by Connell and validated in other research contexts (p. 491)³³.

³³ However, Campbell & Carroll (2007) acknowledged several limitations in their study such as lack of control for a variety of social characteristics such as class, culture and sexual orientation in their participants, and this may have affected their conceptualisation of masculinity.

In conflict with above, Sandberg & Eriksson (2007) found in their study of men providing care to an ill spouse that the change in their relationship with their wives altered the way men looked on themselves as individuals. In addition, neighbours and friends could not understand the men's role as carers, and as a consequence social isolation was common. Caregiving activities were seen as conflicting with traditional notions of masculinity and the men received little support or understanding for their situation (Sandberg & Eriksson 2007, p.12).

Other work has shown that while men may not identify themselves as natural carers, they go through a process of negotiating with the dominant masculine ideology in undertaking a traditionally feminine role. To this end, Ribeiro *et al.* (2007) explored from a social constructionist perspective, the experiences of a specific group of older husbands (n=53) caring for their dependent wives. They attempted to understand how they saw themselves as men in the caring role. The authors found that the men in their study did not identify themselves as natural caregivers or nurturers. Participants evidenced several negotiations with the dominant masculine ideology in order to maintain their sense of masculinity and legitimate their presence in a feminine role, when describing their gendered understanding of themselves. This was achieved through reframing their definition of a man and reinforcing that of a husband, as well as by retaining varying degrees of power over the caregiving relationship. In shaping these older men's masculinities, the social visibility of the role within particular gendered community-based social networks was also found to be important (Ribeiro *et al.* 2007, p. 302). Ultimately, Connidis (2010, p. 88) highlights that the Ribeiro *et al.* (2007) study '...emphasizes the ambivalent situation that caring creates for men: its reflection of socially constructed views of gender makes the negotiation of masculinity a significant element of caring for spouses among old men'.

Calasanti & King (2007) found that men's approach to caring for partners with dementia reflected gender relations and dominant views of masculinity. Focusing on data gathered from in-depth interviews with nine husbands, they identified six strategies that husbands used to deal with problems that arose in caregiving – exerting force, focusing on tasks, blocking emotions, minimizing disruption, distracting attention and self-medicating. Calasanti & King (2007) conclude that these strategies were congruent with '...structural positions of working, middle, and professional classes, whose occupational roles taught them the values of independence and pride in skills' (p. 525). Similarly in their 2004 study, Kirsi and colleagues interpreted the husband caregivers' texts and talk as cultural representations of lived life. The

results of their study challenged interpretations of men as either ineffective or capable caregivers. Kirsi *et al.* (2004) highlighted, instead, the contextual nature of the way that men construct their agencies, depending upon the purposes and audiences of their narration (p159).

Eriksson & Sandberg (2008) applied a qualitative constructivist approach in seeking to describe, from a gender identity perspective, the experiences of seven older men involved in the process of caring for a partner at home and placement into a nursing home. In their work, Eriksson & Sandberg (2008) found that men go through two transitions in their gender identity during the caregiving process and the placement of their partner into a nursing home. As a result of their wives' illness and the social responsibility of daily care they assumed, the men re-evaluated their own identity from being a *loving husband* into the identity of a *caring husband*. With the move to a nursing home, there was then a transition for the men from *intimate care to a relationship* based on friendship. Men were left in an almost 'gender vertigo' (p. 136)³⁴. In these transitions, starting over appeared to be a crucial part of the process of caring, having a direct effect on men's identities (Eriksson & Sandberg 2008, p. 136). Following analysis of older male caregivers own narratives and interviews with care providers, gender emerged for Milligan & Morbey (2013) as a characteristic that influenced how older men care. Milligan & Morbey (2013) identified different levels of gender conceptualisation which subtly influenced care providers' experiences of older carers and their subsequent assessment of needs. Milligan & Morbey (2013) contend that a focus on gender facilitates recognition of the specific features of male carer needs (p. 31).

Baker & Robertson (2008) have proposed that a focus on gender role conflict rather than gender identity may be a more useful way to investigate men's construction of caring. Gender role conflict is based on the observation that traditional masculine roles tend to lead to behavioural and emotional conflict with the self and others (O'Neil 1995, as cited by Baker *et al.* 2010). Guided by an assumption of the benefits of men's differential response to women in managing illness, Baker and colleagues (2010) therefore sought to assess the utility of gender role conflict alongside gender identity, in investigating appraisals of strain and gain in male caregivers of partners with dementia. As part of their study, seventy men, completed a

³⁴ Gender vertigo is understood as the notions of renegotiations when mastering instabilities in life (Eriksson 2002), such as experiencing the onset, work and ending of caring for an ill wife and the reconstruction of gender identity that follows this transition (Eriksson & Sandberg 2008, p. 136).

range of questionnaires³⁵. A series of regression analyses revealed that gender identity did not appear important in carer's evaluations of strain or gain. Only the 'restrictive affectionate behaviour between men' subscale of gender role conflict had explanatory power in analyses with all strain and gain variables (Baker *et al.* 2010, p. 319). Overall, the findings of this study suggest that male caregivers with traditional beliefs about masculinity were more likely to say that (a) they were not feeling burdened, (b) they felt uncertain about caring and (c) they were more likely to articulate positive aspects to being a spousal carer than men with less traditional beliefs about masculinity. According to Baker *et al.* (2010, p. 326) 'Some men may connote 'care' as feminised activity and may struggle to construe themselves in the caring role. This may explain why some men are reluctant to access services'. To this end, Baker and colleagues (2010, p 326) in their concluding comments cite Brown & Chen (2008), who noted that understanding how men think about themselves as caregivers and perceive possible supports may contribute to strategies that will optimally engage older male carers and reduce their burden.

Doing well at care work may also be seen as a last chance to be productive for older men, a value that is connected to both masculinities and personal control (Ribeiro *et al.* 2007, Thompson 2004, as cited by Black *et al.* 2008). While the need to do 'emotional' or 'invisible' caring work may blur the lines between traditionally feminine and masculine roles in caregiving, it may also help preserve identity as a husband and a worker while assuming 'feminine' aspects of caregiving (Russell 2007, as cited by Black *et al.* 2008, p. 179). Indeed as earlier noted in this review, Black *et al.* (2008) found, following their analysis of the narratives of four elderly husband carers in the context of dementia, that '...caregiving was seen as a concrete symbol of their identities – or who they were as persons, husbands and workers. Men's perseverance in care work was also significant in mediating suffering' (p. 189). The provision of care to their wives in spite of their illness meant that husbands performed their final 'career' successfully, and thus maintained a sense of identity. Significantly, it also meant that their marriage identity remained intact (Black *et al.* 2008, p. 190). Other qualitative evidence gathered by Boylstein & Hayes (2012) has shown that caring for a chronically ill loved one may actually reinforce masculine identity and threaten feminine

³⁵ The questionnaires completed explored men's gender identity (Personal Attributes Questionnaire), gender role conflict (Gender Role Conflict Scale), and appraisals of carer strain and gain (Brief Zarit Burden Interview and Caregiving Satisfaction Scale). Since caregiver strain is significantly affected by a care-receiver's cognitive and behavioural difficulties, participants also completed the revised Memory and Behaviour Problems Checklist.

identities. Specifically, they referred to aspects of femininity that are closely associated with shared social roles between husbands and wives (Boylstein & Hayes 2012, p. 609). For instance, Boylstein & Hayes (2012) found that the caregiver wives in their study were more likely than caregiver husbands to report that perceived changes in the spouses' identity altered how they identified themselves within their marriage, leading to longer term disruption of marital closeness.

From a social constructionist perspective, Ussher and colleagues (2013) demonstrated in their qualitative study with fifty three informal cancer carers (34 women and 19 men) that cancer caring was not a gender-neutral experience. Instead, they argued that it is closely tied to social constructed expectations of being 'woman' or 'man', with considerable implications for psychological well-being and coping (p. 911). They found many commonalities across genders in the experience and construction of care between the men and women in their study (p. 910-911). Ussher *et al.* (2013) discussed that from a social constructionist perspective, 'doing gender' (West and Zimmermann, 1987) might involve men resisting aspects of normative masculinity through incorporating aspects of feminine gendered performance, such as caring into their repertoire. Male carers may therefore be engaging in the 'undoing' of gender (Deutsch 2007)³⁶. Ussher *et al.* (2013, p. 911) argue: 'In this vein, research with men who adopt atypical gendered roles through being employed in the caring professionals revealed that emotionality and care are reframed in masculine terms, and as a result, men carers were able to divorce themselves from 'essentialized and devalued notions of femininity' (Simpson 2009, p. 160, as cited by Ussher *et al.* 2013).

In 2013, Eriksson and colleagues undertook a qualitative study to explore the process connected to informal caregiving in later life through the position of eight adult daughters of older fathers providing long-term care to their partner. Descriptions of daughters' relationships with their fathers illustrated that being an older man involved in providing care had positive outcomes on relations (Eriksson *et al.* 2013). While some of the daughters expressed doubts about their father's 'masculine authenticity', each appeared to value 'his helping hands' as a carer and the closer more intimate relationships with their fathers that they experienced (p. 235). Ultimately, this study provided important evidence that 'Caring for an old and frail spouse may potentially present alternative ways of being a man beyond traditional 'male

³⁶ The 'undoing of gender' is defined by Deutsch (2007) as social interactions and associated discourses that reduce, dismantle, or challenge gender difference (cited by Ussher *et al.* 2013, p. 911).

activities' and that caring might also sometimes involve a re-construction of gender identities' (Eriksson *et al.* 2013, p. 235). Eriksson *et al.* (2013) highlight that while the men in their study may have been influenced by 'hegemonic' understandings of masculinity (Connell 2005), the outcome of their caring practices may not reinforce such understandings. Instead, they argue that caring, for older men in particular, may generate new understandings of masculinity performance and thus destabilise the ideological basis for gender relations. In so doing, an understanding of men's caring experiences may challenge how informal caring is viewed in society (Eriksson *et al.*, 2013, p. 243).

Finally however, Robinson and colleagues (2014) argue that a focus on masculine ideals and how men reconcile the changes and challenges associated with caring for wives in the context of dementia, does not provide a unifying framework for explaining men's caring experiences in relation to masculinity. Robinson *et al.* (2014, p. 423) point to the work of Hanlon (2009a, 2009b) who offers an example of a gender relations framework with strong potential for informing future research. Hanlon argues that masculinities are critical to understanding relations between male caregivers and their care recipients, contending that there are three categories of men/ masculinities at work in caregiving: *conventional masculinities*, *sharing masculinities*, and *caring masculinities*. *Conventional* men define their masculinity most strongly through traditional roles and responsibilities as breadwinners and stereotypical divisions of labour drawing on essentialist discourses. They view nurturing as 'women's work'; and are reluctant to performing caregiving tasks despite a strong sense of duty towards their family. *Sharers* appear less rigid in their constructions of the gender division of labour and are often involved in all aspects of caregiving despite needing to work for pay for a good sense of self. However, they are acutely aware of the burdens associated with caring and would not willingly choose to care in place of paid work. *Caring or 'care-full'* men have the strongest sense of caring responsibility and do not define their masculinity predominantly through paid work. Hanlon argues that by 'doing care' men can transform or reconfigure their masculinity on a deeper level (as cited by Robinson *et al.*, 2014, p.15). To this end, Robinson *et al.* (2014) contend that applying a gender relations framework to future research may help in explaining apparent variability in the experiences among male caregivers (p. 423).

Summary and Conclusion

The literature on male caregiving has come a long way but clear gaps still exist. The heavy reliance on gender differences until recently has proved problematic as it ignored the force of gender relations as well as structural conditions that influence men's caring experiences. In addition, research on male caregiving tended to traditionally focus on the negative aspects associated with caring, such as 'burdens'. The evolution of more recent work has since begun to focus on understanding how men construct their gender identity in caring. Thus, it has helped to provide the real answer to what caring means for men. Positive steps have been taken within this body of literature and the findings of such work will be very beneficial to my own study. Ultimately, the review of this literature has shown me that rather than simply documenting men's gender differences in caring, in seeking to understand men's caring experiences, it was important for me to focus on how men construct their identities in caring and what the impact of this is on their caring experiences.

Chapter 4: Narrative Methodological Approach and Narrative Methodology

Introduction

The aim of this chapter is to outline the methodological framework that underpinned my research and the methods I used to conduct the study. My goal was to explore the experiences of male carers of a loved one or close relative with dementia and I employed a narrative approach using qualitative methods. The study is positioned within a social constructionist research paradigm. This is based on the idea that knowledge is socially constructed, whereby people continuously create and recreate social reality and in turn are shaped by it in a dialectical process (Berger & Luckman 1967). Thus, I will also demonstrate the relationship between my philosophical thinking, methodological approach and methods used in my study within this chapter, building on foundations laid out in previous chapters.

In the first half of this chapter, I will discuss the theoretical thinking and key conceptual ideas associated with the narrative methodological approach I used. I will focus on four key theoretical ideas namely the temporal nature of narratives, narratives as a means for providing meaning, narratives providing a sense of identity, and narratives as social encounters. I will provide an overview of the development of narrative approaches and the approach in which my own study is located. In developing my argument, I will lay the foundations for a justification of why I chose to undertake a narrative approach to study men's caring experiences. I will also demonstrate how I believe that this approach is linked to my own philosophical thinking.

The second half of this chapter will discuss my 'story' and my experience of applying a narrative methodological approach in data collection³⁷. While the 'practicalities' of conducting my study from a narrative approach will be outlined, I will continue to illustrate how my research was positioned within a social constructionist research paradigm. The layout of this chapter is organised under a number of sub-sections.

³⁷ My story in fact began before I even embarked on this study and all of the experiences that brought me to undertake this study have an impact. I have discussed this in part in the Introduction chapter and I will expand on my engagement in the chapters that follow.

Narrative Methodological Approach

What is Narrative

In Latin, *narratio* refers to a narrative or story, and *narrare* is to tell or narrate (Heikkinen 2002). Labov & Waletzky (1967, p. 12) note that narratives are 'the oral versions of personal experience'. Lieblich and colleagues (1998, p. 2) define narrative research as '...any study that uses or analyses narrative materials'. These include 'naturally occurring' narratives such as conversations between people, life stories collected for research purposes in interviews, or written narratives such as diaries, letters and policy documents (Griffin & May 2012, p. 442).

There is, however, considerable variation in definitions of personal narrative among investigators often linked to discipline (Riessman 2005)³⁸. For instance, sociolinguistics have made a sharp distinction between narrative and story (Riessman 2011). Polkinghorne (1988) uses the terms 'narrative' and 'story equivalent' and argues that narrative can be seen as the process of making a story. Similarly, Holloway & Freshwater (2007a) contend that narratives are resources that people draw on to develop their personal stories (p. 7). However, Frank (2000, p. 354) argues '...people do not tell narratives, they tell stories', narratives come from the analysis of stories. The role of the researcher following Frank's (2000) line of inquiry, is, according to Riley & Hawe (2005), '...to interpret the stories in order to analyse the underlying narrative that the storytellers may not be able to give voice to themselves' (p. 227).

Ultimately, this is what I have attempted to do in my own narrative study. While I use the terms interchangeably, I recognise the difference between narrative and story at theoretical level.

Bell (2009) has built on previous work by Hinchman & Hinchman (1997) to define narrative as:

a sequence of ordered events that are connected in a meaningful way for a particular audience in order to make sense of the world or people's experience in it... This definition assumes one action is consequential for the next, that a narrative sequence is held together with a 'plot,' and that the 'plot' is organized temporally and spatially... More than a list or chronicle, narrative adds up to 'something' (p. 8).

³⁸ While variation in the different approaches to narrative will be returned to later in this chapter, it is important to first outline conflict that exists between the terms 'narrative' and 'story'.

Gill & Goodson (2011) note that Hinchman & Hinchman's (1997) definition of a narrative highlights three characteristics: temporality, meaning and social encounters (p. 157). Thus, I will now discuss the first two characteristics of narrative, namely temporality and meaning. The idea of narratives as a social encounter will be developed further in later sections of this chapter. I will also introduce and develop the relationship between narration and an individual's sense of identity.

Temporal Nature of Narratives

Freshwater & Holloway (2010) note that temporality is a complex term in philosophy about the nature of time and how human beings are bound in time. Gergen & Gergen (1984) argued that 'self-narratives' give an understanding of the 'temporal character' of human action by providing connections, coherence, movement and direction (p. 174-175). Ricoeur (1988) has referred to the temporal property of narrative as the 'chronological dimension'. Many narrative researchers have since used Ricoeur's theories on emplotment and temporality in the further development of narrative research (for example Roberts 2002, Middleton 2011).

The temporal dimension of narratives has been identified as relevant for studying chronic illness due to the experience that develops and alters over time (McMahon *et al.* 2012). Bold (2012) speaks of how it is important to explore narratives in terms of a process as people are always at a point of personal change (p. 19). Therefore, it was crucial for me to recognise both the 'process' and temporal nature of men's caring stories – the temporality being that their experiences have a past, a present and a potential future as the condition of the person with dementia deteriorates further. In seeing their narratives as a process, the plotlines of men's stories may not always be circular, iterative and revised in their telling (Freshwater & Holloway 2010, p. 189). According to Ricoeur's (1986) notions of temporality, through storying people locate their 'now' experience in the context of 'back then' and 'not yet'.

For Riessman & Speedy (2007), what makes 'narrative' is *sequence* and *consequence*: events are selected, organised, connected and evaluated as meaningful for a particular audience (p. 430). Sequence is thus a further defining feature of narrative. Events are only given meaning in terms of their place in the whole sequence or plot (Bruner, 1990)³⁹. Polkinghorne (1988, p. 18) commented on the importance of sequencing in the construction of a narrative which he referred to as 'the ordering process' (that) operates by linking diverse

³⁹ The ideas of Jerome Bruner are outlined further in the following section.

happenings along a temporal dimension and by identifying the effect one event has on another'. Denzin (1989) brought together a number of the defining features of a narrative as well as issues that have been contended, in his definition:

A 'narrative' is a *story* that tells a sequence of events that are significant for the *narrator* and his or her *audience*. A narrative as a story has a plot, a beginning, a middle and an end. It has an internal logic that makes sense to the narrator. A narrative relates events in a temporal, causal sequence. Every narrative describes a sequence of events that have happened (p. 37).

Thus, together emplotment and temporality are two key features of any narrative. In relation to my research, I envisaged that through temporality (and thus narratives), men would structure and locate their caring experiences – with a past, present and future and also as a continual process of reality.

Narratives Provide Meaning

It is widely believed that individuals have a natural desire to share their stories, thus communicating what they feel and think (Holloway & Freshwater 2007a, p. 7). Clandinin & Connelly (2007, p. 17) argue that 'we might say that if we understand the world narratively, (as they do), then it makes sense to study the world narratively'. Other researchers also argue that the stories revealed through narrative can enable individuals to make sense of their lives (Daiute & Lightfoot 2004, Holstein & Gubrium 2000, Martin 2011, Riessman 1993).

Jerome Bruner is a key theorist of narratives within social psychology (Bruner 1987, 1990, 1996, Bruner & Weisser 1991). Bruner (1986) argued that there are two forms of thinking: the paradigmatic and the narrative. The former is the method of science based upon classification and categorisation. The alternative narrative approach organises everyday interpretations of the world in story form. Bruner (1986) also employed narrative as an important means for discovering how we 'construct our lives'. According to his argument, people tell stories in order to explain events and construct a sense of meaning (Bruner 1990). Thus, I believe that narratives have the potential to help people make sense of their lives, enabling men to tell stories to help them to make sense of their caring experiences in an ever changing world - a caring situation that is constantly developing.

Background and Development of Narrative Approaches

The conceptual starting point of narrative studies has gradually dissolved over time (Brockmeier 2013, p. 264). Since the late 1980s and early 1990s, social science researchers have used narrative to understand experience (Pinnegar & Daynes 2007). However, the roots of the current 'narrative movement' (Plummer 1995, p. 19) can be traced to *The Chicago School* and its interest in personal life records of 1920s and 1930s, and at the same time the burgeoning anthropological interest in life histories of people in other cultures⁴⁰(Chase 2008). With gradual acceptance of post-modern research methods, Plummer (1995) notes that stories have recently moved centre stage in social thought. Riessman (2005) points out that:

Research interest in narrative emerged from several contemporary movements: the 'narrative turn' in the human sciences away from positivist modes of inquiry and the master narratives of theory (e.g. Marxism); the 'memoir boom' in literature and popular culture; identity politics in US, European, and transnational movements – emancipation efforts of people of colour, women, gays and lesbian, and other marginalised groups; and the burgeoning therapeutic culture – exploration of personal life in therapies of various kinds (p. 1).

Despite the wide range of interdisciplinary lenses that may be taken in narrative, Chase (2008, p. 58) argues that they are '...all revolving around an interest in biographical particulars as narrated by the one who lives them'. Riessman (2013) posits that a real strength of narrative studies is the fact that it is multivocal and cross-disciplinary (p. 255). Indeed, it is still very much a field in the making (Brockmeier 2013). The different theoretical divisions that exist in approaches to narrative research will be now outlined and in particular, the specific narrative approach that I decided to take.

My Interpretation of Different Approaches to Narrative Research

Plummer (1995) summaries four different schools of thought within narrative research:

'In anthropology, (stories) are seen as the pathways to understanding culture. In psychology, they are the bases of identity. In history, they provide the tropes for making sense of the past. In psychoanalysis, they provide 'narrative truths' for analysis' (p. 15).

⁴⁰ Chase (2008) cites that Thomas and Znaniecki's (1918/1927) *The Polish Peasant* is frequently cited as the first significant sociological use of life history.

Broadly aligned to the different schools of thought, three different contemporary perspectives to conducting narrative research were first applied by Mishler (1986). Squire (2008, p. 3) recognises the three approaches to narrative focus as:

1. Micro level of event narratives which addresses narrative syntax
2. Narratives of experience which address meanings
3. Larger cultural narratives which address contexts

The first approach focuses on the micro level of event narratives and on the narrative syntax or structure of 'grammar' of narratives. The work of Labov & Waletzky (1967) has been extremely influential in this field⁴¹. However, event focused narratives have become the centre of much criticism as focus is only on the individual's actions and meaning in the story and not broader cultural influences (Duffy 2012). The second approach focuses on narrative semantics, or content, assuming a link between narrative and experience (Squire 2008a, p. 9). According to Patterson (2008, p. 37), experience-centred narratives are 'texts which bring stories of personal experience into being by means of the first personal oral narration of past, present, future or imaginary experience'. It is most often related to the work of Paul Ricoeur (1984, 1991). However, Squire *et al.* (2013, p. 5) point out 'What is shared across both event- and experienced-centred narrative research is that there are assumed to be individual, internal representations of phenomena – events, thoughts and feelings – to which narrative gives external *expression*'. In addition, the focus on 'experience' tends to reduce the significance of language. Squire (2008b) contends that a solution is to look at the social and cultural character of personal narratives (p. 54). The third field of narrative research thus addresses the co-constructed narrative – assuming that 'social', co-constructed stories are expressions of internal cognitive or affective states (Squire *et al.* 2008, p. 5). Researchers in this field are interested in the social patterns and functioning of stories^{42, 43} (Squire 2008a).

⁴¹ For Labov (1972) a fully formed narrative includes six common elements: an abstract (summary of the substance of the narrative), orientation (time, place, situation of participants), complicating action (sequence of events), evaluation (significance and meaning of the action, attitude of the narrator), resolution (what finally happened), and coda (returns the perspective to the present).

⁴² For example Abell *et al.* 2004, Bamberg 2006, Georgakopoulou 2007, Plummer 2001, Squire 2007(as cited by Squire 2008a).

⁴³ Squire (2013) later argued along with Andrews and Tambouklou that this third form of narrative research does not fit into either of the fields of event- or experience-oriented narrative research (Squire *et al.* 2013, p. 5).

The following sections of this chapter will therefore outline how narratives are social encounters. This approach to narratives was the optimal lens through which I viewed men's stories of caregiving for a loved one or close relative with dementia. I therefore identified my study as aligned both to 'contextual' as well as 'experience-centred' narrative research⁴⁴.

Narrative and Identity

The relationship between life and narratives has a profound implication for the concept of identity (Bamberg 2011). According to Paul Ricoeur (1984, 1988, 1992), identity can be understood in two different ways:

1. Notion of identity as exactly the same, equivalent or identical (Latin *idem*) or;
2. Identity can be used to refer to continuity or something that can be traced through time (Latin *ipse* or 'self-same' *soi-meme*). Narrative fits with this conceptualisation of individual identity as 'self-same' as it provides the practical means by which a person can understand themselves as living through time, a human subject with a past, present and future, made whole by the coherence of the narrative plot with a beginning, middle and end (as cited by Elliott 2005, p. 125).

Many other narrative researchers also believe that identity is a key feature of narrative (for example Miller 2005 Murray, 2008, Lieblich *et al.* 1998, Andrews 2007). Birch & Miller (2009) contend that the link between telling about yourself, assembling life stories and the construction of self-identity is now well theorized (citing the work of Giddens 1991 as an example). McAdam's (1987) previously introduced the idea that 'identity is a life story' (p. 22). Bruner (1990, 2002) also regards narrative not just as a way in which we make meaning of our lives, but also as fundamental to the construction of selfhood. However, selves do not remain the same over time (Wiest 2013). Within a narrative approach, identities are always in transition, they are not static (Yuval-Davis 2006, Georgakopoulou 2006). Over time, accounts of ourselves are revised and re-edited (Miller 2005).

Frank (1995) argued that a major life upheaval creates a *narrative rupture* of one's self-image⁴⁵. Indeed, Arthur Frank has written extensively in relation to the power of narratives in

⁴⁴ Further details on my reasons as to why I chose this specific narrative lens to explore men's caregiving experiences are provided in a later section of this chapter.

⁴⁵ Identity and specifically narratives as tool for exploring selves that are constantly changing was a key concept in relation to my study, in particular asking in what ways men identify themselves with a caregiving role.

times of illness, having discussed stories of illness in 1995 in his now classic *The Wounded Storyteller*. For Bury (2001), an exploration of chronic illness narratives also has the potential to reveal wider issues to do with the links between identity, experience and 'late modern' cultures (p. 264). An important focus of my reading surrounded debates on illness narratives and the potential they have to provide meaning in times of illness. In particular, I was interested in how in times of change and uncertainty such as caring, narration may help men to contrast and reinforce their identity as well as provide a sense of meaning to their experience. Related to this, I was also interested in the link between telling personal stories and wider social issues, as the section below will illustrate.

Narratives are Social Encounters

I would now like to develop the idea of how narratives are social encounters in relation to their temporal nature. I will focus specifically on how narratives explore the interrelationship between the personal and the social on a number of levels.

- *Narratives are constantly changing, they are evolutionary*

Narratives are constantly changing as experiences are always evolving. For instance, Gilbert (2002, p. 255) highlights that narratives must be seen as representations '...like a continually evolving sketch book of memories and life experiences'.

- *Narratives are constantly changing and are tied to context*

However, people do not tell stories in isolation; narratives are linked to the wider culture that is constantly changing. Personal narratives are an individual and social product (Riessman 1992, as cited by Schneider 2007, p. 30). Stories must be understood as 'located' and seen as social constructions located in time and space, within social history and social geography (Goodson 2013). In relation to the micro level context of narratives, elements such as the time of day and place influence the story told. The researcher is also part of the field, jointly participating in the construction of the narrative (Loots *et al.* 2013)⁴⁶. On a macro level, cultural, society and political contexts all influence the individual story that is told. To this end, Rappaport (2000, p. 6) has argued that 'personal life stories are negotiated in the context of narratives told by the communities in which we live'. These (micro and macro) discourses are on constantly shifting ground (Riessman 2008).

⁴⁶ My own position in this study is discussed in detail at various points over the coming chapters.

- *Wider narratives always at play*

Narratives are also social encounters in yet another sense – there are always wider narratives at play when a story is told⁴⁷. There are two key ways in which wider narratives are taking place when a personal narrative is told, each of which is now outlined in turn:

A. Narratives provide meaning of wider culture and society norms and expectations:

Narratives provide perspectives on the influence and power of social structures on individual experiences (Andrews *et al.* 2004, Robertson 2007). Norman K. Denzin (2004, p. xii) has argued that both the self and society are storied productions. A story has a ‘cultural locus’ that must be taken into account in the framework of meaning (Denzin 1989, p. 73).

B. The story told is within influence of wider ‘voice’:

An individual narrative is also influenced by wider culture and society norms and expectations. In turn, this has an influence on individual identity and construction of meaning. We do not have complete control of our personal stories (Ricoeur 1991). There is always an ‘authorial voice’ at play (Duffy 2012, p. 421). Thus, the stories exchanged are governed by cultural meta-narratives that vary according to time, place and socio-political context (Wiklund-Gustin 2010). Every word that people use in telling their stories is a microcosm of their consciousness (Vygotsky 1987, p. 236-237).

The dialogic nature of narratives has also been given increasing attention across narrative literature in recent years. For instance, following post-structuralist thinking and the work of Bakhtin, narratives have come to not only offer a window into the experiential world of an individual, but instead narrative is viewed as a performance, as narrative in context (for example Phoenix 2013, Riessman 2002, 2008 as cited by Loots *et al.* 2013, p. 109)⁴⁸.

Therefore, I believe that narratives may be viewed as an important means of positioning oneself as a social actor in a social world (as well as providing sense-making device in terms of individual experiences). In this sense, narratives provide material through which

⁴⁷ Culturally-oriented approaches to narrative, inspired by the postmodern and poststructuralist cultural and linguistic turn in the social sciences also questioned that notion of narratives as offering a window into the experiential world of a single subject (Loots *et al.* 2013, p. 109).

⁴⁸ I will return to discuss the dialogic nature of narratives in Chapter 5.

to understand the dynamics of a time and a place, as well as personal experience (Williams 2004, p. 279).

- *Thus the same story can never be told twice*

As a consequence of narratives ever changing, instead of the term *narrative identity*, Frank (2010) found it more useful to think of *narrative identifying* (p. 49)⁴⁹. The meaning of events and experiences is constantly being reframed within the contexts of our current and ongoing lives (Mishler 2006, p. 36). For Freeman (2010) the stories we tell are always provisional and revisable. Such is the nature of liquid, late modernity (Giddens 1991, Bauman 2007). Thus, I propose that the stories I gathered are not fixed and the meanings attached to men's caring experiences will shift in the context of constant developments taking place in a social world⁵⁰.

Why Use a Narrative Approach to Study Men's Experiences of Caring?

Having outlined key theoretical ideas surrounding narrative research, I will now justify why I 'framed' my study within a narrative approach, and in particular how important links exist between this literature and my own philosophical thinking. Firstly, I believe that the narratives gathered would allow me the opportunity to gain an insight into how male carers make sense of their experiences. Specifically referring to life stories, Atkinson (2002) comments that they serve as an excellent means for understanding how people see their own experiences, lives, and interactions with others (p. 137). However, I also believe that allowing men to tell their own stories (as far as possible and acknowledging my own influence), would provide understanding of the construction of their realities (of caregiving), and the stories they tell about their realities (of caregiving) (Atkinson 2002).

A narrative approach would also provide insight into how men's realities are constantly constructed and re-constructed in the context of wider narratives and through continuous dialogue. To this end, I wanted to utilise the multilevel, dialogic potential of narrative research (Squire *et al.* 2013, p. 2). Through framing research in terms of narrative we are able to see the different layers of meaning and the interactions between different stories (Loftus & Higgs 2010). I felt that in framing my research from a narrative perspective I would be able to

⁴⁹ Interpretation in narrative research, according to Frank (2010, p. 104) 'aspires to be an ongoing dialogue with the story' taking into account its hermeneutic and dialogical tradition'.

⁵⁰ I will return to this contentious issue specifically in relation to the 'validity' of my study at various points throughout this thesis.

explore the different layers of meaning for men who are providing care to a loved one or close relative with dementia. Thus, I would do much more than just explore people's stories of experience but also provide meaning of wider social change (Squire *et al.* 2013).

Taken together, I believe that there are important links with the ideas of social construction I earlier developed in my Introduction chapter – namely that realities are constantly being constructed and re-constructed in a particular time and place. They are also 'social' realities. I therefore believe that taking a narrative approach complemented and strengthened my study's ontological and epistemological underpinnings. The potential was there for me to focus not just on the verbatim translation of events, but on linking individual experience – insider perspectives – with public concerns and the development of social theory (Gilbert 2002). The narrative approach I have taken is heavily associated with the social constructionist paradigm on another level. For instance, in seeking to explore how men convey their caring experiences to others (i.e. me) and construct meaning, the narrative approach I assumed would allow me to explore how they construct meaning (subconsciously) according to socially constructed norms. I also understand their stories told would not be a transparent window into male caregivers' lives, but instead as ways in which they construct meaning through social interaction, specific to a particular time and place. These narratives were part of an on-going and constitutive part of reality (Phoenix *et al.* 2010, p. 2).

The changeable nature of reality as noted within social construction theory was also important to me in examining the dialogical relationships in men's experiences of caring. For instance, Loftus & Higgs (2010, p. 284) refer to the work of Mikhail Bakhtin (1986) in viewing that in narratives there are also complex dialogical relationships being enacted between our personal and professional narratives that affect how we live out our working lives. Thus, I understood that men's narratives are constantly changing and so too are 'realities' (i.e. men's stories), showing their capacity to challenge social patterns and structures. To this end, the narrative approach I assumed would also provide important evidence of the constant dialogical tensions between the individual (men) and social (social expectations and norms) in the construction of meaning in their caring experience.

While the research paradigm of social construction guided my work, 'narrative' had the potential to be much more than 'just' a methodological approach. For instance, I was particularly interested in the ideas of Clandinin & Connelly (1994) and how they viewed

narrative as both a phenomenon and method⁵¹. Pinnegar & Daynes (2007) also suggested that narrative research is both a method of research and a phenomenon within the social science. I saw parallels with some of the key ideas of Clandinin and Connelly and my narrative framework. While a narrative methodological approach guided my study, in other ways I also viewed it as a phenomenon for viewing understanding built through telling stories. Ultimately, narrative provided me with access to men's interpretations of their identities, cultures and social worlds in the context of providing care in dementia.

My Story of Conducting a Narrative Study (Part 1)⁵²

The first half of this chapter has demonstrated that narratives are not simple – they are about something much greater than just stories. I will now provide a detailed account of the issues I faced having decided to apply a narrative methodological approach. I will tell my story of my experiences of conducting a narrative study. I hoped to elicit a sample of men's personal narratives of their caring experiences in the context of dementia. In 'reality', it proved not as straightforward as this. Through data collection, I did much more, as the following sub-sections of this chapter detail.

Ethical approval

Before recruitment could begin I first had to gain ethical approval and I applied to the Faculty of Health Sciences Ethics Committee in Trinity College Dublin. At this stage, I was excited but I also felt apprehensive in spite of my previous qualitative research experience. I did not have

⁵¹ Clandinin & Connelly (2000) drew on Dewey's two criteria of experience to develop a narrative view of experience. Drawing on Dewey's first criterion, interaction, they wrote: 'People are individuals and need to be understood as such, but they cannot be understood only as individuals. They are always in social context' (p2). They drew on Dewey's second criterion of continuity: 'experiences grow out of other experiences, and experiences lead to further experiences. Wherever one positions oneself in that continuum – the imagined now, some imagined past, or some imagined future – each point has a past experiential base and leads to an experiential future' (Clandinin & Connelly 2000, p. 2).

⁵² My story in fact started long before I began data collection, and a whole range of experiences brought me to this study and so influenced how I approached this study. The foundations of my 'story' have been laid out in Introduction chapter.

a clue what I had let myself in for and how ethical challenges would emerge despite approval for the study⁵³.

Sampling

I initially proposed to identify thirty male carers to participate, through convenience sampling. With convenience sampling, the researcher chooses the sample according to ease of access (Ritchie *et al.* 2003). My final sample size was sixteen and justification for this number of participants in my study was based on the sheer amount of data I had to analyse. Kelly (2010) notes that a research design employing deep case analysis, using an in-depth narrative interview technique, may thus be limited to a small number of cases. The men's stories became the data. Details gathered on the participants as part of data collection is outlined in Chapter six.

The sampling technique I chose enhanced the 'validity' of my study (Robinson 2014b). For instance, key decisions that I considered in order to enhance rigour were the relationship of my sample to the target population, the appropriate choice of sampling strategy, the robustness of the sample sourcing approach, and the overall fit between research questions and total sample strategy (Robinson 2014b)⁵⁴. In terms of transparency, I acknowledge that the process of recruitment may have been influenced by my own background and connections. Thus, while outlining the recruitment process, I also undertook appropriate reflexive acknowledgement of any conflict of interests or possible bias (Robinson 2014b).

Inclusion and Exclusion Criteria

The criteria for inclusion mean that some voices may be excluded (Wiklund-Gustin 2010). This was an important consideration for me and I undertook various recruitment strategies. The inclusion criteria were male carers who:

- Provide physical and/ or social care to a loved one or close relative with a chronic illness in the home⁵⁵

⁵³ Specific ethical issues that I faced in data collection and how I dealt with each one will be discussed in a later section of this chapter.

⁵⁴ My target population of male carers were given contextual richness by locating them clearly within a particular culture as I have previously discussed in Chapter 2.

⁵⁵ The inclusion and exclusion criteria changed as my study developed to men providing care in the context of dementia, as outlined in the following paragraph.

- Understand the research purpose and process
- Willingly volunteer to participate

The exclusion criteria were male carers who:

- Does not provide physical and/ or social care to a loved one or close relative with a chronic illness in the home
- Has a diagnosis of dementia and is unable to participate in the interview process
- Does not understand the research purpose and process
- Unwilling or unable to participate

In addition to the above, I acknowledged that the care provided by men could be shared with other family members and this was highlighted in several men's stories. Initially I decided not to limit my sample to a particular condition. My study focus was not on caregiving in specific chronic illness contexts but rather on exploring the experiences of caregiving for men from a narrative perspective. However, in spite of my various recruitment strategies, early on in data collection it became apparent that each of the men I had spoken with was providing care to a loved one or close relative with dementia. Following consultation with my supervisory team, mid-way through data collection I took the decision to limit my sample further and only speak with male carers who were providing care in the context of dementia. I felt that speaking with men who were providing care in other chronic illness contexts could in fact 'muddy the waters' as their caring experience may differ depending on the specific condition. I did not want the focus to alter in terms of providing a comparison of male caregiving experiences depending on the specific chronic illness. I believe that this decision protected the integrity of my research.

Recruitment Process

Non-government organisations (NGOs) that work with family carers in Ireland, acted as gatekeepers⁵⁶. Three organisations (one that was dementia specific and two that were generic caring) forwarded recruitment packages to selected individuals on their databases inviting them to participate (See Appendix 3). Access to these organisations was first gained as a result of successful networking through membership of the Family Carer Research Group to which I had made a presentation on my study. I then met with representatives of the

⁵⁶ See Appendix 2 for Access Letter sent to NGOs.

individual NGOs. They were aware that I had previously worked in the area of informal caring as well as my previous research experience. This may have helped ease of access considerably as they may have had a certain confidence in my ability. Additionally, several NGOs advertised information on my study in their online newsletters (see example in Appendix 4).

I was aware that by its very nature, recounting sensitive information might deter some men from participating, and there might have been issues in getting enough participants. Key stakeholders warned me of this. However, I was surprised with the high level of response. There were a number of factors at play that contributed to this. Firstly, as outlined above I was known by the specific NGOs prior to beginning my PhD. In addition, I believe that the way my study was promoted helped recruitment. For instance, men were not scared by being seen as an 'experiment' as might have been the case in a highly structured quantitative study. In spite of the different strategies used, I acknowledge several limitations. Many of the men I spoke with were recruited through carers support groups facilitated by the specific NGOs. Men not attending or in receipt of such supports and services, as well as men from different cultures or indeed non-dementia specific male carers may have had other issues that were significant to their experience.

Data Collection

In the following sub-sections I will provide an account of how I gave sixteen men the opportunity to disclose their personal caring experiences in the context of dementia through narrative in-depth individual interviews, including setting, context, the stages and processes I followed, additional ways I elicited narratives, as well as specific ethical issues I faced. I will then discuss how each of the narratives gathered was co-constructed.

Narrative In-Depth Individual Interviews

From the outset, I wanted to represent the 'truth' of men's stories - the lived experience of their stories of caring and the meaning they make of that experience (Seidman 2013, p. 9). The data collection process was collaborative, requiring me to establish trust with each man (Gill & Goodson 2011, p. 160). The style of interview I applied made this possible (Suárez-Ortega 2013).

Sarantakos (2013) posits that the theoretical and methodological basis of narrative interviews was developed by Schütze (1977, 1979, 1981, 1982, 1983, 1987), and the principles of narrative interviewing stem from phenomenology and the philosophical branch of the Chicago

School (p. 289). According to Holloway & Freshwater (2007a, p. 12) 'The narrative (interview) is a journey or pathway through time which is told by its author, who tells the listener what happens on the way. The narrator takes a reflective stance on events and processes on the journey'. I aimed to transform the interviewer-interviewee relationship into one of narrator and listener and allow men to view themselves as narrators of their stories of caregiving (Chase 2008, p. 68). In so doing, I encouraged men to '...become narrators, to break free from the question and answer format and begin simply *narrating* (Wiest 2013, p. 77). A dialogic dimension existed in the interviews through the engagement between the storytellers (men) and the listener (me) (Guillemin & Heggen 2012). The sections that follow will outline both the steps I took to prepare for the interviews and how they developed in practice.

Pilot Phase: Deciding on the Right Question in Order to 'Hear' the Participant Voice

Duffy (2012) warns that it is important to be aware that no one story will ever capture a full life story and the narrative researcher must limit the scope of the research question. During my pilot phase, I gave particular attention to my research question, as I considered the aspects of male caregivers' lives that were most important. The research question which thus guided my study was as follows: *How do male carers perceive their own experience of providing care to their loved one or close with dementia?* Ultimately, I was looking for both the large and small stories that come together to form the themes in a male caregivers' life, and that, together, shaped the male caregivers' identity (Duffy 2012).

Researchers prepare for narrative interviews by developing a broad question that will invite the participant to tell their story, once they have a sense of the broad parameters of the story that the narrator has to tell (Chase 1995). I undertook a number of steps in order to limit the scope of my research question as part of my pilot phase. I firstly undertook an extensive review and analysis of both the socio-historical contexts of male carers and existing literature on male caregiving. I then organised through one of the NGOs to meet informally with several male carers (n=4) who were attending a carers support group through their service. The purpose of this meeting was to ask for their opinions on what may be considered important to male caring experiences⁵⁷. At the same time, I was conscious of not asking for a 'formula story' (Loseke 2001, as cited by Chase 2008). On the one hand, I had to be prepared to ask questions that invited men's particular story; while on the other hand, the very idea of a particular story is that it cannot be predicted or prepared for in advance (Chase 2008, p. 72).

⁵⁷ I will return to discuss this in further detail in the section below.

Although any narration is always enabled and constrained by a host of social circumstances, *during interviews* as narrator researcher, I needed to orient to the particularity of the narrator's story and voice (Chase 2008, p. 70). The 'stages' of my narrative interviews below will demonstrate how I went about ensuring this⁵⁸.

In July and September 2011, I undertook two pilot interviews. During the pilot phase, I was apprehensive of how the narrative style of interviewing would work out. For instance, I found it difficult at times to not jump in and just let the participant tell me his story. Instead I found that I was conscious of confirming my active listening, through nodding. In fact, at times I was worried that I may have been over doing this. I also found it difficult to decide when was the right time to end recording and bring the interview to a close. In fact, in my first interview, I ended up turning back on the recording in order to record additional information. I feel it was very significant to this man's story, as when the gap in recording took place, he became visibly upset when speaking about his wife. I was concerned that as a consequence of this style of interviewing, important information as part of each man's story may not be included in the recording. Within a more semi-structured interview that I would have undertaken in previous studies, I may have been able to probe such questions. In addition, I left my pilot interviews wondering whether as a consequence of meeting with me on one previous occasion (through focus group discussion), whether each of the men felt more at ease talking with me. I also questioned whether the subsequent men that I would speak with would be as open with me in terms of telling me about their experiences.

Upon personal reflection and following discussion with my supervisory team, several changes were applied to the narrative interviews. For instance, I revised the wording of the opening statement in order to enhance the narrator's story and voice (Chase 2008). Further to conducting the pilot phase, I was also eager to enhance narratives and allow future participants the choice of bringing personal photographs into the interview setting. Finally, I decided to complete a Demographic Information Sheet upon completion of the interview. I felt that asking men to complete such a standardised set form of questions before hand could in fact inhibit the narrative interview process. Data collection for the main phase commenced in October 2011 and was completed in September 2012.

⁵⁸ I also recognise that my own 'story' did influence each story told and I will discuss this at various points through the remainder of my thesis.

Stages of My Narrative Interviews

While I decided to adapt the three elements of the narrative interview as outlined by Flick (2009)⁵⁹ to use to guide the flow of conversation, I also considered the work of many other narrative researchers, for example Brown & Addington-Hall (2008), Elliott (2005), Holloway & Jefferson (2008), Moen (2006) and Riessman (2008). As I prepared for the interviews, I found myself confused at times with varying opinions of how to conduct a narrative interview. I am cautious to use the term 'stages' loosely as each interview was also a social relationship and following Seidman (2011, p. 97) '...a reflection of the personalities of the participant and the interview and the ways they interact'. Like Atkinson (2002), my interviews were best carried out as an art. Thus, while I used a loose structure, the extent to which it was applied evolved differently depending on each individual interview and its context. As I began to speak with men, I had to strike a balance between having a flexible interview focus, neither too constructing nor too open or unfocused (Kvale 1997, 2007).

Stage 1

I chose to begin each interview with the following statement:

I would like to hear about your experiences of caring for your family member/loved one with chronic illness⁶⁰. Please feel free to tell your own story in any way you feel comfortable. Please give as much detail as you like to, because for me everything is of interest that is important for you (Adapted from Maple et al. 2010, p. 243).

Similar to the approach taken by other narrative researchers such as Warnes & Daiches (2011) in their study of the stories of young motherhood, I invited each man to 'tell their story' about being a carer. Once they began to speak, it was crucial that their narration remained uninterrupted. I did not ask questions, applying a certain degree of distancing (Wiklund-Gustin 2010, p. 34). As an active listener, I signaled (for example, by reinforcing 'hm's') that I empathised with the narrated story (Flick 2009). Non-verbal communication such as encouraging nods helped display a sense of understanding (Warnes & Daiches 2011). If uninterrupted, respondents are likely to continue in an extensive narrative (Bloor & Wood 2006).

⁵⁹ Flick (2009) makes specific reference to the narrative interview styles of Riemann and Schutze (1987) and Hermanns (1995).

⁶⁰ As previously noted, I later changed my sample to only include men caring in the context of dementia.

For Frank (1995), participants express what they want to say rather than what the researcher wants to hear. To this end, I had to learn that silences and pauses were ok and indeed would become an important element when I came to analyse the stories. It was crucial that I gave each man space to think, reflect and add to what they had said. There was no rule of thumb and each story would be different (Seidman 2013, p. 95). Andrews (2007) highlights that patience can be challenging as a researcher's inclination may be to either rush through the silence, or to impose onto this space their own interpretative frameworks of meaning (p. 39). Such minimal interrogation lets participants control the ordering of their stories and reduces researcher power (Gill & Goodson 2011, p. 160). A major challenge was to convince men that I was interested but also remain 'neutral'. I was already an active participant, although I was silent. How I introduced myself and sat had an impact on the story told. The length of time men spoke during this first phase was on average ten minutes.

Stage 2

While the general style of each narrative interview was 'unstructured' (Mishler, 1986), the importance of asking the right kind of questions in order to generate narratives could not be ignored either (Mishler 1986, Riessman 1993). At this stage, I therefore sought further detail about particular issues men had raised during their initial narrative (Flick 2009, Brown & Addington-Hall 2008). Following up themes in participants' own words respects and retains the meaning frames (Holloway & Jefferson 2008). In order to achieve this, I wrote down key phrases that the participant spoke of during their initial narrative, which I may have returned to during this second stage. This also ensured that I avoided interrupting participants when they were talking (Seidman 2013). Such open-ended 'prompts' allowed flexibility for each man to speak freely and lead the direction of the interview (Warnes & Daiches 2011, p. 113).

While the basic structure of the in-depth interview is designed to ask participants to reconstruct their experience and to explore their meaning, some participants require more prompting than others (Seidman 2013). Riessman (1993) advocates for the development of an interview guide with five to seven broad questions relating to the research topic, supplemented by probe questions in case the participant has difficulty getting started. To this end, in advance of beginning data collection, I developed an interview guide for use only when and if an individual participant had trouble in expressing their experiences. It was formed following an open-ended conversation with a group of four male caregivers as part of the pilot phase in which they identified a number of key topics that they felt were important to the male carer experience. The specific issues identified by this group are outlined in

Appendix 5. Applying the principle of user involvement had the potential to impact on the focus and content of the narratives. Indeed, all of the men in my study varied in the way in which they told their stories. Some men spoke almost continuously without solicitation, whereas others needed prompting to help them continue (Blix *et al.* 2013). For instance, some appeared more nervous and hesitant in speaking with me and I referred to the interview guide in two of my interviews. When I did use this interview guide, I avoided manipulating participants to respond to it, and continued to ask questions in an open and direct way, thus avoiding imposing my own interests on the men's experience (Seidman 2013, p. 94). Thus, open-ended questions were adapted on an individual basis to capture the subjective diversity of each participant's narrative (Riessman 2008).

During this stage, interviews assumed a temporal nature, moving thematically back and forth between stories about the past (life before caring), reflections on the present (current caring experiences) and thoughts about the future (continued deterioration of the person with dementia) (Blix *et al.* 2013, p. 267). I treated the developing narratives as 'accounts and as 'performances' (Frank 2009, p. 312). I noticed how men also appeared to undertake a reflexive process within the interviews for example, 'Oh that's how I do things...' Some expressed anticipation asking – 'Am I doing this right?' I created a dialogue and interchange between myself and men during this stage of the interviews in the different voices that I assumed, moving back and forth applying an authoritative voice, while also applying a supportive voice, as well as an interactive voice at other times (Chase 2008, p. 74-77). Privileging dialogue is key in developing a knowledge base in narrative research (Josselson 2007). In the main, during each interview, I developed a supportive voice that pushed each man's voice into the limelight (Chase 2008, p. 75).

Stage 3

Flick (2009) refers to the third stage in narrative interviewing as the balancing phase. At this point, I asked men more abstract questions, aiming for more description. Flick (2009) suggests asking 'how' questions and then only afterwards to complement them with 'why' questions' aiming at explanations. Participants were taken as experts and theoreticians of themselves⁶¹. According to Czarniawska (2004, p. 48) '... (the) power of knowledge...lies on the side of the interviewee'.

⁶¹ Rather than viewing the men in my study as research *subjects*, I decided to use the term *participant* throughout. Frank (2010) has previously outlined the crucial semantic difference between the two terms. He compared the

As previously highlighted, knowing when the right time to conclude the interview was a particular issue that I faced during the pilot phase. Concluding a story is interactionally complex (Holstein & Gubrium 2000). As a consequence, I asked each participant if they had anything further to add to their story⁶². However, as I continued my data collection, I realised that many men continued to speak to me following the formal conclusion of the interview. For instance, after I had turned off the recorder they spoke further about their experiences of caring. I was careful to document this additional information in my field notes⁶³. In addition, I was cautious of spending time and not rushing off especially given the highly personal information men had spoken about, and for some had become emotional, thus ensuring their well-being. To this end, I offered information on support services for carers to two men. I also asked men to complete a Demographic Information Sheet upon completion of the interview⁶⁴.

Setting and Context of the Interviews

On receipt of reply slips, I contacted each man by telephone to discuss their potential involvement and established any concerns. All men agreed to participate in an interview. I invited them to speak with me at a time and place that was convenient to meet, in order to ensure that they felt comfortable. The majority of interviews took place in men's own homes, as a consequence of their caring responsibilities they felt that this was the only way they could speak with me. Interviews were subject to participants having time and free from worry regarding the welfare of their loved ones during the interview process. However, the individual with dementia was present in the home at the time of men speaking with me in several cases. Some men preferred to meet with me on the campus of Trinity College Dublin. Others chose to meet me at a neutral venue and these interviews took place in public venues such as a local café and hotel.

research subject to a medical patient, as an object of another's investigation, only allowed to act in ways that the other prescribes and is subjected to the investigator's interpretative authority. In contrast, participants do things and following the dialogical shift in research practice, they are not data for investigators; instead, they co-construct with investigators what count as data (p. 98).

⁶² I also gave myself a checklist to complete before end of each interview, see Appendix 7.

⁶³ While I was exhausted after each interview, I was determined to complete my entry into my field notes on the day of each interview (See Appendix 6 for example).

⁶⁴ A copy of the Demographic Information Sheet used in my study can be found in Appendix 8 and the findings are discussed in the following chapters.

At the time of meeting each participant, I revisited the information sheet, consent forms, and addressed any concerns they had before seeking their consent (this information was enclosed in the Recruitment Packages, see Appendix 3). Written consent was then obtained before all interviews. It was proposed that interviews would on average last forty minutes. In practice, interviews lasted between 20 and 150 minutes and they were all digitally audio-recorded following consent from each of the men. In relation to recording, before commencing fieldwork I considered how its presence may inhibit participants, especially given the narrative style of my interviews. However, I believe that the benefits of recording outweighed the risks of not doing so. For instance, by preserving the words of the participants, I had their original data (Seidman 2013, p. 117). Recording was also of benefit to the participants as assurance that there was a record of what they said, giving them more confidence that their words would be treated responsibly (Seidman 2013). I tried to ensure that the recording was not intrusive. I decided on a modern device with a microphone able to pick up sounds from a distance, ensuring that it did not necessarily have to be placed in between myself and each man, acting as a physical 'barrier' and becoming intrusive. In fact, I made light of it with men, joking 'let's just try ignoring it's there'.

I was also keen to undertake informal conversations before the recording began, showing my 'insider knowledge' of informal caring. However, in deciding to, I understand that this may have influenced the story told and I return to this issue at various points throughout my thesis. In so doing, I wanted to create a 'discursive space' – for men to feel comfortable in disclosing information to me (Creswell 2007). Thus, I created an informal space – rather than a traditional interview structure, where by men were aware of my background. I also ensured a level of informality by bringing along a packet of biscuits and having a cup of tea together. I let men decide where they wanted to talk to me as I was entering their environment. In many cases, we ended up speaking at the kitchen table. Each of these steps helped me to establish a relationship with the participant, ensuring that I did not force men's stories.

Additional Ways of Eliciting Narratives

Enabling participants to narrate their experiences lies at the heart of narrative research (Flick 1998). However, some participants may find it more difficult than others to do this (Robinson 2002). Photographs can help participants to remember details that they may not have included in their face-to-face interview (Creswell 2002). Rich (2004) argues that the image

acts as a catalyst for the generation of the 'real data' (p. 154).⁶⁵ Following my pilot phase, I applied to the Faculty of Health Sciences Ethical Committee in October 2011, and was granted permission to include photographs as a 'trigger' to encourage men to tell me their stories of caring. I felt that the use of personal photographs would provide important information on the participants' background. I also anticipated that they may act as a way of starting conversation, making men feel more at ease in telling me their story. Three men specifically referred to and showed me personal photographs during the course of their interviews. However, several other men proudly showed me photographs once the recording had finished. In other cases where photographs were not specifically referred to by the men themselves, they were clearly visible as I sat in their home and I included this information in my field notes.

Ethical Issues as a Constantly Evolving Process

According to Wiles (2013, p. 4) 'Ethics is the branch of philosophy which addresses questions about morality'. I soon realised that ethics in my narrative research was an ongoing process, not only linked to the development of design (Webb 2006). Just as the stories told change over time, ethical matters shifted and changed (Clandinin & Connelly 2007). Ethics for me thus involved no fixed rules, and as I undertook this study it was a balancing act of promoting benefits and reducing harm, through constantly balancing my dual roles of insider and outsider (Bold 2012). For instance, Bold (2012, p. 55) contends that ethical 'dilemmas are often caused by the dual role of the narrative researcher, that of being in a close relationship with the participants...and also being an academic professional with a responsibility to disseminate findings'.

Through using a narrative approach, I considered that I was an agent of change in which men had the opportunity to reflexively examine their experiences of caregiving (Duffy 2012). I had to be careful to step back and allow narratives emerge (Wiklund-Gustin 2010). The approach I took to interviews as described above allowed me to do this⁶⁶. I was also guided by the previous work of other qualitative researchers who were new to the narrative research

⁶⁵ However, there is a problematic relationship between memory and identity in storied representations as the meanings of photographs may change over time (Harrison 2004, p. 129). It was crucial that I also acknowledged this.

⁶⁶ At the same time, data collection also involved my own self-reflection as I have documented in my Discussion Chapter.

technique such as Thomas (2008) and her work with cancer patients and their informal carers. For instance, similar to Thomas (2008), I ensured that all interviews were conducted sensitively and respectfully. All men had every reason to feel safe and to speak with me openly⁶⁷.

Throughout data collection, I constantly reconciled the benefits of men's stories with the benefits of my own research agenda (Atkinson 2002). Plummer (2001) identifies exploitation as perhaps the most crucial ethical issue in life history approaches in that participants are encouraged to provide their personal, and perhaps painful, stories. However, it is the researcher that benefits, both professionally and materially, from the reporting of these stories in which the subject of the narrative is anonymised and generally receives no credit or reimbursement (Plummer 2001, as cited by Wiles 2013, p. 82). While there was no immediate benefit for men speaking with me, there may have been a positive therapeutic element. Many men thanked me for involving them in my research and giving them the opportunity to speak about their caring experiences. In having someone interested in listening to their stories, they felt that it had given them the chance to consider issues that they hadn't talked before.

In order to guard against the potential exploitation of 'opening Pandora's box' (Lieblich 1996), I took a number of steps in data collection to ensure that men did not become emotionally distressed. I had a responsibility to be sensitive, respectful and fully present to each of the men I spoke with (Duffy 2012, p. 438). Duffy (2012, p. 437) advises that these ethical guidelines are situated within the category of ethics that McNamee & Gergen (1998) refer to as *relational responsibility*. In practice, participant wellbeing was given a priority over my research at all times. However, some men found recalling their personal experiences saddening. Men were told that the interviews would be stopped or suspended if they became distressed. In two instances, I asked the men if they felt comfortable in continuing to speak with me as they did become emotional and were visibly upset. Both men told me that they wanted to continue speaking with me. I was aware that interviews may have revealed specific support needs for some men. To this end, I had contact details of carer support services (for example, the National Freephone Careline/ local carer support groups and resource centres) and was prepared to offer these if the participant was deemed to be in need of further support. I sent information on to two men following a request made. I also spent time at the end of each interview speaking with men in order to ensure that they had a social circle in

⁶⁷ Interviews were held in either participants' own homes or another location of their choice.

place either informally or formally with family, friends and/ or neighbours so as to safeguard that they were not isolated. Given the nature of dementia, I also understood that men may have had to defer or terminate interviews without advanced warning. One man stopped speaking with me after being interrupted by a family member asking for assistance in looking after his wife. In addition, time was allocated at the end of each interview for discussion of any sensitive matters that may have arose and which a participant may wish to have discussed outside the recording stage⁶⁸.

On another level, I felt somewhat overwhelmed by the openness expressed by many men in telling me their stories. I found the constant challenge of finding the right balance as I began to interpret and analysis the stories – in order to give men a voice while also being respectful of the highly personal stories told. Indeed, 'Voice' is an important conceptual issue that I was faced with throughout the research. Atkinson (2002, p. 133) asks: 'If you ask someone to tell his or her life story, will what you get be in that person's authentic voice, or in a voice that he or she thinks you might be looking for?' He warns that the type or quality of the relationship between interviewer and interviewee may have something to do with what you get (Atkinson 2002, p. 133). I used a number of strategies in data collection in order to maintain the voice of the men. The approach I took to the interviews allowed men to feel comfortable and gave them power and control over how they would like to tell me their story. At same time, I recognise that wider voices are always at play when any one individual is telling their story, and narratives are social encounters as I have previously outlined and will return at various points in my thesis.

Anonymity has been cited as another particular ethical issue in narrative research given the close relationships that may develop between researcher and participants (Butler-Kisber 2010). Compromising participant's identities was something that I was keenly aware of. I took continuous steps throughout in order to ensure to protect participants' confidentiality and keep their identities anonymous:

- I applied the use of pseudonyms to each participant, organisations and locations mentioned in each story. I chose each pseudonym rather than giving men the option of doing so themselves. Researchers have found that participants sometimes choose the names of real people, such as their friends (Corden & Sainsbury 2006).

⁶⁸ Before speaking with me, I also took a number of specific steps to ensure that men were as fully informed as possible about the nature of their involvement in my research before seeking consent.

- Each participant was assigned to a code known only to me.
- Research materials including audiotapes and transcripts of interview data were kept secure in a locked filing cabinet, accessible only to me. Signed consent forms were stored away from data. All computerised information collected was anonymised by using identity numbers for participants and password protected.

While I undertook a number of ethical guidelines as outlined above, in practice, each interview differed as every man had a different story to tell and each setting differed. Therefore, just as I have spoken of how there were no specific 'rules' for my style of interviewing, so too there were no specific rules for every ethical instance during data collection. While guidelines acted as general 'rules of thumb', I was also required to adhere to ethical capabilities grounded in the situatedness of research, rather than on universal codes of ethics (Guillemin & Heggen 2012, p. 702). I applied the ethical framework of 'ethics of care' as a means of thinking about ethical dilemmas and issues that arose (Wiles 2013).

Co-construction of Narratives

Following from ideas developed in the first half of this chapter, I view each of the stories collected and told in my study as a co-construction on number of levels⁶⁹:

1. Between myself and each participant - we actively shaped the stories together. As researcher, I was a collaborator in the evolving story that unfolded with each man (Gilbert 2002). Following Hydén (2013), the approach I took in my interviews, allowed participants and myself to shape the form that each interview would take. I was an active participant, as Riessman (2011, p. 315) pointed out through '...subtly prodding men to 'say more' or by pausing at key points in the expectation that 'more' could be said'.
2. Influence of context – issues such as the time of day and the place of interview also had an important influence on what was said and each story that evolved.
3. Wider narratives - constantly evolving societal and cultural influences had an impact on what each man said and did not say. While all narratives have a narrator they also

⁶⁹ Mishler (1986) has suggested the importance of a process of co-construction in order avoid the methodological traps of personal interpretation, whereby the speaker and listener are jointly engaged in creating a reality that is agreed and co-constructed between them.

have an audience, who may be actual or imagined, narrators may shape their narratives for different audiences (Griffin & May 2012, p. 443). Indeed, the men were aware that their stories were going to be published as part of my PhD thesis, and so I was not their only audience member (Wiest 2013). The anticipated audience also included service providers of formal care supports. Some men were excited by the prospect of key stakeholders hearing their story. In so doing, this may have acted as a motivator in how I approached the interviews.

Continuously Evolving Process of Ensuring Quality and Protecting Study Rigour

I would now like to discuss specific steps I took in data collection in order to ensure quality and protect study rigour. Such issues were constantly developing as my study progressed. Within narrative research, scholars have called to evaluate stories in terms of their credibility and authenticity rather than viewing them as factual constructions (Holloway & Freshwater 2007b). According to Duffy (2012, p. 46) 'Trustworthiness and credibility in narrative research refer to the degree to which the participants have been fully included in the research process and have had the opportunity to reflect upon and comment upon their story as retold by the narrative researcher'. The responsibility of the re-storying process is therefore shared between the researcher and the participant (Duffy 2012). Storied texts serve as evidence for personal meaning, not for the factual occurrence of events reported (Polkinghorne 2007, p. 445). Instead, narrative truth involves a constructed account of experience (Josselson 2011a). Bruner (2010, p. 45) warns that stories, unlike logical propositions, 'cannot be context free, cannot live in a vacuum'. The test for a good story is therefore not its *verifiability* but its truth-likeness or *verisimilitude* (Bruner 2010, p. 45). In defence of the 'validity' of narrative research, historical truth is not the main issue; it is more important that the story produced is deemed to be 'trustworthy' than that it be 'true'. Ultimately, we are seeking the subjective reality (Atkinson 2002). Trustworthiness was thus an issue that had to be constantly addressed as my study evolved.

The rigour of my study was maintained throughout data collection and analysis by following the 'trustworthiness' criteria proposed by Lincoln & Guba (1985)⁷⁰. Their criteria focused on

⁷⁰ The second criteria that Lincoln & Guba (1985) propose for assessing a quality study alongside the four trustworthiness criteria, is *authenticity*. This will be defended in the final chapter of my thesis.

the credibility, dependability, confirmability and transferability of the research findings⁷¹. Credibility was established through prolonged engagement with each man that I spoke with, as well as peer debriefing through regular meetings with my supervisory team. Because interview texts are co-constructed, interviewers need to guard against simply producing texts they had expected (Polkinghorne 2007). Through assuming an open listening stance and carefully attending to the unexpected and unusual participant responses during data collection, I ensured that each participants' voice was heard, and the text created was not primarily my own creation. During data collection, it was my responsibility to empower participants by acknowledging that they are the only ones who have access to their experienced meaning (Polkinghorne 2007, p. 482). Holloway & Freshwater (2007b) contend that understanding can best be achieved through listening to people's stories (p. 710). Dependability was achieved through demonstrating both in this chapter and the chapters that follow, the appropriateness of all methodological decisions that I took. I continuously audited throughout data collection and analysis, keeping records and personal notes, and examining the process (Flick 2009). In line with Lincoln & Guba's (1985) criteria, I kept field notes in order to enhance the 'truth' in my study gathered at a specific moment in time (See Appendix 6 for an extract from my reflexive field notes). Transferability was achieved through the thick description and rich details of how I went about undertaking my study and in particular in the detailed field notes I gathered following each interview. Confirmability will be returned to later as it examines the product to attest that the findings, interpretations and recommendations are supported by data.

Guba & Lincoln (1989) believe that member checking allows participants to alter or extend issues that may arise from their narratives. Duffy (2012) also spoke about the importance of providing meaningful opportunities for participants to review transcripts in ensuring trustworthiness (p. 37). I did not member check the data collected as I viewed the narratives told as constantly evolving as men's experiences were changing. However, I used sub-categories within member-checking to aid in the establishment of trustworthiness of the interpretation – namely peer and audience validation (Loh 2013). In terms of peer validation, I constantly liaised with fellow PhD students and my supervisory team as well as other academics working within similar branches of research – to provide some sort of

⁷¹ *Credibility*, parallels internal validity; *Dependability*, parallels reliability; *Confirmability*, parallels objectivity; and *Transferability*, parallels external validity (Bryman 2008, p. 377)

corroboration with regard to interpretation of my data (Loh 2013, p. 6). I also maintained regular consultation throughout with the primary readers and users of my study – the audience (Loh 2013). For instance, preliminary findings and discussion were sent to key stakeholders as a way of member checking (Hardy *et al.* 2009). In addition, men themselves helped determine what issues to pursue in more detail in each interview when I asked them if there was anything further they would like to add to their story, as well as through informal conversations before and after each interview (Mishler 1986). In so doing, this served as a form of member checking (Guba & Lincoln 1989).

Conclusion

This chapter has outlined in detail both the methodological approach and methods that I took to collecting data in my exploration of the caring experiences of men in the context of dementia. In telling my story, I have illustrated how all decisions made during data collection were located within a narrative methodological approach and the wider theoretical framework of social construction.

Chapter 5: Development of Data Analysis Framework

Introduction

The purpose of this chapter is to give a detailed account of the narrative analytical framework I developed in order to analyse the vast amount of material gathered during data collection. Ultimately my role was to make sense of men's stories of caring in the context of dementia. However, as will be outlined in this chapter, I soon found it difficult to decide what was the best way to do this in order to ensure that men's voices were heard. Following extensive reading on narrative analysis, I chose to apply a multitude of approaches to analyse men's stories. Hardy *et al.* (2009, p. 16) propose that by choosing a transparent and theoretically based approach to analysis, along with a truly collaborative method thus increases the credibility and transferability of narrative-based research findings.

Multitude of Approaches to Narrative Analysis

My initial struggle in deciding how to proceed with analysing my data was to try and understand the different narrative analytic approaches and how they relate to my study. Like Squire and colleagues (2013) noted as one of the most frequently asked questions, I too found myself asking 'What do I do with stories now I've got them?' (p. 1). Such confusion according to Mauthner & Doucet (1998) is not uncommon when utilising narrative analysis. For Riessman (1993), the purpose is to see how respondents impose order on the flow of experience to make sense of events and actions in their lives. Therefore, the task for me was to decide how I could best achieve, through a systematic narrative analytical approach, an *understanding and meaning* of the caring experiences of a sample of men in the context of dementia.

Both grounded theory and thematic analysis approaches focus on codes and categories rather than people as units of analysis through the use of cross-case comparison (Ezzy 2002). With narrative analysis the focus of attention shifts from 'what actually happened?' to 'how do people make sense of what happened?'⁷² Proponents of narrative analysis argue that other approaches neglect the fact that people perceive their lives in terms of continuity and

⁷² Bingley *et al.* (2008) observe that it is important to distinguish between qualitative analysis applied to narratives and narrative analysis as a method. In the former, general methods of qualitative analysis such as thematic, discourse and conversation analysis may be applied to the interpretation of narratives as well as other sources of data while in the latter specific, analytic techniques have been developed devoted to narratives alone.

process and neglect the perspective of those being studied (Bryman 2008, p. 556-557). However, with narrative research, Squire *et al.* (2013, p. 1) contend that 'Clear accounts of how to analyse the data, as found for instance in grounded theory and in Interpretive Phenomenological Analysis are rare'. Stephens (2011) highlights that narrative research is not a method per se, but instead is a theoretical approach to interpreting talk (p. 63).

Realising that there were no overall rules regarding analysis techniques, I instead viewed narrative analysis as an umbrella term used to describe a range of approaches⁷³. One thing is however certain across the disciplines – the central feature towards careful listening and reading of the words and stories of the teller (Roberts 2002, p. 132-133). In line with social constructionism, I found myself influenced throughout analysis by a position that focuses on the links between the narrative and broader culture (Gergen & Gergen 1984). For instance, Gergen & Gergen (1984) argued that 'self-narratives' give an understanding of the 'temporal character' of human action by providing connections, coherence, movement and direction (p. 174-175). Thus, while examining men's stories of caring in the context of dementia, I was also interested in the temporality and location of men's stories of caring were taking place within a particular place and time and how wider ideas and societal expectations surrounding the role of men influenced what was said. Indeed, Gergen & Gergen (1997) describe self-narratives as 'fundamentally social' (p. 163). According to this view, self-narratives are not individual but are a result of social interchange - a social phenomenon (Gergen & Gergen 1984, p. 174 as cited by Roberts 2002, p. 126). I also understood that in the analysis, the men's narratives were indeed a co-constructed performance between the men and myself (Griffin & May 2012).

I gave careful consideration to ideas associated with narrative thinking that have previously been discussed in detail in the methodology chapter, most notably the issue of trustworthiness of personal narratives. Thus, I acknowledged the possibility of a variety of truths within the men's stories of caregiving (Miller 2006). These 'truths' were influenced by social and historical factors (Gergen 1985). In addition, these narratives were not 'fixed texts', and would change with each telling (Griffin & May 2012, p. 443). However, while theoretical assumptions associated with social construction and narrative thinking guided my analysis, I was also open to new ideas and challenges (Murray 2008). Thus, as Murray (2008, p. 121)

⁷³ Daiute & Lightfoot (2004) state: 'Narrative analysis (has) assumed a multitude of theoretical forms, unfolds in a variety of specific analytic practices, and is grounded in diverse disciplines' (p. vii).

highlighted ‘...rather than imposing a framework and rather than simply describing the narrative account, narrative analysis requires the analyst play with the account’. In the sections that follow, I will therefore demonstrate the analytical framework that I developed to *play* with men’s accounts of caring in the context of dementia.

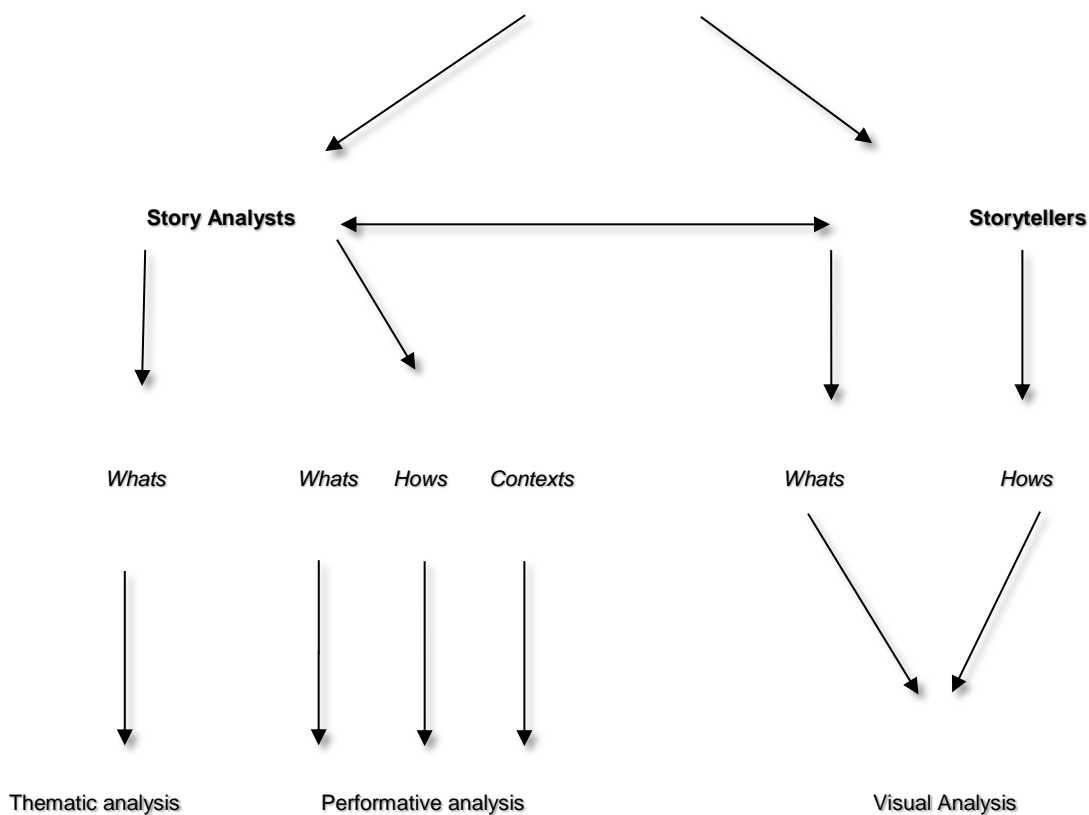
Several typologies of narrative analysis have been proposed⁷⁴. Stephens (2011) notes that such typologies help researchers to consider the focus of their own analysis in relation to their research question, in asking what the best option may be either through: pursuing the culturally available structure of narrative forms; the interpersonal relations involved in narrative construction; the constructive function of different stories or the social forces and power relations that shape narratives (p. 64). However, Frank (2010, p. 121) warns ‘Typologies should never be considered final’. Riessman’s (2005) model is probably the most widely used and known model; she offers a heuristic effort to describe a range of contemporary approaches to narrative analysis particularly suited to oral narratives of personal experience⁷⁵. According to Riessman (2005, p. 2) ‘The typology is not intended to be hierarchical or evaluative... in practice, different approaches can be combined: they are not mutually exclusive and, as with all typologies, boundaries are fuzzy’. In Figure 5.1 overleaf, a multitude of approaches to narrative analysis are illustrated which have been adapted from the work of Phoenix and colleagues (2010) who introduced a typology of narrative analysis. They believed that their typology was different from others that had already been created ‘...inasmuch as it introduces different layers or levels of analysis through the idea of narrative analysts as *story analysts* and *storytellers*’ (Phoenix *et al.* 2010, p. 2). This idea of viewing narrative analysis in the ‘plural’ sense was vital to me as I began to develop my own analytical framework. I considered various contemporary approaches to narrative analysis, focusing on the work of Riessman, as well as other narrative theorists such as Labov & Waletzky (1967), Labov (1972), Holloway & Freshwater (2007a), Bamberg (2004a, 2004b), De Fina & Georgakopoulou (2008), Frank (2010), and Phoenix *et al.* (2010). Thus, there were a multitude of influences in my decision over which approach to take in my own narrative analysis of men’s stories of caring in the context of dementia.

⁷⁴ For example Langellier (1989), Mishler (1995), Lieblich *et al.* (1998), Bury (2001), Cortazzi (2001), Riessman (1993, 2008), Frost (2009) and Phoenix *et al.* (2010).

⁷⁵ In 2008, Riessman updated her 1993 book, *Narrative Analysis*, which has probably been the most cited methodological source for narrative research (Frank 2010).

Figure 5.1: A Typology of Approaches to Narrative Analysis
 A Typology of approaches to Narrative Analysis

Narrative Analysis



Structural Analysis

Adapted from work of Phoenix *et al.* (2010); this figure considers the use of Riessman’s (2008) model of four contemporary approaches to analysing narrative research.

Development of My Own Narrative Analytical Framework

I will firstly outline how I came to decide to apply a variety of analysis techniques to my data through a number of interlinked stages. With no single analytical technique dominant, I examined each of the men’s stories of caring in the context of dementia through structural, thematic and dialogic/ performance analysis. Thus, I will also justify how taking a multitude of approaches to analysis allowed me to examine in-depth from a narrative perspective, the multiple levels of meaning and interpretation in their caring experiences. Existing narrative analysis typologies did prove a valuable resource by assisting me in making principled and strategic choices regarding when and why to use different types of analysis (Phoenix *et al.* 2010, p. 2). The challenge that I found myself faced with was to provide a systematic

approach to analysis for the purpose of fulfilling a PhD but also allowing men's voices to be heard. I was faced with the constant challenge of finding a right balance between analysis – in order to give men a voice - and also be respectful of the highly personal stories told. It was difficult to say the least, as I was faced with the 'delights and dilemmas' of narrative analysis (Sparkes 2005, p. 194)⁷⁶.

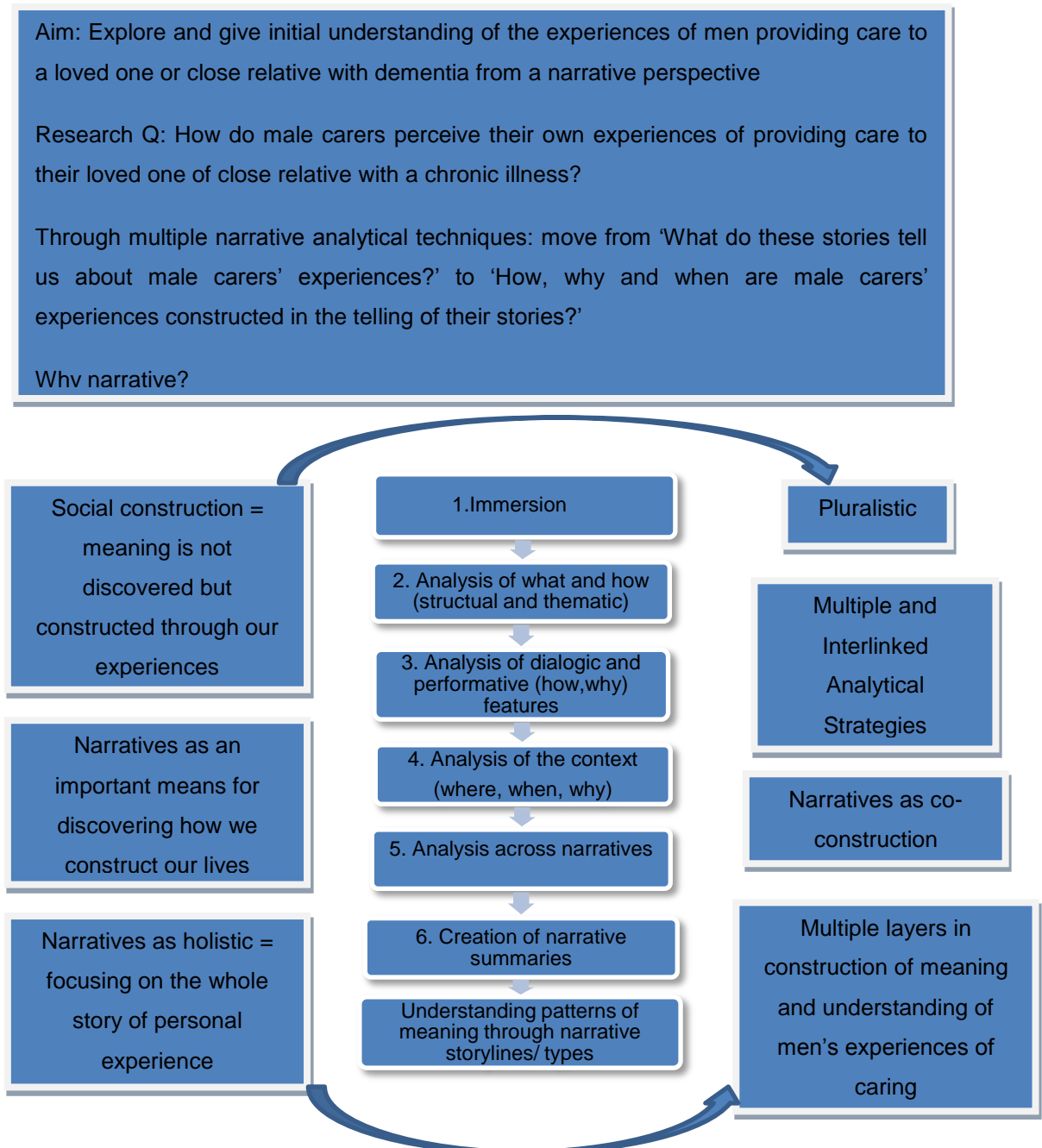
Hiles & Cermak (2008, p. 144) wrote that '... in narrative analysis we must focus on both the what and the how of the re-telling, upon both the story that is being told as well as the way in which it is being retold'⁷⁷. Therefore, analysing the men's stories as meaning making processes of their caregiving experiences required me to focus on a number of aspects. I examined the stories told in terms of their content, form and function (Halliday 1973), while keeping the text as whole as possible, in seeking to answer my research question: *How do male carers perceive their own experiences of providing care to their loved one or close relative with dementia?* In other words, I was interested in how the narrators made interpretations in their stories (Frost *et al.* 2010, p. 445). Similar to other narrative work completed by Hennings *et al.* (2013), I was interested in exploring both what was said and how it was said, keeping a focus on the whole story so as not to lose its temporality or the person within the story. I also considered the context of each story (Frost 2009). Following Riessman (1993, 2008), I too was interested in how men's stories of caring may be silenced, contested or accepted. I applied a number of models of narrative analysis in a flexible manner following on from Frost (2007), in order to answer the following questions and in so doing, uncover the multiple layers of meaning within the stories:

1. The content of the stories told – the *what* of the story
2. The way the stories are structured/ formed – the *how* of the story
3. The function of the story is being told in a particular way – the *why* of the story
4. The context in which the stories are being told – the *where* and *when* of the story

⁷⁶ Over the coming sections, as well as the chapters which follow, I will also to demonstrate how I had to deal with a transformation of emotions, as well as moral and ethical issues as I analysed the data.

⁷⁷ Coffey & Atkinson (1996) similarly suggested that narrative analysis is as much about 'how things are said' as about what is said' (p. 77).

Figure 5.2: Development of My Narrative Analytical Framework



I have included above the process of narrative analysis that I drafted and used as a rough guide as I began analysis. This became my analytical framework (See Figure 5.2). However, in practice, the questions that I came to ask of my data were constantly developing as I

worked with the narratives. Like others, such as Gallas (1994)⁷⁸, I did not decide on which categories of information were relevant beforehand, nor did I predetermine the questions I was going to ask of my data. Therefore, it is true to say that I found myself crossing over and back and between the phases, and applying as well as testing different techniques as I emerged myself in the men's stories.

Doucet & Mauthner (1998) highlighted that this part of the research process can be deeply uncomfortable, as choices about the direction to take are made and other avenues are left unexplored (as cited by Simons *et al.* 2008, p. 120). However, while feeling apprehensive, with '...no formulae or recipes for the 'best' way to analyse the stories we elicit and collect', I also felt nervously excited as '... one of the strengths of thinking about our data as narrative is that this opens up the possibility for a variety of analytic strategies' (Coffey & Atkinson 1996, p. 80)⁷⁹. I found myself 'stuck' at times in my interpretation and analysis of the men's stories and following the advice of Frank (2010), there were many times when I just went off – preferably for a walk – and tell the story again, as if I were practicing for a performance (p. 108). Indeed, my mantra as I undertook interpretation and analysis soon became: 'Listen and wait. You won't get it before you are ready, but readiness is an active achievement, including the achievement of patience' (Frank 2010, p. 108).

Holistic Nature of Men's Stories of Caring⁸⁰

Instead of selecting specific sections of text for analysis, as some scholars have previously done (for example Labov 1972), the starting point for my analysis was to understand what a narrative is in relation to the stories told to me. Thus, similar to the approach taken by Brown (1998), I took the decision not to distinguish narrative discourses sharply from other speech events that structural narrative analysts would define as arguments, question and answer

⁷⁸ The narrative work by Gallas (1994) studied children in a classroom setting, as cited by Riessman (2008, p. 135).

⁷⁹ I also found myself influenced by the writings of Frank (2010) (while specifically referring to dialogical narrative analysis), in seeing 'method' as a heuristic guide rather than a procedural guide (p. 72).

⁸⁰ Within the context of my study, I have used the terms 'narrative' and 'story' interchangeably, representing everything that participants chose to say to me about their experiences of caregiving. I found the definition of a story in narrative research provided by Ollerenshaw & Creswell (2002, p. 332) particularly useful in my own work, who viewed it as '...a first-person oral telling or retelling of events related to the personal or social experiences of an individual. Often these stories have a beginning, middle and an end'.

exchanges and other non-narrative discourse (as cited by Riessman 2008, p. 124). For instance, in several of my interviews, despite the 'open' approach that I took to conducting interviews, several participants relied on me to ask questions and so the layout of their 'narratives' may be viewed as quite different to others. Not all of the interactions took a narrative form per se, in some instances there were rapid question and answer exchanges between myself and the participant (Riessman 2008, p. 118). This was particularly the case where some men seemed unsure of how best to tell me their story. However, I felt that I should be respectful of the manner in which each story was been told as ultimately this is how the men attached understanding and meaning to their own experiences of caring in the context of dementia. I also believe that in searching for only strict narrative discourses as outlined by Labov & Waletzky (1967), I may have missed vital information which men spoke about (or did not speak about) and how they attached meaning to the manner of telling their story. Thus, I came to realise that what made my approach narrative was not the way that I asked questions in the interview setting, it is in fact the way that I regarded what was being told (Andrews 2013).

I was ultimately influenced in my decision of how to interpret men's 'stories' by the definition of a story provided by Lieblich *et al.* (1998, p. 7): 'The story is one's identity, a story created, told, revised, and retold throughout life. We know or discover ourselves, and reveal ourselves to others, by the stories we tell'. I therefore decided that it was necessary to analyse the stories that were told to me in a holistic manner rather than from a categorical perspective⁸¹. Hence I took the caring story of each man as a whole, and interpreted sections of the text in context with other parts of the narrative (Lieblich *et al.* 1998). In focusing on narratives as a whole, I preserved the narrative aspect of the story. I did not pick out chunks of text to analyse. My aim in doing so was to analyse the meanings within the context of the narrative, rather than taking excerpts out of an interview transcript and analyse these excerpts out of context as it were (May 2010). Viewing the narratives in my study as holistic in nature required me to pay attention to the sequencing of themes within narratives, thus foregrounding the 'specifically narrative aspects of texts' meaning' (Squire, 2008b, p. 50).

⁸¹ In such *categorical* analysis, short sections of the text are extracted, classified, and placed into categories for analysis (Elliott 2005, p. 38).

It also involved preserving ‘the sequential and structural features that are hallmarks of narrative’ (Riessman 2008, p. 12)⁸².

Key Phases in my Narrative Analytical Framework

In this section, I will illustrate the key phases that I undertook in the development of a narrative analytical framework for my data. As previously noted, I was strongly influenced by the work of other narrative researchers as I grappled to find my way through what felt like the unknown, at the time of embarking on analysis. For instance, I adapted the framework applied by Brown & Addington-Hall (2011) in their own narrative analysis of how people with motor neuron disease talk about living with their illness. Most notably I also included a consideration of the dialectic and performative features of the narratives. To this end, I was strongly influenced by Presser’s (2010) study in which she undertook a narrative analysis of men who had committed serious violent crimes⁸³. In addition, I could not ignore the temporal nature of the narratives in my study. Ultimately, I believe that each of the narratives represented men’s telling of their caring experiences – past, present or future, told at a particular moment in time, in a specific context, and in a co-constructed manner. While I actively shaped the stories told by men, the context (at both macro and micro levels) and its influence on the men’s narratives formed an important part of the interview data and were analysed, as well as the relations of power that existed between myself and the men (Presser 2010)⁸⁴.

In considering the work of Riessman (2008), my analysis ultimately encompassed a mixture of analysing the told (the content of what is said) and the telling (how it is told) of men’s narratives through various techniques of structural, thematic and dialogic/ performance analysis. However, I was also influenced by Phoenix and colleagues (2010) in seeing this process as ‘plural’ and not as ‘singular’. In the first stage of analysis, I applied a method of

⁸² By taking a holistic approach, my findings from analysis of each man’s story are presented in the form of case studies, which I have termed ‘narrative summaries’ and these are outlined in further detail in the following sections.

⁸³ I understand that Presser (2005) previously spoke of how here overall method was one of grounding theory in the data, and this is where our work differs considerably.

⁸⁴ I was further influenced by the narrative practice ideas developed by Gubrium and Holstein (1998) who recognised that ‘stories are analyzed as much for the ways in which storytellers and the conditions of storytelling shape what is conveyed as for what the contents tell us about lives’(p. 163). Indeed, as outlined later in this chapter, temporality would become vital to the storylines that developed across the narratives in my analysis.

thematic content analysis to understand *what* men said about their experiences of caring. In the additional phases of analysis, focus shifted to *how* the men account for their experiences, as well as asking *why*, *where* and *when*.

1. *Immersion:*

This involved firstly transcribing each of the sixteen interviews, a crucial step for me in beginning to listen to the stories, and thus immerse myself in the data (A full transcript of one of the interviews is included in Appendix 9). Transcription is more than a trivial, mechanical task (Elliott 2005). It is an integral part of the analytic process (Riessman 2008, Silverman 1993, Wengraf 2001, as cited by Elliott 2005).

In total, it took me over three months to complete the transcription process. I began this in June 2012 and it was completed in late September 2012⁸⁵. Following this, I began to read and re-read each of the transcripts⁸⁶. Such prolonged engagement through reading and listening to the audio, allowed me connect with men's stories. It also allowed me to connect with the men's stories emotionally and visually (Warnes & Daiches, 2011, p. 117). While I undertook the painstaking task of transcribing each of the interviews myself verbatim from the original recorded audio, I found this quite emotional at times. I felt like I was brought back to the time and context of each man's caring story. In addition, it ensured that I maintained quality, validity and rigour in my analysis (Lee *et al.* 2013).

In deciding to transcribe each of the interviews verbatim, I also included the audio of each recording and was able to attach this to each transcription file that I created with the assistance of Nvivo 12⁸⁷. Through including the audio, I was able to record potentially significant verbal material both expressed by the men and by myself that were captured on the research tape and which could not be captured through text, such as tone of voice, emotions, humour, pauses, utterances such as 'umms' and errs', false starts and any

⁸⁵ While I began to transcribe the interviews as I continued to gather data, at that stage I having completed 13 interviews, I wanted to do my best to avoid imposing on the generative process of the interviews of what I thought I had learned from other participants (Seidman 2013). However, I also recognise that pure separation of generating from analyzing data is impossible (Seidman 2013, p. 116).

⁸⁶ When reading for holistic content, an initial general reading of each text is helpful in allowing the meaning in texts to arise (Lieblich *et al.* 1998).

⁸⁷ I imported the audio of each interview as a media file into Nvivo.

interruptions (Elliott 2005). I was especially interested in recording any 'back channel utterances', given the style of the narrative interview I had applied. According to Elliott (2005), this occurs when the researcher uses words such as 'right' or utterances such as 'mmhmm' to indicate that the participant should continue and is being listened to (p. 56). Thus, as well as focusing on the content of what was said in transcribing the interview, I also started to note the manner in which it was communicated during this initial stage.

Listening to myself on the interview recordings also required me to begin to think critically about how my own presence and interventions may have influenced the men's choices of how and what to tell me of their experiences (Frost 2009). For instance, during this stage I also reviewed my own reflective field notes in order to help me situate the context of each interview, such as my feelings and reactions, men's emotional responses and body language. As Ochs (2011, p. 65) contends 'While a narrative may be crafted through one communicative channel... narrators may draw upon a multiplicity of communicative processes'. Through constructive reflexivity within my field notes, I began to question how I had influenced what was said to me. The role of 'I' in the stories also became important and I began to question how much do I include myself? Regular engagement with my supervisors was crucial as I had many questions both of my data and of myself. In addition, I met regularly with an informal network of fellow PhD students. Thus, this stage of 'immersion' was more than a simple or routine task (Elliott 2005, p. 57)⁸⁸.

2. *Analysis of Narratives:*

The formal 'analysis' of each of the sixteen men's narratives took place over four interlinked sub-stages that will now be discussed in turn, namely:

- a) Analysis of the *what* and (initial) *how* of Each Story Told (Structural and Thematic)
- b) Analysis of Dialectic and Performative Features (*why, how*) of Telling
- c) Analysis of Context (*where, when*) of Telling
- d) Creation of Narrative Summaries

⁸⁸ The continuous reflections that I undertook both on the men that I spoke with and on my personal conduct in the interactions we shared are reflective of Denzin's (1971) work on naturalistic approach to inquiry. They are also part of the research data.

a) Analysis of the *what* and (initial) *how* of Each Story Told (Structural and Thematic)

During this stage of analysis I engaged with a range of aspects within men's narratives that helped to shape their caring experiences. The first step was to examine the 'what' and (initial) 'how' of each story. To this end, I identified the main plots, themes and overall content of the stories told (the what's). At the same time, I also undertook an initial exploration of the 'how's' – the ways in which each story is formed, told and structured, so that both thematic and structural analysis techniques were applied (Sparkes, 2005). The way that the narratives were put together was examined during this stage in conjunction with looking at the content of the narratives in order to understand what meaning is made of men's caring experiences (Elliott, 2005). According to Holloway & Freshwater (2007a, p. 85): 'Structural analysis focuses on the way in which a story is put together'⁸⁹. I decided against applying a formalised approach which explicitly examines the specific relation between the form and content of narratives in the context of interviews⁹⁰ (Elliott 2005, p. 50). Instead, among others, during this stage, I found myself influenced by the work of McAdams (1993) who advocated for three elements to be considered in examining narrative content and form - narrative tone, imagery and themes:

1. Narrative tone – I examined both the *content* of the story and the *form* or *manner* in which it is told. In identifying the narrative tone, I looked at what men reported in relation to the experiences told but also the *way* in which this was been done. For example, a person's tone could be predominantly optimistic or pessimistic. I also took note of any unspoken pauses and hesitations within the transcript. In addition, I highlighted incidences where men appeared to be telling me 'stories within stories' (Frost 2007). In examining tone alongside theme, I was able to establish points at

⁸⁹ I will revisit the 'structure' of men's narratives at a later point in my analysis, specifically in relation to dialogic and contextual factors.

⁹⁰ The Biographic-Narrative Interpretive Method (BNIM) approach to narrative analysis was developed by a group of researchers at the University of East London, Centre for Biography and Social Policy (Chamberlayne & Rustin 1999; Chamberlayne *et al.* 2000 as cited by Elliott 2005). What is distinctive about this method is that it advocates producing a summary of the content of a biographical interview (i.e. the 'life lived') and a separate summary of the form of the biography as told in the interview, and then requires the analyst to examine the connection between these analytic documents in order to produce a case history documenting theories about how the two are related (Elliott 2005, p. 50).

which the tone of men's voices emphasized key themes within their narrative. Listening to the pitch of men's voices allowed me to pick up points in their story at which their mood changed. At the same time, I was also able to identify incidences whereby *what* was said was in conflict with *how* it was said.

2. Narrative imagery – every personal narrative contains and expresses a characteristic set of images. To this end, I explored the unique way in which imagery was employed by men to make sense of their caring experiences, paying attention to the kind of language they used in describing and characterising events. Firstly, I examined each man's narrative for use of figures of speech and metaphors that provided vivid imagery of their caring experiences (Frost 2009). McAdams (1993) notes that a focus on imagery may provide clues to personally meaningful symbols. Like other narrative researchers such as Frost (2009), I found the metaphors that men used in their stories striking to hear⁹¹. Frost (2009) points out that metaphors are grounded in socially shared knowledge and conventional usage, and they can reveal shared cultural and social understandings of knowledge (p. 12). Specific examples of the metaphors men used in their stories are provided in the chapters that follow.

Secondly, I examined the personal photographs that formed part of men's' stories. In data collection, men were invited to bring personal photographs into the interview, in order to encourage them to tell me their story. According to Harrison (2004, p. 133) 'Photographic images have material and symbolic significance that act as important vehicles of communication'. While three men showed me personal photographs during their interviews, several others proudly showed me photographs following the completion of the interview. Personal photographs were also clearly visible as I sat in men's homes and this was included in my field notes.

3. Narrative themes – I also identified the dominant themes, patterns and motivation to what was told in each man's story. Crossley (2007, p. 141) believes that it is useful to look at both imagery and themes together.

⁹¹ According to Coffey & Atkinson (1996), metaphors are figurative uses of language, which at their simplest are 'devices of representation through which new meaning may be learned' (as cited by Frost 2009).

In examining narrative tone, imagery and themes I hoped to initiate an exploration of the multiple layers of understanding to the men's stories of caring. In practice, I went through each interview transcript individually, on a number of occasions, firstly by reading the transcript and on subsequent occasions both listening to the audio and reading the transcript simultaneously. As I read and listened to each man's story, I systematically picked out the segments relating to tone, imagery and themes. I then assigned each element a title and defined and described it in turn. I used Nvivo as an organising tool to assist in the efficiency and transparency of my analysis through managing the vast amounts of data I had gathered (Bazeley 2007). In Nvivo, I assigned each element that I created as a 'free node', providing a link to both the segment of transcript and audio from the original recording. In focusing on these three elements or dimensions, my aim was to avoid examining the stories simply for content. I subsequently constructed an inventory of the narrative elements that I gathered in which each free node was assigned under one of three parent nodes in Nvivo, namely narrative theme, narrative tone, and narrative imagery (see Appendix 10).

My decision to use Nvivo as an organising tool in my analysis was not without serious contemplation. I found myself questioning whether there was a danger of losing the focus of my inquiry in using computer assisted qualitative data analysis (CAQDA). For example, it has been argued that the use of CAQDA can lead to artificial treatment of data and also holds the potential to lead to theoretical inconsistency due to the high levels of quantification often required (Sarantakos 2013). Some qualitative researchers may find themselves in a 'coding trap', labeling and coding too much and too quickly (Seidman 2013). However, I was attracted to using computer software to assist me in managing and organising the enormous amount of words that were generated from the men's stories (Seidman 2013, p. 132). Having discussed this with my supervisory panel, I decided to use Nvivo 'loosely' in that I did not allow it to guide my analysis. I was interested in how it allowed for flexibility in my analysis (Sarantakos 2013, p. 396). It assisted me in ensuring efficient and accurate analysis as computers do not make mistakes in recognising or counting codes (Sarantakos 2013, p. 396).

Slowly, I began to see what men were saying and the manner in which they were speaking in their narratives. Crucially, through this process, I became aware that the structure of their narratives may provide fundamental meaning, rather than just the words told. In beginning to identify underlying narrative structures, it encouraged me to pay even closer attention to the stories the men told. However, taken by itself, I would have failed to illuminate the way in which narrative structures were also 'dynamic, fluid and accomplished in social action'

(Phoenix *et al.* 2010, p. 6). Thus, the next stage in my analysis was to begin to examine the dialogic and performative features of telling as well as the context of the narratives.

b) Analysis of Dialogic and Performative Features (*why, how*) of Telling

According to Presser (2010), social scientists need to write themselves into analysis, especially if undertaking interviews, because they have co-constructed the data. I have jointly created the story together with each man not only through the questions asked, but also through the interaction and the power dynamics within that interaction. While I carefully listened to each man's story in analysis, I brought my own interpretation to their material. In so doing, I took interpretative authority in structuring understanding (Josselson 2011b). However, I was once again left feeling apprehensive as I contemplated how best to proceed. As Frank (2010, p. 74) points out 'dialogical narrative analysis refuses to say, as too many methods do effectively say: *these are the rules; here are the steps to implement these rules; follow my direction or suffer rejection*'. Instead, it is a practice of criticism that seeks movements of thought, posing questions and my role was to decide which of these questions were the most useful to emphasise (Frank 2010, p. 74). Riessman (2008) highlights that unlike structural and thematic approaches to analysis, meaning does not reside in a speaker's narrative, but in the dialogue between speaker and listener(s) (that is me), investigator and transcript, and in text and reader (p. 139). According to Frank (2010) 'Dialogical narrative analysis studies the mirroring between what is told in the story – the story's content – and what happens as a result of telling that story – its effects (p. 71-72). Riessman (2002) drew on Goffman's conceptualisation of 'face' and Langellier's (1989) notion of performance narratives to argue that the narrator performs a preferred identity during a social interaction such as an interview, and the identity that is accomplished is situated in that particular social interaction. In taking a dialogic/ performative approach to analysing narratives, Riessman (2002) highlighted that the analyst is therefore able to consider the social positioning of the narrator, that is how the narrator chooses to position himself or herself in relation to the audience, characters, and events. Therefore, Riessman (2008, p. 105) contends that '...if thematic and structural approaches interrogate 'what' is spoken and 'how', the dialogic/ performative approach asks 'who' an utterance may be directed to, 'when' and 'why' that is, and for what purposes?'⁹²

⁹² Literary theory has also informed dialogic/ performative analysis and Riessman (2008) points to the work of a Russian literary scholar Mikhail Bakhtin, whose concepts have influenced thinking on dialogue. According to

Taking this into consideration, I began to reconsider the narrative elements identified in the above stage and re-read each man's story, this time focusing on the relational and performative aspects to examine what kind or type of story was being told (Presser 2010). In practice, I considered how I was positioned in relation to what was being told to me and how I responded to it. There is no doubt that the narrative accounts in my study were co-constructed. While men were the narrators of their stories of caregiving (Chase 2008), I influenced what was told to me, how it was told and also how the stories have been analysed. Indeed, throughout the development of my study, the philosophical framework as well as background, the context of both time and history all influenced the story that was told. Ultimately, I understand that as a researcher, I have had an impact on each stage within the research process. As stated from the outset of my thesis, I have always been interested in other people's stories and the empowering potential of working with people and not just for people, in gathering evidence-based research. For instance, the principle of user involvement was integral to the open-ended conversation I held with a group of four male caregivers as part of the pilot data collection phase.

At the same time, men's stories about their caring experiences are partial and positioned. Both their telling as well as my listening and interpretation are all influenced by wider culture, as well as values and beliefs – both men and myself are socially and culturally positioned. Thus, focusing on the performative aspects of men's narratives of their caregiving experiences, required me to not only focus on matters internal to the individual, but also concentrated on the interactional and institutional domains associated with male caregiving (Phoenix *et al.* 2010). There is no such thing as impartial telling nor is there unbiased listening. According to Sparkes (2005):

Asking *how* questions about the narrative initiates reflection on the performative dimensions of stories and to the manner in which they are artfully constructed for particular purposes at particular times, in specific contexts. Thus, rather than ask 'what does the story tell us about X?' the question becomes 'how is X constructed in the telling?' (p. 203).

Bakhtin's view, narratives are polyphonic – they are multi-voiced; the author (speaker) does not have the only word as authority over meaning is dispersed and embedded.

Therefore, I revisited the inventory of narrative elements I had earlier constructed, in light of the dialogical and performative features of each story identified during this stage. I posed the following questions of each story, advocated by Phoenix *et al.* (2010)⁹³:

- Why was the narrative developed that way, and told in that order?
- How does the participant locate himself in relation to the audience, and vice versa?
- How does the participant locate characters in relation to one another and in relation to himself?
- How does the participant strategically make preferred identity claims?
- What other identities are performed or suggested?
- What was the response of the listener/audience, and how did it influence the development of the narrative, and interpretation of it?

In answering these questions of each man's story, I decided to undertake a similar line of inquiry used by Presser (2010). For example, in examining the 'how' of the stories in her study, she analysed the coherence of the narratives and also the interaction between herself and the men she interviewed in order to capture the flow of the interview. During this stage of analysis, I examined the consistency and logic of each whole narrative. In order to achieve this, I undertook a similar technique to Presser (2010) examining reasons as to what was told, and what appeared to be going on between myself and each man (p. 2075). In listening to the recordings once again, I also took note of incidences where I may have influenced what was said, thus examining my own role as a collaborator in producing the men's narratives. I considered how I may have guided the interview, for example through interruption or introduction of a new topic (Frost 2009). Thus, my own reflexivity and intersubjectivity was particularly important at this point, as I began to examine the dialogue between the researcher and researched, the text and reader, the knower and known (Riessman 2008, p. 137). Narrative researchers have also previously spoken of how they had to remain reflexively aware of shared knowledge and understandings with participants and how they were conscious of withholding their own story (Frost 2009). In my case, I was

⁹³ Riessman (2003) advocated the performative approach in relation to studying illness narratives and following her line of inquiry, Phoenix *et al.* (2010, p. 6) suggest that performative analysis asks these questions.

conscious of while at one end, men viewing me as a women in my late 20's (at the time) with perhaps little experience of informal caring, while in fact having a knowledge of both the policy context surrounding caring as well as personal experiences. In my methodology chapter, I spoke about specific strategies I undertook to maintain a balance between insider and outsider while collecting data. Acknowledging this within my field notes at the time of interview proved crucial as I returned to the information I had documented during this stage of analysis⁹⁴.

While I had specifically examined narrative tone during the initial analysis, at this point, I once again began to look at the structure of the narratives more closely with the performance genre in mind (Riessman 2008, p. 112). The words and styles that men had selected to tell me about their caring experiences were interrogated further (Riessman 2008, p. 137). For instance, I examined each narrative for the existence of certain linguistic features or 'elements' such as repetition, pauses and expressive sounds as well as emphasis on certain words. Following the guidance of Riessman (2008), such features appeared to be important ways in which men appeared to 'dramatise' and perform their stories. Significantly, I also looked at how I too may have 'dramatised' these stories, and linguistic features that I used. Thus, while not looking at the structural framework proposed by Labov and colleagues (Labov 1972, Labov & Waletzky 1967) per se, some similarities are apparent as I agree that certain elements existed in men's stories, particularly in providing meaning of their caregiving experiences in the context of dementia.

Through the creation of memos of each participant and the co-construction of the accounts, Presser (2005) came to see the accounts provided in her study as a 'situated, collaborative negotiation of narrated identities' (p. 2070). In my own analysis, I began to construct a detailed narrative summary of each man's story. This incorporated the what's, how's and why's of their caring experiences in the context of dementia. Thus, I understood that the men's narratives were not fixed; instead they were a dynamic and fluid process composed for a specific audience (Riessman 2003, Sparkes 2005). From a dialectic stance, I also had to recognise that in each interview there were at least two people immediately involved in the

⁹⁴ I will return to outline how I was on a journey of continuous self-reflexivity throughout my thesis in Chapter 8.

conversation (i.e. myself and each man), but at the same time there was also an orientation towards future wider audiences (Stephens 2011, p. 67)⁹⁵.

c) Analysis of Context (*where, when*) of Telling

Unlike exemplars of structural narrative methods, context was given considerable attention in my analysis (Riessman 2008, p. 116). Frank (2000) has referred to the *storytelling relation*. By this, he means that data emerges from within the relation between the teller, the listener and the context of the telling of the story. Context was thus a key analytical concern of mine, through being attentive to the *where's* (for example, place) and *when's* (for example, time) of each story (Holstein & Gubrium 2004). Presser (2005) advised that the context of the interview should be included as data, including resources that allowed for it to take place (p. 2069). The wider social context within which a narrative is told cannot be ignored either. For instance, in Plummer's (1995) work on the changing shape of the 'coming out' stories that gay men of different ages tell, he proposed that the stories people tell about a particular issue reflect how that issue is viewed in society (as cited by Griffin & May 2012)⁹⁶. For Hydén & Antelius (2010), the narrative text gets its life through storytelling and it is therefore imperative to take social and cultural contextual aspects into account in the analysis of narratives (p. 600).

During this stage, the conditions under which the interview took place, the time of day, and the degree of formality established were all considered (Clandinin & Connelly 2007). A close reading of contexts involved including myself as an active participant in each narrative (Riessman 2008, p. 116). Thus, as I examined the context of each of the narratives, I also considered the performative dimensions of the narratives⁹⁷. Phoenix & colleagues (2010)

⁹⁵ Indeed, I also recognise that the readers of this thesis and my research study also play an important part in the interpretive process. The audience read the narrative texts from my work in numerous ways as they bring them to interpretation, their positioned identities and cultural filters (Riessman 2008, p. 111).

⁹⁶ In earlier work, Plummer (1983) persuasively argued that studying an individual biography does not bring with it the isolated individual, but rather an awareness of the individual *in society* (as cited by Elliott 2005, p. 39).

⁹⁷ Plummer (1995) pointed out that there were two approaches to examining narratives in its social context. First, there are those who are most interested in the 'stream of joint actions in local contexts' (p. 24), who are researchers that focus on specific interactions between individuals as they narrate and attend to stories. Second, there are sociologists whose focus is on how narratives are 'bound into wider negotiated social worlds' (p. 24) (as cited by Elliott 2005, p. 50). For me, I believe that I examined both levels of the narratives in their social context.

posit that it is vital to examine the influence of investigator, setting and social circumstances on the production and interpretation of a narrative. In relation to myself, who I am (in terms of my own gender, class and ethnicity) and my own role in the interaction were all considered in how I may have shaped what the participants said (Griffin & May, 2012, p. 447). For Murray (2008), a useful strategy is to keep a detailed log of each interview recording as much detail as one can recall about the interview setting. As a consequence, I revisited my own reflexive field notes from each interview once again in light of the narrative elements I had proposed. It was important for me to remember that one part of a narrative cannot be understood in isolation or 'taken out of context' from the rest (Smith 2000, p. 328).

Like Presser (2010), I had an interest in both the macro and micro levels of the stories being told; the macro level – the broader social, economic and political context, and the micro level – the research context. I therefore also considered both levels of the context while preparing the narrative summaries of each man's story. I used thematic material that I had focused on in an earlier phase of analysis and located the men's narratives in broader historical and economic contexts. I noted how public issues and attitudes concerning male carers and informal caregiving in dementia were situated within their personal stories. Thus, I examined how the stories had been told relation to 'wider' stories⁹⁸. This therefore may have been a key way in which the men may have framed what they said to me. The argument for looking at collective narratives is that the social world is storied (for example Shotter 1993, Weedon 2004). We don't as individuals tell stories, but, there are stories about who we are as a social group, thus a key question in examining the context of each narrative was how are male carers viewed?

d) Creation of Narrative Summaries

Following steps a), b) and c) I created detailed narrative summaries of each of the men's stories incorporating the what's, how's, why's and when of each story. These narrative summaries were stored as memos in Nvivo. Through the use of this computer software, I was able to link the narrative summaries to the original audio recording of the interview. I once

⁹⁸ In fact, I believe that I had already begun to examine the wider narratives at play in preparing earlier chapters in my thesis such as the detailed review I had conducted on policy developments relating to informal caring and ideologies of masculinities which together demonstrated how men as carers are currently positioned in Irish society today. Such also helps in understanding the macro level context influences.

again used the work of Presser (2010) to guide my own analysis at this stage⁹⁹. For instance, in her analysis of the qualitative interviews that she had undertaken with men who had committed serious violent crimes, Presser (2005) created memos on each of her participants based on the original narrative. Like, Presser, my narrative summaries read like a running summary of, first, how the man's narrative was unfolding and, second, what was going on between myself and the participant. They also contained rudimentary analyses of the interaction (Presser 2005 p. 2075). While summarising each interview could be viewed as a tedious task, it was an essential part in the development of an analytic frame encapsulating all of the men's narrative accounts of caregiving (Murray 2008, p. 124).

3. *Analysis across Narratives*

In line with the steps taken up to this phase, I began to broaden my focus and compare and contrast the narrative elements of each man's story in relation to each other. This was the very essence of undertaking a narrative analysis; the stories told have meaning not only among themselves, but also in relation to other stories. The theoretical basis for doing so was social constructionism (Berger & Luckman 1966). The focus for me during this stage was therefore on answering how men narrate their caregiving experiences (that is how do they construct their experiences of caregiving?). Commonality across each of the man's narratives was therefore examined (Brown & Addington-Hall 2008) in relation to the narrative elements I had identified. In so doing, I also sought to understand how men created and displayed their meaning of caregiving in their stories, in a specific moment in time and a particular context, as well as for a specific audience (Riessman & Speedy 2007, Phoenix *et al.* 2008).

4. *Narrative Storylines/ Types*

In the final stage of analysis, I decided on how best to present my understanding across the men's narratives. To this end, I considered previous narrative work undertaken by Brown & Addington-Hall (2008)¹⁰⁰. It was during this stage that I faced the ultimate challenge in my analysis – all stories *do* something, they have a purpose and my task was to find out what it was the 'coherent directionality' (Riley & Hawe 2005). However, I also recognised that there

⁹⁹ Excerpts from several of the men's narrative summaries are presented in the following chapter.

¹⁰⁰ I have borrowed the use of 'patterns of meaning' from Brown and Addington-Hall's (2011) work which explored patients' experiences and how they talk about living and coping with motor neurone disease and this is discussed further in the following chapters.

were potential limits to what I *could* achieve in the timescale that I had. Thus, I had to decide to focus on particular aspects for the purposes of my final thesis. Regular discussions with members of my supervisory team were particularly useful during this phase.

Instead of trying to 'fit' the men's stories within particular storylines¹⁰¹, I took the decision to present common overarching 'themes' across narratives, which I viewed as patterns of meaning illustrating how men's stories of caring took place at a particular time and place and were co-constructed through dialogue. Nvivo helped me to visualise the patterns of meaning through the creation of tree nodes. During analysis, I was influenced by the work of Tom Kitwood in his now classic 1997 book *Dementia Reconsidered*. Kitwood (1997a) proposed, in contrast to theorists who had offered hierarchies of needs - a cluster of needs in caring for the person with dementia, with love as the central element for person-centred care. This cluster is closely interconnected, with one all-encompassing need – for love. Kitwood (1997a:81) proposed that it may therefore be helpful to think of five great needs which come together in the central need for love in dementia – for comfort, attachment, inclusion, occupation and identity. He argued that the fulfilment of one of these five needs involved, to some extent, the fulfilment of others and that their boundaries are blurred. The multiple dimensions of the narratives identified in my study are presented over the following two chapters.

Strengths of My Multi-Layered Approach to Analysis

The approaches which I took in my analysis were intended to make the most of the rich data I had generated by narrative methods (Simons *et al.* 2008, p. 128). However, I acknowledge that narrative analysis has come under scrutiny in some circles. For instance Atkinson & Delamont (2009) have argued that it is a common failing to imply that participants' voices 'speak for themselves' and narrative materials provide a privileged means of access to participants' personal experiences or their sources of self-identity (p. 311)¹⁰². However, in deciding to apply a variety of analysis techniques to my data through a number of interlinked stages and examining each of the men's stories through structural, thematic and dialogic and performance analysis, I have treated the narrative materials in my study 'seriously' (Atkinson

¹⁰¹ For example, Frank's (1995) narrative storylines in understanding chronic illness (restitution, chaos and quest); Gergen & Gergen's (1984) narrative forms (heroic, tragic, regressive, progressive); and Murray's (2000) levels of meaning (personal, interpersonal, positional and societal).

¹⁰² They believe that narrative materials should be instead recognised as forms of social action and they are based on socially shared conventions (Atkinson & Delamont, 2009, p. 315).

& Delamont 2009). For instance, similar to other narrative researchers such as Simons *et al.* (2008) who argued that the innovative use of iterative, sequential methods in their own analysis revealed greater complexity and depth of understanding of the phenomena than would have been achieved with one method alone (p. 120)¹⁰³. Like other narrative researchers such as Frost (2007) I too felt that no one model of narrative analysis alone answered the question of why the story was constructed in that way or what the intended message conveyed was (p. 4).

In applying several approaches to analysing my data, I have demonstrated a form of 'a within-method pluralistic approach to narrative analysis' (Frost 2009, p. 9)¹⁰⁴. Like Frost (2009), undertaking such a combination of approaches in the analysis of my data through the systematic manner which I have done so as outlined in this chapter, offers a form of within-method triangulation through encouraging the viewing of data from several perspectives (p. 24). I have not prioritised one narrative analysis technique over the other. Instead, I have privileged the men's narratives to guide me from one perspective to the next, and through which, multiple layers or constructions in understanding of men's experiences of caregiving have built up (Frost 2009, p. 24). The multiple layers that emerged following my own analysis will be presented in the key patterns of meaning in the following chapters. Indeed, Lieblich *et al.* (1998) emphasised that no story is one-dimensional in its voices and identity can have many components and layers. Significantly, like Frost (2009), using a pluralistic approach to analysis also provided me with pivotal access to both the spoken and unspoken 'sense-making' that the men brought to their caring experiences (p. 23)¹⁰⁵.

I was conscious of the need to demonstrate quality throughout my study, and saw this as a particular challenge which I faced in undertaking a qualitative piece of research, due to the implication that it may lack legitimacy when compared with the methodological standards and

¹⁰³ Simons & colleagues (2008) applied a sequential approach to their analysis of nurses' accounts of practice experience. Initially, they applied a method of thematic content analysis to understand what the nurses said about their experiences. In the second analysis, focus was shifted to how the nurses accounted for their experiences.

¹⁰⁴ While using the ideas of Frost (2009) as a template, the various strategies I applied to narrative analysis are different to those that she used in her study that explored the transition from first - to second-time motherhood among British, white, middle-class women.

¹⁰⁵ According to Frost (2009, p. 24) 'Pluralism respects the philosophy of narrative analysis and draws on its established methods to gain rich insight into the varied meaning the individual's world'.

rules of quantitative research. Indeed, I believe that the transparency, thoroughness and systematic nature of my analytical framework which I have outlined in detail in this chapter, positions it well in terms of meeting criteria for high quality assessment (Riessman 1993, Willig 2007, as cited by Frost 2009, p. 24). In addition, my decision to use Nvivo to assist in organising my data demonstrates the clear audit trail of process to analysis I undertook. I was also aware of the potential for contradictions arising in interpretation (Frost 2009). However, involvement and advice from my supervisory team throughout the interpretation process provided a further layer of accountability to my study (Yin 1989, as cited by Frost 2009). I have acknowledged my own presence and the effect which I had on the stories told throughout. Indeed, this has been made transparent by the application of rigorous analytical reflexivity as promoted in the work of Clandinin & Connelly (2000)¹⁰⁶. I also believe that the analysis of what men said but also considering observation and symbolic elements in my multi-layered analysis has been crucial to foment transparency in my study (Suárez-Ortega 2013, p. 193). For instance, I took into account what men wanted to say but did not in their stories, what was half said, what was said with gestures or facial expressions but not verbally, and what was narrated that at first seemed nonsensical (Polkinghorne 2007, Zylinka 2005).

Conclusion

The analytic approaches that I chose were aimed to offer a narrative interpretation on a number of levels of men's caring experiences in the context of dementia within a social constructionist way of thinking. In my narrative analysis, I have drawn upon the theories of social construction to interpret men's caring experiences. In this sense, I appreciate the personal significance of men's stories of caregiving as a reflection of the individual's internal world, whilst also considering the influence of the social and cultural context (McMahon *et al.* 2012, p. 1124). Following a social constructionist approach to meaning making, the analysis of narratives has demonstrated how men construct their reality in their interaction with others. Thus, following Frost (2007) as a critical narrative researcher I too have also demonstrated how I took careful consideration of the context and interpersonal relations of the story construction when drawing on its content and form to examine it. I believe that this was clearly demonstrated in how I moved back and forth in the plural focus of my analysis.

I was also aware that I brought my own subjective perspective to the objective, socially constructed text (Emerson & Frosh 2004). Similar to other narrative researchers who also

¹⁰⁶ I have earlier spoken about specific strategies I took in this regard in my methodology chapter.

held my own epistemological stance such as McMahon *et al.* (2012), narrative analysis allows for interpretations to be made at several different levels and an emphasis is placed on the ongoing construction of meaning (p. 1124).

As Suárez-Ortega (2013, p. 193) argues 'The researcher's task is to find the meaning in each narration'. Over the remaining chapters, I will outline how the multi-layered approach that I took in my analysis allowed me to explore the deep layers of meaning of men's caring experiences in a specific context and for a specific audience at a particular moment in time. However, it was always important for me to bear in mind that no matter what approach to narrative analysis was chosen: 'there is no canon, that is formal rules or standardised technical procedure for validation...Narrative truths are always partial – committed and incomplete' (Riessman 2008, p. 186).

Chapter 6: Contextualising Men's Stories of Caring in Dementia

Introduction

The aim of this chapter is to allow the reader to begin to build up an understanding of each man's story of caring for a loved one or close relative with dementia based on the multi-layered analytical approach outlined in Chapter 5.

I begin with a profile of the men whom I spoke with in my study and present key demographic information that I gathered. This information was collected through a demographic information leaflet before each interview commenced as outlined in further detail in the methodology chapter. Following this, I will present segments from the narrative summaries of four interviews. In so doing, I will provide both a context for the men's stories as well. Significantly, I will also illustrate how the key stages in analysis developed and were applied in practice. I took the decision not to include the full narrative summary of each man's story¹⁰⁷. In the final section, I will present an extended excerpt from one man's story to demonstrate the range of narrative strategies men used in telling me their story¹⁰⁸. For instance, men vividly described to me turning points at which significant change occurred to their situation and thus had an impact on their caring experience.

Profile of Participants¹⁰⁹

In total, I spoke with sixteen men in my study. The majority of men were husbands caring for their wives (n= 14). However, I also spoke with one man who was caring for his father and another man who was caring for his adult sibling. Fifteen of the 16 men were living with the person with dementia. Only one man had another individual living in the same house as both himself and his wife with dementia – and this was his son. Two men caring for their wives stated that they did not have any children. Demographic information was gathered on the number of children men had given the source of support that they may provide to them. Two men also stated that they were not the primary carer of the person with dementia, and instead

¹⁰⁷ In spite of protecting participants' confidentiality and keeping their identities anonymous, I was cautious of avoiding readers being able to identify the men I spoke with due to the in-depth nature of the interviews.

¹⁰⁸ I have included an additional example of turning points used in men's stories in Appendix 11

¹⁰⁹ A copy of the demographic information sheet is included in Appendix 8.

they shared caring responsibilities. This information is documented in Table 6.1 below. While I employed a number of recruitment strategies, I only spoke with one man who was living in a rural area¹¹⁰.

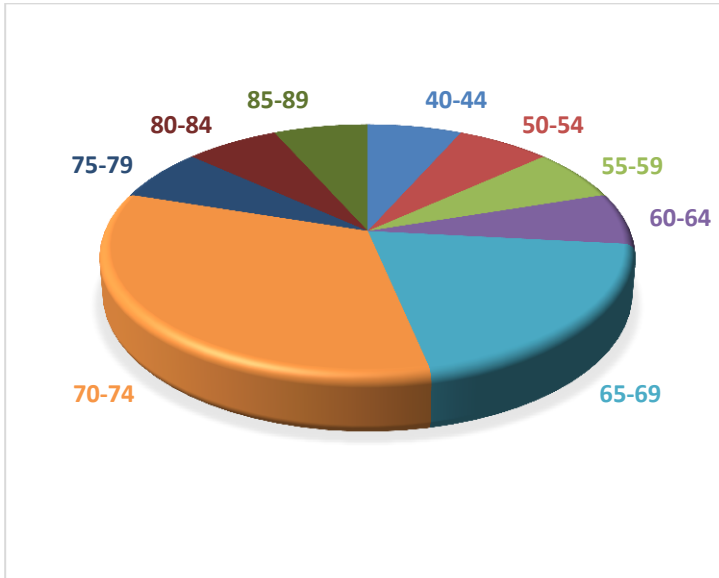
Table 6.1: Participants caring status and living arrangements

Name	Relationship with PwD	Location Living	Living with PwD	Others living	Primary carer	No. of Children
Michael	Husband	Urban	Yes	No	Yes	3
Cormac	Husband	Urban	Yes	No	Yes	7
David	Husband	Urban	Yes	No	Yes	3
Brian	Husband	Urban	Yes	Yes	Yes	2
Paul	Husband	Urban	Yes	No	Yes	-
Tom	Husband	Urban	Yes	No	No	4
					shared	
Luke	Husband	Urban	Yes	No	Yes	4
Connor	Husband	Urban	Yes	No	Yes	-
Noel	Father	Urban	Yes	No	Yes	-
Robert	Sibling	Urban	No	No	No	3
					shared	
Alan	Husband	Urban	Yes	No	Yes	2
Patrick	Husband	Urban	Yes	No	Yes	2
Stephen	Husband	Urban	Yes	No	Yes	2
Mark	Husband	Urban	Yes	No	Yes	2
Matthew	Husband	Urban	Yes	No	Yes	4
Donal	Husband	Rural	Yes	No	Yes	3

¹¹⁰ This may be viewed as a potential limitation, given that the urban/ rural divide of 56.8% and 43.2% identified in the 2011 Census of Ireland across the general caring population (CSO 2012).

The average age of the men in my study was 68 years¹¹¹. The most common age category among the men I spoke with was those aged 70-74 years old (n=5). However, the oldest man I spoke with was 85 and the youngest was 43, thus reflecting the wide age range. The Figure below (Figure 6.1) illustrates information on participants based on their age category.

Figure 6.1: Percentage of participants based on age category



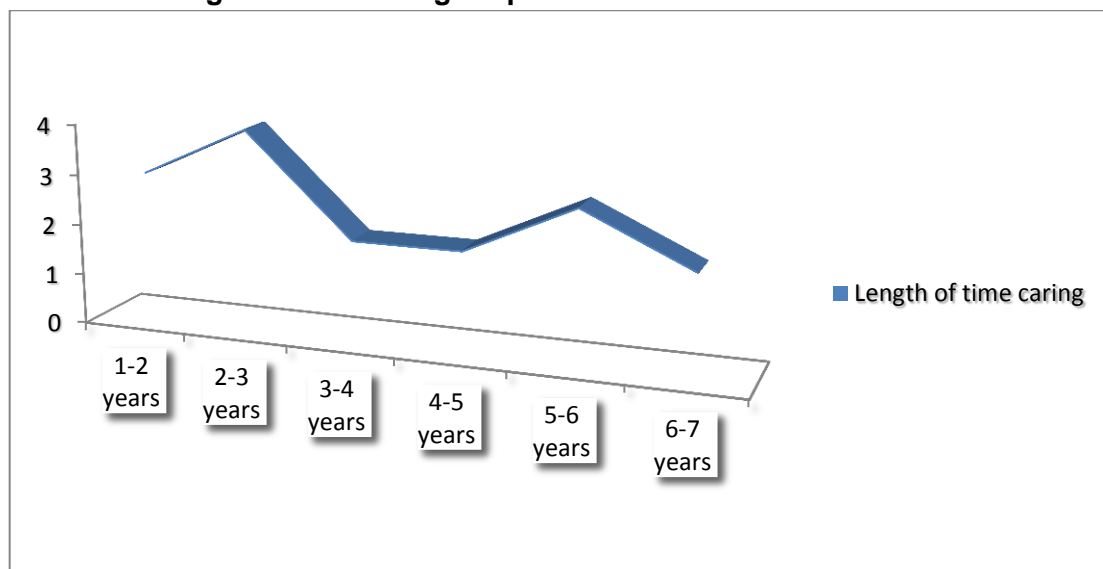
The length of time caring among the men ranged from 1 – 2 years to 6 – 7 years¹¹². The majority of men had been providing care for 2 – 3 years (n=4) (see Table 6.2 overleaf). Interestingly, those men caring 1 – 2 years also stated that they did not provide direct physical care¹¹³.

¹¹¹ In comparison with findings from Census 2011 on the average age of the generic population of carers across Ireland, the greatest proportion of carers was in the 40-55 age category for both males and females (CSO 2012).

¹¹² This reflected the longevity associated with dementia.

¹¹³ This may be due to the symptoms associated with early onset dementia.

Table 6.2: Length of time caring for person with dementia based on number of years



Only two men continued to work outside of the home while caring for their loved one or close relative with dementia. These men were ‘younger’ carers, at ages 43 and 51 years old respectively¹¹⁴. However, of men who were retired from paid work, four of those men already noted that their caring responsibilities had an influence on their decision to retire. In addition, one of men who was continuing to work outside of the home noted that he was no longer in a position to work on a full-time basis as a consequence of his caring responsibilities.

Narrative Summaries of Men’s Stories of Caring

Stories of caring in the context of dementia were beautifully told by the men. There were some very sweet and touching moments in their caring experiences illustrated in their stories. This was in spite of the multiple challenges that men were facing, and instances where they described how they sang together with the person with dementia, and the intimacy involved in bathing and washing. In presenting my findings I did not want to depersonalise these men’s experiences. One of the key stages in my analysis, as outlined in the previous chapter, was the formulation of narrative summaries of men’s stories of caring. In doing so I was able to contextualise the data I collected by situating it within a particular place and time (Clandinin & Connelly 2000). In providing a narrative summary of each man’s caring experience, I have provided the reader with a feeling of being in that space.

¹¹⁴ Thus, the fact that 14 of 16 men were not in paid employment may be associated with their age.

I was cautious of choosing to present only four men's narrative summaries in this chapter. However, I was guided by Frank (2012) and the narrative analysis undertaken by other researchers such as Brix and colleagues (2011). Choosing stories for focused attention is, according to Frank (2012, p. 43) based on 'practical wisdom gained through analytic experience'¹¹⁵. Brix *et al.* (2011) discussed four specific life stories in their own article like I have and they justified their decision as follows '... (they) were not chosen because they were considered as particularly representative of the sum of the interview material, but rather because of their particular distinctness and clarity with regard to the phenomena to be explored' (p. 2680). Following Ahlsen *et al.* (2012) and Riessman (2003, 2008), I have let the stories of four men (Paul, Luke, Patrick and Donal), in light of their vividness, indicate the development of my narrative analytical framework. In so doing, I hope to allow the reader to get a sense of the main features of each man's story and provide an insight into their experiences of caring. The summaries also illustrate the different dimensions and elements in the storylines that are evident as a consequence of my analysis.

I have tried in as much possible to privilege the men's words in the narrative summaries, limiting the extent to which I edited each story. In so doing, following Frost's (2007) line of inquiry, I view them as more than simple representations of events in their lives but as providing insight into the ways that they make sense of their caring experience (p. 19). The narrative summaries do a lot more than just provide an understanding of the flow of each interview. Both their telling as well as my listening and interpretation have been influenced by wider culture, as well as values and beliefs – both men and myself are socially and culturally positioned. There is no such thing as impartial telling nor is there no unbiased listening. The narrative accounts in my study have been co-constructed. I have influenced what was told to me, how it was told and also how the stories have been analysed. Indeed, throughout the development of my study, the philosophical framework as well as background, the context of both time and history also influenced the story that was told. Men's stories about their caring experiences are partial and positioned. Thus, the narrative summaries also incorporate a post-structural and post-modernist stance as the narratives produced were not only expressions of internal states, but were dialogically constructed (Squire *et al.* 2013). In addition, from a social constructionist stance, the meaning of this experience is constructed in

¹¹⁵ From this perspective, the interpretation and discussion of the four stories is informed by the knowledge developed through engagement with the stories of all of the participants in the study (Brix *et al.* 2011, p. 268).

a social world that is ever evolving (Crotty 1998). Given that my research is placed within an interpretivist epistemology, my own personal views and interpretations are also included within the narrative summaries¹¹⁶ (Sarantakos 2013).

Pullen & Simpson (2009) spoke of how they presented *fragments* of accounts from individual transcripts in their own empirical work. Thus, like Pullen & Simpson (2009), the key segments of the narrative summaries presented of four men's stories in this chapter are illustrative of particular issues that emerged in their story, while also resonating across other accounts from the wider data set of the sixteen men's stories in my own study (p. 569). Expressions of indecision, contradiction and confusion also emerged within men's stories and helped me form a picture of life that is complex and chaotic at times (Hatch & Wisniewski 1995). I chose these four stories as they were representative of the cross-cutting issues across the sixteen men. They illustrate the richness of the other stories but are also specific to a particular situation and context. The four men's stories will now be presented in turn¹¹⁷. Each of the narrative summaries demonstrates my analysis through including:

- What was said, how it was said (tone and pitch of men's voices) and crucially how sometimes this was in conflict
- Images and metaphors used
- Emphasis on certain words as well as repetition
- Pauses, silences and any interruptions
- Emotions
- Humour
- Hesitations, uncertainty and/or avoidance
- Performative features in men's stories
- Dialogue and exchange between myself and men
- Co-construction of interview – reflections on how I may have influenced what was said by men
- My own feelings and thoughts upon reflecting on excerpts from my own field notes
- Where the interview took place and information on the setting
- The trust built up during the interview between myself and the men

¹¹⁶ I understand that as a researcher, I had an impact on each stage within the research process.

¹¹⁷ To protect anonymity, pseudonyms were chosen to represent participants and their families.

Paul's Story

Paul is 43 years old. He has been caring for his wife who has dementia for the past two years while he continues to work outside of the home. This interview took place in Paul's office, about 5pm on a weekday. Having spoken over the phone previously, he told me that the best option was for me to come to his workplace. Going to his home was not an option he said as he did not want to speak to me while his wife was present. In addition, he could not come to see me as a consequence of time constraints. Indeed, it soon became very clear as Paul began to tell me his story that time management played a massive part of his everyday life. Paul was professional in his appearance, dressed in a suit. At first, it felt quite strange entering the office environment, almost as if I were the one being interviewed. I was invited to go into a room, which was the company's meeting room – and sit at a long table which I assume was where the board of directors met. I decided to sit at one side and when Paul came in he sat at the other. In fact Paul sat throughout turned to one side, never fully facing me - interestingly I feel maybe as if he did not want to let me in. Before the recording began, we were interrupted first by a staff member asking Paul to sign a document and then by a phone call from his wife. He simply said *You know I can't talk. I'm in work. I'll be home soon.* He then hung up, sighed and turned the phone on silent. He explained to me that his wife may ring up to 10 times a day, wondering where he is.

I found this interview very difficult at a number of levels which I documented at the time. Given the number of sensitive interviews I have conducted over the years, I was shocked that this was one of the first interviews where that I had to stop myself from crying in front of the participant. Paul was younger than the other men I had spoken to up to this point and so too was his wife. I began to think of my own personal situation as I was soon getting married. I also wonder with this interview taking place in his workplace, whether Paul thought he would be more assertive in this environment or perhaps able to hold back his own emotions.

The tone and pitch of Paul's voice throughout his story is significant. It was almost as if he was illustrating the tiredness and exhaustion he felt through his voice. At the beginning of his story, his voice appears quite strained almost as if I can hear the anxiety as well as his sadness for the current situation. He is also quite hesitant in beginning to speak with me. He begins his story by providing me with some background information, telling me that he has been married to his wife for eight years and it was three years later that his wife began to show signs that she might be unwell after she had decided to give up her job. However,

there was a sense of disbelief even up to the point of ignoring that she might have dementia, due to her young age, and it was felt that perhaps she might be suffering from anxiety. Indeed, the metaphor that he uses to describe his feelings at this point is very powerful of how his head went into the sand. He then becomes quite anxious in telling me about the eventual diagnosis of his wife's condition about a year ago, and he is heard tapping his hands against the table in the recording. In my original field notes I had recorded how he did this early on in his story, wondering perhaps as a sign of his discomfort or unease, thinking back to that time.....

Paul tells me how he must continue to work as he has a mortgage to pay and financial commitments that cannot be ignored. However, it is apparent that he is under considerable pressure as he tells me that while he may not be physically present to provide full time care for his wife during the day, in an emotional and psychological sense she is constantly on his mind. He tells me emphatically how he feels that he is never away from his caring role, emphasising certain words as if to stress his point.....

As he outlined the day to day situation, I was struck by the repetitive nature of daily life - the exhausting routine Paul details particularly between Monday and Friday where he must juggle working full time and caring for his wife. Even when at home, he has to catch up on work that he may have missed out on due to his caring commitments. While his tone is strained, in seeing it as a daily routine it is almost as if Paul has normalised his current situation. It may also be his way of being able to continue to care and cope in such a challenging situation. I found the comparisons that Paul makes with *shifts* when referring to the daily routine and the 'evening shift' of the weekend when he is at home and not working significant. It is almost as if he is comparing his current caring situation to a job, and again perhaps this is how he copes with his situation. While speaking about the weekend he also refers to the importance of trying to do things together with his wife and to get out, again perhaps trying to maintain a sense of normality. However, with a sense of regret, he recognises that this has become more difficult recently.....

I am interested in finding out about Paul's own health. He appears to be suffering from anxiety and stress and worryingly, he relates that he has near panic attacks at times. He also suffers from high blood pressure. However, he appears unable to acknowledge his own

health needs in light of the continuing demands to care for his wife. Thus, he says firmly that he feels fine.....

Given Paul's comments earlier about juggling work commitments and caring for his wife, I am interested to hear about his feelings on having to undertake household tasks. He speaks proudly about how he would have undertaken many such tasks before his wife's illness and that he did not see it as women's work. In his use of how creative thinking helps one manage, particularly in dealing with his dislike of ironing, I wonder whether he was applying skills from his working environment to cope with caring.....

It is at this point in his story, Paul's tone changes from the highly strained tone in the early parts of his story. In an almost inflated as well as proud way, he tells me how he has learnt how to straighten his wife's hair. He begins to relax, becoming more confident in telling me about his experiences and showing a sense of humour by laughing and joking at times. Using humour, Paul makes a number of significant points in relation to his involvement with his wife's personal care. The love which he feels for her is an important feature in ensuring that he protects her sense of dignity through continuing to take her to the hairdressers as before and have her hair done as she would have liked it. However, I wonder whether in doing so he may be also trying to maintain certain features that remind him of how his wife was before her illness, trying to hold on to a certain sense of normalcy as well as her identity. Paul may be trying to balance between these feelings as is evident in the wide range of emotions he displays through his tone of voice. He feels that he has surprised himself with how he has coped with the more intimate aspects of personal care. Paul feels that it has actually been a way in which they have bonded and can be close. This is particularly important especially given his earlier comments on how close himself and his wife once were and this is a 'new' way in which they can maintain a certain albeit different level of togetherness and thus maintain their identity as a married couple.....

While it is apparent that Paul is a well-educated man and is determined to continue his career in conjunction with caring for his wife, the need to keep working is crucial financially. Later in his story, he is highly critical of the lack of state support. He becomes bitter and in expressing his disbelief at the lack of support, particularly given the years his wife worked as a civil servant. There is an almost palpable sense of relief to have got his feelings off his chest and

in particular in his use of such language as *Fuck off* which he may not be used to expressing.....

Sensing that Paul's story may be coming to a close, while also conscious that he needed to leave a certain time, I decide to ask him how well he sleeps particularly given his earlier comments on worrying and his wife being on his mind. He tells me that when he goes to bed, he does sleep but he is exhausted during the day. He recognises that he should get more sleep but when his wife goes to sleep, he feels as if he can eventually have time to himself. This is a significant as well as poignant point at which to end his story as it powerfully illustrates how Paul is no longer able to spend time relaxing together with his wife and undertaking activities together. The sense of togetherness is very strong throughout Paul's story as if he too is on this journey of a slow gradual deterioration together with his wife. At another level, Paul's closing comments demonstrate his commitment and determination to continue in working in spite of the many challenges he faces in caring for his wife.

Luke's Story

Luke is 81 years old. He has been caring for his wife who has dementia for nearly the past two years. There are no other individuals living with them. I was conscious that upon beginning conversation he recognised my surname as my own grandparents live in the same large urban estate that he lives. This interview took place in Luke's own home on a cold October weekday at about noon, while his wife was at Day Care. Once I entered, I noticed how tidy everything was. I was invited into the front room and I noticed family photographs from various occasions over the years throughout the room. Luke was slightly nervous in speaking with me at first, asking for my reassurance. However, he appeared very capable of telling me his own story in a way that he felt comfortable. In my field notes, I noted how he placed heavy emphasis on certain words and spoke at a slow pace, almost as if he was carefully processing his thoughts and words beforehand.....

While support from his adult children was important in the early stages of his story, it also appeared to be a source of tension at times in terms of giving their opinion on her care. This was evident in the strength and determination Luke displays in emphasising that *he* would be his wife's carer.

I began to get a sense of the strong sense of closeness between Luke and his wife, as he tells me about life before dementia and now. This *couple* appeared to do almost everything

together, for example in telling me of holidays they used to go on with their camper van. There is a strong sense of nostalgia as he reminisces about such experiences. For instance, he sadly recalls how they did go away on holiday last year with the camper van as they had done many times before, and his wife just wanted to come home. With a sense of regret in his voice, he tells me that this has required him to accept that things are no longer how they used to be.

However, Luke follows this by telling me how it has now come to a stage where he has had to become closer to his wife through meeting her needs. While as a couple they are no longer able to express closeness as they previously did before dementia, a new closeness has developed, in needing to be more physically close to each other than ever before, through assisting his wife with her own personal care.....

As Luke expresses that through caring for his wife, he has become closer to her, he appears to view this as a positive side to his caring rather than the losses he experiences. It may provide him with a sense of meaning in his caring role and a strategy that he uses to help him continue in spite of the challenges....

Luke's vivid recalling of the first time he noticed that his wife believed that he was not her husband is extremely powerful. He sadly recalls that he now feels that he has two identities – with his wife's disorientation and confusion, and not recognising him as her husband. Despite feeling isolated at the time that his adult children were not around to help when this first occurred, Luke tells me how he calmly followed his wife out of the house one cold evening when she went to look for her husband. In so doing, he illustrates how he was protecting her and ensuring she was safe. While there are aspects of her disorientation that Luke finds strange to deal with, he feels that he is learning to adjust and adapt to her behaviour. His distinction between husband caring and carer when speaking about the bedroom and sleeping arrangements is very significant, in that it appears that he may want to separate the two. The bedroom was once the place where they would have been most intimate as a married couple before his wife was unwell. While he may be appearing to adjust to these changes in saying that it is something he must fit into, he also expresses a strong sense of loss in the tone of his voice.....

Luke tells me how he tries to maintain a certain routine in keeping up going to mass together, thus also maintaining a certain sense of normalcy. He speaks about how they go to a coffee morning together run through _____ (organisation name). He does however recognise that

they do not get out like they used to, and that they should get out more. Such feelings of isolation are displayed through the sense of sadness in his tone....

In dealing with his wife's challenging behaviour, Luke feels that there is a need to be strict with her at times. Showing authority may help him cope with challenges he faces in caring. It may also be related to the managerial aspects of caring he outlined earlier in his story in terms of needing to control his wife's behaviour. Luke appears to view his caring experiences as learning as he goes along and as his wife's condition slowly deteriorates. Thus, it is almost as if he is on a journey alongside her.....

Luke talks about the future once again in relation to acknowledging the gradual progression of his wife's condition. He somberly talks about *the ultimate stage of caring* as he sees that it will lead to her gradual complete dependence on him. I find his reference to it meaning that he and his wife will become even closer significant....

Luke downplays his own health during his story. In doing so, he may be trying to show his strength and ability to care for his wife, thus putting his needs second. He tells me how he has undergone major surgery on two different occasions over the past few years to put stents in his heart. Although towards the end his story, he shows a certain level of anxiety and uncertainty over his own health, expressing worry at his recent weight loss. Having talked to me for over an hour, he may have felt comfortable sharing these thoughts with me at this point. He tells me how his adult children tell him off for doing too much, sarcastically recalling how his son took away the ladder to stop him from painting the house.....

At this stage, the interview appears to be coming to a close and I give Luke the opportunity to add anything further to his story. Following on from earlier comments made, he expresses concern over how much his wife knows about her condition and how much she should know. In so doing, he demonstrates the love he has for his wife, wanting to protect her own sense of dignity.

Luke tells me how he would be lost without his wife, repeating and emphasising the word *lost* several times. Obviously he is therefore fearful of losing her. He once again reiterates how they were always together and how he cannot understand how his own adult son now travels a lot with work. This is powerful as while Luke is trying to hold on to his wife, in fact he has already lost part of her through her condition as she no longer recognises him as her husband at times. Luke appears to be trying to hold on to what he can of the life they once

shared together in continuing to care for her no matter what. He may also be fearful of being left alone, having never been alone and always together with his wife....

Patrick's Story

Patrick is 67 years old. He has been caring for his wife who has dementia for the past five years. There are no other individuals living in the house with them. Although he is now retired, Patrick was working outside of the home when he began caring for his wife. This interview took place at a location in Trinity College Dublin following a request that he would prefer not to meet me in his own home. Among my initial feelings upon speaking with this man, I noted in my field notes a lack of direct eye contact, as well as a heavy use of past tense when speaking. Humour also appeared important to his story in speaking about his caring experiences. Although Patrick seemed somewhat apprehensive when beginning to tell me his story, he had no difficulty in expressing his experiences. At times, I felt that I had to stop myself from interrupting him. I feel that he enjoyed the company associated with talking to somebody.

Patrick started his story by proudly telling me that he has been married to his wife for forty years. I straight away get an insight into the love he has for his wife in his expressions of admiration towards her appearance, recalling her toothy smile. At the same, these expressions are also tinged with a sense of sadness as apparent in the nostalgic tone of his voice....

When Patrick speaks of the suspicions that his wife may be unwell and how it took some time to get a diagnosis, it is as if he did not want it to be true that she had dementia. He speaks of the lead up to her diagnosis in a regretful manner, not wanting but knowing what the outcome would be. However, he expresses gratefulness at the assistance he has received, first through social workers and now through the provision of assistance in the home by a home support worker who looks after his wife several times a week....

References to balancing and carrying on caring while working outside of the home are then made as Patrick was working outside of the home at the time of his wife's diagnosis. It shows his sense of determination to keep a sense of normality. In telling me about his experiences of working while providing care, Patrick also illustrates how his own caring situation has developed alongside the gradual deterioration of his wife's condition, whereby at one point he was able to leave his wife alone and his now adult children may have been present. She then

began attending day care and following on from this, the home care support workers became involved....

Patrick's current caring experiences show parallels with a parent caring for a small child. His reference to being relieved when his wife behaves, such as when she is quiet sitting watching television and also how he is now required to spoon feed her is significant. Such examples also show how his wife's condition has slowly deteriorated. Patrick's reference to his wife's loss of weight despite his best efforts is also powerful. *Fading away* appears to symbolise a metaphor for the loss of her own identity, as a consequence of the dementia. Indeed, Patrick's emphasises heavily the words *fading away* as if to signify their importance....

Patrick explains to me how it is easier to control his wife's movements if she is in the same room as him. However, this may be a way in which he can maintain a certain level of normalcy and remain together as a couple in the physical sense, albeit altered.

Patrick recalls how he has had to work out different patterns to deal with his wife's behaviour. In so doing, he demonstrates how he has learnt how to cope through trial and error and the experience he has built up through caring. However, he almost regrettably notes how he is feels frustrated with current developments in his wife's behaviour such as when she becomes over active and vocalising or mouthing off as he puts it. He finds it a challenge to deal with....

Patrick's reference to the relief he feels when he can get his wife to sit down quietly and watch television is very powerful. At one level while he expresses relief, the manner in which he tells me about how he feels displays a deep sense of nostalgia. For instance, he puts on an old comedy that they would have watched before her illness and he feels for a moment it as if it sinks in and his wife laughs. It appears that it is also a way in which he can revisit the memory of being together and enjoying watching a comedy. By putting this on television, he can forget if only maybe for a brief period of time the current situation. It is as if he is using memories from the past to deal with the challenges of the present despite his wife's disorientation as a consequence of her condition....

Patrick then expresses his worries, for only a brief moment, over what would happen should he be unable to continue to look after his wife. He recalls feeling almost embarrassed at how he feels the general assumption of many people upon seeing himself and his wife together would have been that his wife would be caring for him. He quickly changes the subject to proudly tell me how he acknowledges that caring is difficult and how he has involved himself

in various research as well as fundraising for _____ (organisation name). This may be an important coping mechanism for Patrick. He admits that it is a way in which he can have some sort of an audience as he says that he is at home a lot on his own, with no one listening....

Patrick speaks positively about the social club run through _____ (organisation name) which he had gone to with his wife. However, he reluctantly recalls how he now no longer brings her due to her behaviour. He appears grateful as well as relieved in telling me that there are several other male carers who also attend the social club, so as he is not on his own as a male carer there. However, he feels annoyed at how the women within such groups dominate what happens, while men sit like zombies, not contributing to the conversation. Indeed, he feels as if he and other men are being judged by women in the group on their ability to provide care. Thus, Patrick also appears to be questioning his own confidence in caring for his wife as a man and is afraid of being judged by others. He expresses concern over what other people may think of male carers in general and their ability to provide care, which he feels are linked to wider expectations over roles of men and women in society. While at one end he appears to use humour, speaking in a sarcastic tone to get his point across, it is apparent that this is also a source of frustration for him....

At this point in his story, Patrick acknowledges that it is difficult to have patience with his wife at times. I find it significant that at this stage he feels that he has gained a certain level of trust with me so as to open up in such a way. It is as if he is acknowledging to me the real challenges he faces in caring that he may be afraid to admit to others, as a consequence of public attitudes of male carers not capable of caring especially given his earlier comments. The assistance he receives through the home support worker, day care and respite offer him a sense of relief to the frustration he is experiencing in coping with his wife's behaviour. However, while questioning his own confidence in caring, it is as if he is trying to justify that he is the best person to care for her. For instance, he expresses worry as well as frustration that others such as the home support worker and even his own adult daughter are not able to handle her behaviour like he can. Despite providing brief periods of relief, he feels that he is almost always on guard. He also expresses annoyance at the differing opinions of his wife's consultant and GP....

Patrick expresses with pride how he was recently asked to speak at a carer's event on his own experiences. However, he was offended at how one person did not like the way he was

speaking, as he feels that it is important at times to take a light hearted view of his situation. He notes that speaking at these events give him something to do and someone to listen to him. However, it may also be related to the loneliness and isolation associated with caring. This may be an indicator as to why he spoke to me for over an hour, providing him with a sense of company and a break from the isolating nature of everyday life which he describes in his story....

I feel at this point Patrick seems to be rambling almost, and I take a conscious decision to control the flow of conversation, in spite of the nature of the interview. I interrupt him in a polite way, thanking him for what he has shared with me and ask him to tell me a little bit more about his experiences of respite which he referred to earlier in his story....

There appears to be a sense of bitterness with Patrick feeling that in caring for his wife, it is as if he is still working to a certain extent. For instance, he regrettably tells me that while he retired several years ago, he must stick to a range of schedules and time constraints as a consequence of caring....

At this stage, I feel as if Patrick starts to ramble again and I decide to direct the flow of conversation. In light of his comments of feeling as if he was still working, I ask him to tell me a little bit more about when he was working....

However, Patrick appears to be juggling with his emotions of caring. While feeling determined and committed at one end, he expresses frustration and bitterness. He is also juggling with trying to adapt to life post his own working life - feeling a sense of loss for something that took up a huge part of his life for so long. In being his main responsibility, it was a way in which he constructed his own sense of identity. Therefore, Patrick appears to be experiencing multiple levels of this balancing act in his caring experience....

Overall Patrick expresses deep frustrations with the attitudes of others to both male carers and dementia, noting quite bluntly to me that at times he feels that he should carry a placard with him saying *yes I am a carer to someone with dementia*....

The image that Patrick portrays of leaving his wife alone, strapped in the car while he goes into the shopping centre and in so doing controlling any potential movement that she can make, is very significant. While he is doing his utmost to protect his wife, he tells me with a sense of unease and nervousness, feeling that he is being judged and almost as if he is

afraid to disclose such personal information to me. It does, however, show the level of trust he has in speaking with me at this point of the interview....

Patrick's recalling of at night when his wife would go to sleep and he reads beside her in the bed is very powerful. This may be something that, together, as a married couple they have done for years. It may create a sense of normalcy and a way in which he can hold on, both to the togetherness and identity as a couple, as well as their own identities as individuals before dementia....

Patrick then recalls a particular incident that happened that I feel goes some way in explaining why he feels so judged. On one occasion, he brought his wife to hospital as a consequence of a fall. He was questioned by a member of the nursing staff as to whether he had been drinking and so as to assume that it was his fault that she was injured as he was not behaving responsibly. Patrick's sense of constantly being judged and not feeling like other people believe that he is capable of caring for his wife as well as being pitied or looked down on, is a powerful theme that runs throughout the course of his story. It also shows his strong sense of determination and pride to continue caring in spite of the challenges he faces. While Patrick feels that he is being constantly watched by others, at the same time, he is in fact constantly watching his own wife as a part of his caring role....

The photographs of Patrick and his wife, as well as family members that he shows me towards the end of his story are crucial in allowing me to visualise the individuals which he has spoken about. The images give weight to the words he has spoken. In particular, the photos he shows me of his wife before she became ill detail the love and respect, as well as the qualities that he admired in her before dementia, such as her toothy smile and her youthful look. This is in stark contrast to the more recent photos of her that show the dramatic physical impact of dementia and his wife's almost gaunt look. He shows me with a sense of pride, pictures of his daughter with her new baby as well as a picture of himself with his new grandchild. The sense of togetherness between Patrick and his wife is obvious in the picture he shows me of them both at a wedding several years ago....

Patrick expresses a sense of sadness that his wife is unable to be involved with her new grandchild. In one of his final comments, he notes that she has herself become babyish as a consequence of her condition, thus acknowledging himself that sometimes it is like dealing with a child. While he is slightly sarcastic in mentioning that it is almost like dealing with a

bold child at times, a sense of sadness is apparent in his voice, in recognising that this is his reality.

Donal's Story

Donal is 74 years old. He has been caring for his wife who has dementia for the past two years. There are no other individuals living with them and he took early retirement as a consequence of his caring responsibilities. This interview took place in a local hotel suggested by Donal. He felt that this would be the easiest place for us to meet, as he lived somewhat out from the town and he was concerned that I would not be able to find where he lived. I was somewhat disappointed at not being able to visit Donal's home, as he had told me that he was living in a rural area and I would have liked to see where he lived. I wonder whether the isolation and loneliness which he outlines to me in his story may be heightened as a consequence of living in a rural area....

I found it quite powerful that on many occasions throughout his story Donal began his narrative by clearing his throat, perhaps as a way of preparing himself for what he was about to say....

I was somewhat shocked to hear about the serious health issues that Donal has been dealing with himself while also caring for his wife. In particular, Donal's recollection of how he had to ensure his wife was cared for while he was in hospital having a knee and hip replacement is powerful in illustrating how he is constantly on call in his caring role. He outlines incidences that have happened such as bruising on his wife when she was in respite, and the distress he experienced as a result. In so doing, he provides examples of his justification for not feeling comfortable with his wife being in respite, and she has not been since. He feels determined to continue to provide care for her at home as apparent in the emphatic tone of his voice....

Donal recalls how, in the beginning, it was particularly difficult for him to cope and adjust to caring. He feels that it is at this point that the carer needs support and he did not think he got this. Instead, he feels that it has taken years. This is significant as it is almost as if getting the support required has also been a gradual progression and a developing scenario for him, almost reactionary rather than proactionary, while at the same time his wife's condition also deteriorates and moves through different *stages*. Through his own hindsight, Donal speaks

about the need to be prepared for what lies ahead and what is expected of him and thus help carers like him to cope in their role....

Donals' reference to *once the in-house support goes in the evening he may not see anyone until the next day* is particularly powerful both in describing the isolation he is experiencing as well as the protectionary role he has assumed. I can almost imagine him, one eye open, watching his wife to ensure that she is ok, while reading his book late into the night and also trying to get some sleep. Thus, the protectionary feature of caring for his wife appears to have impacted on his own sleep, in that he is literally, constantly on call. (However, he does not say to me that that he feels that there is a direct link). While his wife may not physically require his assistance, he must protect against any potential dangers. At the same time, he is on his own....

Donals' reference to being like a new man when returning from a few days to himself and having in-house support while he was away shows the positive effect of time away from caring. It is as if his identity is somehow changed with a short relief from caring. Later in his story, he positively tells me about how he enjoys being in younger people's company, and when he is, he doesn't feel as old. This may be associated with him wanting company so as not to feel lonely or isolated. In addition, through speaking with younger people, he is able to forget about the ailments and ill health associated with old age. The example that he provides of going to a rugby match and being the oldest person there is like this is his own little space in which he can escape everything associated with aging and caring, and perhaps his identity of carer....

The photographs that Donal takes out to show me are a powerful tool in allowing me to understand his story further. He is extremely proud but also nostalgic as he speaks. Through the photographs, I gain images of his adult children as well as himself and his wife when they were younger. This strong sense of nostalgia is apparent later in his story when he reminisces about life before dementia, particularly when telling me how he and his wife began their relationship together....

The fact that his wife still makes him laugh despite her condition is important to Donal. This may be an aspect of what made him fall in love with her and the happy times they shared

before she was ill. It may therefore be something that he is still able to hold on to in spite of the gradual deterioration in her condition....

I was quite taken aback at how open Donal was in referring to aspects of life before dementia that he misses, in particular the sexual closeness that they once shared. The absence of such intimacy may have left him feeling isolated in his current role as carer, unable to be close with his wife as they had been before. Towards the end of his story he once again makes reference to the loss and loneliness he experiences in missing the female company of his wife, as was the case in life before dementia. With some hesitation and without actually referencing sexual relations, it is obvious that this is what he is missing. It is a cause for frustration as the ultimate way in which they were close and maintained a sense of togetherness is no longer there. In addition, the fact that they were married for a number of years and it was a common feature of their relationship that is now gone, may have resulted in the identity of their marriage being damaged.

While Donal speaks positively of the supports that he currently has in place and in particular he cites being able to call on neighbours if needs, he expresses anxiety over not being able to cope if something went wrong. As part of his protectionary feature of caring for his wife, he seems to feel that no one will be able to look after her as well as he can. However, at the same time he displays to me how he is dependent and stresses the importance of having in house support and a routine of carers in place, enabling help him to cope and also have time to himself. Thus he appears to be actually contradicting himself without necessarily making reference to it. This may be yet another level at which he is fighting or juggling with his feelings, almost the push and pull effect of caring that he is experiencing. Donal's feelings of assisting his wife in more intimate aspects of personal care are yet another example of how he is struggling or fighting this push-pull element of caring. In one sense, he expresses that he would sooner wish if someone else was available to do this for her. However, as part of his duty, he must ensure that all aspects of her personal care are looked after. His involvement may therefore be related to ensuring the protection of his wife's own dignity in spite of her condition. Donal also shows a sense of determination in suggesting no matter what needs to be done, he does it, who else will do it if he doesn't. Whether he feels unhappy about such aspects of care, he insists that he just gets on with it....

Turning Points

Many men's stories were peppered with key moments that stood out for them. For instance, they described specific occasions at which significant change had occurred in their situation and thus held a significant meaning. In analysing the narrative strategies men used in their stories, I termed these specific events: 'Turning Points'. According to Wennäs-Brante (2012, p. 22) 'A turning point is a break in the narrative, a 'before-and-after' incident that in some way contributes to a changed position or outlook'. Bruner (2001) claimed that at a turning point, individuals free themselves from their history, and he accentuated the difference between the present – the narrator's awareness – and the past – the protagonist's awareness (as cited by Wennäs-Brante 2012, p. 22).

I have included below an extended excerpt from the transcript of one man's story to outline a turning point that was vividly described. In so doing, I will also demonstrate how my multi-layered approach to analysis allowed me to examine not only what men said but of how they spoke, images and metaphors used, pauses and silences, dialogue and exchange that occurred, and my influence as well as wider cultural influences on the story told. Turning points thus provide evidence of the narrative strategies men used in telling their stories.

Matthew

Matthew is 74 years old. He has been caring for his wife who has dementia for the past five years. This interview took place in his own home midmorning on a week day. Matthew's wife was at a day care facility and he was at home alone. No other individuals were living with them. The following quote is directly taken from the story he told me:

...Eh she's very religious actually so she likes actually going to Mass. So we endeavour to go to mass every day. And eh I suppose it springs from her own family, they were very religious as well and the father and the mother were keen mass goers as is her sister. She has a brother a priest so eh religion is very strong in the family (Matthew, P15)

Yeah (Ann)

And she likes going to mass. I suppose eh I always had the suspicion that Alzheimer's was hereditary even though they say oh no it's not hereditary but I always suspected myself. And I think ____ (wife's name) case actually eh, ... I think there was a change in her condition when she became 60. 60 was a sort of turning point. When she was aged 60 (Matthew).

Do you think so? (Ann)

I do yeah. Up to 60..... (Pauses) (Matthew)

Ok (Ann)

You'd notice it sort of, if she put things away and she wouldn't know where she put them. Now to the outside observer you wouldn't notice any change at all what so ever, like you'd think she was as normal as anything but for instance, I bought her a Seiko watch. And eh... she hid the watch, put the watch away because she was going out to work in the garden, and we spent four months looking for the watch. And she had put it away for safe keeping and went out into the garden you know. So she has a habit of taking things, and hiding things and not remembering where she actually eh...put them. And that's one of the conditions that I noticed say when she became 60. And I told her sister, and her brother about the condition as well so they were aware that ____ (wife's name) was developing the symptoms of Alzheimer's and eh but as I say to the outside person you wouldn't suspect it what so ever, it was only if you were there with her constantly on a daily basis. And the other thing is in relation to cooking and things like that getting the proportions wrong, she was mixing bread and things like that, the portions were all wrong and eh that's another sort of tell-tale sign, and asking the same question 'over and over' again, is sort of the other tell-tale sign, that would tell you that there's something wrong with her. So eventually anyways I brought her to her own doctor, about 5 years ago, Dr (Doctor's name), they have a practice down in (place name) and sent her into eh there's a hospital in eh (place name) where she had scans done and eh just to see was there anything wrong with her brain but the scans didn't actually show up anything. And the other condition was that she always sort of had dry eyes and she was always sort of looking for sprays for her eyes and things like that. And I think, I don't know whether that was a symptom as well that she thought she had sort of dry eyes but we brought her to a number of eh people to have a look at her eyes to carry out a number of tests but eventually we got her a spray that she kept using constantly. But I don't think it was really dry because she hasn't used the spray in a long time (laughs a little). But eh eventually anyway, all the tests were negative and the scan didn't show any, anything wrong about her brain. So anyways her doctor eh about 5 years ago again decided well I'll send her to this doctor down in (place name) that looks after, a geriatric's doctor down in (place name). And we went for an interview down there and he interviewed her. And the interview was going fine and then he asked sort of a key question like eh well what day is it (wife's name)? And she said the 17th of September whatever, it wasn't that day at all. And he said ok, he let her go, maybe it's a

slip or whatever. And he asked her the same question again eh through the interview, and she repeated, gave him the same answer. The 17th of September was the day we got married. Not the current date (Matthew).

Ok (Ann)...

In the quote above, Matthew outlined key points in time that had an impact for him. The extended narrative demonstrates specific events that stand out for him in which the strong sense of togetherness he has shared with his wife has slowly slipped away. There is very little input from me – allowing Matthew to speak without disruption or prompting. He begins in a confident tone telling me of how he tries to ensure that his wife goes to mass, illustrating the protective features he assumes in providing care. It may also be an important way in which he is able to maintain a certain sense of normality and togetherness with his wife. Matthew appears to then become somewhat hesitant; pausing as he speaks about his suspicions of Alzheimer's being hereditary. This may also be a reflection of the wider narrative influencing Matthew's story – the cultural narrative of attitudes to dementia. In telling me that the general public would not notice any difference, he highlights the misunderstandings surrounding dementia in society. It also highlights how as his wife's dementia was able to remain hidden and away from public knowledge, he was able to continue with a certain sense of normality. However, his pausing may also be a reflection of the uncertainty that he feels about what he next tells me. For instance, in referring to his wife turning sixty as a turning point, Matthew recalls as how this was when he realised that she may be unwell. Indeed one occasion seems to stick out for him, as he regrettably recalls when his wife misplaced a watch that he had given her as a present. This was obviously a gift with a lot of sentimental value. In fact, Matthew pauses on several occasions to almost illustrate the sadness that he feels over her misplacing such an important gift. He made her own family members aware of this potential developing condition but importantly to the outside world her condition was invisible, thus developing further comments that were highlighted above. Matthew then reminisces about specific qualities relating to his wife's identity that stands out. For example, she was no longer able to continue to do the cooking. This was very important as he earlier told me proudly about how his wife had stayed at home while he went to work. In addition, his emphasis on the words 'over and 'over' illustrate his own frustrations that he was experiencing at the time of his wife constantly repeating herself.

Matthew then speaks quite fast as he tells me how he took his wife to the doctor and various tests were undertaken, as her symptoms developed further. However, it was not possible to give a definite diagnosis. He even laughs at one point, perhaps as a way of coping with the uncertainty surrounding his diagnosis. There is a sense of hope in his voice that perhaps his wife did not have dementia following inconclusive results. However, another incident stands out in his mind which he then regrettably recalls. He tells me how his wife confused the current date with their own wedding date when with the Doctor. This incident appears to act as a seal for Matthew, giving him a definite answer to his suspicions over her condition.

Focusing on men's turning points as in the above extended excerpt from one man's story - demonstrates how men described their caring experience as an enacted drama – full of a range of emotions that were constantly in flux¹¹⁸. Men were also taking on and performing new roles and assuming a new identity through their caregiving experiences. Thus, while there was dialogue taking place between myself and the men, men were also having their own internal dialogue as they spoke. This was expressed in the tone of their voices, as well as through pauses and hesitations. Turning points also provide an important guide as to 'continuity' of men's stories and caring experiences. Episodic changes over time were evident within men's' storylines, and these 'points of time' were described to me through turning points. The turning points highlight the temporal nature of men's caring experiences.

Conclusion

The aim of this chapter was to allow the reader to begin to build up an understanding of each man's story of caring for a loved one or close relative with dementia. A profile of the participants was first presented. I then outlined segments from the narrative summaries of four men's stories that I constructed as part of my analytical framework. Following this, I presented an example of specific events that occurred which held a significant meaning to men's caring experiences, namely through turning points. In so doing, I also provided further detail on the various narrative elements that made up each story which my multi-layered approach to analysis allowed me to examine.

The information in this chapter provides an important understanding of key steps taken in my analysis, while also allowing men's own story to remain as is. I have demonstrated how I took

¹¹⁸ Appendix 12 illustrates the range of codes collated with the assistance of Nvivo by providing an example of the coding density from the excerpt of one man's story.

each man's full narrative account, and examined how it was structured and connected to the broader context within the theoretical framework of constructionism (Murray 2008). Analysis across the men's stories was the final stage of my analytical framework, following which key patterns of meaning emerged. This is the focus of the following chapter.

Chapter 7: Men's Collective Narratives: Patterns of Meaning across Men's Stories of Caring in Dementia

Introduction

The purpose of this chapter is to present findings of men's collective narratives of caring in the context of dementia following the multi layered approach I took to analyse the data¹¹⁹.

Key Patterns of Meaning in Men's Narratives

Narrative research has been termed as 'a fundamentally hermeneutic enterprise' which aims '...to illuminate human experience as it is presented in textual form in order to reveal layered meaning that people assign to aspects of their lives' (Josselson 2011a, p. 240)¹²⁰. Through the multi-layered approach I took in analysis, I identified six key patterns across men's narratives in which they described their caring experience in the context of dementia, namely the all-consuming nature of caring, determination and pride, loss and sadness, admiration and respect, intimacy and closeness, and future. Multi-layered dimensions exist within each pattern of meaning. They are also interlinked and there is considerable overlap between them¹²¹. The interconnectedness between the patterns of meaning is outlined in Appendix 13.

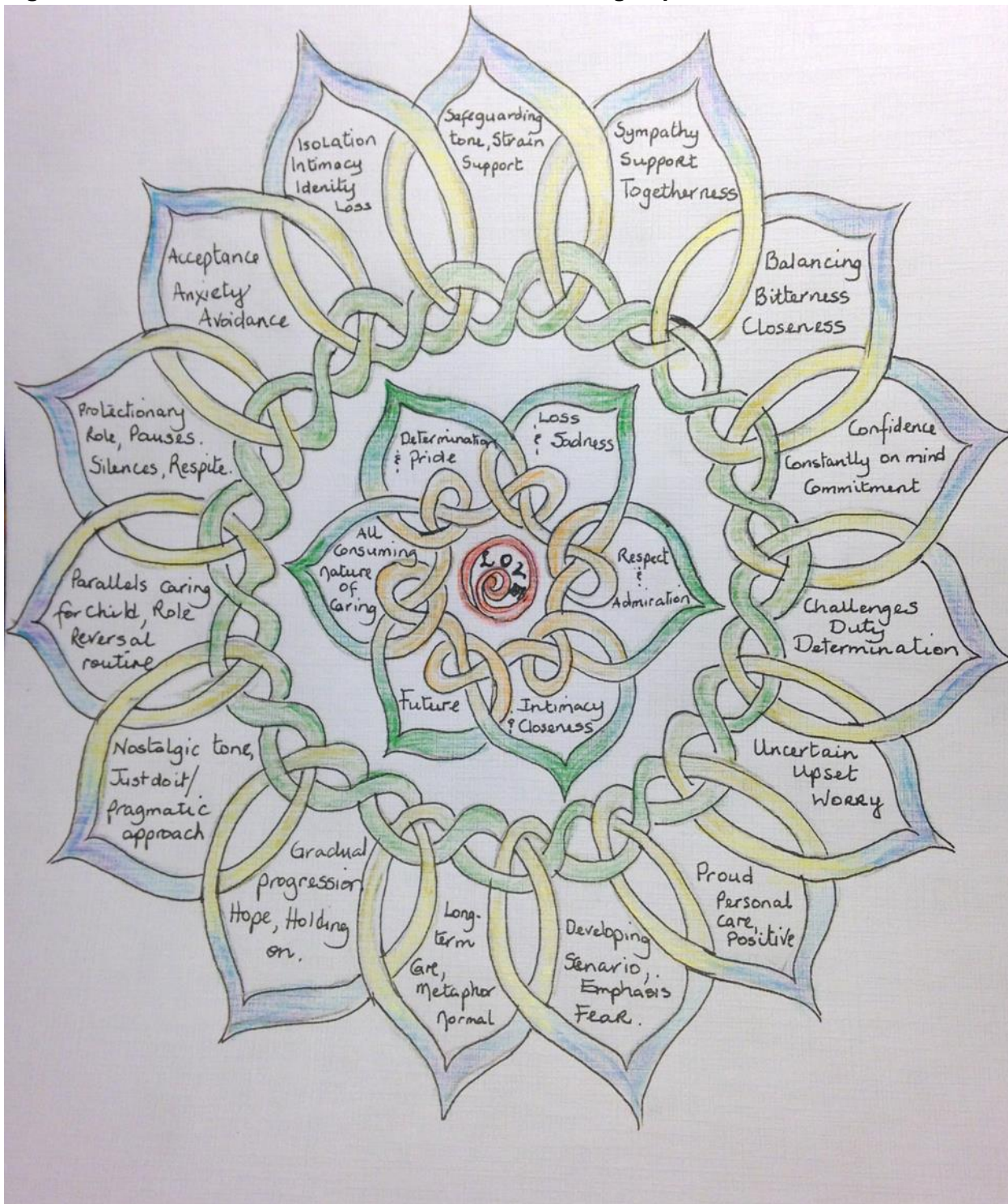
Taken together, these patterns of meaning represent a complex patchwork of how the men in my study experience caring in the context of dementia. Ultimately, they demonstrate that men were making sense of their caring experiences in very complex ways, involving a multitude of emotions. My multi-layered analysis allowed me to ensure that these patterns encompassed not only *what* men said but *why, how, where* and *when*. In so doing, I identified the key defining feature that bound each man's story together – Love. I have illustrated this in Figure 7.1 overleaf.

¹¹⁹ The basis of the framework that I developed has previously been outlined in detail in Chapter Five.

¹²⁰ According to Josselson (2011a, p. 228) 'Analysis from the stance of the hermeneutic circle involves gaining an overall sense of meaning and then examining the parts in relation to it – which will involve changing our understanding of the whole until we arrive at a holistic understanding that best encompasses the meanings of the parts'.

¹²¹ Patterns of meaning were established with the assistance of Nvivo in which I created tree nodes to reconstruct the data I had gathered into a framework for analysis. Tree nodes were established following the application of thematic, structural and dialogic/ performative approaches to analyse the sixteen narratives (See Appendix 10).

Figure 7.1: Love as the Central Feature of Men's Caring Experiences



The story of men's caring identified how each pattern of meaning represented a dimension of their experience. However, each pattern of meaning is dependent on each other and is defined by the central feature of love for the person with dementia. I was influenced to this end in the work of Kitwood (1997a) who proposed a cluster of needs in caring for the person with dementia (comfort, attachment, inclusion, occupation and identity), with love as the central element for person-centred care. Kitwood (1997:81) noted that this view was expressed previously by Frena-Gray Davidson (1993) who asserted that caring in dementia involved a generous, forgiving and unconditional acceptance, a whole hearted emotional giving without any expectation of direct reward. In my study, men's unconditional love for the person with dementia permeates across the patterns and holds together both their stories and so too their experiences of caring. Love is the fundamental piece to the jigsaw that makes up men's caring experiences. It describes men's feelings, emotions and actions that make up their stories. In so doing, Figure 7.1 demonstrates the multi-layered dimensions within each pattern and also the interconnectedness between and within the six patterns of meaning. Like Kitwood (1997a) proposed five needs which come together and are interconnected in the central need for love in dementia. In my study, each pattern is wound together, and rather than display as a quilt in which men's experiences may appear 'flat', the circular effect as displayed in the illustration shows how men were continuously moving from feeling to feeling within the patchwork that is their caring experience. The men's stories were constantly changing as a consequence of the multitude of emotions they expressed that were always evolving. The shape of the pattern with its jagged edges in Figure 7.1 also represents the delicateness of men's experiences. The never-ending love that men in my study have for the person with dementia in spite of the evolving challenges they faced is similar to the love advocated by Davidson (1993). It acts like an umbilical cord between each man and the person with dementia and the essence of men's love is that it is constant. This chapter will show that while each man's story was unique, love is the common feature among their stories following my multi-layered analysis. Each pattern or layer of meaning across the men's narratives will now be outlined in turn in relation to the central feature of love¹²².

¹²² Through the application of terms by other narrative researchers such as Frost's (2007) reference to narrative analysis offering 'many ways of uncovering layers of meaning' (p. 5) and given that I had been influenced by the wider proposition argued for within the literature for a 'pluralistic' approach to narrative analysis (Frost 2009, Phoenix *et al.* 2010), I came to decide on the term 'pattern of meaning' within my own work. I also borrowed the use of 'patterns of meaning' from narrative work by Brown & Addington-Hall (2008).

All-Consuming Nature of Caring

An ever constant determination associated with caring for their family member with dementia ran throughout each man's story on a number of levels. Following the diagnosis of dementia, many men spoke of a time in which they were involved in providing subtle care. With the gradual deterioration in the condition of the person with dementia, they spoke of the growing caring responsibilities that they assumed. For example, repetition of words accompanied by a sense of apprehension in the tone of voice, helped illustrate the unease that Luke was experiencing as the situation developed for him:

eh so when we, when I got to the stage that I 'knew' that we were going to have to adjust completely and I would have to get closer, when I say closer, closer to her needs. Eh now at the moment, up to this now anyway, the only that I had to watch was that she bathed properly, at least twice a week, three times a week (Luke, P07).

Men spoke of the requirement for someone to be constantly present as the condition progressed. Caring became a full time task and many men assumed 24/7 responsibility over the person with dementia's activities of daily living. Strong feelings of frustration and anxiety were evident in men's tone. For example, the strong resentment that Michael felt at the loss in his own independence was highlighted through repetition and his emphasis on certain words:

I have someone beside me all the time, that's it. I have got to care for that person 'all' the time. The independence is totally gone, I can't say 'I'm going down for a pint, I'll be back in an hour'. I can't 'do' that, you can't, she must be with me at all times. That's gone (Michael, P01).

A requirement for constant vigilance was powerfully highlighted through the safeguarding tone expressed by many men. References to constantly being on guard were highlighted in the protective features men described of their caring roles and how they had come to 'supervise'. The quote below illustrates the extreme measures that one man had to take in caring for his wife, almost as if he was a guard and she was his prisoner:

...I cannot let her go outside the gate or anything like that. Last night she started acting a bit strange, she just couldn't get any sort of thinking done. 'Now I'm going now' she said. I was just at the computer 'And I'll be going now, I'll be back in a minute' 'Where are you going? 'I don't know'. So with that then I locked it, I locked the thing. She was starting to act a bit strange, and she did go up to the door because I heard her trying to open it. And I said ah no it's too late now unless you want to go out for a walk with me. So she just dropped it... (Michael P01).

Another man described the precautions he had to take; Alan was now required to keep a constant vigilance, also like a prison guard in his own home. The emphasis he placed on

certain words reiterated the importance of following certain steps:

...just in more recent times now she's inclined to open the hall door and go out...so that's a new development, I have to eh, eh either put the chain on or on occasions she can open the chain, other times she becomes slightly confused, 'best' to turn the key (Alan, P11).

In spite of some men speaking of how they had become accustomed to caring, there appeared to be new challenges emerging as the condition progressed which they had to watch going forward. Even in earlier onset dementia, men were required to guard against potential dangers, albeit more subtly:

...the other basic thing that you have to watch all the time is that... if she's having shower, I've got to make sure that the door's left open and be there.....Well the thing is by doing what I'm doing, I'm not infringing on her. And she's keeping her own, own independence by doing those things. And I'd make an excuse, like up in the bedroom, making the bed, very simple (Mark, P14).

Men spoke of how when they received brief periods of respite, they were still thinking about the person with dementia. Thus, they were constantly on their mind even when not physically present, demonstrating the all-consuming nature of their role. Both emphasis on and use of the metaphor 'psyching' in the quote below, helps to illustrate the strain that Alan was experiencing:

Well it gives me, it gives me a little bit of time. But you have to try to manage your time (laughs) because the hours can disappear very quickly. I mean on a bad morning it could take me 40 minutes to drive out to (place name) depending on traffic and weather conditions and another 40 minutes back. So that's an hour and a half and I'm only home (laughs little), so I might do some vacuuming or do something in the house and have time to have my own lunch, whereas she will have had her lunch in the centre. And when lunch is over then I'm 'psyching' myself up to going back out again (Alan, P11).

In-house support alleviated some of the strain as well as isolation experienced. However, the constant scheduling associated with caring was difficult for some men. The tone of men's voices as well as emphasis on certain words underlined their frustrations of how life had become almost a 'time table':

And it's the same, 'every' day, and that's why I like the little bit of respite, the four times a year. You know. Because 'that' part can get, in other words it's just gets 'monotonous' (David, P03).

Men who were working outside of the home while caring or had previously done so, provided powerful images of how they were constantly juggling work commitments with caring. Strain in the pitch and tone of their voices, almost illuminated the exhaustion that they felt:

So everything is kind of left, left to me eh I'm trying to continue my career, I still have a mortgage to pay, I still have financial commitments so I'm kind of not available to be a full time carer for her,

although in that, eh I suppose, it's never really out of my head, although I'm away from it, 9 to 5, it's not, I'm never really away from it (Paul, P05).

In terms of their own identity, many men expressed satisfaction in the new skills that they had learnt as part of their caring role. For instance in having responsibility for household tasks, men spoke with confidence, demonstrating the knowledge they had built up:

As I say I do all the cooking for (wife's name), I do all her washing, ironing and eh I try to do a wash every day, it's easier to keep it up to date but it's been difficult in this weather with all the rain and so on (Matthew, P15).

Thus, men were recognising changes that were taking place to their own identity as a consequence of their caring in a positive way, as evident in the way that they spoke. Despite this, some men found this process of renegotiating their own identity difficult in now being required to undertake tasks they had not done before. They appeared to be still adjusting to the all-consuming nature of their caring role, and a sense of uncertainty and apprehension was evident in how they spoke:

I had done a little bit of it but obviously I have to do a lot, do a lot more. So, that, in terms of that. Eh, even in terms of you know, washing the floors, having to find out what you use and what cleaning materials or what's suitable. You know that end. Basic stuff that I hadn't concerned myself with (Stephen, P13).

Other men also appeared to be also juggling their feelings of life post working with challenges that they now faced in providing care:

So it's 'almost' as if I'm still working..... But in a different context (Patrick, P12).

Determination and Pride

Despite such ever present challenges, the men also demonstrated in their stories the determination and pride that they experienced in ensuring that they continued to care for the person with dementia. For instance, many men appeared to be balancing feelings of loneliness with resilience and strength in continuing to care for their family member:

But eh as I say it can be very lonely, that's the big, big thing about it. Because the person that has Alzheimer's, doesn't talk. Like I said to you earlier on, you lose the ability to talk, because you're not talking to people. But the main thing is to get out (Cormac, P02).

Men's determination was evident in their stories on a number of levels. For instance, men's confidence in what they were doing was evident in how they spoke:

Ah I surprised myself. If she gets soiled and I have to clean her up and that you know. I thought I could never face anything like that and I just take it all in my stride (Michael, P01).

Men also displayed determination in ensuring that adequate supports and outside help were in place for the person with dementia. While some were critical of the lack of support that they had received, a strong sense of pride was expressed at how they had sought assistance:

...I'd heard about that in eh (day care centre name) and I met this eh (staff member name)...and eh she was very receptive to me on the day and I couldn't believe my lucky stars when she said that they, they could take (wife's name)... So that was a lucky break but I kind of pursued that myself, it wasn't eh... (Alan, P12).

Many men also revealed a strong determination to hold onto a certain level of normalcy. For example, one man bluntly told me of his determination to continue to do things as he had done before assuming caring responsibilities:

But I think the most important thing for me is if I want to do something, I'm going to do it. And (wife's name) has to come along with that (Matthew, P15).

Other men spoke of the importance of getting away - to another space, and the sense of relief that they felt with no physical reminders of caring. Donal spoke with a sense of excitement:

It gets me down at times. Like you know. And I eh, when the (paid carers) come in in the evening, me, me eh nip down to the pub. Have a few drinks (Donal, P16).

Similarly for Connor who continued to work outside of the home, the tone of his voice demonstrated how through being at work he was able to switch off from his carer identity:

So (wife's name) lives in one world. There's an intersection, she primarily lives in one world to some degree in the mainstream. I live in the mainstream but I spend a lot of time, living in her world. So I'm moving across the borders all the time (Connor, P08).

Many men expressed determination to continue to care for the person with dementia within the home in spite of the continuous challenges faced, and thus fulfil the absolute commitment they had for them. In particular, Donal's determination was evident through his repetition of certain words to emphasise his feelings:

But eh... I do do it and I eh, as I say, you wouldn't volunteer to do it. But eh, it has to be done, you do it. You do what you have to do (Donal, P16).

Another man expressed pride in telling me how caring for his brother was 'our' duty among family:

Yeah well I feel, I feel it's our duty (Robert, P10).

The influence of past experiences from the relationship that men had with the care recipient appeared crucial in providing meaning to their current experience. The togetherness that they

had shared before illness provided men with strength, as evident through the sense of duty that they expressed:

There's no 'resentment' or anything. But I mean, my wife is my wife. And it is my duty to look after her. Simple as that. And I will do so to the best of my ability (Brian, P04).

Some men also demonstrated their commitment to caring for the person with dementia in telling me about the negative attitudes of others that they experienced. The sense of bitterness apparent in men's tone as they spoke revealed how they found the attitudes of other people, including family members, both towards male carers as well as towards dementia difficult to deal with. In addition, emphasis placed on certain words highlighted the frustrations at how they felt that their own identity was being judged. Thus, there appeared to be a wider narrative taking place that was influencing how men experienced their caring role:

That's the way a lot of men are looked on now but they're not, you know, there's almost an 'embarrassed' feel, particularly in the caring area, where women feel that 'they' are the ones that have the right to care. Roles I suppose (Patrick, P12).

Some men spoke of how they had to learn to change their own preconceived notions of dementia that they once had. In so doing, Connor powerfully described to me the devotion he had for his wife, as evident through his repetition of the word 'stretch':

I said I'd rather cancer. I'd rather anything, just for me. And even that was very revealing about my own attitude to dementia, my own understanding of it. I mean I really realised I'd such prejudices and such deep seated fear, I still do. It's a fearful thing, the mind do you know. That someone, and you know still appropriate behaviour and being out in public and she's wandering off and talking to people. So you know you kind of get embarrassed, to learn, to deal with all that and then create a space like you know. So you're stretching. You stretch your heart all the time you know. Yeah. You stretch your capacity to understand. Eh yeah. It's a huge stretching exercise (Connor, P08).

Several men felt it was important to tell me that they did not feel ashamed caring for their loved one with dementia. However, others spoke regrettably at incidences when they felt embarrassed:

Yeah I'd like to get out more often, where I'm at home, I'm just, I should try but the risk is that she wouldn't be quiet or that she'd put you off, or even attempting it, in case, you these kind of embarrassing bits you know (Patrick, P12).

The unpredictable nature of dementia was highlighted in some men's stories. There was a strong pride among men in telling me about the strategies that they had learnt to help them deal with the person with dementia's behaviour. In so doing, they also illustrated the skills that they had built up, as well as a sense of 'mastery' associated with their caring experiences:

So there's a considerable learning curve involved for, for me in terms of all of that activity. She had been very much the, you know, the person who did all of that, the house, all that work. So I've had to, to learn a lot...Eh...getting to grips with that (Stephen, P13).

At the same time, many men were continuing to learn in their caring role as the situation was constantly changing, and sense of anxiety was apparent in how they spoke at times: *you know that you're coming to reach a stage, you know fairly soon and it's, it's a new ball game. And that obviously is a worry alright yeah... (Tom, P06).*

Some men were very proud in telling me about the how they had adapted skills from their working life to assist them in their caring role. They also showed confidence in their leadership skills. For instance, keeping a routine and remaining in control was helpful in learning to overcome the challenges that they faced as men spoke with a strong sense of satisfaction. In particular, I found the comparisons that one man made with 'shifts' when referring to the daily routine of combining working outside of the home and caring significant. It was as if he was comparing his current caring situation to a job and also as a way of helping him cope:

On Saturday and Sunday then it's, it's the kind of evening shift, for, what goes on for two days eh...just ehm... I mean basically Saturday and Sunday I do all the cooking, maybe get some of the laundry done, some housework basically. Eh... I suppose as well as putting her to bed at night, I'm kind of getting her out of bed in the morning, so it's kind of dressing and washing again (Paul, P05).

Assuming a managerial approach to caring was evident in the responsibility men took for decision making. While expressing pride, they spoke poignantly of how they now had to support the person with dementia¹²³:

...if you sat her down in front of the television, you might have to sit for a while, she'd sit, and then take an interest in a film, or something like that, and she sat down quietly. And that was a big help, and she'd be quiet. Eh she has a bit of an obsession with food, that you have to virtually spoon feed her, kind of nearly force it down her. She's as slim as, hardly any weight on her, but when she was an awfully slow eater, in her prime, but now she's some obsession with food, that you can't get it into her quickly enough and you have to, you know, almost spoon feed her to get it into her. I work out my own kind of bits and pieces, ways to deal with that (Patrick, P12).

Men also appeared to incorporate aspects of their life before dementia that had a positive effect into dealing with the challenges of their current caring situation:

¹²³ Specific parallels between caring for person with dementia and caring for a young child are outlined in a later section of this chapter under the protective role that men assumed.

I mean I have an involvement with a couple of organisations in (place name)... I'm on the board of the local community centre and eh I'm chairman of the local _____ (organisation name) (Alan, P11). Cormac told me in quite a powerful way, through the use of the metaphor - and it all melts away - of how listening to music releases some of the strain he feels in caring, helping him to relax.

Loss and Sadness

Many of the men's stories were filled with feelings of emptiness. Men's loss was evident on a number of levels such as the loss that they were experiencing for the person with dementia as a consequence of their condition, their own loss of a sense of self, and a loss of the past as well as a planned future. The slow gradual nature of dementia meant that the losses that they were experiencing appeared to have gathered pace over time. Matthew pre-empted future losses he would face as the condition deteriorated further with a strong sense of fear and anxiety in his tone:

You know how do I handle people, a person who's incontinent, like who has to be changed, and wearing a nappy and paddy pads? That, I dread. That is the big big thing. I don't mind doing anything else but, a person being incontinent and where you have to sort of put them into Paddy pads and change them and so on. That really will be a test for me (Matthew, P15).

At various stages during many of the men's stories, their strained voices illustrated the sadness as well as apprehension that they were experiencing. One man recognised that he was grieving for the life he once shared together with his spouse who he was now caring for and the slow way he spoke highlighted the loneliness that he was experiencing:

Eh it's hugely challenging eh, emotionally, I grieve all the time (Connor, P08).

While some men used humour in their stories, through laughing and being sarcastic, feelings of sadness were never far away. For instance, in Alan's story, he appears to have been using humour as a way of coping with feelings of anxiety, and in so doing detaching himself from becoming emotional while speaking with me. However, in the later stages, he did become physically emotional:

you would see her trying to figure out where's the fridge, where's the (laughs a little) and she could put marmalade on her bread before butter and that think of thing, so you just have to watch that (Pauses)...so it's, it's a full time task (laughs a little) (Alan, P11).

Emphasis on certain words, as well as pausing at times also illustrated the huge loss that men were experiencing and the sadness that they felt:

Well there's one thing that I do miss, the support from my wife, that I used to have, and the caring and that she 'used' to give me, and that we used to give to one another, that we used to work as a team here but we're no longer a team now, all 'that' has been taken away from me (Pauses...) Eh she used

to look after me, she used to look 'out' for me you know. And now 'I'm' the one that has to make the decisions whether they are good or bad (Pauses...) (Michael, P01).

Many men recalled life before dementia with a strong sense of pride. However, these expressions were also tinged with a sense of longing as was evident in how they spoke. The men's stories demonstrated the inseparability between the person with dementia as they nostalgically recalled particular things that they once did together and the years that they had spent together before dementia:

...we always travelled together always eh, we travelled all over the world together, literally, and we had a camper van, which just went away last week, and eh we travelled all over Europe and that, from the South of Italy to the North Pole and as far as Russia (Luke, P07).

Some husbands became visibly upset while telling me their story of the life that they had shared with their spouse before dementia and the struggles that they now faced:

You know your heart might be back there or I say, is that going to help me get through the day....Eh...It is cruel. Yeah, there's no doubt about it. It's cruel and sad and tragic and all those things, and all that. But I'm, as you can see, I'm devastated (voice breaks and becomes emotional).....Eh...and I wish it were otherwise. But it's not. You know. I can't change it. I can't make her better (almost whispering), I can just help her to live (Connor, P08).

Many men spoke bluntly about the silences associated with caring for someone with dementia. There was a strong sense of sadness expressed for the loss in communication and ability to converse with them, as evident in the repetition of certain words in the following quote:

Oh I mean I miss conversation, I conversation. I miss her company, I miss her ability to empathise with me, she can't care for me (Connor, P08).

The references made by Michael, to the loss of his own voice powerfully demonstrated the isolation that he was experiencing:

...and you have to clear your throat, and this happened to me a couple of times. And I say what's wrong, every time the phone rings. And then I realised it was because I wasn't talking you know. You've got to clear your throat all the time. Someone rang 'Have you got a cough or...every time I ring you cough?' So I said that's what it is. Just one of these things you don't realise you know. But eh I suppose you do lose the, the art of conversation, when you're not you know say going out and say well remember what happened last week or the week before or something like that or... (Michael, P01).

Despite being required to be almost always physically present together, many of the men were experiencing a loss of the relationship they once shared with the person with dementia

and things that they had undertaken together. Significantly, it was the person with dementia who held the key to unlocking these losses. The strong sense of closeness that they had previously shared was evident in the following metaphor:

You had this wonderful picture of going to Italy... And what you discovered was, you didn't get to Italy, but you landed in Holland.... And he said it's about making the best of being in Holland. It's all flat, and boring (participant and interviewer both laugh). So he said to me, we found that image very helpful. And I said (person's name) it's a great image, and I'm glad it helped you. The only difficulty was, we got to Italy. So we were in Italy (Connor, P08).

Men expressed a mixture of regret and guilt at no longer being able to undertake activities and hobbies with the person with dementia, as consequence of their condition:

Well we used to, we used to see more of our friends and that kind of thing. Because we'd have nights' out and that type of thing, we don't have anymore. You know, cause eh she's not, just not capable of doing it you know. And she can, as I said her patience isn't as good as it was, and she's tired type of thing, she's all over the place. So eh we've curtailed that, a lot of the social life because of that you know (Mark, P14).

Loss of the identity of the person with dementia was very strong throughout men's stories. They spoke about how the characteristics which constituted their individual personality were slowly slipping away. The behaviour of the person with dementia was also difficult to cope with at times. Men expressed frustration but also sympathy. Specific moments appeared to have acted as a 'catalyst' in recognising such shifts in identity. Men spoke of these turning points in a long extended narrative, full of a range of emotions, both in what they said and how they spoke¹²⁴. Some men also powerfully demonstrated such losses through metaphors. For example, Michael spoke of a 'glaze', denoting the confusion that his wife was experiencing:

...you're trying to cope with a person who doesn't even know where they are themselves you know. They are somewhere else, they're somebody else you know. You can see a glaze on their eyes (Michael, P01).

Many men poignantly noted how they felt that the person with dementia was now a different person as a consequence of their condition:

Eh, you know you're whole life, you're living with a stranger, and your whole life is turned round like you know (Donal, P16).

Indeed, the sighs and pauses in their voices at times also expressed the losses that men

¹²⁴ A detailed example of turning points within men's stories has been provided in the previous chapter.

were feeling:

Eh...so there's a kind of...that can be difficult, but it's like, it seems to me that, as eh, I don't know any carer, as a man I'm caught between that person and newer life to be somehow is not here (Connor, P08).

Physical changes to the person with dementia were a cause for upset in the men's stories as another way in which they were slowly slipping away. This was also evident in how men spoke:

She seems to be fading away, like in weight terms, you know, and despite all that she eats, her metabolism, or something, seems to be (Patrick, P12).

Several husbands¹²⁵ spoke sombrely of specific incidences when their spouse did not recognise them:

Then she says to me (clears his throat) 'Are we married?' She says to me about, about two months ago 'Are we married, are you my husband, are you my husband?' 'Ah yeah' I says '... (Michael, P01).

However, some men spoke of how they were trying to sustain the identity of the person with dementia. This was despite, in many cases, sadly the person with dementia no longer knowing themselves:

I try to, when we're finished our dinner in the evening, I leave her. And she washes, she cleans the table, and washes up. And she does it a lot more slowly than she used to but she does it perfectly. And I do that not because I don't want to help but it gives her, that independence, that 'feeling', that she's done something (Luke, P07).

Some men found hope in brief moments of clarity, which they were almost 'holding on' to and thus provided them with strength to continue, as evident in Patrick's description of watching a film with his wife:

And eh, after a while, sometimes with various successions she'll seem to take interest in the film. Now she never makes any comment or anything like that but I don't know which way it's going, sinking in, but, if you put on an old comedy, like we've some of those Carry On films, you know, they're slap stick and she'd give some version of a laugh at some of the jokes (Patrick, P12).

Men also spoke about the loss in their own sense of identity that they were experiencing. One man sadly recalled that he felt that he now had two identities – as per how his wife with dementia saw him:

¹²⁵ The loss of physical intimacy and closeness that the men were experiencing is outlined in further detail under the pattern of intimacy and closeness.

Eh she, one of the problems that she, and it is a problem for me as a carer in that, she... there are two of me, there are two of me, all the time..... there have been various stages of eh 'Where did you come from?' so there's this situation, and that is now, it's a strange aspect of it now, is, for instance, last night, she made, or kept back eh vegetables for Luke (Luke, P07).

Although some men spoke of experiencing issues with their own health, the needs of the person with dementia came first. For instance, while Paul recognised that he was experiencing stress, he was quick to downplay any health issues: *But I know, I can feel when I am stressed, because, like I suppose I get eh ... stress in my case is kind of, presents itself by kind of like very bad indigestion, and heartburn or... so I know when I get stressed, I feel it, in the chest, but it's heartburn, it's not a heart condition, but eh (laughs) at least I hope it's not, I'll know some day if I'm wrong. But eh otherwise I'm fine, I mean I know when my blood pressure goes up, I, my face gets red, and my temples kind of throb a bit so (Paul, P05).*

Men appeared to be balancing their emotions and adjusting to the losses that were occurring in their caring experience. For instance, while at one end they accepted and acknowledged what was happening as evident in the following metaphor provided by one man in his story: *...obviously I have a problem, which is not going to get any better. One would be a fool, not to look, the writing is on the wall, that's it (Brian, P04).*

At the other end, they continued to speak of how they found the losses hard to accept, and how things were no longer the way that they used to be:

Like looking after a baby, cause they go right back. It's very hard to accept though (Cormac, P02).

Indeed, some men referred to their own constant process of adjustment that was taking place as an ever present challenge:

We have this challenge you know. And it's about, I mean, one of the things I wrote down here, you have to reframe all the time. I'd to reframe things in my head (Connor, P08).

While many men felt distressed about their situation, they noted that it would be of no benefit for them to get upset when caring for the person with dementia. They were dependent on them. Keeping calm and patient appeared to be a coping strategy that many had established in their caring role:

And I say no because I know if I start breaking down, floods of tears, and constantly upset, I can't look after her. So I've time enough for that if she's gone (David, P03).

Day care and respite helped men alleviate some of the losses that they were experiencing in allowing them to feel re-energised:

So on the Wednesday now what I do, when she's gone, I'll put the head down, and I'll sleep you know (Cormac, P02).

Getting out and socialising with other people was an important way of alleviating the loneliness associated with caring. For instance, Donal told me about his enjoyment of socialising with younger people. It may also have been a way in which he could create a space in which he was able to forget about the ailments and ill health associated with old people, and perhaps too his own identity of carer:

I like young people's company, because it keeps me young like you know. It does yeah (Donal, P16).

Attending a carer's support group with other male carers provided an important feeling that men were not alone, thus removing feelings of isolation:

You were, you weren't 'alone' anymore if you know what I mean. That's 'one' thing I got from it. You didn't feel, ah I'm on me own doing this. There's nobody else in the world (Mark, P14).

As a consequence of the multiple losses faced, many men appeared determined to hold on to what they could, as if slowly parts of their life were being taken away from them. They were optimistic that they would be able to continue caring for the person with dementia. Despite a sense of hope, apprehension was evident in the tone of men's voices over the possibility that they would require 24-hour care:

I would hope to and try to continue with the caring myself. I couldn't see the situation where I would have to eh, that I would want to have her go to a home (Luke, P07).

However, there was also a sense of fear apparent in how men spoke of how they may be unable to control future losses:

I'd be lost, I'd be lost without her (Luke, P07).

In spite of the various coping strategies, several men regrettably admitted in their stories that the eventual death of the person with dementia was something that they had no control over:

And that chest thing started in August of last year. She has it more than a year now. But the doctor won't give her any medicines or anything for it, he says there's nothing we can do with it you know. All we have to watch he says is that it's not on her lungs, because, of course, that's what kills Alzheimer's patients.... And that's what Dr ____ says, he says I can't guarantee that won't go on her chest. And he says then we're in trouble. That's what killed her sister (David, P03).

Admiration and Respect

While at one end, men's stories were filled with multiple levels of loss and sadness, their stories also displayed the extreme admiration and respect that they had for the person with dementia. For instance, a strong sense of admiration in the tone of their voices was evident as they spoke:

(Wife's name) has taught me a lot. Has taught me a lot of what I do, is what she would have done with me and others, so she was nearly a role model for me you know. She was a very empathic, she was,

had great empathy for people and was able to you know didn't....there wasn't a shock about her, didn't kind of, she was just very accepting of people in their diversity you know. Not terribly bothered by class or status or, you know, other things. Just said, there they are. You know. Very accepting of me. So in a way, she, I learnt a lot from her. Bit of payback time or something you know. I don't mean that in that sense (Connor, P08)

Men noted how they felt that if the roles were reversed, they would do the same. In particular, husbands expressed a sense of duty associated with caring for their spouse, demonstrating their commitment through marriage. Although regretful, it was as if caring for their spouse was part of the marriage contract that they had entered into:

For me, being a carer, I wish it never happened. (Laughs). I'm being honest. Eh but it has happened and I have to get on with it. And that's my attitude. So it's as simple as that, I have to get on with it (Mark, P14).

There was an almost 'just do it' attitude portrayed by men in their stories. This was evident in the following quote by one man, whose constant repetition of the word 'do' emphasised the significance of assuming responsibility for providing care:

I do do it and I eh, as I say, you wouldn't volunteer to do it. But eh, it has to be done, you do it. You do what you have to do (Donal, P16).

Some men were very upfront about their expressions of love towards the person with dementia:

...what keeps me going. What keeps me going?.....Eh (whispers) I love her.....That keeps me going.....I like her, I love, I like the way, you know...(Connor, P08). However, many of the men expressed constant challenges that they faced in trying to maintain the 'love' that they had for the person with dementia, particularly as their sense of identity was in transition due to the gradual deterioration of their condition. They provided vivid images of the parallels between caring for a person with dementia and a parent caring for a young child:

Like in the morning, I cut her toast into tiny little squares and she'll take one or two of them, and walk off, down the hall, we've a long hall, and it's gone when she comes back up, or at least, mainly it is, I find the odd one scattered along the hall (Patrick, P12).

The person with dementia's rejection of their love was difficult for men to deal with, particularly husbands. In the quote below, it appears that Luke was using humour to avoid becoming emotional by the huge sense of loss that he was experiencing:

oh yeah she would set up the bed in the back room, and I'd sleep in the back room and eh, she was still, she wasn't ready for bed, so I very quickly got ready for bed and got into bed. (Laughs) Apart from anything else, it was cold, (Laughs) so I wasn't going into the back room but that's one aspect of it, eh,

it's not a carers' aspect because, if we weren't husband and wife, it wouldn't be a carers' problem at all (Luke, P07).

For men caring in earlier on-set dementia, there was a sense of uncertainty over what their role involved, which was evident in the way that they spoke. However, despite such confusion and the multiple challenges that they constantly faced in their role, all men displayed in their stories a love that was never-ending. For example, one man used the metaphor of a beacon to describe how he continued to love his wife:

There's a lovely line eh in a book by eh oh I can't remember now..... she talks about knowing when the light is gone, love remains for shining.... (almost whispering and becoming emotional) So I just hold onto that... I mean I just hold onto a series of phrases and poems and things like that. Eh they're just nourishment you know. It's like, they, they are, it's like they're beacons you know (Connor, P08).

Men's admiration for the person with dementia was also evident within the way they gently spoke when recalling talents and skills they had admired in them before they became ill:

It's a pity because she was a brilliant cook. My wife was a brilliant cook (Brian, P04).

Such expressions were also tinged with a sense of sadness and nostalgia. In the following quote, Patrick placed heavy emphasis on certain words, which were in fact the qualities he admired in his wife. Later in his story I was able to see these qualities myself, through the photographs he proudly showed me:

Kind of a youngest gawe to her you know. A younger, youngish, it was like looking at a teenager most of her life even if, mostly eh, 'slim', fit, and eh very active, 'jolly' kind of a person. You know she'd a big 'toothy' smile all the time and she always you know very active, in everything, person (Patrick, P12).

Devotion for the person with dementia was evident in some men's comments around the uncertainty over outside help. For instance, in the quote below, Alan spoke about his discomfort over placing his wife in respite. The emphasis placed on the metaphor used to describe his feelings of guilt, demonstrates how Alan felt a lot more comfortable knowing where his wife was and who was minding her:

But eh in terms of well respite in that regard, I haven't fully considered it and I would feel, well I was very upset when she went off first on the bus to the HSE place, so I wouldn't altogether at this point relish her, going in somewhere when I 'swanned' off for a week you know just (Alan, P11).

Indeed, the devotion that men had for the person with dementia was important in counteracting the loss and sadness associated with caring that they were experiencing, thus providing them with strength to continue. A strong sense of 'we-ness' was evident in the way Paul highlighted the longing he had for memories that he had once shared with his wife:

One of our (sighs) favourite habits, as a couple, during the time we were going out, and after we got married, was after work on a Friday evening, we'd go to a quality restaurant, and have a lovely meal (Paul, P05).

It appeared that men were using the past to cope with their current situation:

we 'don't do it' anymore so it's, it wouldn't be worth the stress, so when we do go out for a meal now, it's probably to, to a pub where it's just so much easier, it's just because it's self-service, it's, got wider spaces, there's no tied to tables, I mean one of the difficulties that (wife's name) has is simply sitting at a table (Paul, P12).

While husbands did not directly express that protecting their wives was a crucial role that they played, the protective features of caring were evident in their stories on a number levels, demonstrating the admiration and respect that they had for them. It also highlighted the insight and knowledge that they had over the person with dementias' needs. Firstly, several men expressed frustration and anger at the behaviour of others, such as when they did not treat the person with dementia with respect. References were also made to people's misunderstandings about dementia and of not knowing how to react. Donal spoke confidently of how he had learnt ways of ensuring his wife felt included:

If you talk over their head like, and you don't include them in the conversation like. Even just to say something now and again you know. Eh you know you learn all these things as you go along like (Donal, P16).

Furthermore, the protective role that men assumed was apparent from the onset of dementia, in the gentle reassurance that they provided to the person with dementia when they had become worried over their growing disorientation and ensuring that they found out what was wrong. At another level, some men appeared to be protecting the dignity of the person with dementia in wanting to gain a better understanding of their condition:

I read a book there, Dr Kitwood, have you come across him. He's from Leeds I think. He wrote it in the 1990s. He's the man who first advocated that dementia patients be treated as human beings, not as someone to be just locked away (David, P03).

A major part of the protective role that men assumed was in their requirement to make important decisions on behalf of the person with dementia that that they could no longer make themselves. This involved everything from organising power of attorney to assuming responsibility for activities of daily living such as washing, dressing, eating and sleeping, in that they came to control every aspect of their behaviour. Many men assumed a managerial approach to providing such care:

And I sleep with her because I find it more convenient, I, she, she's grand when she's like that, she's

resting down like she's nice. And eh I can have control over her, because if she tries to get up during the night I say no. Be quiet, go back asleep (Patrick, P12).

This conceptualisation of a protector was associated with a desire to maintain the person with dementia's self-esteem and dignity. For instance, it involved safeguarding attributes associated their identity before dementia. In so doing, the men were also holding onto a certain sense of normalcy. This was significant especially given that the individual no longer knew themselves:

...In fact she's with her, her youngest sister now today, going to the dentist. And she's going to Peter Marks to have her hair done and they'll have lunch along the way. So well hairdresser and lunch is the norm on a Thursday, a pattern they have (Alan, P11).

Ensuring that the person with dementia was comfortable on a daily basis was another way in which the men could maintain a sense of dignity. For instance, men proudly spoke of multiple adaptations they had made in order to ensure that they were safe and could remain at home: *Yeah I did a number of things, I mean I put a toilet downstairs which she never uses now because she's incontinent but she did use for a while eh I got, I put down this flooring so it's easier to, she has a wheelchair, it's easier to move along, and easier to walk a little (Tom, P06).*

Several men also spoke of how they were cautious of ensuring that other individuals who may become involved in the care of the person with dementia continued to protect their sense of self-worth at all times. A sense of unease expressed in how they spoke illustrated such worries:

Again it's easy to talk in hours, but you have to set aside in advance, you have to pick them, you have to think how many carers do you need, you have to meet the carers, you have to see are they ok, you have to see does he get on with them (Noel, P09).

Some men referred to the importance of how the person with dementia was treated with respect by healthcare professionals and in so doing, ensuring their dignity was protected: *Anyway, but eh, like (public health nurse name) great. She eh will interview (wife's name) in a way that's not imposing. She'll throw a question at her, what did you do yesterday? I can't remember. Don't worry about it, it's alright (Cormac, P02).*

In protecting the person with dementia's sense of dignity, many men displayed their devotion, particularly when required to look after incidences of incontinence. These men were not only protecting the person with dementia in the physical sense, but also protecting their feelings. Poignantly, once again this was in spite of they themselves not being aware:

He seems to be do you know, he keeps apologising, will you take your, don't be worrying, forget about it. It's an accident, accidents happen. He says I'm awful sorry, I'm really terrible sorry. I'm sorry. You

don't need to be sorry because do you what I mean it happens to us all. Trying to, you know, eh get him round (Robert, P10).

The tone of some men's voice when speaking about their responsibilities following incidences of incontinence may have appeared blunt and almost cold. However, it also illustrated how they were trying putting the needs of the person with dementia above their own. Thus, the way men spoke demonstrated a 'just do it' attitude and showed their determination to protect the person with dementias' sense of dignity at all times:

...you just get on with it... you just, you just have to be pragmatic about it, and realise that if you don't do it, nobody else will. The distress will cause distress for me, it will cause greater distress for ___ (wife's name) so the easiest thing to do is just, get on with it, clear the mess, and everybody's happier then. It makes for an easier life just to, just to do what you got to do (Paul, P05).

Many of the men also demonstrated the admiration and respect that they had for the person with dementia through their expressions of sympathy and feeling sorry for what was happening to them. Nonetheless, there was a sense of guilt expressed over particular incidences where they felt that they could have done more. They also questioned at times whether they were doing the right thing, as evident in Brian's emphasis on certain words as he spoke:

she won't go for a walk, and there's no sense in the television, she picks up a paper and doesn't absorb it. I feel terrible for 'her'. I mean how, trying to keep her going, and involved, and, is a major, major priority. It makes me feel 'guilty' when I'm doing enough..... I mean what else can I do other than to be there for her. But it 'does' make me feel guilty (Brian, P04).

Furthermore, some men expressed guilt at their own feelings of frustration associated with the monotonous nature of caring:

Well... it is difficult at times. One of the problems lately is, I won't say I get bored, but I was never one for everything the same every day (David, P03).

Intimacy and Closeness

Men's stories illustrated the deep sense of togetherness in which they had shared their lives with the person with dementia before their illness. At one end, husbands expressed a strong sense of sadness for the physical intimacy and closeness they once shared with their spouse in their stories, particularly sexual relations:

Yeah, I miss, I miss female company. Do you know we've had marital relations together for over 20 years like you know so (Donal, P16).

David was quite blunt in telling me how sharing a bed together had to stop a consequence of his wife's illness. For him, all of the aspects of life together with his wife and how they

expressed physical intimacy before dementia had been taken away:

It was terrible, to wake up and nobody in the bed with you. Of course sex went by the way (David, P03).

The emphasis Alan placed on certain words highlighted the loss he was experiencing for the physical intimacy and sexual relations he once shared with his wife¹²⁶:

Eh well you know obviously there are certain things, say in relation to intimate relationships they're, they're kind of gone and I've kind of learnt to 'live' with that and 'understand' that and 'accept' that and eh it doesn't bother me as much as I thought it might eh you know (Alan, P11).

Patrick told me that it was easier control his wife's movements if she was in the same room.

Sleeping in the same bed would be a classic example of how a married couple may have traditionally expressed intimacy and thus be physically close:

And I sleep with her because I find it more convenient, I, she, she's grand when she's like that, she's resting down like she's nice. And eh I can have control over her, because if she tries to get up during the night I say no be quiet go back asleep, where as if I was, we have empty bedrooms, but, if I was down there, I'd have to get up and put her back in, where as I kind of get her to calm down again or whatever you know, tell her go asleep you know, and she knows, you know, so, you work out as best you can, the different, patterns you know (Patrick, P12).

There was a strong sense of loss expressed by men for other ways in which they were once close with the person with dementia, such as going away together on holidays and going out to socialise with friends. The tone of men's words was significant, expressing a mixture of feelings of happiness, sadness and longing. They also placed emphasis on certain words, such as when Paul spoke about no longer going to a restaurant with his wife:

...That hasn't happened, in a number of years now. But as I say, that's a very simple thing, very, I suppose it's a very 'coupley' thing to do, we loved it and we 'don't' do 'it' anymore so it's... (Paul, P05).

There was a sense of confusion over boundaries of closeness expressed by some men as the illness progressed. For instance, Connor used the metaphor of a 'shadow' to powerfully

¹²⁶ The fact that men were comfortable and willing to speak about such personal issues and bring them up themselves without prompting illustrates the power of the narrative approach I took in speaking with them. My own reaction was also significant and upon reflection, I felt slightly uneasy and surprised by men's openness at times. For example, I was quite taken aback at how open Donal was in referring to aspects of life before caring that he misses, in particular the intimacy and sexual closeness that he once shared with his wife. However, other men were more hesitant; almost embarrassed in speaking about the loss of intimate relations they once shared together with the person with dementia, as demonstrated in the quote above by Alan.

illustrate what was no longer possible:

And a big challenge is to love the person in front of you.....So I try not to chase after shadows...I don't want to love a shadow (Connor, P08).

Images were portrayed both through metaphors that men used to describe their experiences, as well as the personal photographs that several men showed me during their stories. The proud and nostalgic way in which these men talked to me about their photographs illustrated the closeness that they had once shared with the person with dementia. For example, this was demonstrated in the conversation I had with Patrick as he showed me family photographs while telling me his story:

That again would be a few years ago, and that's (wife's name) here now at my niece's wedding, that's only about 4 or 5 years ago.

(Ann) That's lovely. Ah that's really nice of you two together.

Yeah, yeah down at my niece's wedding.

(Ann) Ah she's a very pretty woman.

Yeah she is.

(Ann) (wife's name) very pretty, smiling away there.

Yeah she's usually, this big toothy smile.

(Ann) And her arm around you, linked.

Yeah it's nice that one. Now that's my son again another few years ago. Again (wife's name), she wouldn't be able to smile like that. That's (daughter's name) again, just for some, her birthday or something.

(Ann) She wouldn't be able to smile like that now, no?

No. I miss that out of her. Because that was her almost, if you hide it, she dominated it, in a photograph, her 'big' smile would light up a room almost (Patrick, P12).

For many men, a significant role change occurred as a consequence of dementia which meant that they were required to provide greater levels of emotional intimacy. For some men who were not yet required to provide direct physical assistance in intimate and personal aspects of care, there was a requirement to strike a balance between being physically present in order to avoid harm, while also protecting the person with dementia's sense of

dignity and independence. This was demonstrated through the safeguarding tone in which they spoke:

...the other basic thing that you have to watch all the time is that... if she's having shower, I've got to make sure that the door's left open and be there. Things like that. It's more safety I find, than anything else, that you've got to watch them (Stephen, P13).

Some men found the developing situation in which they would be required to assist with intimate levels of personal care in the near future a cause for concern, and a sense of apprehension was expressed in their voices:

So I mean putting pads on her or gee I feel she's going back to a baby stage. You know like you put diapers on, on, on children, or is this what I'm returning to you know. And if she's wet in the bed, having soiled sheets on the bed, God that will blow my mind (Matthew, P15).

Other men's repetition of certain words helped express the uncertainty that they were feeling: *I got to the stage that I knew that we were going to have to adjust completely and I would have to get closer, when I say closer, closer to her needs (Luke, P07).*

Indeed, there was almost a contradiction within their stories, in that many men expressed being closer than ever to the individual they cared for, while at the same time they were no longer able to be physically close in the way that they once were:

I have someone beside me all the time, that's that's it. I have got to care for that person all the time (Michael, P01).

The structure of connectedness within the caring role required men to surrender roles that had once defined their own identity. Through the provision of such intimate care they needed to re-adjust their own identities. The sense of acknowledgement in men's voices at learning new skills demonstrated a level of acceptance they had for the situation. At the same time, there was a strong sense of confidence expressed in the assistance that they provided with intimate levels of care. The way in which the men were approaching personal care issues was also significant. While time consuming and challenging, it was a problem that had to be solved. This was evident in the pragmatic way that they spoke:

I timed it actually, it takes 45 minutes, to toilet her and change her if she's soiled. You've to rinse out the clothes and leave them soaking in a bucket or something like that you know. But, I really surprised myself that I could do that, because I'd be queasy even looking at something, soil on the street or something like that, you know (David, P03).

The 'new' intimacy which developed as a consequence of their caring role and the responsibilities that they assumed had a positive impact for many men. They spoke about the development of a sense of closeness that they previously had not shared with the person with

dementia before. It was also a 'new' way in which they could ensure dedication to the relationship and show their commitment:

so she's still very image conscious and very, wants to look her best and kind of have her colour done and her hair straightened so, somebody's got to do it... So I mean something like that is kind of, I mean, for me bonding, it can, it gets you very close to somebody (Paul, P05).

For some men this 'new' intimacy was a way in which they could maintain a certain level of normalcy as well as their shared identity in marriage, through their involvement in personal care. Many men expressed a strong determination to maintain a certain sense of 'togetherness' with the person with dementia in spite of their condition:

And we'd go to the Concert Hall or whatever. And the only thing we can go to now theatrically wise is musicals. There's no point in bringing her to a play... It wouldn't register with her...excuse me, so we've lost that. Because I wouldn't, I wouldn't, I'm not used to going anywhere on my own (Brian, P04).

Other men also conveyed a sense of gratitude for what they were still had:

She's perfectly healthy other than that, she's never been sick a day in her life. She's raised 7 children and they're all, thank god healthy, and we've got 8 grandchildren and 3 on the way (Cormac, P02).

At the same time, there was an acceptance among men that this was a developing scenario and the situation would continue to change as the person with dementia's condition progressed, and so too would their experiences of intimacy and closeness. However, such acceptance was tinged with regret:

I know in my heart and soul it's not going to get better. It's probably going to get worse so I try and make the best of it. That's it (Brian, P04).

Future

While there was a general understanding that the person with dementia was going to deteriorate further, many men told me that they preferred to take things on a day by day basis. They confidently told me that they did not want to think about what was going to happen as it was too distressing¹²⁷. However, it was obvious both in what many men were saying and how they spoke that they were also balancing feelings of fear and avoidance when thinking about the future. For example, what men said and how they spoke was at times in conflict. In particular, this was evident in the emphasis placed on certain words:

So that's why I don't, I mean I 'know' it's there. I 'know' all the problems that lie ahead. I'll 'deal' with

¹²⁷ In some men's stories it was in the later stages of speaking with me that they expressed doubt over their ability to cope in the future. On one level this illustrated the power of the narrative approach that I took. At another level, it was as if the men let their guard down, feeling comfortable at admitting their feelings of anxiety.

them when they arise, I'm not going to deal with them when they haven't, you know the old story, you can't mend something when it's not broken yet or don't try to mend it (Mark, P14).

Therefore, for many men what the future held was a constant concern and a sense of uncertainty prevailed through the tone of their voices:

I'm trying to think if there's anything more I can say you know. I mean I'm very fearful of overdoing things. My confidence. I see a range of fears like along with the current quote like you know Jesus will we manage as it goes on. No we're managing ok. But when you look into the future like will we manage and? So you've all those kind of fears and all that do you know (Connor, P08).

Many men spoke about things that they had hoped to do together with the care recipient but were now no longer possible as a consequence of dementia. The sombre tone to their voices illustrated the huge loss that they were experiencing for a planned future:

I try not to internalise it too much, think about what the future holds or what the lost opportunities or forgotten plans, I just, obviously I mean if I sat down and thought about that, I'd probably need medical help myself so I just 'don't' (Paul, P05).

Some men made specific reference to the stages of caring for someone with dementia. For Luke, the ultimate stage meant total dependence. His repetition, as well as emphasis on certain words and pausing in the quote below highlight the worry and uncertainty that he was experiencing:

I would see a progression stage where perhaps eh (wife's name) will become more docile, in other words, I will have to decide 'every' move. That's what I think, I think what the stage is and like the 'ultimate' stage, would be eh where she doesn't know anything, that's the ultimate stage. Where although I would anticipate (pause)...although I wouldn't say anticipate, but I would 'hope' to and 'try' to continue with the caring myself. I couldn't see the situation where I would have to eh, that I would 'want' to have her go to a home (Luke, P07).

Thus, men appeared to be constantly learning and adjusting while new roles and responsibilities were developing as the person with dementia's condition continued to deteriorate. Men who were caring for a person with earlier onset dementia recognised that the future would impose more challenges. The apprehension that they expressed in their tone over the future was also evident through their emphasis on certain words as they spoke:

Well it can only go 'one' way, and that is. You know there's no cure, there's no improving. It can 'only' get worse. That's sort of somewhat depressing. So I thought, as I say I try to 'avoid', 'dwelling' on it (Stephen, P13).

Future involvement in personal care was expressed with a sense of worry by some: *Otherwise I say God I'll never do anything if that's going to be, well what I'm thinking about (Matthew, P14).*

While other men expressed confidence of their future responsibilities:

So I mean we haven't got, we're not in the situation where she needs help showering and all that, she's quite capable of doing it. As I said, I'll be grand. I mean if it comes to it, well, that's something we have to do. You know (Mark, P14).

Several men spoke openly about having taken legal steps such as ensuring that power of attorney was in place should it be required. In contrast, they spoke cautiously about making plans for assistance and considering long-term care in the future. They articulated feelings of sadness and guilt, and the slow way in which men spoke highlighted their concern over the constantly developing scenario:

Now I know this is a nice safe environment for her and all the rest do you know but eh...it will come when she will 'need' it, when she will be 'better' off in a home than here you know..... Well eh I don't, as I say, I know the next step is going to be, she's going to have to go in for full-time care, that could be about a year away, I've to prepare for that now you know, now I don't know, I don't know 'how' it's going to happen but it's going to happen you know but as I say there is a time when she's going to need full-time, full-time care, 'more' than I'm giving her even... (Michael, P01).

Many men appeared to be strongly against the person with dementia going into long-term care. They expressed pride in what they were doing to avoid this from happening and hoped to continue doing so in the future:

I don't think I'd have any problem doing it. And I don't think (wife's name) would have any problem, once I was doing it. She'd be more concerned I think if maybe a stranger was doing it (Mark, P14).

The potentially high costs associated with long term care as well as in-house support were used as a marker for the person with dementia remaining at home in the future. However, with a strong sense of resentment evident in their voices, some men admitted that long term care may be the only option in the future and they may be unable to control such losses:

I'm very weary about putting her back into any nursing home again like you know. I know the time will come like when I won't be able to cope with it, when I won't be able to manage it. I'm not looking forward to that like you know (Donal, P16).

Indeed, many men expressed a strong sense of fear over what would happen to the person with dementia should they no longer be in a position to continue to provide care, for instance as a consequence of their own potential ill-health¹²⁸. Tom used the metaphor of a 'ball game' to describe what would happen if he was unable to continue to care for his wife, denoting a

¹²⁸ However, as previously highlighted, many men appeared to not be as open in disclosing issues with their own health to me. Perhaps in avoiding speaking about it, they did not have to think about future health concerns.

complete change in circumstances. I found it interesting that he used this metaphor traditionally associated with sport, especially given the references that he made in his story to enjoying playing tennis. There was a sense of determination expressed by men that adult children would not take on the responsibility of caring should they be unable to continue caring themselves:

It wouldn't be practical for my son and his wife who work and two children too, to try and look after her, to, it just, so the 'only' thing she could do is go into a home. But I don't, I don't particularly think or want to think about it (Stephen, P13)

Healthcare professionals provided advice on the future deterioration of the person with dementia. Still at the same time, many men poignantly admitted that they knew what the eventual result would be and no medical assistance could prevent this. The sense of regret that they felt was evident in how they spoke:

Obviously I mean they've got a very good insight into what way the illness is 'progressing' and at the end of the day, there's nothing much they can do, except tell you what to expect next I guess (Paul, P05).

One man anxiously pointed out that one of the negative sides of the support group he attended was meeting other carers who were looking after people with more advanced stage dementia and hearing their stories of what he may have to cope with in the future:

... if you like one of the negative sides of (support group name) is that, most of the carers who I meet there, are caring for people who are at a much more advanced stage of the illness (Stephen, P13).

For one man who had in-house support in place, he spoke of being optimistic about the future and of what it would hold for him. He also made reference to the financial reward that he would receive upon his fathers' death. The positive tone in his voice was in stark contrast to the feelings of strain and isolation that he experienced before such support was in place, conveyed to me earlier in his story:

Eh the future, the future's okay, my life is going pretty well at the moment.....I 'do' look forward to the day, provided my dad gets 'everything' he needs, inheriting some money from his estate (Noel, P09).

Several men spoke of having had previous experience with other family members who had dementia. Such experiences may have allowed them to prepare for what lay ahead:

(wife's name) would go down and look after the father and the mother. So that was our first introduction to Alzheimer's. I knew nothing about it until (wife's name) father developed the condition way back in the 80's and eh, as I say we have experience, and now what see in the father now has been repeated in (wife's name) case (Matthew, P15).

An emphasis on routines and schedules was also significant in men's stories, as they spoke

about the gradual deterioration in the condition of the person with dementia. Through having a purpose to each day, these men could therefore block out the future – particularly for those who were appearing to be trying to accept what was happening:

I know the personal care necessity is going to increase, within the short term, and eh, I'll just have to get a routine for that, once I get the routine going, it will work (Luke, P07).

Conclusion

This chapter has presented a detailed overview of the six key patterns of meaning to men's caring experiences in my study, namely the all-consuming nature of caring, determination and pride, loss and sadness, admiration and respect, intimacy and closeness, and future. Multiple dimensions existed within each of the patterns of meaning. No one pattern was hierarchical, nor could one be separated from the other, each was dependent on each other. Love is the central feature of each of these interconnected patterns of meaning, holding together men's stories of caring. It is love for the person with dementia that helps men to make meaning of their caring experiences. The findings will be discussed in the following chapter on a number of levels taking into consideration the all-encompassing love that guided men's caring experiences.

Chapter 8: Discussion of Findings

Introduction

My study findings offer a comprehensive narrative understanding of sixteen men's caring experiences in the context of dementia. While each experience is unique, analysis revealed that the men's stories represent a complex patchwork of six interconnecting patterns of meaning, with love for the person with dementia as the central feature binding their stories and caring experiences together. In this chapter, I will therefore discuss the all-encompassing love that guided men's caring experiences in relation to the image of a rose, a conceptual model of dementia care and existing male carer literature. I will then review the key feature of love across men's stories in relation to the narrative methodological approach I took and the research paradigm of social construction that guided my work. Finally, I will consider my own reflections, namely continuous self-reflection and position(s) as I emerged myself deeper into my thesis.

The Relationship between the All-Encompassing Love of Men's Caring Experiences and the Image of a Rose

Across men's stories, an enduring love for the person with dementia underpinned and drove men's resilience in continuing to care despite the constant and always evolving challenges they faced. Such an unconditional personal regard for the person with dementia is what helped these men to make meaning out of their caring experiences. The diagram I displayed at the start of the previous chapter (Figure 7.1), illustrated both the interconnectedness between the six patterns of meaning and the central feature of love – binding men's caring experiences together through a complex patchwork. Below, I have included this diagram again, but replaced it this time with the image of a Rose (See Figure 8.1 overleaf).

In Figure 8.1 each of the patterns of meaning represents a petal on the flower, namely the all-consuming nature of caring, determination and pride, loss and sadness, admiration and respect, intimacy and closeness, and future. The centre of the rose is the strongest part, hence why love is displayed here as the central feature revolving around all six patterns of meaning. In general, the central bud of a rose is surrounded by five petals, representing in the image below five of the patterns of meaning. However, the all-consuming nature of caring is displayed in this image as wrapped around the central feature of love, symbolic of how it requires constant support from love to keep going. Like a rose, each petal is dependent on each other for survival. This image therefore represents the interconnectedness and evolving

nature of men's caring experiences as expressed through their personal stories. In so doing, it also displays the multidimensionality of men's caring experiences and the many layers of meaning that were identified in analysis. The overlapping of each of the petals is an indication if one falls, the next may follow. Ultimately, this mirrors the interdependency between each of the patterns of meaning and the deep attachment and inseparability between the men and the person with dementia. Moreover, the circular nature of the rose is a portrayal of the interconnected nature of men's caring experience and how there is no hierarchy in the patterns of meaning.

Figure 8.1: The Symbol of a Rose Mirroring the Interconnectedness between the Six Patterns of Meaning and the Central Feature of Love



I believe that the image of a rose is significant on a number of levels. A rose is one of the best known and most favourite plants in the world with over one hundred different species. No two flowers will be the same and there may be subtle differences within the intricate detail on each petal depending on a wide range of circumstances, such as level of support and attention provided through watering, feeding and climate. This is why it was so crucial to tell these men's experiences of caring as individual stories – unique and different but with patterns of meaning that guided them on their caring journey.

The rose symbolises all in love and maintaining radiance. Traditionally, a man may have given a woman flowers to express his interest in her. The physical beauty of a rose is important particularly given the physical changes to their loved one with dementia noted in their stories. Men spoke of strategies they used to try and uphold the person with dementias' identity such as going to the hairdressers, going out for lunch and meeting with friends. The rose may also be representative of the men's relationship with the person with dementia and what they are now required to do in their role, slowly becoming responsible for all aspects of the person with dementias' daily care. Like all flowers, roses require regular care and attention such as through watering – in order to ensure survival. The strong protective role that men assumed in which they were almost always on guard watching out for potential dangers, is comparable to the attention that must be given in order to ensure that roses flower well – such as being situated in fertile soil so as not to become too dry.

Moreover, there are times when a rose may appear almost dead, particularly at certain times of the year or when it may be neglected. However, through constant pruning and watering, it can become alive again. There is a certain parallel here with the brief moments of clarity described by men – whereby if only for the briefest of periods, they were transported back to life before dementia. These brief moments of clarity also appeared to be ways in which men could 'hold on' to and maintain both their own and the person with dementias' identity, holding onto a sense of normality and providing them with strength to continue providing care. Similarly, the gentle and tender way in which men described to me their involvement in caring for the person with dementia is comparable with the careful nurturing that must be paid in nurturing a rose. For instance, men spoke softly of how they ensured the person with dementias' sense of dignity was protected in their day to day caring tasks. Indeed, the delicate nature of the petals is a reflection of the delicate nature of how men were balancing with a whole range of emotions in their caring role. Furthermore, the literature acknowledges

a pre-death grief that takes place in the context of dementia caregiving, in which clinical death of the person with dementia occurs before biological death.

On another level, roses have thorns and can make you bleed – this is representative of the constant challenges men face in their role of providing care to their loved one with dementia. The thorny stem is symbolic of the potential dangers men had to guard against in their caring role. Men displayed determination and pride in how they confronted any issues that arose. In particular, early and mid-stage dementia were described as nearly a ‘black hole’ where the person with dementia was resisting assistance and men struggled to feel empowered and supported. Correspondingly, the colour of the rose is noteworthy. Red is a colour associated with feelings of love and passion but it may also be associated with danger and violence. The colour red may therefore be symbolic of the uncertain future men face in their caregiving journey as the condition of the person with dementia gradually deteriorates further. It may also be expressive of the challenging behaviour of the person with dementia that men had to deal with, as well as the frustrations that they experienced in their caring role.

The longevity associated with roses is important too, having the potential to last for many decades depending on how they are cared for, with aspects such as drainage and soil key. I believe that this mirrors the pre-existing relationship between men and the person with dementia, with men’s stories filled with nostalgic memories shared together. The centrality of this relationship to men’s caring experience and the intertwined nature of their caring was illustrated through the strong sense of togetherness they described. This togetherness is also akin to the intertwined nature of the petals of a rose outlined above. However, if the core of the rose is neglected and becomes rotten, each of the petals will slowly rot away. Men powerfully described to me the multiple ways that they stood up to the daily frustrations they faced in their caring role. Finally, while the rose is a symbol of love, the particular meaning attached to a rose will depend on the context. For instance, as I highlighted above they may be given as a romantic gesture, for a special occasion such as a birthday, but may also be used to show compassion at a funeral. This is symbolic therefore of how men’s meaning in caring was constantly evolving as the dementia journey progressed further. Indeed, men spoke of how they recognised that the condition of the person with dementia was going to deteriorate further.

In displaying the image of the rose to represent men’s caring experiences, I would also like to acknowledge the work of Tom Kitwood in his now classic 1997 book *Dementia Reconsidered*.

The pioneering and revolutionary work in the 1990's of the late Tom Kitwood reconceptualised dementia by broadening the conceptual lens to include personhood¹²⁹ (Cahill *et al.* 2012). In fact his work was mentioned by one of the men in their story of caring. I have previously outlined how was influenced by his work as I undertook my own analysis. For instance, Kitwood (1997a) proposed a cluster of needs in caring for the person with dementia, with love as the central element for person-centred care, in contrast to previous theorists. This cluster is closely interconnected, with one all-encompassing need – for love. He proposed five needs which come together in the central need for love in dementia – for comfort, attachment, inclusion, occupation and identity (Kitwood 1997a, p. 81). The fulfilment of one of these five needs involved, to some extent, the fulfilment of others and that their boundaries are blurred¹³⁰. Kitwood (1997b) contended that it is possible to maintain personhood in dementia ‘...through the sensitive meeting of this cluster of needs... in a way that corresponds to the uniqueness of each individual’ (p. 20). According to Downs (2013, p. 53): ‘The person-centred approach introduced optimism to a field more familiar with pessimism and despair’. I believe that my men’s caring experiences and the six interconnecting patterns of meaning in their stories display how they were walking a fine line in keeping personhood intact, thus expanding previous work undertaken by Kitwood (1997a). Without knowing themselves, the men in my study demonstrated how personhood was operationalised in practice through the provision of compassionate and effective care in the context of dementia (Downs 2013). My findings demonstrates the multiple and interrelated elements that make up men’s enduring love for the person with dementia and the efforts that they went to in trying to uphold their sense of personhood in the face of their failing of mental powers. In line with the provision of a global sense of self-worth that person centred care achieves (Kitwood 1997b), men’s enduring love for the person with dementia acts like a fuel, motivating them in their everyday caring experiences. The centrality of the relationship and total maintenance of the person with dementias’ sense of personhood was part of what made caring bearable for the men.

¹²⁹ Kitwood (1997a) provided the following definition of personhood: ‘It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust’ (p. 8).

¹³⁰ According to Kitwood (1997b): ‘The pattern of need that is shown will vary according to personality, and often the intensity of the needs increase with the advance of cognitive impairment’ (p. 19).

The Relationship between the All-Encompassing Love of Men's Caring Experiences and Existing Male Carer Literature

Aspects of the all-encompassing love documented in men's caring experiences and through the image of the rose are also evident in existing male carer literature on a number of levels. For instance, a major part of men's love was emphasised in their stories through the protective features of their caring, as highlighted in previous work (Sanders & Power 2009). However, they were demonstrating more than just protecting the person with dementia; they were displaying the intuitive knowing they had for the individual. Men appeared to be constantly reading the situation as evident through their focus on ensuring that the person with dementia was treated with dignity at all times. The knowledge they held was a consequence of the relationship they had shared together before dementia. The insight that men had was also empowering, in spite of the constant challenges they faced as they spoke with pride and confidence of their growing responsibilities. Similar to Sandberg & Eriksson (2007), it supports men's feelings of inner growth, satisfaction and self-esteem in caring. This also supports an emerging perspective within male carer literature that men are capable, nurturing and innovative (Russell 2001). Caring, therefore, shifts from being burdensome and socially isolating to an experience in which men have pride in care (Boylstein & Hayes 2012).

In their stories, men displayed their never-ending love for the person with dementia in wanting to continue to care for them at home for as long as possible. When the person with dementia was at home, they would know who was caring for them. This was very strong within existing literature (Sandberg & Eriksson 2007). In so doing, they also demonstrated the strong sense of commitment and duty they had. Previous research has discussed the importance of this in the context of marriage with men acting out reciprocity (Atta-Konadu *et al.* 2011, Parsons 1997, Eriksson & Sandberg 2008, Campbell & Carroll 2007). Other work has found that acting out of love and reciprocity was associated with a sense of satisfaction in men's caring (Ribeiro & Paúl 2008). The men's determination and pride in this study to control what would happen in the future was also situated within the role of protector. In their study, Sanders & Power (2009) also found that men assumed a protectionary role through caring. Similarly, Lynch (2007) introduced the concept of 'love labour' as a component that sustains primary care relations over time. Love labour is bound up with notions of moral duty, an ethics of responsibility and reciprocity. The men clearly displayed love labour in their stories in their pre-existing relations with the person with dementia. The patterns of meaning acted as 'care

maps' in which men constantly internalised the multi-dimensional aspects of caring needs, involving mental, physical, cognitive and emotional work in order to ensure the sustainability of care (Lynch 2007). Lynch (2007) also argued that love labour is person-centred, person-centric and other-oriented.

In previous research, male carers have been found to adopt an approach to caring that is task-oriented and focused on problem-solving (Pretorius *et al.* 2009), and as a consequence reporting positive caregiving experiences (Baker & Robertson 2008). The men in my study were doing the same, demonstrating an immense sense of pride such as in the adaptations they had made to the physical environment for the person with dementia. In so doing, it provided them with a sense of satisfaction (Pretorius *et al.* 2009, Baker & Robertson 2008) and the men appeared to evaluate their caregiving in relation to the successful performance of tasks (Calasanti & King 2007). Personal care responsibilities were spoken about in a pragmatic way similar to Calasanti (2010), as problems to be solved. They applied a 'just do it' approach to caring, appearing to leaving any emotions and personal feelings to one side. McDonnell & Ryan (2013) refer to a sense of duty and getting on with it approach among sons providing care in their study. However, in my study love is actually the key feature that guides men's' motivation to 'just do it' and consequently their caring is full of emotion. For instance, the men developed a new sense of intimacy and closeness through the care they provided to the person with dementia. Similar to Sanders & Power (2009), as provider of personal care, this assisted in men's positive feelings of caring. Eriksson & Sandberg (2007) found that intimate involvement gave men a sense of meaning in this new phase of their lives. Being so close allowed men to bond with the person with dementia, but in a different way as before. Thus, this was also a new way in which they could continue to show commitment and 'love' for the person with dementia. In their research, Sanders & Power (2009) found that the new type of intimacy and closeness in caring illustrated a different type of dedication and devotion in men's relationship with the care recipient. Boylstein & Hayes (2012) studied how understanding marital closeness changes in the context of caring.

Men's experiences of caring for the person with dementia in my study were one of a constantly developing scenario, with new challenges emerging as the condition progressed and so their commitment was constantly tested. Similar to previous studies (Ducharme *et al.* 2006, Russell 2001, Sandberg & Eriksson 2007), men felt isolated in their role. In parallel with other work, multiple levels of loss were evident in men's stories such as communication, intimacy, activities, mental health, friends and self (Sanders *et al.* 2003, Sandberg & Eriksson

2007, Boylstein & Hayes 2012). The men in my study recalled sadness and loneliness but also optimism and hope, demonstrating the power of the togetherness they shared, and continued to share, with the person with dementia. Hindsight was important in their stories – with men using the past to cope with now and their memories of togetherness were nostalgically recalled. It was almost as if the men shared an umbilical connection with the person with dementia – through many years of shared memories and experiences, poignantly which the person with dementia was no longer aware of. To this end, Sandberg & Eriksson (2007) previously spoke of caring as process building on the history of the relationship. Thus, such losses appeared to have helped men to cope, providing them with a sense of meaning and inspiration to continue. It is therefore far too simplistic to think of the burden of care placed on men – their stories detailed a much more complex scenario. While there is no doubt that the men's caring experiences in my study were stressful at time – this burden was intricately associated with the love they had for the person with dementia. Dementia brought new challenges in both care and men's relationship with care recipient but the centrality of love to the care experience allowed men to find meaning as the condition progressed. While their relationship was constant, it demanded new kinds of engagement for it to hold strong. For instance, men appeared to be constantly finding new meaning in their role through maintaining a sense of personhood such as describing how they looked after their wives' hair. They also spoke of how they adapted daily routines so as they became the norm. Men were determined and took pride in their caring (Ribeiro & Paúl 2008) and positive aspects of caring were evident for example, in the sense of gratitude expressed in their stories.

At the same time, men's love was ever changing as they were constantly learning new roles and taking on increased responsibilities as the condition of the person with dementia deteriorated. In this context, a new togetherness also emerged – growing out of the shared history men still had for the memories that the person with dementia had lost. For men, their love for the person with dementia would never go away and the togetherness of men's caring illustrated the intertwined experiences of carer and the person with dementia. Men in their caring roles undertook an intertwined journey that cannot be separated from that of the person with dementia; both are dependent on each other and love is the key to their experience. Atta-Konadu *et al.* (2011) commented on the importance of recognising spousal couples as a dyadic unit in the context of caring. Like Kaplan (2001) proposed, the men appear to embody a sense of couplehood with the person with dementia. In viewing their experiences through the lens of couplehood, caring in dementia can be interpreted beyond

burden and burnout, and instead as an inter-subjective self that is self-constructed in the context of couplehood (McGovern 2011). While extremely time-consuming and emotionally draining, caring responsibilities also brought a sense of satisfaction, allowing men to maintain a sense of self- both of them and of the person with dementia.

However, role reversal and the transition into the concealed world of household tasks were difficult to adapt to (Russell 2007b, Sandberg & Eriksson 2007). Like Kirsi and colleagues (2004), as previously documented in earlier research, men were learning to negotiate this and changes to their identity; they were reconstructing their identities when providing care. Caring provided alternative ways of being a man beyond traditional 'male activities' (Eriksson *et al.* 2013b). As boundaries became blurred between that of carer and husband, there was a strong sense of 'mastery' in men's stories as they expressed pride and satisfaction in learning new tasks and knowledge they built up as their role evolved. While retirement can lead to older men's estrangement from the masculine man-as-breadwinner associations with paid work (Buchbinder 2002), their stories demonstrate the potential for men's personal growth in retirement, with caring providing them with a sense of purpose and worth. In so doing, caring may act as a replacement role for paid-work (Milligan *et al.* 2013). However, in line with Campbell & Carroll (2007), the men in my study appeared to create a vision of masculinity that de-emphasised certain elements associated with hegemonic masculinity. Men were resisting traditional discourses surrounding masculinity in their stories. For example, they expressed satisfaction in skills learnt as part of their caring role traditionally not associated with masculine behaviour such as household tasks. The gentle and tender way in which men described their involvement and responsibility for intimate personal care also de-emphasised hegemonic masculinity. However, similar to previous studies, men also developed a new self in caring in which they felt positive when they performed duties well (Black *et al.* 2008, Calasanti & King 2007), thus reinforcing a masculine identity (Boylstein & Hayes 2012). For instance, they demonstrated leadership skills through keeping a routine and in control as well as not showing emotion. However, keeping calm and patient was important as there was no use in getting upset, despite feeling distressed at times. Men appeared to have gradual acceptance of the situation, the person with dementia was not going to get better. They were unable to change the course of what was happening but they could control how it was managed. For example, this was evident in men's self-inquiry into the condition constantly building up knowledge, and so too a sense of 'mastery' in the role of carer. Ultimately, the multi-dimensionality of men's caring experiences demonstrated how the positive aspects of

caregiving are not at the opposite end of a continuum from burden (as evident in the findings of Boerner, Horowitz & Schulz 2004, Cafferata & Stone, 1989, Kramer 1997, as cited by Carbonneau *et al.* 2010).

While there is no doubt parallels with previous work and aspects evident in my study, I did not aim to set out to explore what was different or unique to the male caring experience versus other carers. Instead, a narrative exploration and analysis allowed me to demonstrate how love is a central feature across men's caring experiences with each pattern of meaning interdependent on each other. Previous work has revealed that love and other emotions contribute to why people care and their experience of caring (Hennings *et al.* 2013). In my study, the multi-dimensionality of men's love was the key to understanding how and why the sample of men continued to care for their loved one or close relative with dementia – the first time this has been explored in an Irish context.

The Narrative Methodological Approach and Research Paradigm of Social Construction that guided My Study

The narrative methodological approach enabled me to undertake a deep exploration of the complex patterns of meaning embedded within these men's stories of caring. As first introduced in the methodology chapter, four key points will be returned to and I will discuss each in turn in relation to my findings - namely the temporal nature of narratives, narratives and identity, narratives as social encounters and the dialogic nature of narratives. In so doing, I will also demonstrate their reference to the research paradigm of social construction in which my study was situated.

1. The Temporal Nature of Narratives

The stories told highlight the temporal nature of men's caregiving experiences. The love they have for the person with dementia has a past, present and potential future as their condition deteriorates further. Like O'Shaughnessy and colleagues (2010): 'Temporal models of experiences of couplehood in dementia care suggest that spouse carers' experiences of their couple relationship changes over time, and as their partners' cognitive and functional abilities change' (p. 238-239). Thus, the narratives told are a process whereby the plotlines of men's stories may not always be circular and revised with telling and retelling (Freshwater & Holloway 2010). There is no end to their stories as their realities are continually changing. However, their love of the person with dementia remains constant and unconditional in the face of evolving challenges such as the

behaviour of the person with dementia. Problematic behaviour of the person with dementia has previously been documented as part of the carers' struggles (Schulz & Maritre 2004, Quinn *et al.* 2009). Perlick and colleagues (1995) highlighted that caregiving is a dynamic process, liable to change over time in response to prevailing factors in the individual care situation. Keady & Nolan (1994) identified six stages in the caring journey specifically relating to dementia; building on the past, recognising the need, taking it on, working through it, reaching the end, and a new beginning. The unfinalisability of men's love in my study has important links with the work of Mikhail Bakhtin's philosophy of dialogism. Bakhtin contended that life is dialogic and meaning comes through dialogue. Through language, meanings are continually generated (Hynes 2014a). With unfinalisability, there are always more stories to be told, more dimensions. For Bakhtin, you cannot see into a person's thoughts, so that stories are always incomplete (Hynes 2014a). Thus, just as men's love for the person with dementia is never-ending, so too is their story told.

2. Narratives and Identity

Identity is a key feature of narrative. However, identities do not stay the same, they are always in transition and change over time (Yuval-Davis 2006). In this study, I have demonstrated how in times of change and uncertainty, such as caring, narration allowed men to contrast and reinforce their identity as well as provide a sense of meaning to their experience. Men's love for the person with dementia provides them with meaning and through telling their stories they have had the opportunity to make sense of their caring experiences in an ever changing world – a caring situation that is constantly developing.

The men negotiated their changing circumstances through a narrative framework. Men's situation was one of an ongoing journey – whereby they appeared to be constantly adjusting their caring experiences and so too a sense of 'self'. Perry & O'Connor (2002) previously found that spouse carers in their study, while preserving the personhood of the individual with dementia; they were also preserving the identity of themselves as husband or wife. The existing relationship was central to men's caring journey and they documented ways in which they preserved both their own identity, the identity of the person with dementia and their joint identity in their stories, such as through continuing with hobbies, getting out and going on holidays. Similar to Sandberg & Eriksson (2007), through various strategies the men spoke of how they had to maintain continuity in their

relationship with the person with dementia, while dealing with the everyday struggles involved in providing care.

3. *Narratives as Social Encounters*

By applying a social constructionist stance, I was able to think beyond men's personal narratives, to the ways in which their stories were constructed within a wider social context and at a specific moment in time. According to Riessman (2008, p. 8) 'stories must always be considered in context, for storytelling occurs at a historical moment with its circulating discourse and power relations'. I have previously highlighted how at a micro level, the men's stories were told in a specific context (such as the time of day and place of interview). At a macro level, the men's stories have been told within a particular historical chapter in which broader societal changes are taking place as examined in Chapter 2 of my thesis. For instance, the policy context in which informal caring and dementia is situated in Ireland is constantly evolving. The amount of individuals diagnosed is increasing, and it is one area in which more and more men are required to provide care in the home. I also acknowledge that I undertook this study at a specific moment, during a period of recession, and when a lot of men became involved in caring for family members, both young and old, due to unemployment. Furthermore, this may have led to male caring in general being viewed as culturally acceptable, particularly in incidences due to unemployment, where women became the sole breadwinner and men assumed childcare responsibilities. However, older people may have been penalised to a lesser extent by the recession, having already retired and with no mortgage. On another level, the majority of men I spoke with were older men in long-term marriages; this is a situation that is increasingly no longer the norm. The impact of late modernity, individualisation and its culture of identity politics could throw up something quite different to the male care experience with another generation of younger men as they age and become carers.

In the constructionist view, meaning is not discovered but constructed by humans as they engage with the world they are interpreting (Crotty 1998, p. 48). Our reality is therefore shaped by social constructions. In following this standpoint and applying it to my own work, as well as being guided by other researchers who had previously explored the narratives of male carers from a social constructionist view of reality (Kirsi *et al.* 2004), the determinant of the meaning in men's caring experiences is their contextuality. My men's stories provided rich detail of both the progression of their individual caring experiences

but also of wider society. Wider narratives are always at play in any personal story. My narrative analysis allowed me to identify several wider narratives that were evident in men's stories. For instance, men spoke of the wider cultural and society norms and expectations in which their caring experiences were situated. Several men spoke of having experienced negative public attitudes surrounding their role and feeling that individuals questioned their ability to care. They were frustrated and there was a sense of bitterness in their tone as they spoke of how they felt their own identity was being judged. For instance, the narrative summary of Patricks' story detailed how he felt that his own confidence in his ability to care for his wife was being judged by others. Such views demonstrate how men as carers are positioned in society and expectations surrounding appropriate masculine behaviour. In so doing, men's caring may be seen as a reflection of socially constructed views of gender and dominant views of masculinity (Connidis *et al.* 2010). The idea of men being incapable of caring itself stems from a socially constructed idea and the men in my study appeared to be challenging such perceptions.

In addition, the stories that men told have been situated within a 'wider voice' – an authoritarian voice was always at play (Duffy 2012), in which society and cultural expectations impacted on the meaning of their caring experience. For instance, several men spoke of the high levels of trust and respect they had for the opinions of senior healthcare professionals such as consultant doctors – their judgment was crucial to their experience. This also demonstrates the power of social structures over the norm, and specifically the authority that medical knowledge holds in society. Indeed, Duffy (2012) notes that the authoritarian voice is likely to be the dominant discourse of the specific culture – cultural meta-narratives that vary according to time, place and socio-political context. These social structures colour our interpretations and individual understanding. According to Duffy (2012, p. 422) 'A person's identity is laced together by the signatures of multiple interwoven stories'. There are links here with Bakhtin's philosophy of *heteroglossia* (Hynes 2014b). According to his view, within any utterance, stratifying forces are at work – a dialogic interaction in which centripetal or official discourses and centrifugal or unofficial discourses within a national language are in tension with each other (Hynes 2014b). Hynes (2014b, p. 407) posits that from this perspective 'we understand that words are themselves shaped by history, culture and context within their meanings shifting in the moment'.

The men's stories thus tell us not just about them but about our world, about our society. So stories are never individual – they tell us about the culture in which their caring takes place and relations between subjects and structures (Andrews *et al.* 2004). Men negotiate providing care in the context of social and structural arrangements embedded within cultural views of masculinities and the role of men in informal care, in addition to cultural views on dementia. These social and cultural voices interact and influence men's experiences. As Eriksson and colleagues (2013b) contend, studying men's involvement in informal caring has the potential to provide important insights into notions of masculinities in society. However, social constructions change all the time, such as gendered roles (Lorber 2009). For instance, in my study, through caregiving, men are inadvertently redefining traditional masculine identities of what is considered the 'norm'. It appears that the men were engaged in a process of continually renegotiating – renegotiating the meaning of caring – as their experiences were constantly changing as the person with dementia deteriorated further. However, the men were determined to continue in their role in spite of the burdens and frustrations they faced. At one level, my findings may be attributed to the concept of hegemonic masculinity, a perspective that typifies men as stoic and confident (O'Neill *et al.* 2012).

However, at another level, the findings illustrate the argument put forward that masculinity is not static but rather fluid and subject to change (Connell & Messerschmidt 2005). Indeed, many of the men in my study demonstrated how they were enacting multiple and competing masculinities on a daily basis through providing care in the context of dementia. Nonetheless men illustrated behaviour traditionally associated with masculinity such as how they were strong, determined and displayed a 'just do it' attitude in their personal care responsibilities. Men spoke of how they competently undertook intimate personal care tasks in line with earlier work such as Cahill (2000). Yet the gentle way they spoke and the tenderness that was key to their caring put such ideals out the window; they were unafraid by challenges and protection of the person with dementias' sense of dignity was integral. Love was the central motivating factor in providing meaning to their caring experience. Thus, the broad generalisation that the concept of hegemonic masculinity prevails is not helpful as there are multiple masculinities and diversity among men (Ridge *et al.* 2011). Through caring, the men in my study were therefore providing new understandings of masculinities (Eriksson *et al.* 2013b). Men's involvement in informal caring also provided important insights into the contradictions and tensions

explicit within notions of masculinities in society (Hanlon 2012). In so doing, my findings have challenged gender stereotypes and the methodological approach I took ensured that I did not fall into the same trap as previous researchers such as Croker-Houde (2002) and Miller & Cafasso (1992). For instance, Ducharme *et al.* (2007a) cite that this work had limited scope, as variations that occur among male caregivers were overlooked and instead this research was based on a stereotyped concept of gender roles (p. 5).

4. *Dialogic Nature of Narratives*

Narratives have also been used to explore 'performance' as narrative in context (Riessman 2008). Following this line of thought, through telling their stories, men were also demonstrating how they are in the process of developing 'new ideas' of what it is to be a male carer. In so doing, they are creating an exciting possibility, challenging the notion that caring is burdensome in the deep emotions and personal information disclosed to me. Instead, caring may also be at the same time, an enriching personal experience in which love for the person with dementia is the central feature providing meaning. The men could be said to be promoting 'Otherness' (Pullen & Simpson 2009) through caring, whereby masculinity is both subverted and maintained at the same time. The men's individual stories therefore have *narrative elasticity* (Holstein & Gubrium 2000), with the capacity to shape and revise dominant public narratives (Blix *et al.* 2013, p. 273). With gender viewed as a social practice, social structures control how it is viewed. The multi-dimensionality of caring described by men demonstrates at one end how gendered norms surrounding masculinities and men's role in informal care are experienced. However, the men's stories also reveal how the same societal experiences are being contested. Significantly, men in caring become the 'other', challenging gendered conceptions of male roles and identities. The dialogic and performative nature of men's stories means that they are indeed never-ending co-constructions. The narratives are also a form of social action (Hydén 2010). This thesis is itself 'a story', including my influence as well as that of the readers – the audience – together shaping meaning through interpretation (Riessman 2008).

Taking these four points into consideration, the same story can never be told twice. The stories gathered in my study are not fixed and the meaning attached to men's caring experiences will shift in the context of constant developments taking place in a social world (Riessman 2013). Instead of an objective reality which is true throughout time for all humans, a social constructionist perspective proposes that '...groups of people create their own

realities based on their interpretations and their sharing of those interpretations through communication' (Foss *et al.* 2013, p. 50).

According to Frank (2010, p. 153) 'Stories are always changing as they are retold, and they are resistant to change – they change inevitably, but slowly. What stories do is readily attract other stories, and therein lies faster leverage for change'. I did find a contradiction at times with the tone of men's voices and the words they spoke. However, I recognise that this was not a contradiction in the sense that their narratives are untrue but they represent how they were constantly trying to adjust to the role changes and challenges faced in providing care, an almost always 'balancing act' encompassing multiple voices. In so doing, the men's stories were always multi-dimensional and unfinished, with love for the person with dementia central throughout. Men's stories illustrated how they were constantly re-shaping this love. Therefore, this does not mean that the data I have gathered is unreliable; '...rather it is a sign of them being what they are – narratives revealing how participants ascribe meaning to their lives from the perspectives of 'here and now'' (Wiklund-Gustin 2010, p. 35). The trustworthiness of men's stories is therefore not in doubt.

Continuous Self-Reflection and My Position(s)

I wanted to keep men's own words to the forefront in presenting the findings from my research wherever possible, therefore ensuring to give voice to the men themselves. However, I also tried to include my own reflections throughout as highlighted in the introductory chapter. The research process itself involves socially constructing a world with the researchers included within the body of their research (Josselson 2011b). It is a 'complex' path that has led to the final production of this thesis, but in spite of the challenges I have faced, I have allowed the voices of men's caring stories in dementia to guide my work. There have been times when I felt that I was going down the 'wrong' path, so used to writing in a traditional way and so instead, I had to learn to allow the real experiences of men to be heard and continually ask myself what was the best way of demonstrating this. Nevertheless as I earlier acknowledged, I also understand that men's narratives do not reflect reality. Alternatively, they are a method by which men 'construct' their experiences of caring and in so doing construct a sense of 'self' or identity in co-construction with me as the researcher, taking place at a particular time and place. To this end, my own presence and the effect which I had on the stories told was constantly acknowledged and made transparent by the application of rigorous analytical reflexivity as promoted in the work of Clandinin & Connelly (2000). Reflexivity involved turning the lens back on to myself to recognise and take

responsibility for my own situatedness within my research and the effect that I may have had on the setting and the participants, questions asked, data being collected and its interpretation (Berger 2013, p. 2)¹³¹.

Riessman (2004) believes that in qualitative research the investigator is located at one level in the interview conversation, by virtue of social characteristics and commitments, and at another level between subject and audience, as a translator. I was positioned therefore at a number of levels, I had several hats on that need to be taken into account. Positionality and how I brought myself into the PhD was significant, whereby I found that I was constantly balancing myself as both insider and outsider throughout the research process. In relation to constantly balancing insider/outsider, Mauthner & Doucet (2003, p. 419) have spoken about 'Situating ourselves socially and emotionally in relation to respondents is an important element of reflexivity'. I made a number of conscious decisions in order to re-convert myself and co-construct meaning with the men, ultimately viewing them as strategies I undertook in entering men's worlds. For instance, I have previously spoken of how I undertook informal conversations before the recording began with each of the men, showing my own 'insider knowledge' of informal caring. In so doing, I created both a 'discursive space' and an informal space in which men felt comfortable speaking with me.

Positionality took place during data collection at another level as I was constantly reviewing my own position as a researcher and the paradigm choices and philosophical issues I faced. My role in data collection and analysis was to make sense of men's stories of caring in the context of dementia. However, it involved much more than that, as it was also a process of continual self-monitoring. I felt I was on a journey too – constantly asking questions of myself throughout. So too, I felt that I was on a similarly ongoing reflexive process, considering my reasons for conducting the research, my role in the research, the needs of the participants and the importance of the relationships that were developed in the research context (Stephens 2011). As I immersed myself deeper into my thesis, the stories told by the men challenged my own position and preconceived notions I had surrounding male caregiving.

In narrative research, the relation between teller and listener is a power relation (Hydén 2013, p. 237). My own personal familiarity with the experiences of informal carers had the potential

¹³¹ Reflexivity thus enhances the quality of the research by allowing researchers to consider the ways in which they may both assist and hinder the process of co-constructing meanings (Lietz *et al.* 2006).

to impact on all phases of the research process, such as recruitment of participants, collection of data, analysis of data and write up (Berger 2013). Thus, in establishing a constant balance between insider and outsider, I aimed to guard against the above having a negative effect and not allowing voices to be heard. As Berger (2013) commented I had to be aware of the 'double edged sword', remaining constantly alert to avoid projecting my own experiences and using it as the optimal lens to view and understand men's caring experiences. At the other end, it has also been questioned by some as to whether a researcher who has not shared participants' experience can truly understand and convey it even when reflexivity is used (Pillow 2003). In my case, I was a university educated woman in her late 20s with several years of research and policy experience on various caregiving projects while conducting this study. Thus, while participants and I were very different - that is they were male and I am female, I also have a certain level of 'insider' knowledge and constantly reviewed my own personal and previous work experiences through regular discussions with my supervisory team. Upon reading other empirical work completed by female researchers who also spoke with men in their research (for example, Pullen & Simpson 2009), reflexivity was important to me in acknowledging how gender difference between me as the interviewer and the participants may have influenced data collection and analysis. Seidman (2013) warns that women interviewing men can sometimes be reluctant to control the focus of the interview and male participants can easily dismissive of female interviewers (p. 104). I did not find this to be the case. Instead, the in-depth narrative approach I took in speaking with men gave them the space to tell their stories in a way that they felt comfortable doing so and were able to respond to my open-ended questions. While not wishing to claim that a female interviewer would produce a 'better' interpretation, similar to Pullen & Simpson (2009), I too believe that there was an ease in terms of men sharing their personal reflections and disclosures with me (p. 569). This is also a reflection of the style of interviewing I applied in speaking with the men about their caring experiences in which I allowed, as much as possible, for them tell me their story, hence appearing as an empathetic and non-threatening listener.

In carefully examining what I brought to and how I contributed to the research, this changed significantly. I found myself repeatedly going through a process of both unease and uncertainty followed by growing confidence. For example, as I began to immerse myself further by reading more widely in the area and speaking with more men, and then began to interpret and analysis their stories. I too was going through a continual process of meaning

making. On the other hand, my supervisory team, having not been involved in the data collection, acted as a reflective lens for me, through the many subsequent discussions we had as I undertook the task of interpreting and analysing the data I had gathered (Pullen & Simpson 2009, p. 569),

In recognising the 'co-construction' of stories between myself and each man, similar to other narrative researchers such as Warnes & Daiches (2011), I have previously spoken of how I carefully gathered field notes throughout the research process. Similar to the reflective journal proposed by Lincoln & Guba (1985) and used by Warnes & Daiches (2011) in their own narrative work on stories of young motherhood, I too wrote down immediate feelings that had arisen following each interview, imagery, how and when I asked questions, any non-verbal behaviour and my perceived coherence of the interview (p. 113). I also considered other issues in my field notes, like Hall (2011) in her narrative work on trauma recovery accounts, such as participants' perceptions of the interview setting, the stance of the participant, the flow of the interview, points of intensity, changes in emotional charge and power dynamics (p. 6). Thus, while my field notes situated the context of each interview, they did a lot more – they provided evidence of my feelings and reactions, men's emotional responses and body language. Constructive reflexivity was also taking place within my field notes as I questioned how I influenced what was said to me. In a lot of cases, interesting stories were told and continued after the recording had stopped; such information was documented in my field notes. Hence, these stories have no end!

Reflexivity is also demonstrated by use of first-person language (Berger 2013: p. 4). Thus, as I have alluded from the outset, I have been keen to use 'I' and 'me' as much as possible in my thesis. In addition, when presenting findings I presented them as men (although pseudonyms) rather than as codes or numbers. Justification for my use of 'I' and 'me' throughout my thesis has been as a way in which I was undertaking a continuous self-reflection of my own actions in exploring experiences of male carers. A related issue was the importance of telling stories of caregiving in the first-person voice. To this end, Guillemin & Heggan (2012, p. 704) argue that: 'A narrative told in the first person ensures that researchers focus on their own experiences, reflections, uncertainties and doubts. ... (which) encourages us to join in the meaning-making process....'.

Andrews (2007) highlights that in undertaking narrative research, her work has always led her on to more and more questions, never feeling that she has 'arrived' at a definitive answer (p.

177). However, she believes that this is a consequence of the nature of narrative work 'focused as it is on uncovering layers of meaning, rather than identifying solutions to any given problem' (Andrews 2007, p. 177). Ultimately, I understand that despite my effort, no research is free of biases, assumptions, and my own personality (Sword 1999).

Consequently, as I have previously acknowledged, I felt that I was on a journey too, learning as I went along the uncertain road of conducting a narrative study. Berger (2013) has talked about the researcher's position as fluid rather than static (p. 13). There were various times when I felt overwhelmed and stressed both with enormous amount of reading, and as I immersed myself deeper in data collection and analysis. Berger (2013) speaks about the need to constantly update one's own position relative to their study and repeatedly asking self and discussion with others about the *current* position and how it may affect the research (p. 13). For example, I presented papers at various stages in my research questioning my approach as it developed, such as at doctoral events and so discussing my work with peers, and also constantly discussing issues with my supervisory team.

Finally, I recognise that the men I spoke with were undertaking reflexivity too as they told their story. Gubrium & Holstein (1998) contend that it is important to remember the reflexive agency of the storyteller in narrating their experience: '...he or she is also an editor (as well as author) who constantly monitors, manages, modifies and revises the emergent story' (p. 170). I noticed how men themselves appeared to undertake a reflexive process within the interviews, for example through saying 'Oh that's how I do things...'. Some men expressed anticipation and anxiety – asking 'Am I doing this right?' Finally, while I was the audience for the individual narratives, I understand that that the wider audience – the reader of this thesis – may read the men's narratives in yet a different way.

Conclusion

In conclusion, my study allowed me to undertake a deep exploration of the different layers of meaning to men's caring experiences in the context of dementia. While their experiences of providing care are burdensome and stressful, an enduring love underpinned and drove their resilience in continuing to care for the person with dementia. Caring is a multifaceted experience, involving both challenges and rewards that can be experienced simultaneously. Men appeared to be walking a tightrope expressing despair on multiple levels, fueled not only by losses inherent in dementia but also in navigating resources to assist them in their caring journey. However, the centrality of love is what made meaning out of men's caregiving, as illustrated through the image of a rose. The six interconnecting patterns of meaning in their

caring experience are evidence of how men operationalised person-centred care in practice, without being aware of it themselves. From a social construction lens and using a narrative methodological approach, the men's stories of caring have been co-constructed and created in dialogue within interpersonal, sociocultural and historical processes. They are not a transparent window into men's caring experiences (Phoenix *et al.* 2010). Instead, they constitute an aspect of a socially constructed reality that is in constant flux. For Goodley (1998), the advantage of narrative research is the recognition that individuals' understandings of their social world are fluid and ever changing. I was constantly learning too – throughout the journey of undertaking my PhD – with my own social construction taking place, as I grew in confidence from a 'novice' at conducting narrative research, to an expert in my chosen field.

Chapter 9: Conclusion

It's a different kind of love. Absolutely, absolutely. It's a different kind of love, it's very protective. I wouldn't have protected (wife's name) in the past, she didn't need it. You know, it's very protective. You know you'd kill, it's almost like paternal, maternal you know. I think it kind of goes to that kind of stuff you know.....yeah (Connor, P08).

Introduction

This final chapter aims to bring my story of conducting this research study to a close. The methodological significance of my study will firstly be discussed. Following this, avenues to be considered for future research will be outlined. A number of implications and recommendations for policy and practice will then be made specifically relating to male carers.

This study sought out to explore and give an initial understanding to the experiences of men providing care to a loved one or close relative with dementia from a narrative perspective. The growing prevalence of dementia means that an increasing number of people, including men will take on the caring role for someone with dementia. An explorative narrative approach using qualitative methods was employed¹³². The research question that guided my study was *how do male carers perceive their own experience of providing care to their loved one or close relative with dementia?* Each story was beautifully told in the context of larger political, social and theoretical domains. Social constructionist thinking provided me with a conceptual framework to engage with men. While it is not possible to homogenize men's caring experiences, deep multi-layered narrative analysis identified six interconnecting patterns of across the sixteen men's stories of providing care in the context of dementia, namely the all-consuming nature of caring, determination and pride, loss and sadness, admiration and respect, intimacy and closeness, and future. Love was the central feature permeating across this complex patchwork of patterns of meaning, holding together men's stories of caring. An unconditional love of the person with dementia was the driving force in men's experiences, standing up against constantly emerging challenges as the condition continued to progress. Meaning was constructed through social interaction, specific to a particular time and place.

¹³² As previously outlined, this project did not set out to be dementia specific.

Methodological Significance of My Study

This section will discuss what is gained from a narrative understanding of men's caring experiences. In the previous chapter, I discussed at length the narrative methodological approach and research paradigm of social constructionism that guided my study in relation to the key feature of love identified across men's stories. Both the strengths and limitations of my theoretical approach and methodology chosen will now be considered. Together, the strength of narrative – as a methodological approach – was in the style of interviewing and analysis and also as a conceptual framework that allowed me to explore how men make sense of their experiences of caring in the context of dementia. Here-in lies the relationship between theory, research and practice and how I considered the experiences of male carers by drawing on a social constructionist perspective to narratively explore their meaning and perceptions of care.

My challenge was to provide a systematic approach to analysis for the purpose of fulfilling a PhD while allowing men's voices to be heard. Integrity was key as I wanted to ensure that I remained respectful of the men's stories told at all times. The starting point for this was in data collection, a collaborative process that required me to establish trust with each man (Gill & Goodson 2011). In-depth interviews with minimal questioning were used in order to allow men tell their story of life as a male carer in their own way. The in-depth individual interviews that I conducted allowed me to create a relationship in which I was the listener and men became the narrators of their stories of caring (Chase 2008). Similar to other narrative researchers (for example Lee *et al.* 2013), factors such as the context of the interviews, which took place either in their own homes or in a neutral setting, as well as the inherent power dynamic of the researcher-participant relationship may have impacted on how men constructed their stories (Elbaz-Luwisch 1997, as cited by Lee *et al.* 2013). However, I understand that as a researcher, I have had an impact on each stage within the research process and each of the stories collected was co-constructed. Mishler (1986) has suggested the importance of a process of co-construction in order to avoid the methodological traps of personal interpretation. In co-construction, the speaker and listener are jointly engaged in creating a reality that is agreed and co-constructed between them.

While theoretical assumptions on narrative theory guided my analysis, at the same time I was open to new ideas and challenges, rather than imposing a framework and simply describing a narrative account of men's caring experiences (Murray 2008, p. 121). Instead, I developed a multi-layered analytical framework incorporating several models of narrative analysis in order

to uncover the multiple layers of meaning within the stories gathered. According to Josselson (2011a, p. 227) 'Analysis is a creative process of organizing data so that the analytic scheme will emerge'. In seeking to answer the what, how, why, where and when of each man's story, the thick description of the narrative elements I identified incorporated with themes, tones and imagery provided me with rich and detailed information on men's caring experiences. Like Hall (2011), my approach to analysis necessitated flexibly adapting methods to emergent data. Through the formulation of narrative summaries of each man's story of caring, I contextualised the data by situating it within a specific time and place (Clandinin & Connelly, 2000). Each man's story becomes wrapped around the reader – you can almost see the sadness but also the sweetness and individual gestures that help men every day in their caregiving role. As Brophy (2009, p. 28) contends: 'Narrative research includes emotions and moods, conveying what it felt like to be part of the scene depicted.... (It) deliberately highlights what is unique or different – unlike scientific enquiry it eschews the attempt to find common ground'. I also exhibited the narrative strategies men used to tell their stories such as turning points, in which they highlighted particular occasions that held significant personal meaning. Ultimately, like Frost (2009), using a pluralistic approach and viewing the data from several perspectives allowed me to explore the multi-dimensionality of men's caring experiences in the context of dementia that were socially constructed. Furthermore, shifting the focus from one aspect of the data to another led to deeper and more meaningful explanations (Simons *et al.* 2008).

At a theoretical level, a narrative approach allowed me to demonstrate how the men's caring experiences and thus, their narratives are culturally oriented and experience-centered (Squire *et al.* 2008). My findings have provided more than just information on men's personal experiences of caring in the context of dementia. They have also provided an insight into wider social and cultural voices and how they interact and influence men's experiences. According to Gergen & Gergen (1984), self-narratives are not individual but are the result of social interchange. Like Gergen & Gergen (1984), I also viewed the men's narratives as 'social phenomena' (p. 174). Thus, as Clandinin & Caine (2013) posit: 'While narrative inquirers do not generalize from the experiences of their participants, they add to policy development by pointing out the complexities, contradictions and inconsistencies often inherent in policies and their implementation' (p. 175). For instance, I demonstrated the multi-dimensionality of meaning in men's experiences – caring was much more complex than just positive or negative. Men's unconditional love for the person with dementia was continually

reshaping in light of new challenges as the condition progressed further. In standing up to the frustrations and anxiety, men were also able to reengage and redefine personhood – providing an example of the multi-dimensionality of masculinities. Hanlon (2009a, 2009b) found that by doing care, men can transform or reconfigure their masculinity. Through telling their stories, men have therefore demonstrated how they are in the process of developing ‘new ideas’ of what it is to be a male carer and in so doing, they are challenging the notion that caring is burdensome per se. Instead, caring is multi-dimensional and it can be both burdensome and an enriching experience simultaneously. At the same time, in line with social construction, men’s stories about their caring experiences are partial and positioned, their telling as well as my listening and interpretation are influenced by wider culture, as well as values and beliefs. Social constructionism assumes that the basis for understanding and explaining social life is a subjective sense of reality (Burr 1995). The men and I are socially and culturally positioned on discourses that are on constantly shifting ground (Riessman 2008). Therefore, there is no such thing as impartial telling or unbiased listening as due to the dialogic nature of narratives, there is always an authorial voice at play (Duffy 2012).

I recognise that several limitations to using a narrative approach exist at a theoretical level relating to subjectivity, replication, generalization and transparency (Bryman 2008). Lack of transferability is another criticism of narrative research (Hardy *et al.* 2009). However, I will now document how I believe that I have turned each potential limitation into a strength in undertaking my study:

1. *Subjectivity* – qualitative research is often criticised for being too impressionistic or subjective, relying too much on the researcher’s often unsystematic views about what is significant, and also upon the close personal relationships that the researcher establishes with participants (Bryman 2008, p. 391). I developed a good relationship with many of the men I spoke with and this in turn enabled them to feel comfortable speaking with me. In so doing, I undertook a number of strategies to enter men’s world and I was careful to balance the ‘insider/outsider’ role that I played throughout. For instance, I decided to include personal reflections throughout, including ‘I’ and ‘me’ at every stage of my study. Specifically in the development of my analytical framework and presentation of my findings, I have clearly demonstrated the constant dialogue that took place on a number of levels that contributed to meaning making experience. Furthermore, in seeking to explore the male carer experience, I understand that the meaning each participant has is situated and based on their

individual previous experiences. In applying a narrative approach and the in-depth nature of the interviews, I provided the opportunity for each of the participants to have a form of control over the data collected (Freshwater & Holloway 2010). This was evident both in the wording of the opening statement of each interview, as well as providing men with the option of bringing photographs to enable them to tell their personal story.

2. *Replication* – According to Bryman (2008, p. 391) ‘Precisely because it is unstructured and often reliant upon the qualitative researcher’s ingenuity, it is almost impossible to conduct a true replication, since there are hardly any standard procedures to be followed’. I agree that my study can *never* be replicated. ‘Narrative models of knowing are models of process in process. When we record people’s narratives over time, we can observe the evolution of the life story rather than see it as a text in a fixed and temporal state’ (Josselson 1995, p. 35). In my study, I was interested in what Plummer (2001) described as narrative ‘truth’ (p. 461) to access and understand the subjective world from the person’s point of view, even if it does not match reality. The men’s narratives do not reflect reality but are instead a method by which they ‘construct’ their experiences of caring and also construct a sense of ‘self’ or identity (Bruner 1990, 2002). Narrative truth involves a constructed account of experience, and is not a factual record of what ‘really’ happened (Josselson 2011b, p. 225). Ochs (2011) terms stories as ‘construals of happenings’ (p. 71). Moreover, the next generation of younger men as they age and become carers may experience something quite different over the coming decades as a consequence of late modernity, individualisation and its culture of identity politics. The majority of men I spoke with were in long term marriages and had been the main breadwinner in their relationship, a situation that is increasingly no longer the norm.

I recognise that while the same story could never be told twice may be viewed at one level as a limitation of narrative methodological approach, this is because context is continually changing and so too men’s sense of ‘self’ and identity (Frank 2010). While factual events that occur may not change, we can change or re-figure the meaning ascribed to them over time (Wiklund-Gustin 2010). I therefore view it as yet another strength of conducting further research in this area namely over a longer period and how caregiving experiences change over time, particularly as the condition of the

person with dementia deteriorates and responsibilities and roles change. Incidences apparent within the interviews that I conducted showed how men's experiences were constantly changing, particularly in their references to being a developing scenario as well as insight that they were building up due to their own time caring.

3. *Generalisation* – My sample size may be viewed as small at sixteen, limiting the possibility of generalisation of my study findings. However, the 'in-depth' focus I applied to each of the interviews resulted in an immense amount of data gathered. Riessman (1993) highlights that narrative methods require time due to the attention to detail required and therefore may be unsuitable to explore with a larger sample size. Further to this, I did not set out to compare the male carer experience to other caring contexts. In addition, the majority of men I spoke with were recruited directly through carers' support organisations. Men not attending or in receipt of such supports and services, as well as men from different cultures or indeed non-dementia specific male carers may have had other issues that were important to their experience. Thus, the findings may have been biased to male carers who were in receipt of such support services, providing me with a unique, non-representative sample. My sample could also have been strengthened through a wider geographical base. Only one man identified himself as living in a rural area in spite of Census 2011 findings on the rural/urban divide. For instance, proportionally more carers were found to live in rural areas in Ireland according to figures from Census 2011. While the share of carers in rural areas was 43.2%, this was greater than the rural share of the population (38%), and there were proportionally fewer carers in urban areas (56.8%), compared with their share of the overall population (62%) (CSO 2012). Narrative studies have been criticised for being small scale, subjective and strongly referential, therein also lies their strength (Stanley 1993). They demonstrate (as do I) the value of using narrative methods by revealing hitherto unrecognised complexities of caregiving (Hennings *et al.* 2013). In taking a narrative approach, generalisation was not the aim of my study. Instead, I uncovered the many layers of meaning to men's caring and the multi-dimensionality of their experience in the context of wider societal attitudes surrounding men's role in providing care.
4. *Transparency* – According to Bryman (2008): 'It is sometimes difficult to establish from qualitative research what the researcher actually did and how he or she arrived at the

study's conclusions' (p. 392). I have clearly demonstrated this, particularly in the detailed analytical framework I developed outlining each of the key stages I took in analysis and in the presentation of my findings chapters, thus ensuring study quality and rigour. In so doing, I documented a clear and transparent audit trail allowing the reader to track my analytical process from original text to final analysis through specific examples (Wood & Kroger 2000). According to Burr (2003, p. 159) 'Providing in-depth information about the steps in the analytic procedure enables the reader to make a judgment about its adequacy'. Overall, the rigour of findings was tested by a number of methods involving regular consultation (Mays & Pope, 1995). For instance, I met with my supervisory team regularly to discuss findings and agreement on frameworks such as the patterns of meaning to represent my data. Preliminary findings were presented to key stakeholders such as representatives from carers' organisations that had assisted in recruitment to check my interpretation in relation to their understandings. My findings were not fed back to participants inviting their comment. I believe that the story the men told was a reflection of a specific point in time in their caring journey and so they would be at yet another point when reflecting on the information they had provided me with at a later date.

5. *Transferability* - narrative research has also been criticised for lack of transferability in informing or changing practice, due to the highly detailed nature of results (Hardy *et al.* 2009). However, Hardy and colleagues (2009) '...propose that choosing a transparent and theoretically based approach to analysis, plus a truly collaborative method, increases the credibility and therefore transferability of narrative-based research findings' (p. 16). I strongly believe that I have done just this in my study. I took a number of specific steps throughout the data collection and which I have displayed in the previous chapters for the reader to ensure the transparency of my research procedure. For instance, following the advice of Duffy (2012, p. 436), I have clearly provided the following information about the research process: 1) identifying the research question, 2) disclosing where the research data came from, 3) identifying and describing the steps in the analysis of the data, and 4) attending to the issues of voice in the re-storying and re-presenting of the narrative by clearly indicating who the narrator is - the participant. While the transferability of qualitative research findings to other environments may be challenged, I also aimed to guard against this through the detailed and multi-layered analytical framework I applied and the use of direct

quotations in presenting my findings. Bryman (2008) notes that qualitative researchers are encouraged to produce what Geertz (1973) calls *thick description* – that is, rich accounts of the details of a culture¹³³. Lincoln & Guba (1985) argue that a thick description provides others with what they refer to as a database, making the transferability of judgements possible (p. 316). Excerpts from men’s stories through narrative summaries, as well as extensive use of quotations in my findings chapters, provided an important way in which the reader could clearly follow the multi-layered approach I took to analysis and allow the reader judge for themselves the trustworthiness of my study.

Throughout my thesis, I have defended the quality of my study, specifically its trustworthiness. The second criteria that Guba & Lincoln (1989) propose for assessing quality in a study alongside the four trustworthiness criteria, is *authenticity*. Bryman (2008, p. 379) notes that ‘These criteria raise a wider set of issues concerning the wider political impact of research’. It is therefore imperative to outline how I have achieved this¹³⁴. Guba & Lincoln (2008) believe that together, the authenticity criteria are the ‘hallmarks of authentic, trustworthy, rigorous, or ‘valid’ constructivist or phenomenological inquiry’ (p. 274). I believe that the sections that follow will clearly deal with both the larger political and social impacts of my study, and in so doing the relationship between theory, research and practice.

Future Research

There are several potential avenues for further research that may be considered following this project. As highlighted above, a longitudinal study looking across different periods in the caring trajectory for men and in different contexts may help in understanding the developmental nature of men’s caring experiences, such as changes over time as well as

¹³³ According to Denzin (1989, p. 83) ‘thick descriptions are deep, dense, detailed accounts.... Thin descriptions, by contrast, lack detail, and simply report facts’.

¹³⁴ The criteria for establishing authenticity are as follows: 1) *Fairness* – Does the research fairly represent different viewpoints among members of the social setting? 2) *Ontological authenticity* – Does the research help members to arrive at a better understanding of their social milieu? 3) *Educative authenticity* – Does the research help members to appreciate better the perspectives of other members of their social setting? 4) *Catalytic authenticity* – Has the research acted as an impetus to members to engage in action to change their circumstances? (Bryman 2008, p. 379).

differences in how they perceive their experience. The specific experience of male carers and retirement and its impact on their identity is another consideration for future work, given traditional expectations surrounding men working outside of the home. Previous research has documented how older men can find the transition to retirement challenging (Buchbinder 2002, Brown 2008, Oliffe *et al.* 2013). However, men's ability to reconstruct gendered identities is critical for the transition to successful retirement (Oliffe *et al.* 2013). Caring may therefore provide older men with a sense of accomplishment (Ribeiro & Paúl 2008). Given the deep personal information I gathered, further research focusing on perceptions of change in the identity of the person with dementia and the impact of dementia on intimate relations for male carers is warranted. Similar to Sanders & Power (2009), the men appeared to develop a new sense of intimacy and closeness through the care they provided. However, they continued to experience loss in a constantly developing scenario. In addition, while the majority of men in this study were husbands (n=14), the specific experiences of other male family members such as sons and brothers who provide care need to be explored further. The experience of sons caring for a parent with dementia in a rural part of Ireland was recently explored by McDonnell & Ryan (2013b). Existing literature has documented that the vast majority of research in relation to male caregivers has focused on spousal carers (Neufeld & Kushner 2009). In so doing, the male care experience may be homogenised, while sons and spousal carers may have different caring experiences. Another possible focus may be an investigation of men's relationships with the multiple health and social care professionals involved in supporting the care recipient to remain at home. Some men highlighted specific issues they had faced in their stories; however, it was not within the remit of this study to explore further. A specific focus of this future piece of research may be an examination of how care providers assess the support needs of male carers.

Implications and Recommendations for Policy and Practice

While the first half of this chapter outlined the contribution of my study at a methodological and theoretical level, I will now document the implications of my study for policy and practice and what recommendations may be drawn from my findings in relation to male carers.

Implications of My Study for Policy and Practice:

1. Giving voice to male carers – Research on caregivers has largely focused on the role of wives providing care to their husbands. The caregiving role of men has only recently begun to receive more attention in academic literature. There has been to

date, little published work on the specific experiences of men who provide informal care in Ireland. However, the National Carers Strategy recognises men as a key carer group in Ireland (DoH 2012a). The National Carers Strategy acknowledges that carers are vital to the achievement of supporting and enabling older people to live with dignity and independence in their own homes and communities for as long as possible. Thus, they are the back bone of care provision (Donnelly 2013). This study has acknowledged the increasing role that men play in providing informal care in the home. In allowing men to tell their stories of caring, this study has raised their voices within Irish society in allowing individuals with dementia to remain at home. In Ireland, the 2012 Creating Excellence Report established that the overall cost of dementia in Ireland was €1.69 billion a year and this figure had increased significantly over the previous decade. At 48%, almost half of this cost is attributable to informal care provided by family and friends to people with dementia living in the community (Cahill *et al.* 2012). My study findings may be viewed as a supporting tool for male carers in advocating for men and recognition of the valuable role they play. The existence of male carers has been overlooked as traditionally family care has been associated with a female role. Sharing stories of caring makes men's experiences more visible to wider society and helps in understanding of current discourses around the role of men in caring.

2. Informing key stakeholders of male carer experience – While this was a small-scale qualitative project, the narrative evidence gathered has provided a deep understanding of men's caring experiences in the context of dementia. This evidence is crucial to a range of key stakeholders such as policy makers, government officials, service providers, health professionals and academics working with and for male carers in highlighting gaps in support and their specific needs. Specifically, understanding the variety of experiences men have of the demands associated with dementia care provides important evidence on how services may be developed to meet their needs. Various categories of needs for men have been identified – physical, emotional, psychological, information, education, training and support. Understanding how and why men experience caring is therefore crucial. Indeed, an understanding of the impact of caring on self-identity is important as the evidence gathered can assist in the provision of targeted services and supports. The best way to do this is through listening men's own voices. The evidence gathered through

men's stories will assist in promoting a more open, positive and proactive approach to supporting carers. Ultimately, it is crucial that government policy is reflected in practice and the value of male carers is recognised through supports.

3. Breaking down society expectations and norms – Within a broader-political context, my findings support an argument that policy needs to re-story the value and contribution of informal caregivers to society (Warnes & Daiches 2011, p. 124). According to Sandberg & Eriksson (2007, p. 13) 'Caregiving models and support programmes for informal caregivers cannot be developed from abstract notions of traditional roles or cultural stereotypes'. As highlighted above, with increasing numbers of male carers, their needs cannot be ignored. While the findings of my study provide in-depth evidence of the lived experiences of a sample of men providing care, they also broaden public understanding of caring traditionally linked to women. My study findings also have important implications for public understanding of caring in general. For instance, promotion of the role of men as carers as capable, willing and able. The men I spoke with were very proud and determined – wanting to care. Thus, if adequately supported, caring can be rewarding and fulfilling. My findings have challenged the idea of caring as a burden and how the existing relationship with the care recipient is central in providing strength to continue in spite of difficulties faced. Thus, in attempting to understand the male caring, my narrative study challenges predominant views of caring experience viewed as a burden. Instead, it provides important information on the possibilities and potential rewards that may be experienced through caring and the contextual nature and multidimensionality of men's experiences. Caring is a multifaceted experience, involving both challenges and rewards that can be experienced simultaneously.
4. Intertwined nature of caring – My study has documented the shared journey between carer and care recipient, they cannot be separated. My findings illustrate the complex patterns of men's lives and the meaning these carry for them as they care for their loved one with dementia. The multidimensionality of caring experience identified love for the person with dementia as the central feature that held men's stories together and provided them with a sense of meaning. Sustaining male carers to care for relatives in the home therefore requires support of both policy and services that reflect the specific needs of *both* carer and care recipient.

5. The men's stories contribute to a shared storyline (Warnes & Daiches 2011) that all caring takes place in constant flux. The powerful social and cultural attitudes that shape the context in which men are caregivers provided a challenging backdrop against which to make sense of and narrate their experiences. In addition, the influence of societal and cultural settings is crucial to individual experience. Unique needs emerge over the course of caregiving, with roles and responsibilities constantly changing as a consequence of the continued progression in illness. It is crucial that supports are tailored to specific points in caring journey; communication with all health and social care professionals is key in this regard. Specifically, the needs of people with dementia evolve constantly over time requiring advanced planning, monitoring and coordination (Prince *et al.* 2013). As Prince and colleagues (2013, p. 4) contend 'The challenge is to support 'living well with dementia' across the journey of care'. Male carers form an integral part of this principle.

6. This research adds to the field of study – My work provides the School of Nursing and Midwifery, Trinity College Dublin with narrative data on the male carer experience. It also provides evidence to larger research activities currently taking place in Trinity College Dublin, such as the TILDA Study, the Genio Dementia Programme and De-Stress Study. Firstly, the Irish Longitudinal Study (TILDA) is a large-scale, nationally representative, longitudinal study on ageing in Ireland, collecting information on all circumstances from people aged 50 and over. Secondly, the School of Nursing, Trinity College Dublin is currently carrying out an evaluation of the Genio Dementia Programme. It is a multi-site study evaluating integrated care for persons with dementia at both hospital and community care level. Thirdly, the Institute of Neuroscience, Trinity College Dublin is undertaking the De-Stress study that is examining the health and well-being of spousal caregivers of people with dementia in Ireland. The evidence gathered can also add to the Carer Needs Assessment in the development of an InterRAI Single Assessment Tool for Older People in Ireland. The InterRAI is the agreed Single Assessment Tool to be rolled out in the health and social care services, and will incorporate the development of a carer needs assessment supplement. The InterRAI tools employ a structured, multidisciplinary assessment covering key domains to thoroughly and accurately assess the wide-ranging health and social care needs of older people (McDermott-Scales *et al.* 2013).

Recommendations from My Study for Policy and Practice

A range of potential interventions were highlighted in men's stories which if implemented would assist them in their overall caring experience. I will now propose a number of specific recommendations:

1. Men want to care but they require relief and support from the burdens of providing care. It is imperative that conditions are put in place for men for rest and time to self. Men in this study were extremely determined – wanting to continue to care in spite of the challenges they faced. Time to self was seen as crucial - through respite, day-care support, home-based carers and support from family. While time to self was a vital resource cited by men, for many it was rare and difficult to plan in advance. Financial assistance for respite was also important. Many family carers do not receive the Carers Allowance due to means testing. For them, the Respite Care Grant is the only direct financial state support that they receive for providing care. Respite is essential for all carers and is difficult to plan in advance (Care Alliance Ireland 2014).
2. Support tailored to meet men's needs – It is vital that support services are specifically designed for male carers' needs rather than separate to other carers. Services may treat men's caregiving as non-normative and in so doing create increased dissonance in the role. For example, in terms of support groups, where men may be the only male in attendance, leading to feeling uncomfortable. In contrast, men were highly positive of male only support groups in their stories. Support groups are a way of exchanging information on caring but also have an important social aspect. Enhancing the positive aspects of male caregiving represents an important way in which to support men's involvement in caring. While caring *can* be burdensome, tailored supports will help to alleviate such burdens. It is crucial that training is based on problem-solving coping strategies as highlighted by men in their stories. This does not mean that the emotional aspects associated with caring should be ignored. Rather, as the men's stories demonstrated love is actually the key feature guiding their motivation to 'just do it'. In addition, gender specific training programmes that prepare men for their caring journey are crucial – Men's caring role was constantly changing, with new roles and responsibilities emerging as the condition of the person with dementia intensified. Education holds an empowering force through allowing men to feel confident and creating a situation whereby caring can be rewarding and fulfilling. However, such

education must be continuous and provide men with knowledge to care with confidence throughout their caring journey. The example of six week workshops by specific organisations were provided but carers may need more over different time periods as caring is constant flux. It may be beneficial if this training was provided in a less formal way, with consideration for a more flexible approach encompassing 'tips and hints'. It is also crucial that such training is tailored to the needs of men such as their involvement in household tasks and intimate aspects of care. In addition to enhancing the accessibility of face-to-face education and training, it is important that opportunities are provided for on-line and distance options given restrictions placed on carers and cited by men in the study. Ultimately, men expressed that they wanted to learn. Previous research conducted by Brown et al. (2007) found the availability of gender-specific education programmes assisted the help-seeking process for husband caregivers.

3. Recognise and support male carers as key partners in care – Men acted as advocates for the care recipient and their stories documented person-centered care in practice. This points to the importance of listening to men and creating opportunities for their voices to be heard. The men in this study showed deep insight and knowledge for the person with dementia. It is therefore crucial that all health and social care professionals see and respect men as key partners in care. They should be viewed as 'experts' – co-partners in care linking the informal with the formal care. Informal and formal care providers must work in tandem in order to promote the person with dementia's needs. Allowing men's voices to be heard also facilitates their insight and so too the important role they *must* play in any future policy formulation and implementation. Consultation with all carers is a crucial part in the development of a coordinated person-centred package of care that should be cornerstone of the National Dementia Strategy¹³⁵. The publication of the National Dementia Strategy is an opportunity to commit resources to community-based care that supports people to remain at home for as long as possible, which is where they want to be (Alzheimer's

¹³⁵ For Prince and colleagues (2013), all governments should make dementia a priority. This should be signified by developing National Dementia Plans to ensure that health and social care systems are adequately structured and funded to provide high-quality care and support to people throughout the dementia journey.

Society of Ireland 2014). Ireland one of the last countries in Europe yet to produce a National Dementia Strategy. In addition, continuous as well as additional education and training for all health and allied social care professionals involved in care of person with dementia is necessary on the specific experience of male carers in order to adequately address their needs. Policy and practice must reflect how informal care is now provided in a diverse range of circumstances and not on assumptions surrounding care in the home based on women's role.

4. Introduction of an assessment of male carers' needs – In so doing, recognising that carers are not a homogenous group and have specific needs. In Ireland, a phased national implementation programme of interRAI Single Assessment Tools (SAT) is planned within older persons acute and community services. As part of the Single Assessment Tool implementation programme, a commitment has been given to develop an interRAI Carer Needs Assessment Supplement in partnership with the InterRAI Consortium (Donnelly 2013). The development of the Carer Needs Assessment Supplement aims to both identify carers' individual needs to support them in their caring role and further support the Irish National Carers' Strategy in meeting its goals (Donnelly 2013). As part of a review of international carer assessment, Donnelly (2013) found that a recurring theme was the importance of commitment from senior management, policy makers and funders towards carers and their assessment. Care Alliance Ireland (2013b) has previously argued for the need for family carer assessments. In seeing male carers as partners in health and social care, they should be given access to an assessment process that would allow them to identify their needs. Care Alliance Ireland (2013b) noted that assessment builds carer morale and capacity and is central to care planning. They can also act as a monitor for health and social care professionals of programme effectiveness and in so doing can inform policy and service provision. It is imperative that policy and practice are more sensitive to the specific context of each 'case' as there is no one solution. Support must therefore be tailored to individual needs identified in assessment.
5. Support mechanisms specifically targeting men from the beginning of the dementia caring trajectory are crucial– Many men did not actively seek support and portrayed a 'just do it' attitude. While this may have provided them with a sense of satisfaction, at

the same time, it was evident that many were experiencing stress. They also expressed fear over what would happen if they became ill. In previous work, Ducharme and colleagues (2006) contended that male carers have a tendency to minimise their needs. In general, men in my study were underplaying their needs. Seeking support may be perceived as public acknowledgement of vulnerability and ultimately an admission of failure. It is therefore crucial for all stakeholders to support and encourage men in their 'new' role of providing care. There is also the challenge of a male carer accepting help and feeling guilty that they are letting the person with dementia down. There was a sense of pride among the men in my study in not wanting outside help and many expressed discomfort over the option of long-term care. However, this may lead to a situation where men only seek or receive support when a crisis point is reached. Crisis points are expensive and put pressure on the healthcare system. Thus, it is crucial that health and social care professionals create proactionary rather than reactionary opportunities to provide support to men in their role. In addition, it is crucial that men engage support early in the dementia trajectory, as part of a collaborative approach to care. It is imperative that these supports are focused on providing quality interventions in the everyday lives of men.

6. Centrality of the relationship between carer and care recipient must be considered in any future policy decisions – Future policy and practice must be built around the centrality of the relationship as evident in men's all-encompassing love for the person with dementia. The relationship between carers and care recipient influences the ways in which men understand and practice their caring. It is crucial that the nature of the relationship and knowledge preserved by men does not get lost in policy formulation. It is not just about financial implications, stakeholders must listen and take on board carers' experience. A real commitment must be explicit in both policy and practice, giving men opportunities to continue to care and care with confidence. Centrality of relationship cannot be separated in policy decisions. This is how my study is giving voice. For instance, coordinated person-centered packages of care (linking informal with formal carer) must reflect both the needs of people with dementia and their carers (Cahill *et al.* 2012). While patterns of meaning were common across men's stories, each story was unique. According to Prince and colleagues (2013, p. 6) 'No two families are alike in their needs for care and support, and we need to find ways to make care more person-centred, and care packages more flexible and

individualized'. Therefore, personalised care budgets have the potential to put the person with dementia and their caregivers in control of their packages of care, and empower them to ensure that their preferences are respected, and their needs met (Prince *et al.* 2013).

7. Information and education in order to enhance public awareness on male caring – negative societal attitudes to men's involvement in care was highlighted in men's stories. There was also a lack understanding surrounding the impact of dementia. Public awareness campaigns of male carer needs and the role they play will help change public attitudes. In so doing, they have the potential to create and promote the notion of men as carers who ought to be celebrated alongside all carers. For example, a national media campaign encompassing an integrated information and education strategy about the role of male carers in providing care should be considered. Carers Week is an excellent platform to display their needs. Non-government organisations act as important advocates on behalf of all carers, making public representatives on their behalf.
8. Finally, all future direction in policy and practice relating to both male and female carers should be considered in line with the goals and guiding principles of the National Carers Strategy. Policy and practice go hand and hand and cannot be separated. The vision Statement of the Strategy (DoH 2012a) states the following:

Carers will be recognised and respected as key care partners. They will be supported to maintain their own health and well-being and to care with confidence. They will be empowered to participate as fully as possible in economic and social life (p. 2).

As a consequence, it is imperative that all carers are represented in the decision-making processes at local, regional and national government levels. They must be consulted and given appropriate input into the development of any policies that may affect them, in so doing promoting their inclusion in decisions relating to the person they are caring for. The expertise of carers must be acknowledged and addressed by all those involved in dementia care, from policy makers through to services and wider society. In addition, historically scandalous under-spending by Government across health and social care sectors even in the height of the Celtic Tiger (Allen 2007) will

impact directly on any services the state may be challenged to provide in the future. Services must be provided with the capacity to deal with funding rather than only ensuring that resources are available. Any 'positive signs' in our economy must be viewed within the context of international fragile and limited growth, and the restoration of any cutbacks will take many years (McGreevy 2014).

Conclusion

This chapter has assessed the contribution of my study on a number of levels. In listening to the stories of sixteen men, I have addressed gaps in literature on male caring in Ireland specifically in the context of dementia. In terms of its methodological and theoretical contribution, through undertaking a narrative inquiry and from a social constructionist lens, I have demonstrated the multi-dimensionality associated with meaning in men's caring experiences, set within wider political and social domains and the larger life story in which men's stories are 'nested' (Gergen & Gergen 1984). An all-encompassing love for the person with dementia was key to understanding how and why this sample of men continued to care. I have also provided crucial implications and recommendations for future direction of policy and practice targeted to male carers. While I have recommended several potential avenues for future research, I recognise that there is no 'real' end to my study: the dialogic nature of narratives means that stories are never ending co-constructions (Riessman 2008). As Bakhtin (1986) contends, they hold an *unfinalisability* as reality is constantly changing. Context encompasses 'infinite dialogue in which there is neither a first or a last word' (Bakhtin 1986, p. 167-168). In undertaking this study, I have also entered into an ongoing dialogue with the participants (Josselson 2011b).

I mean I think even this morning, trying to get her to take her tablets it's becoming more difficult or to take a tablet and swallow and throw her head back. I say 'Is the tablet gone?' 'Yes.' 'Is it in your mouth?' 'Yes.' Another, another sip of water to try to get the tablet down and eh...but I know that by her demeanour it has gone down but it is becoming more difficult. So the difficulty is continuing along this straight line, eh...however slowly (Alan P11).

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Appendices

Appendix 1 Review of Literature

Reference	Study design	Key findings
Ray M. (1996), UK	Aim: explore impact of chronic illness and disability on long-established marital relationships Qualitative, grounded theory. Sample: 13 couples In-depth joint and singly biographical interviews.	Core category of maintaining continuity and managing change.
Reference	Study design	Key findings
Baker K.L. & Robertson N. (2008)	Aim: systematic literature review of existing knowledge on men coping for someone with dementia. In total 93 articles included in review.	Majority of articles, little detailed analysis of gender as mediating variable for coping. Future research must address role of gender in mediating appraisals.
Reference	Study design	Key findings
Baker K.L., Roberston N. & Connelly D. (2010), UK	Aim: explore how facets of masculinity might relate to male carers' appraisals of strain and gain in dementia care. Quantitative. Sample: 70 men caring for partner with dementia Series of questionnaires on gender identity, gender role conflict and appraisals of carer strain and gain.	Regression analysis found contrasting findings to previous studies. Gender identity did not appear important in carers evaluation of strain and gain.
Reference	Study design	Key findings
Russell R. (2001), USA	Aim: explore the richness and diversity of experiences encountered by male cares, as well as their subjective meanings. Qualitative. Sample: 14 elderly men caring for wives with dementia. In-depth open ended interviews.	Three main themes following analysis: feelings of isolation and invisibility of care work, style of caregiving that jointly utilizes management and nurturing, and feelings of commitment, responsibility and devotion.

Reference	Study design	Key findings
Russell R. (2007a), USA	Aim: explore how elderly men caregivers adapt to transition from work to family care Qualitative Sample: 30 elderly men caring for wives with dementia. In-depth open ended interviews.	Two major themes following analysis: demonstrating both struggle and success. Most significant struggle – coping with isolation. By contrast, many men were able to make transition through use of style of caring incorporating combination of management and nurturing skills
Russell R. (2007b), USA	Aim: investigate two specific areas of care work with men – meal preparation and personal care Social Constructionist lens, Qualitative. Sample: 30 elderly men caring for wives with dementia. In-depth open ended interviews.	Analysis revealed many men struggled with demands of care work, especially entrenched gender norms and masculine scripting. Men found to be less avoidant of hands-on, personal care than reported in the past.
Campbell L.D. (2010), Canada	Aim: explore what caregiving means for a group of adult sons caring for an aging parent and identify ways in which their understanding of caregiving was the same or different. Qualitative. Sample: 48 caregiving sons, married and never-married. Qualitative face-to-face interviews.	Analysis revealed that some themes common to both groups, yet also systematic differences. For example, caregiving for married sons was more limited, while caregiving for never-married sons was a more central element in their lives.
Calasanti T. & Bowen M.E. (2006), USA	Aim: explore the ways gender influences caregiving experiences. Qualitative, in-depth interviews Sample: 22 spousal caregivers for persons with dementia, mostly rural, 13 women, 9 men	Analysis revealed husbands and wives both cross gender boundaries in order to care for spouses with difference challenges to each. Not only must they take on responsibilities their spouses used to perform, they also cross invisible gender boundaries.

Reference	Study design	Key findings
Ducharme <i>et al.</i> (2007), Canada	<p>Aim: based on Pearlin <i>et al.</i>'s model, to determine factors associated with health of older husband caregivers and their intention to end home caregiving for their wives.</p> <p>Quantitative, multi-site study across four regions.</p> <p>323 husbands caring for functionally or cognitively impaired wives.</p> <p>Standardised interview involving series of quantitative scales measuring background-contextual factors, primary objective stressor, primary subjective stressors, secondary stressors, resources and dependent variables.</p>	<p>Results from analysis showed role overload was linked to psychological distress and lower self-perceived health.</p> <p>Role captivity was associated with psychological distress and intention to end home caregiving. Likelihood of ceasing caring increased with high relational deprivation.</p> <p>Quality of prior relationship, frequency of disruptive behaviours, family conflicts and self-efficacy were associated with this variable.</p>
Reference	Study design	Key findings
Cohen <i>et al.</i> (2007), Israel	<p>Aim: Assess the effect of stress-related factors on psychological distress and perceived health of family caregivers of liver transplant recipients.</p> <p>24 caregivers of liver transplant recipients treated at a liver unit.</p> <p>Quantitative standardized interviews - Pearlin's caregiving stress questionnaire was administered to assess the subscales of patients' symptoms as perceived by caregivers, caregiving activities, perceived overload, relational deprivation, personal gain, and social support; also, a depression questionnaire and a perceived caregivers' health questionnaire were administered to participants.</p>	<p>Analysis revealed that caregivers were found to experience considerable caregiving overload. Women reported performing more caregiving activities, higher perceived overload, and higher level of depression than men.</p>

Reference	Study design	Key findings
Pinquart & Sorenson (2007)	Aim: explore existing evidence gathered of the effects of caregiving on physical health. Meta-analysis integrating results from 176 studies on correlates of caregiver physical health.	Caregiver depressive symptoms had stronger associations with physical health than objective stressors. Higher levels of care recipient behaviour problems were more consistently related to poor caregiver health than were care receiver impairment and intensity of caregiving. Higher age, lower socioeconomic status, and lower levels of informal support were related to poorer health. Predictors of physical health are not identical to predictors of psychological health. Associations of caregiving stressors with health were stronger among older samples, dementia caregivers, and men. Negative effects of caregiving on physical health are most likely to be found in psychologically distressed caregivers facing dementia-related stressors.
Reference	Study design	Key findings
Ekwall A.K. & Hallberg I.R. (2007), Sweden	Aim: to examine association between gender, extent and content of care, satisfaction, coping and difficulties in the caregiving situation among older (75+) caregivers and to identify clusters of caregivers. Quantitative, cross-sectional. The sample consisted of 171 informal caregivers aged 75 and over identified from an age-stratified sample in a postal survey among older people.	Male caregivers proved to be more satisfied than female caregivers; caregiving had seemingly widened their horizon and had helped them to grow as persons. Based on satisfaction scores, those satisfied had a higher proportion of male caregivers and a significantly higher amount of caregiving hours per week. They used other coping strategies than the respondents in the other cluster, i.e. less satisfied in using more problem-solving strategies.

Reference	Study design	Key findings
Parsons K. (1997), Canada	<p>Aim: to investigate the male experience of caregiving for a family member with Alzheimer's disease.</p> <p>Phenomenological approach.</p> <p>Sample: 8 men (5 spouses and 3 sons).</p> <p>Qualitative interviews.</p>	<p>From analysis of interviews, key themes of enduring, vigilance, a sense of loss, aloneness and loneliness, taking away, searching to discover, the need for assistance, and reciprocity. An additional theme was identified from the experience of the son caregivers: overstepping the normal boundaries. The themes were interrelated to form a whole that captured the experience of caregiving for the male caregivers. Alzheimer's disease shaped these men's feelings toward every aspect of caregiving. Findings from this study challenge the primacy of the concept of "caregiver burden" as the predominant aspect of caregiving.</p>
Harris P.B. (1993), USA	<p>Aim: investigate the male experience of caring for spouse with Alzheimer's disease.</p> <p>Sample: 15 male caregivers from diverse backgrounds caring for their wives with Alzheimer's disease.</p> <p>Qualitative, in-depth interviews.</p>	<p>Common themes: commitment, social isolation, the loss of companionship, control, sense of accomplishment, a problem-solving approach, burden lessening with years of caregiving, and limited expectations of children. A generated typology of male caregivers included four types: the worker, the labor of love, the sense of duty, and at the crossroads</p>
Sanders <i>et al.</i> (2003), USA	<p>Aim: identify experience of grief and loss among male caregivers of loved one with Alzheimer's disease.</p> <p>Qualitative data obtained through close-ended question at end of large quantitative study</p> <p>Sample: 71 male caregivers.</p>	<p>While not all caregivers perceived themselves to be grieving, expressions of loss were present in all statements.</p>

Reference	Study design	Key findings
Ribeiro O. & Paul C. (2007), Portugal	<p>Aim: to explore the positive aspects of care reported by older men caring for dependent spouses.</p> <p>Qualitative, in-depth personal interviews.</p> <p>Non-random purposeful sample of 53 elderly men caring for chronically ill wives.</p>	<p>Using open coding and content analysis, positive aspects were identified in 32 of the 53 caregiving situations. The most prevalent themes were 'satisfaction' and 'perceived social honour'. The findings show that positive returns from the caring experience and role were strongly associated with previous good marital relationships and the husband's good self-rated health, and manifested in both specific coping strategies and global and situational meaning-making processes.</p>
Reference	Study design	Key findings
Mays G.& Holden C. (1999),USA	<p>Aim: To describe the lived experiences of male caregivers of severely mentally ill relatives and their perceptions of this non-traditional role.</p> <p>Qualitative study of informal interviews with purposively selected 10 male caregivers, using informal interview guide that addressed psychosocial, physical, financial, and crisis-management categories.</p>	<p>Data yielded three themes of caregiving: expressions of burden, duration and depth of commitment, and role affirmation.</p>
Reference	Study design	Key findings
Sanders S. & McFarland P. (2002), USA	<p>Aim: Qualitative study, 18 sons interviewed about the factors that led them to assume the role of primary caregiver for a parent with progressive memory loss, such as Alzheimer's disease, as well as the personal challenge that they experienced in this role.</p>	<p>Analysis demonstrated that sons experience a range of emotional reactions, personal and professional conflict, as well as learn about new roles and responsibilities as they attempt to access the needed services for their parent.</p>

Reference	Study design	Key findings
Atta-Konadu <i>et al.</i> (2011)	Aim: to explore with men carers their experiences of adopting roles previously performed by their wives with dementia and described this process from the perspective of the women who lose these food roles. 9 male care partners and their wives theoretically sampled and interviewed (dyad and individually) as part of the Eating Together (Phase 1) study. Using grounded theory methodology, 3 years of interview data from these participants were analysed.	The substantive theory developed describes the process of <i>sliding into food-related roles</i> . This shifting of roles is driven by the need to <i>reciprocate nurturance</i> . Spousal couples reciprocate nurturance by <i>keeping standards</i> and <i>watching over</i> one another. Additionally, they <i>navigate through the sliding into food role process</i> by <i>coming to terms</i> with the need for food-related role changes and <i>working things out</i> . Spousal couples find the process of sliding into roles less challenging when they were successful in promoting each others' self-worth and preserving identities throughout the process.
Reference	Study design	Key findings
Eriksson H. & Sandberg J. (2008), Sweden	Aim: to describe, from a gender identity perspective, the experiences of older men involved in the process of caring for a partner at home and the placement into a nursing home. Qualitative constructivist approach. Interviews with 7 men that have been informal carers and experienced the placement of their wife in a nursing home.	Analysis indicated that men go through two transitions in their gender identity during the caregiving process and placement. From the mutual loving relationship of being a <i>loving husband</i> , the social responsibility of daily care of their wives changes the situation into that of being a <i>caring husband</i> , and finally with the move to a nursing home there is a transition from <i>intimate care to a relationship based on friendship</i> .
Reference	Study design	Key findings
Boeije H.R. & Van Doorne-Huiskes A. (2003), The Netherlands/ Belgium	Aim: examine how spouses experience caregiving when predominantly motivated by a sense of duty and address whether any differences between female and male caregivers can be detected.	Participants involved in this study maintain caregiving despite the unfavourable changes they have noticed in their relationships. They interpret caregiving as something they just have to do.

	<p>Interpretive framework. Qualitative semi-structured interviews were conducted with 8 male and 5 female caregivers providing total care to their spouses who are disabled as a result of multiple sclerosis (MS). Analysis consisted of fragmenting and connecting the data and involved close reading and constant comparison.</p>	<p>Males and females develop different perspectives on caregiving, which are illustrated by two exemplary case stories summarized respectively in the phrase 'You have to be satisfied with it', and as 'I have to become harder and less self-sacrificing'. Explanations for outcomes are sought in differences in moral orientations between women and men and in gender differences regarding their feelings of duty and rights. The results shed light on previous findings that female caregivers report more stress than male caregivers.</p>
Reference	Study design	Key findings
Neufeld A. & Harrison M.J. (1998), Canada	<p>Aim: to explore reciprocity in the relationships of men caregivers of cognitively impaired older adults. The objective was to identify the context in which reciprocity was present or absent, the characteristics of reciprocity in caregivers' relationships with the care recipient, family and friends, and the men's feelings about reciprocal social support during caregiving. Qualitative. 22 men caregivers interviewed three times over 18 months. Study findings were confirmed in a focus group discussion with 7 caregivers.</p>	<p>Three variations in reciprocity in the men's relationship with the care recipient were identified: waived reciprocity generalised reciprocity and constructed reciprocity. Those experiencing constructed or generalised reciprocity described positive feelings, whereas men identifying waived reciprocity described either positive or negative feelings. When reciprocity was absent the men described giving care on the basis of obligation with either mixed or negative feelings. Reciprocity in relationships with friends and family was also described.</p>
Reference	Study design	Key findings
Gerstel, N. & Gallagher S.K. (2001), USA	<p>Aim: to analyse the effects of social structure, social relations, and gendered caregiving ideology on the care men give to kin and friends. Quantitative. Household interviews with 188 married respondents. 94 husbands and 94 wives. Random sample.</p>	<p>Wives and daughters were found to pull men into caregiving, while adult sisters substitute for them.</p>

	Face to Face interviews with measures focusing on 1.amount and type of caregiving 2.employment characteristics 3.family characteristics and 4.gendered ideologies concerning caregiving.	
Reference	Study design	Key findings
Hequembourg A. & Brallier S. (2005), USA	Aim: to investigate the influence of gender on the division of responsibility among adult children who are providing care to their elderly parent and how parental caregiving provides an opportunity for the explicit (re)negotiation of gender dynamics across household boundaries. Qualitative in-depth interviews with 8 pairs of male and female siblings.	Findings explored the ways that “helper brothers” and “co-provider brothers” divide care with their sisters, and the impact of this division of care on the sisters' roles as coordinators of care and their future plans for their parents' care. “Specialised knowledge” also emerged as an important factor in the gendered division of care among the respondents.
Reference	Study design	Key findings
Sandberg J. & Eriksson H. (2007), Sweden	Aim: to gain understanding of the experience of older men as caregivers for an ill spouse. Narrative approach. Interviews were conducted with three older men between 65 and 78 years, who had been caring for their wives for between one and 12 years.	Two main categories emerged: taking on a new and unfamiliar role, and learning to live with the new role. The results also show how the men seek to maintain continuity in their relationships with the wives they are caring for. The findings can be understood in the light of a major life transition of how older men providing care for a spouse create new roles and how they cope with the changes in the marital relationship.
Reference	Study design	Key findings
Kirsi <i>et al.</i> (2004), Finland	Aim: finding out how husbands signify their action as spousal caregivers. Qualitative, social constructionist framework. 11 Free form written texts and 13 focused interviews with husbands who had cared for wives with dementia.	Husbands' written material described their action of caregiving mainly in a passive voice that echoed duty and responsive agency. Analysis of the interview talk revealed a wider spectrum of voices and more agentive talk about caregiving. The results challenge interpretations of men as either ineffective or capable

		caregivers and highlight, instead, the contextual nature of the way that men construct their agencies, depending upon the purposes and audiences of their narration.
Reference	Study design	Key findings
Fraser C. & Warr D.J. (2009), Australia	Aim: to explore experiences of caring for partners or children with a range of mental illnesses with a sample of men living in rural area. Qualitative, focused interviews. 10 men, 5 caring for child, 5 caring for wife with a mental illness.	The findings suggest that the primary relationship between carers and care recipients influences the ways in which the men understand and practice their caring roles. Fathers consistently described proactive approaches to caring and were strongly focused on managing the illness condition. Husbands tended to take reactive approaches to caring in which they were more concerned with managing situations that were associated with their partners' illnesses.
Reference	Study design	Key findings
Black et al. (2008), USA	Ethnographic research that explored experiences of suffering in late life. From a group of 60 oldest-old (age 80 and above) male participants, four were primary, at-home caregivers for wives with dementia.	Men's narratives showed the inter-relation between masculinities, a sense of personal control, and experiences of suffering within caregiving. Three thematic "tools" of control emerged as strategies men used to mediate their suffering: 1) the power of the little; 2) preserving self-identity and marriage-identity and, 3) finding purpose in the role of caregiver.
Reference	Study design	Key findings
Boylstein, C. & Hayes J. (2012), USA	Aim: to examine how people caring for a spouse with Alzheimer's disease reconstruct the meaning of closeness within their marriage. Qualitative, In-depth interviews were conducted with 13 men and 15 women.	The majority of caregivers experienced significant disruptions in their marriage as a result of their respective spouse's dementia. The caregiver wives in the study sample were more likely than caregiver husbands to report that perceived changes in the spouses' identity altered how

		they identified themselves within their marriage, leading to longer term disruption of marital closeness.
Reference	Study design	Key findings
Sanders S. & Power J. (2009), USA	Aim: to examine the changes that occurred in the roles, responsibilities, and relationships of husbands providing care for their wives with memory loss and other chronic health conditions. Qualitative, phenomenological approach. 17 husbands living in rural communities. Two interviews, semi-structured approx. 4mths apart.	Husbands experience changes in the ways that they adapt their marital roles to the new roles they assume as caregivers. It was found that the husbands had to learn how to form new types of relationships with their ailing wives.
Reference	Study design	Key findings
Brown <i>et al.</i> (2007), USA	Aim: to gain understanding of the help-seeking process of older husbands caring for wives with dementia. Grounded theory design. Convenience sampling. Unstructured interviews conducted with nine husband participants. Interviews were analysed to discover the core category and the relationships of related categories to develop a theory of help-seeking that was grounded in the data.	The core category, 'Doing the best I can', was preceded by the antecedent of 'changing patterns'. Husbands made choices to use action/interaction strategies of 'Relinquishing', 'Reaching out' and 'Shouldering' which were influenced by a variety of internal, relational, situational, and experiential facilitating or hindering intervening conditions. The consequence of help-seeking process was 'Continuing on', which had categories of: 'Keeping at home', 'Staying together', and 'Taking care of myself'.
Reference	Study design	Key findings
Pretorius <i>et al.</i> (2009), South Africa	Aim: to explore the experiences of men caring for spouses suffering from dementia from a salutogenic perspective. Qualitative, semi-structured interviews with 10 husbands. An orientational analysis approach was followed and the data was analysed in terms of Antonovsky's sense of	Stressors most often reported were cognitive impairment, behaviour problems, a lack of free-time, erosion of the relationship, family conflict and financial concerns. Factors facilitating caregiver coping included support from their daughters, their ability to find meaning and satisfaction within

	<p>coherence construct. Qualitative findings were compared to participant responses to quantitative measures.</p>	<p>the context of the care-giving task, and the successful utilization of active, problem-focused coping strategies. Men's approach to care giving differs from that of their female peers. Task-oriented problem-solving, effective use of the available support resources and the ability to find both meaning and satisfaction in their caring appear characteristic of effective male caregivers of demented spouses.</p>
Reference	Study design	Key findings
Cahill S. (2000), Australia	<p>Aim: to develop an understanding of the caregiving experiences of men. 26 aged husbands who care at home for their cognitively impaired wives. In-depth interviews collected quantitative and qualitative data about men's caregiving experiences via a semi-structured questionnaire.</p>	<p>Findings challenge the literature about the role gender plays in evoking care and service responses. Men demonstrated a strong injunction to care, performed intimate personal care tasks competently, received limited government support and derived some satisfaction from the caregiving role. Despite similarities between male and female caregivers being noted, some gender differences in the way in which men approached the care role were described.</p>
Reference	Study design	Key findings
Sibley <i>et al.</i> (2012), UK	<p>Aim: to investigate the perception of support for adults with MS and of men caring for adults severely affected by MS. Questionnaire survey design. Questionnaire developed from initial qualitative interviews. Widely disseminated via UK MS Society. 231 men took part (85% online, 15% by post).</p>	<p>Mean age was 60 years, and 52% reported spending at least 50 hours per week caring. 34% had not tried to access advice/information about support/services. Of those that had, most found it 'very' (15%) or 'fairly easy to find' (54%). Men aged under 55 years reported most difficulty in accessing information. 25% of men had received no support/services in the last year. Of the remainder, 67% reported the support/services had 'made things easier'.</p>

		Younger men repeatedly differed in their perceptions, suggesting that they either have higher expectations, greater need or both.
Reference	Study design	Key findings
Munro I. & Edward K.L. (2008), Australia	Aim: to investigate the emotional effects of HIV/AIDS on the gay male carers of gay men with the disease. Phenomenological inquiry. 12 participants. Two semi-structured interviews with each participant.	The results produced emergent themes relating to coping with HIV/AIDS, living day-to-day with HIV/AIDS, coping with the last phase of AIDS towards death, saying goodbye and remembrance. This research highlights the resilient coping style of carers of persons living with HIV/AIDS.
Reference	Study design	Key findings
Milligan C. & Morbey H. (2013), UK	Aim: to gain a deeper understanding of men's caregiving. Phase 1: written narrative a/c's gathered from 15 older men (50+) about their experiences of caring for wives/ partners and forms of informal/ formal support. Phase 2: semi-structured and small group interviews conducted with 9 care providers	Gendered role assumptions influence older male carer identities. Mixed experiences of social care support, less likely to ask for help. Practical solutions to managing challenges but difficulty acknowledging emotional aspects of caring.
Reference	Study design	Key findings
McDonnell E. & Ryan A. (2013b), Ireland	Aim: to explore the experiences of sons caring for a parent with dementia. Individual, semi-structured interviews were conducted with a purposeful sample of sons ($n = 13$) in a rural area.	The key themes that emerged were 'the parental bond', 'a binding role', 'coordinating care and support' and a 'getting on with it' approach to care. The study highlighted the commitment of sons to their caregiving role and the strong sense of duty that motivated them to provide care.
Reference	Study design	Key findings
Calasanti T. & King N. (2007), USA	Aim: Adopted a feminist, structural approach to husbands' experiences of caring for wives with Alzheimer's disease. This framework posited that men and women draw upon	The husbands' approaches to caregiving and their strategies for dealing with the work and feelings involved were rooted in their sense of selves as men. Their overall approaches to

	gender repertoires that create gendered experiences of stress and coping strategies. Qualitative, constructivist approach. In-depth interviews with 22 spousal caregivers and observations within support groups. Analysis focused on 9 husbands, strategies they reported using to deal with problems that arose in their care work, and extent to which these are congruent with the masculinities of white men in the USA.	caregiving are outlined and identified 6 strategies husbands used to deal with problems stemming from care work—exerting force, focusing on tasks, blocking emotions, minimising disruption, distracting attention, and self-medicating—and tie these to their structural positions as working-, middle-, and professional-class men.
Reference	Study design	Key findings
Kramer B. (1997), USA	Aim: This cross-sectional study takes a beginning step toward understanding the differential predictors of negative (i.e., strain) and positive (i.e., gain) appraisals among 74 husbands caring for wives with dementia.	Using a multivariate model of caregiver adaptation, results indicated that social resources and health were important for understanding the variation in both positive and negative appraisals. Unique predictors of strain included memory and behaviour problems, and emotion-focused coping. Alternatively, education and problem-focused coping helped to explain variation found in appraisal of caregiver role gain.
Reference	Study design	Key findings
Hayes et al. (2009), USA	Aim: to examine how Alzheimer's disease and related disorders (ADRD) affect caregivers' perceptions of change in the identity of their afflicted spouse and the ways in which accompanying changes in caregiver identity influence intimate relations. Also explore how gender shapes the ADRD caregiving experience among married couples, specifically, the extent to which intimate relations are also gendered relations. Sample: spousal caregivers recruited from 2 support groups.	Identity change on the part of sick spouses had important implications for intimacy, although not always in adverse ways. The majority of caregiver husbands and wives reported diminished intimacy as a result of the ADRD. Many men and women believed they would retain feelings of closeness to their afflicted spouses as long as they were alive. Wives were more likely than husbands to report that changes in their spouses' identity altered how they identified themselves within their marriage.

	In-depth interviews with 13 men and 15 women whose spouses had ADRD.	
Reference	Study design	Key findings
Duggleby <i>et al.</i> (2012), Canada	Aim: To explore the hope experience of male spouses of women with breast cancer. Thorne's qualitative interpretive descriptive approach. Sample 11 male spouses of women with breast cancer. 24 open-ended tape-recorded telephone interviews were completed.	Participants described their hope as tangible and important to them. Hope was influenced by their partners' hope and courage and gave participants the courage to support their partners. The overarching theme was engaging hope. The participants described their hope as always being there, but with the diagnoses of their partners' breast cancer, they needed to engage their hope. Other themes were finding balance, discovering what works, and focusing on the positives.
Reference	Study design	Key findings
Duggleby <i>et al.</i> (2014), Canada	Aim: to examine the relationship of the quality of life of male spouses of partners with breast cancer with the following factors: (a) demographic variables of male spouses and their partners, (b) levels of hope of male spouses and their partners, (c) self-efficacy and loss and grief of male spouses, and (d) quality of life of partners with breast cancer. 600 surveys mailed to women with breast cancer (stage 1–3) and their male spouses. 110 surveys were completed.	With the use of generalised linear modelling, participating male spouses with higher quality of life scores: (a) were older ($P = .01$), (b) had higher hope scores ($P = .01$), (c) had lower feelings of guilt scores ($P < .01$) (subscale of loss and grief), (d) had higher general self-efficacy scores ($P < .01$), and (e) had partners with breast cancer with higher quality of life scores ($P < .01$). Hope, self-efficacy, feelings of guilt, age, and their partners' quality of life significantly related to quality of life of the male spouses of women with breast cancer.
Reference	Study design	Key findings
Bowers S.P. (1999), USA	Aim: to explore the relationship between gender role identity and caregiving experience with a sample of elderly widowed men. 200 males (82.5% Caucasian) were interviewed 12 to 16 months after the death of their	Men who had served as caregivers scored higher on the masculine dimension of the Bem Sex Role Inventory, and masculinity was a significant predictor of well-being for both caregivers and non-caregivers. Following a cognitive

	wives.	dissonance model (Hirsch, 1996), the results do not support the adoption of feminine or androgynous ideals as a way of coping with this life demand. Instead, the results add to the growing body of work in support of a masculine model of well-being.
Reference	Study design	Key findings
Kirsi T. <i>et al.</i> (2000), Finland	Aim: discourse analytic study on 15 stories written by Finnish husbands who were giving or who had given care to their demented wives.	The authors identified articulations of four different ways to speak about one's actions and experiences as a family caregiver. We called these four modes of speech the factual, familistic, agency, and destiny speech repertoires. Using different speech repertoires in their narration, the husbands adopted the respective identities of an observer and reporter, a responsible caregiver, an independent actor, and a victim or a drifter. The speech repertoires and identity constructions varied according to the contexts of the writers' speech and bore different functions for the writers' narration. The main finding of the study was the diversity of husbands' experiences of caregiving and the contextuality of the ways in which these experiences were talked about.
Reference	Study design	Key findings
Gollins T. (2001), UK	Aim: To understand not only what caring tasks male carers do but also how they view their caring activities. Grounded theory. 20 semi-structured interviews with men who are or who have until recently been informal carers.	Male carers experience care in different ways to women. Male carers approach to caring is to see it as an activity, not as part of their identity. Male carers 'buy into' the gender deal. They avoid expressing emotional aspects of being a carer.

Reference	Study design	Key findings
Ribeiro O. <i>et al.</i> (2007), Portugal	Qualitative. Drawing on data from in-depth personal interviews with a sample of 53 older men caring for their impaired wives, authors report findings on these men's caregiving experience, specifically on the way they see themselves <i>as men</i> within such role.	When describing their gendered understanding of themselves, participants evidenced several negotiations with the dominant masculine ideology in order to maintain their sense of masculinity and legitimate their presence in a feminine role. This was accomplished by reframing their definition of a man and reinforcing that of a husband and by retaining varying degrees of power over the caregiving relationship. The social visibility of the role within particular gendered community-based social networks was found to be important in shaping these older men's masculinities.
Reference	Study design	Key findings
Campbell, L.D. & Carroll M.P. (2007), Canada	Using arguments relating to gender-as-performance and hegemonic masculinity, the authors investigate conceptualisations of gender and masculinity in a sample of 58 adult sons who provide care to an aging parent.	Following analysis from the interviews with these male caregivers is a vision of masculinity that is in some ways quite different from the hegemonic ideal. However, like earlier investigators who have studied hegemonic masculinity, the authors also find that the existence of a nonhegemonic vision of masculinity does not threaten the hegemonic ideal.
Reference	Study design	Key findings
Ussher J.M <i>et al.</i> (2013), Australia.	Aim: to examine difficult and rewarding aspects of cancer care with informal carers in order to identify what was underlying these gender differences in distress. In-depth semi-structured interviews with 53 informal cancer carers, 34 women and 19 men.	Women were more likely to report negative changes in the relationship with the person with cancer; neglect of self, social isolation, and physical health consequences; anxiety; personal strength and growth; and to position caring as a privilege. Men were more likely to report increased relational

		<p>closeness with the person with cancer, and the burden of additional responsibilities within the home as a difficult aspect of caring.</p>
Reference	Study design	Key findings
Eriksson et al. (2013b), Sweden	<p>Aim: to explore the processes connected to informal caregiving in later life through the position of adult daughters of older fathers engaged with long-term caregiving responsibilities for a partner. Qualitative. Sample of 8 daughters, with fathers having primary caregiving responsibility for their ill partners was recruited and in-depth interviews were carried out</p>	<p>The daughters' descriptions of their relationships with their fathers show that being an older man who engages in caring can have a positive outcome on relations. Even if some of the daughters have doubts about their fathers "masculine authenticity", all of them appeared to cherish "his helping hands" as a carer and closer more intimate relationships with their fathers. Caring for an old and frail spouse may potentially present alternative ways of being a man beyond traditional 'male activities' and caring might also sometimes involve a re-construction of gender identities.</p>
Reference	Study design	Key findings
Robinson C.A. et al. (2014), Canada	<p>Aim: purpose of this scoping review was to examine the empirical evidence published since 2007 on men as family caregivers of persons with dementia. Studies published in English between 2007 and 2012 were included in the review. A total of 30 articles were selected for inclusion.</p>	<p>Studies were grouped into three major themes for review: men's experiences of caregiving, relational factors, and outcomes of caregiving. The reviewed studies build on and support previous findings related to stress, burden, accessing services, and the importance of relational factors to men's caregiving experiences. However, there is a need for a framework that explains these findings in relation to masculinities. Such a framework would provide the necessary account. Furthermore, there unifying context for a more powerful explanatory appears to be the potential for fully linking men's</p>

		caregiver research to men's health issues as a means to articulate strategies to sustain the health and well-being of men caregivers.
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Appendix 2 Access Letter

Re: Potential research project

Dear

I am writing to you in connection with a research study entitled: *Men as carers: Exploring the experiences of male carers in chronic illness*. The purpose of this study is to explore and develop an initial understanding of the experience of male carers providing care to a loved one or close relative with chronic illness. It is envisaged that through listening to the stories of male carers, useful insights into their experiences of caring for their loved one or close relative with a chronic illness will be provided. At the end of this research, information will be gathered on male carers' perceptions of the caring role in chronicity; the coping mechanisms they employ; the impact of caring on their health; specific social, emotional, financial and support needs of men in providing care to a loved one or close relative with chronic illness and the impact of societal attitudes on the male carer experience. Recommendations for future development of research and policies specifically targeted to male carers of individuals with chronic illness will also be proposed.

I am undertaking this research because there is currently very little research on the specific experiences of men providing care to a loved one or close relative with chronic illness in Ireland.

This project will focus on informal male carers of a loved one or close relative with a chronic illness. The study will involve interviews with informal male carers. The broad themes that will be addressed include:

1. meaning and experience of carer role
2. care needs of the cared for person (patient)
3. experience of support services for the informal male carer

The research project is being undertaken as part of my PhD study with the School of Nursing and Midwifery, Trinity College Dublin. I would be most grateful if you would consider assisting me in recruiting participants for this important study. I would be delighted to meet with you at a time and place of your convenience to discuss this proposal.

Yours sincerely

Ms. Ann Stokes
Ph: 0879336858 Email: astokes@tcd.ie

Appendix 3 Recruitment Pack

Letter to Carer

Re: Title of study: *Men as Carers: Exploring the experience of male carers in chronic illness.*

Dear

I am writing to invite you to participate in a study being undertaken by the School of Nursing and Midwifery, Trinity College Dublin.

The study is looking to explore the experiences of men providing care to a loved one or close relative with chronic illness. By carer, I mean the person or family member who is providing the most assistance to a loved one with chronic illness.

Please read the enclosed information, which describes the nature and purpose of the study and what participation will involve. You will also find a consent form. This is for your information. If you decide that you wish to participate in this study, I will ask you to sign the consent form when we meet. Before you sign this, I will discuss the research with you and answer any questions you may have.

I am undertaking this research as part of my PhD study with the School of Nursing and Midwifery, Trinity College Dublin because there is currently very little research on the experience of male carers in Ireland. I hope that the results from this research will attempt to give voice to and tell the story of Male Carers' overall experience of providing care to a loved one or close relative with a chronic illness. Overall, it is envisaged that this research study will form part of a wider body of research work currently being undertaken in the School of Nursing and Midwifery, through promoting public awareness of the needs of informal caregivers in chronic illness.

Should you wish to discuss your involvement in this study, please complete the reply slip attached and return it as soon as possible using the stamped addressed envelope provided. I will then contact you to discuss participation and answer any questions you may have. You do not have to take part in this study but may volunteer to do so. If you agree to take part you may change your mind at any time. Should you decide not to participate in this study, you will not be contacted further regarding this matter.

Yours Sincerely,

Ms. Ann Stokes
School of Nursing and Midwifery, TCD
The Gas Building
D'Olier Street
Dublin 2 Ph: 0879336858 Email: astokes@tcd.ie

Participant Information Leaflet

Title of study: Men as Carers: Exploring the experience of male carers in chronic illness

Name of researcher: Ms. Ann Stokes, School of Nursing & Midwifery Studies, Trinity College Dublin

1. INTRODUCTION:

You are invited to take part in this study because of your experience of caring for a loved one or close relative with a chronic illness. For the purposes of this study, male carers are defined as individuals who provide physical and/or social care to a loved one or close relative with a chronic illness in the home.

2. PURPOSE OF THIS STUDY

The purpose of this study is to explore and give an initial understanding of the experience of male carers providing care to a loved one or close relative with chronic illness. It is envisaged that through listening to the stories of a sample of male carers, useful insights into their experiences of caring for their loved one or close relative with a chronic illness will be provided. At the end of this research, information will be gathered on male carers' perceptions of the caring role in chronicity; the coping mechanisms they employ; the impact of caring on their health; specific social, emotional, financial and support needs of men in providing care to a loved one or close relative with chronic illness and the impact of societal attitudes on the male carer experience. Recommendations for future development of research and policies specifically targeted to male carers of individuals with chronic illness will also be proposed.

3. PROCEDURES: WHAT WILL THE STUDY INVOLVE?

The researcher wants to find out about your experience of caring for a loved one or close relative with a chronic illness. She would like to meet you for about 40 minutes to hear about your experiences. This meeting will take place at a time and venue most convenient for you. The researcher may ask to meet you on a 2nd occasion to clarify points that were raised in the first interview. This second interview will last no more than 20 minutes. If you choose to participate in the first interview, you should not feel in any way obliged to agree to the 2nd interview. With your permission the interviews will be taped so that after meeting the researcher can make an accurate record of the discussion for her research. After the interview the recording will be analysed. Your name will not be used in the recording and will not be included in the interview transcripts. An identity number will be used instead. The tapes will be kept in a secure place. If you wish to have a transcript of the interviews, the researcher will be happy to provide you with this. The findings from this research may be submitted for publication or presented at a conference. You will not be identified in any publication or conference paper from this research. This research may help others to have a better understanding of the experiences of male carers.

4. WHO CAN TAKE PART IN THE STUDY

You are invited to participate in this study *if*:

- you provide at a minimum, companionship to a loved one or close relative with a chronic illness in the home with some physical caring assistance, in addition to assisting with household chores
- you are over the age of 18 years of age
- you are able to articulate your experiences in English
- you understand the purpose and process of the research
- you willingly volunteer and consent to participate in this research

5. WHO CANNOT TAKE PART IN THE STUDY?

You cannot participate in this study *if*:

- you do not provide at a minimum, companionship to a loved one or close relative with a chronic illness in the home with some physical caring assistance, in addition to assisting with household chores
- you are not over the age of 18 years of age
- you are unable to articulate your experiences in English
- you do not understand the purpose and process of the research
- you are unwilling or unable to participate in the study

6. BENEFITS:

There is no promise or guarantee of any benefit from this research. However, the study is an opportunity for men to tell their experiences of providing care in chronic illness and its impact on their lives. Indeed, you may express an interest in both relating your stories and having someone interested in hearing these stories. It is envisaged that this research study will form part of a wider body of research work currently being undertaken in the School of Nursing and Midwifery, TCD, through promoting public awareness of the needs of informal caregivers in chronic illness.

7. RISKS:

There are no known risks to those who take part in this study. However some people may become upset while talking about how the caring role may have affected their daily lives. If this happens, you may end the interview. If you wish you may resume the interview at another time of your choosing.

8. CONFIDENTIALITY:

Your identity will remain confidential and an identity number will be used instead. Your name will not appear in any report, paper or publication. Your identity will not be given to anyone outside the research group. All information will be kept anonymous and confidential.

9. COMPENSATION:

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails the rights of those who take part in the study. There is no payment for taking part in this study.

10. VOLUNTARY PARTICIPATION:

You do not have to take part in this study but may volunteer to do so. If you agree to take part you may change your mind at any time. If you decide not to participate, or if you withdraw, you will not be penalised and will not be giving up any benefits that you had before this offer to take part in the study.

11. PERMISSION:

This research has been granted ethical approval by the Faculty of Health Sciences, Trinity College Dublin.

12. FURTHER INFORMATION:

You can get more information or answers to your questions about the study, your participation in the study, and your rights, from Ms. Ann Stokes, at the School of Nursing and Midwifery, Trinity College Dublin by telephone at 0879336858 or by e-mail astokes@tcd.ie

If the study team learns of important new information that might affect your desire to remain in the study, you will be informed at once.

Reply Slip

Name of carer _____

I wish to be contacted to discuss participation in the study entitled: *Men as Carers: Exploring the experience of male carers in chronic illness.*

I can be contacted at the following telephone number _____. Alternatively, I can be contacted _____ at _____ the _____ following _____ address:

I understand that by agreeing to discuss the study with the researcher, I am not consenting to participate in the research.

Signature of carer _____

Informed Consent Form

Project Title: *Men as Carers: Exploring the experiences of male carers in chronic illness*

PRINCIPAL INVESTIGATOR: Ms Ann Stokes (B Soc Sc, MA Social Policy) PhD Student, School of Nursing and Midwifery, Trinity College Dublin Ph 0879336858 email: astokes@tcd.ie

Background: The purpose of this study is to explore and give an initial understanding of the experience of male carers providing care to a loved one or close relative with chronic illness. It is envisaged that through listening to the stories of a sample of male carers, useful insights into their experiences of caring for a loved one or close relative with a chronic illness will be provided. At the end of this qualitative piece of research, information will be gathered on male carers' perceptions of the caring role in chronicity; the coping mechanisms they employ; the impact of caring on their health; specific social, emotional, financial and support needs of men in providing care to a loved one or close relative with chronic illness and the impact of societal attitudes on the male carer experience. Recommendations for future development of research and policies specifically targeted to male carers of individuals with chronic illness will also be proposed.

DECLARATION (Please read and tick if you agree):

I have read the study information sheet and this consent form

I have had the opportunity to ask questions and all my questions have been answered to my satisfaction

I understand that all information collected in this study will be treated as confidential and that my identity will remain confidential

I understand that my permission will be sought to record my interview

I understand that I may be asked for a 2nd interview and that I am not to agree to this if so inclined

I understand that if I wish to do so, I may have access to my interview transcript

I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights

I have received a copy of this agreement and I understand that the results of this research may be published

I understand I may withdraw from the study at any time

DECLARATION:

I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

PARTICIPANT'S NAME:

CONTACT DETAILS:

PARTICIPANT'S SIGNATURE:

Date:.....

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURE:..... **Date:**.....

Men as Carers – tell us your story.....



Are you male, over 18 years of age and looking after an adult family member in the home who has Alzheimer's or Dementia?

I am a researcher from the School of Nursing, Trinity College Dublin would like to meet with you to hear about your experiences as a man providing care to an adult family member with Alzheimer's or Dementia.

Taking part in the study will involve;

- Talking with a researcher, at a time and place that is convenient for you. You will be asked questions about how looking after someone has affected your life.

The rights of privacy and confidentiality will be protected during and after the study

If you would like further information on how to participate in this study, Please contact:

Ann Stokes School of Nursing and Midwifery, TCD

Ph: 0879336858 Email: astokes@tcd.ie

Appendix 5 Key Issues Identified by Group of Male Carers in Pilot Phase

- Coping Mechanisms
- Own health
- Future
- Legal issues
- Changing responsibilities
- Information awareness
- Support
- Loneliness and isolation
- Changing relationships

Appendix 6: Extract from My Reflexive Field Notes

Michael (P01)

This interview took place mid-morning on a weekday in Michael's own home following his preference to do so as his wife was out at day care. He lived in an urban location and the interview itself took place in the kitchen which was very bright, fresh and homely. The kitchen and house in general were very tidy and he was very welcoming, wanting to show me about the house. In particular, he was very proud of the improvements that he had made. This was the first interview I conducted and I was apprehensive of how the narrative style of interviewing would work out. For instance, I found it difficult at times to not jump in and just let Michael tell me his story. Instead I found that I was conscious of confirming my active listening, through nodding. In fact, at times I was worried that I may have been over doing this.

Michael began his story by telling me about when he noticed that his wife was unwell before a diagnosis was given. Interestingly, Michael made reference to the specific phases of dementia his wife had gone through as he saw it. He noted that the aggressive nature of his wife's behaviour had eased and she had now forgotten how to be aggressive. In talking to me about how he had learnt to deal with his wife's behaviour particularly her aggression, Michael may also have been expressing to me the skills that he had built up through his caring. He told me how an important tool in learning how to cope was through self-teaching himself and by looking up information sources, for example through the internet. However, he came across as somewhat frustrated and bitter at times at not being directed or guided by relevant professionals on such issues.

A strong sense of loss was expressed for the life that Michael and his wife had before dementia and an associated sense of closeness between him and his wife particularly in his references to holidays that they went on. He vividly recalled one specific incident that appears to stand out. He spoke of the stress of taking his wife on holiday and her wandering off and getting lost, vividly describing the panic he experienced in trying to find her.

Michael spoke of how his wife's condition was gradually getting worse and worse, and as a consequence, he was needed more and more to assist her in all aspects of daily living. For example when she should wash, dress, eat etc. I found it interesting how he coped with caring for his wife and the various situations that had arisen by sitting down and thinking

about how he could help her, thus putting her needs first. I believe that protectionary features of his caring were evident in the language he used throughout his story with references to being constantly on guard, for instance in needing to lock the door or relaxing the rules when out at the shops. I got a sense that it was almost as if Michael was a guard and his wife was a prisoner. He appeared to be in a constant state of anxiety, needing to look out for potential dangers. I also found metaphors he used to describe his experiences very powerful in providing vivid images of his experiences, such as 'I'm asleep with one eye open'.

Michael acknowledged how people were slow to ask about his own needs especially regarding taking time away from his caring responsibilities. I feel that there was a sense of annoyance and bitterness on this issue evident in the tone of his comments. In particular, there appears to have been tension with his adult son and his involvement in assisting him with caring. He referred to having to 'barter' to get a week off, highlighting strains that may have existed in their relationship. However, he seemed to value and respect the opinions of his doctor as if using his comments as a way of defending his decisions surrounding his wife's care.

Michael poignantly told me that it is nearly worse when he does get time away from caring as it is only a temporary respite, what he really needs is more help. However, later in his story, he admitted to wanting respite and how it would be much more beneficial than help for a few hours as there was only so much he can do with a few hours to himself. I feel that it was almost as if he was trying to justify his decision over placing his wife in respite in his own mind referring to the security system in place at the centre. He also spoke about the fact that his wife wouldn't know where she was going. I wonder whether he was also justifying his decisions to me as well as his own adult son.

Michael talked about his fears of what would happen if he was not around to care for his wife. He spoke about the inevitable situation, according to him, of his wife going into long term care as her condition deteriorated further. Indeed, there was a sense of anxiety evident in the tone of his voice as he spoke. In terms of long term care, this seemed to be another issue that he was struggling with in terms of his feelings, as he questioned whether this was the right thing to do. He also referred to the potential idea of long term care abroad in reference to the cost of respite in Ireland of which he was highly critical. Interestingly, towards the end of his story, Michael highlighted that he was cautious of the savings he would need to use if his wife went

into long term care and so was trying to hold this off. He pointed out that his wife being aged under 65 and having dementia proved a 'stumbling block' in terms of receiving support. However, he also noted how allowances were made within the system in terms of the day care she attends and he was grateful for the efforts made by specific organisations.

Michael told me that he accepted that his wife was not going to get better only worse but felt that the gradual progression of her condition may indeed have been easier to deal with than a more rapid deterioration, with the various stages helping him to cope. However, throughout his story and despite the positivity that he displayed at times through being optimistic and grateful, I feel that there was also a strong sense of sadness for the isolation and loneliness he experienced in caring for his wife, particularly in the way that he spoke. For instance, he made an important reference to the silence and lack of communication in caring for his wife. The story he told me of how when someone rings the telephone he may need to clear his throat was extremely powerful, almost as if he had lost the art of conversation.

I found it difficult to decide when was the right time to end recording and bring the interview to a close. In fact, I ended up turning back on the recording in order to record additional information. While this extra bit of recording was just over four minutes, I feel it was very significant to Michael's story, as when the gap in recording took place, he became visibly upset when speaking about his wife. When the recording began again, he raised the concept of role reversal in his caring experiences. I wonder perhaps if this was another element in explaining how he felt and the meaning that he attached to his caring experience. The slow gradual nature of his wife's illness meant that he almost didn't feel it creep up on him and it was only looking back, in hindsight, that he felt that he was able to see the huge losses he had experienced and the impact of dementia. It is also during this extra recording that I feel I got a deeper insight into the extreme love and respect that he had for his wife, and in particular the life that they shared together before she became ill and the admiration he holds for her. I wonder therefore whether the long pre-existing relationship which they shared as husband and wife provided Michael with an important sense of duty and commitment in his caring role.

I was concerned that as a consequence of this style of interviewing, important information as part of Michael's story was not included in the recording. After the interview he referred to his adult daughter living abroad who has said that she would move back to care for her mum.

Unfortunately, he did not refer to this once during the interview. Within a more semi-structured interview that I would have undertaken in previous studies, I may have been able to probe such questions. In addition, I left this interview wondering whether as a consequence of meeting with me on one previous occasion (i.e. through focus group discussion), whether Michael felt more at ease talking with me. I also questioned whether the subsequent men that I would speak with would be as open with me in terms of telling me about their experiences.

Appendix 7 Checklist to Complete Before the End of Each Interview

- Explain how/when/where interview data will be stored and disposed of
- Answer any questions the participant raises
- Remind the participant of researcher contact details and that they can have a copy of the interview transcript if they wish
- Check participant well-being
- Thank participant for their involvement

Appendix 8 Demographic Information Sheet

Demographic Information Sheet

Project Title: Men as Carers: Exploring the experiences of male carers in chronic illness

1. Participant Code: _____

2. Age: _____

3. Relationship to cared for person:

Parent

Parent in-law

Husband/ Partner

Adult Child (over 18)

Sibling

Grandchild

Other, please state

4. Where do you live?

Urban location

Rural location

5. Do you live with the care recipient?

Yes No

6. Who do you live with (apart from the care recipient if answered yes above)?

7. Are you the person who provides most of the care?

Yes No

8. How long have you been providing care (in months/years)?

0-6mths	6mths – 1 yr	1 – 2 yrs	2-3yrs	Other (please state)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____

9. Please state the primary medical condition and any other secondary conditions that the care recipient has?

11. How many hours of care would you say you provide in:

One day One week

10. Do you provide physical care?

Yes No

11. Would you receive periods of rest/ time to yourself?

Yes No

Examples of periods or rest/ time to self:

Undertaking exercise/ leisure activities

Socialising with friends

Reading

Shopping

Other, please state _____

12. Are you:

Single

In long-term relationship

Married

Widower

Separated/ divorced

Other, please state

13. Do you have children?

Yes No

If yes, how many: _____

14. Are you currently working outside of the home?

Yes No

15. Has caring had an impact on your working hours?

Yes

No

Slightly

Other, please state _____

Appendix 9 Full Transcript from one interview

P11 Interview Transcript 29th March 2012

Interviewer: Ok so this is P11 the 29th of the 3rd 2012. And Alan I just want to start by saying thank you so much for agreeing to speak with me today.

P11: You're welcome.

Interviewer: And like I said before we started the recording just please feel free to stop me at any time if you'd like to and we can stop the tape.

P11: Sure ok

Interviewer: So I'd suppose what I'd like to do today is I'd like to hear about your own experiences of caring for your wife, in your case who has eh dementia...and what I'd like for you to do is for you to feel free for you to tell me your own story in any way that you feel comfortable. And as well I suppose I'd like you to feel free to give me as much detail as you'd like to do because for me and as part of the work I'm undertaking here, everything is of interest to me that is importance to you and your own experience so if you'd like to start off and we can see how it goes...

P11: Well eh (Pauses)...It's not a particularly interesting story and eh I suppose it started when...it *'really'* kicked in about 6 years ago when I retired and eh...It just as soon as I retired I noticed that my wife was eh, was being forgetful and we were at that time attending the memory clinic in _____ (Hospital name) and met the Professor and initially she was diagnosed with mild cognitive impairment but in the intervening 6 years it has moved on in a *slow* progressing fashion to the point now where I have to do virtually everything for her...From, from...(long pause)... the blueshings in the morning, to dressing ehm,...breakfast and tablets and managing her through the day with toilet and right through to the evening...and if I'm not there I must ensure that someone else is there with her. Now it's fair to say that I am getting a reasonable amount of support from two sons that I have and also the fact that she's able to attend a day care centre ran by _____ (Organisation name) twice a week. Previously they would pick her up on a bus, take her, take her there and take her home. But they don't take her by bus anymore because invariably she was opening the seat belt and standing up and they weren't able to cope with this...so it behooves me to

(laughs a little) to drive from _____ (place name) to _____ (place name) and if I don't do it do it one of my sons will drive her, he drives her on a Friday morning and my other son collects her on a Tuesday afternoon, so at least it's, it's made the task, task easier...but we need to be with her all the time (laughs a little) eh even for walks to the shops, to church, anything and everything and eh she's quite mobile, very mobile, quite agile, really she'll walk up and down the stairs. She would manage that stairs without any bother, easier than me and she's good, fairly good at walking. Ehm, but she'd be inclined to follow me around the house during the day, as indeed she follows the carers in the community centre, she walks around after them. She's on her feet most of the day, which I suppose helps to conk out at night...and then at night then, she'll be up several times to go to the toilet and it beholds me, assuming I hear her, I hear her most times, to go with her to, to manage, her manage her, otherwise we would end up in more difficulty (Pauses)...Eh that's it, that's it in summary.

Interviewer: Yeah, yeah

P11: (Pauses) you know it's full time care (Pauses)... You know what are the thoughts that occur to you, you should ask? You know she wouldn't be able to cope or to make a cup of tea, nothing like that and we've tried her on that and occasionally we'd say, 'Put the, put the milk in the fridge' and that would... You would see her trying to figure out where's the fridge, where's the (laughs a little) and she could put marmalade on her bread before butter and that think of thing, so you just have to watch that (Pauses)...So it's, it's a full time task (laughs a little).

Interviewer: Ok (long pause)..... So when you say it is a full time task, how do you feel about that?

P11: Eh Well I've grown accustomed to it, I've grown accustomed because it's been so, eh, so very slow and gradual over the 6 year period and... by nature I'm fairly patient, most of the time you know (laughs a little). I mean if I do say loud words to her or give out, oh next minute I'm sorry I've even said that. I mean I think even this morning, trying to get her to take her tablets it's becoming more difficult or to take a tablet and swallow and throw her head back. I say 'Is the tablet gone?' 'Yes.' 'Is it in your mouth?' 'Yes.' Another, another sip of water to try to get the tablet down and eh...But I know that by her demeanour it has gone down but it is becoming more difficult. So the difficulty is continuing along this straight line, eh...however slowly. So I'm, I'm patient and I'm understanding, and I realise it's not her fault. Her mother and father did have dementia before her, and she's the eldest of six, and none of the other,

none of the others have been affected...In fact she's with her, her youngest sister now today, going to the dentist. And she's going to Peter Marks to have her hair done and they'll have lunch along the way. So well hairdresser and lunch is the norm on a Thursday, a pattern they have. Ehm on a Wednesday afternoon there's a lady comes out to sit with her from _____ (Organisation name) so I'm... And then on the weekends one of our sons will invite us to their house or apartment to have dinner so that saves me cooking every day.... (Long Pause)...Do, do you want to prompt me with another question? (Laughs)

Interviewer: No, no this is all good... Eh and when you talk about family there and the role that they play in ..?

P11: Yeah the two boys and her sister?

Interviewer: Yeah

P11: And indeed her brother's very good, he lives in _____ (place name) and once a month he'll invite us down to go down there for the day, to have our lunch and dinner, not every month but quite often but eh quite often, quite often, quite good... And the other, other members of the family are in the country. She has a deceased brother and sister. Her brother sadly died of Motor Neuron a few years back and her sister died of Cancer only last year, I think, last year, so all very sad...but she, she doesn't have full appreciation of that stage at the moment..... (Pauses and becomes emotional).....

Interviewer: Ok, yeah and how important is that support network to you?

P11: Oh well I think the support network is very important, I mean it gives me some freedom, and latitude, I mean I have an involvement with a couple of organisations in _____ (place name) ... I'm on the board of the local community centre and eh I'm chairman of the local _____(group name) we won a match yesterday (laughs).

Interviewer: Ah excellent

P11: What's seldom is wonderful (laughs). And eh...so I'm quite a committee person and I've been advised to keep those activities up, continue to be involved and I mean there have been times I've said to myself, ah I should really pack this in, or pack that in but in. Eh, in order, order to attend these meetings or to get involved with these organisations I obviously do need support and I tailor it around _____ (wife's name) visits to the centre and eh the lady coming

out to visit which was yesterday. And then I use my two sons for back up, and they don't have any hesitation in providing that backup. So in other words I, I would certainly wouldn't be able to do any of this... Just in more recent times now she's inclined to open the hall door and go out...So that's a new development, I have to eh, eh either put the chain on or on occasions she can open the chain, other times she becomes slightly confused, 'best' to turn the key. That's only, that's only in 'very' recent times I've had to recourse to that. Prior to this she never made any attempt to eh open the hall door, so that's if, she went out it would be very difficult. Even if she has a mobile phone which I keep charged and she has in her hand bag, everything, everything goes into the handbag. But eh under normal circumstances, she wouldn't be able to answer the phone, and it's one of these that you just 'press' a button and it flips open and you're ready to talk but eh...She's had it a couple of years and in the beginning she used it, but she was never great with technology. Eh... (Pauses) ...So there some of the precautions we have to take.

Interviewer: And how does that make you feel when you're talking about the door and...

P11: Well eh obviously it took me back a little but ehm, and in fact I watched her on one occasion and she opened the hall door and went out and just tried to open the car in the driveway and no she wouldn't drive, I mean she, she hasn't driven in quite some, several years now. She hasn't driven since I retired, her license is now eh ceased ehm. But it's something, I have to, it's a new thing I have to watch going forward.... (Pauses)...

Interviewer: Ehm just you talked about needing to, I suppose assisting your wife in different aspects of her care, and you had referred to her personal care eh how, how do you...

P11: Yeah, yeah showering and the like?

Interviewer: Yeah, How do you feel as her husband?

P11 I don't ehm, I don't have a major difficulty....First of all, I mean, for the shower, I actually have to coax her into the shower (Laughs little). She's not going to go into the shower of her own volition so I have to organise everything from her shower cap to her dressing and also as part of her medication I apply a patch to her back every morning, an xlon patch. I have to do that, because it's, it's for the most part of her back she doesn't she, I mean I can put it on her arms as well or her chest, high up eh you just move it then to a different spot every time when you're finished moving down the back then you start at the front again. But she's no objection

with that just takes it in her stride. But eh, I'd have to do a personal assistance in the shower, lucky enough I've a large shower and eh it facilitates me helping her with her shower.

Interviewer: Ok and did you receive any training at all?

P11: No, no (laughs) no, no

Interviewer: Ok

P11: No, none...and the same then will apply to toilet or, it's best for me and occasionally if she gets up in the middle of the night and I happen to be conked out maybe had a glass of wine or two too much and I wouldn't hear her, and I pay the price then you know... And you know she'll wear pads which I have to replace and order as required which I get through the district nurse. So they keep in touch with me maybe once a month, 6 weeks and they ring and see how things are getting on but...And the district nurse in fact organised eh a day care centre in a HSE place and she went there for 6 months but they weren't able to cope with her '*manoverability*' because she would get up and walk around and leave the room and it wasn't a particularly secure centre in _____ (place name) because a lot of the people they have they can talk to and will just sit there and stay there, or others are not able to move except with assistance. But _____ (wife's name) would happily get up and move around and walk around (laughs). So that was too much of a liability, so they couldn't take her anymore on a Monday but _____ (Organisation name) are better geared and they have a more secure ehm '*centre*' where she's now out in _____ (place name)... (Pauses)

Interviewer: ...And she goes there....

P11: Twice a week, Tuesday and a Friday. She'd, she'd be out there (sighs), from half 9 or 10 o'clock until the latest 4 o'clock...

Interviewer: Ok. So it gives you...

P11: Well it gives me, it gives me a little bit of time. But you have to try to manage your time (laughs), because the hours can disappear very quickly. I mean on a '*bad*' morning it could take me 40 minutes to drive out to _____ (place name), depending on traffic and weather conditions, and another 40 minutes back. So that's an hour and a half and I'm only home (laughs little), so I might do some vacuuming or do something in the house and have time to have my own lunch, whereas she will have had her lunch in the centre. And when lunch is

over then I'm '*psyching*' myself up to going back out again. But the fact that my sons '*interleave*' with me is making life a bit easier, now if they're away or one, one of my son's goes abroad a bit but not as much now as he used to but obviously I'd have to step into the breach and do it myself then (Laughs).

Interviewer: Ok and do you mind me asking, you said when your wife is in day care that you referred to vacuuming, ehm would have been involved in say household tasks previous to...?

P11: Well no...the truth would be yes I would have been involved in vacuuming, making the bed, eh...But I never had to do any ironing before, I never had to manage to eh, I never had to manage the washing machine, to a lesser extent the dishwasher so...eh (Pauses)

Interviewer: Ok, and how do you find all that?

P11: Well I find it quite good yeah, I find it... I haven't had any great difficulties, I find myself involved in cooking now ehm.... Now I don't get myself involved in very many of the experimental dinners my '*sons*' would...but there are, eh available in the shops you know Donegal catch is easy enough to cook, I put on veg and spuds. And eh there are other Cully and Sully type dinners that seem to be quite good because I have to watch the salt content in relation to my '*own*' blood pressure because eh... I'm trying to maintain my own health as well.

Interviewer: Really okay.

P11: So I'm on say high blood pressure tablets, I'm told they're not particularly high but I'm on them anyway and... Over the past several years I'm been monitored for eh prostate, PSA, high level of prostate reading, but eh my specialist guy out in _____ (place name) is eh pretty happy you know I'm higher than the norm. But that's, that sometimes happens and he looks for a straight line graph and occasionally it '*pop*'s up, but I had a few biopsies, and again touch word (Laughs), everything is fine. But it's just a question of monitoring those for myself and for _____ (wife's name) ... I take _____ (wife's name) to _____ (Hospital name) for her 6 monthly check up, in the, in the we call it the senior clinic. I can't pronounce all these words (laughs). So I'm, I'm fairly flexible and eh, fairly, fairly flexible and I think I can cope with '*most*' situations. But obviously I suspect that going forward as the situation becomes '*more difficult*', I am wondering '*how*' I will be able to cope.

Interviewer: Are you?

P11: Yeah, well I am I mean I am wondering. I mean I would be keen to manage _____ (wife's name) certainly for obviously as long as I can. You know because you see and hear stories of other people being so difficult, so awkward to manage that they have to go in somewhere. Now I wouldn't appreciate that but eh...It's incredible to realise how eh '*incapable*' she is, of even some of the most minor tasks, so they're obviously drifting out of her mind all the time. You would tell her something now and it wouldn't even take five minutes for that to have gone, you know... (Voice lowers)... eh (Pauses)....

Interviewer: And you talk about that, how her memory ehm... how would you describe your relationship together?

P11 Well I think it was a very good one, it was a very compatible one. I mean eh I've been very lucky that's I've worked '*virtually*' all my, I've worked since I was 16 (Laughs). And we're married since 1969, and eh you know _____ (wife's name) managed the two boys and she engaged in meals on wheels for 25 years in the local community, and she was on the school committees. She would organise holidays you know, come into town make the bookings with the travel agent, that kind of thing. So I never had to do any of these things. Because I worked in the city centre, I worked on _____ (street name) with _____ (company name) and then I worked with _____ (company name) for 10 years after I was made redundant from _____ (company name) (laughs a little). So I kind of, I was lucky I always got work. I was in facilities so ehm...as I said earlier I am fairly flexible about a lot of things you know (Pauses).

Interviewer: Is there anything you miss eh now, say from before your wife became ill?

P11: Eh well you know obviously there are certain things, say in relation to intimate relationships they're, they're kind of gone and I've kind of learnt to '*live*' with that and '*understand*' that and '*accept*' that, and eh it doesn't bother me as much as I thought it might eh you know... Eh financially we don't have eh any major concerns luckily enough, you know that would make it much worse if there were... And eh I am on a medical card (laughs), however, long that will last. And we do have free travel, eh sadly I drive into town fairly (Laughs) ...but eh so we're not strapped in that respect eh that's not a concern. I listen to Joe Duffy and the stories that emanate I say God help these people, they might be saying God help me (Laughs). But eh no we're managing it but it's eh certainly eh a '*total*' commitment, you can't take your eye off the ball for too long, you know because given that _____ (wife's name) is very mobile, and it's probably a good thing that she '*is*' mobile. But eh, you don't know what she's doing in the house, she'd be picking up papers and moving things around

and, I'd take a file out and there's files and correspondence, and she'd move them around and they'd go missing, so I have to be very careful how I manage papers and keep them away from her you know. Post, she'll open post belonging to the lads or stuff marked confidential, it doesn't matter, she'll open it. But then she's not able to explain, say if Christmas card came in, she wouldn't be able to explain who it's from, you'd have to take her through line by line, so it's eh '*tricky*' you know (Laughs)..... (Pauses)...

Interviewer: Okay..... (Pauses).....And you had referred to the district nurse and her eh contact, just in terms of supporting you in your role as carer, do you have any thoughts on that or...?

P11: Well no, I get the impression that these people are very '*busy*', and on the few occasions that the district nurse came out, she only came out to the house a few occasions, a very nice person but eh she was no sooner there than she wanted to go, she was very busy, she had other people to meet. Now she did set up the contact whereby I can order the pads for _____ (wife's name), eh she set up the day care in _____ (place name) which '*didn't*' work. And in fact in relation to the contacts with _____ (Organisation name) it was me who eh '*pursued*' that and organised that...and eh I tried calling them and I had great difficulty getting answers on the phone, so I jumped into the car because I knew there was a centre in _____ (place name) because I knew there was a centre there. I'd heard about that in eh _____ (place name) and I met this eh _____ (member of management)...and eh she was very receptive to me on the day and I couldn't believe my lucky stars when she said that they, they '*could*' take _____ (wife's name). And eh it kind of moved on from there then... Now _____ (place name) is closed down and there's _____ (place name) which is a bit fair way. So that was a lucky break but I kind of pursued that myself it wasn't eh...immediately and that's probably now, only about eh 18 months maybe, 18 months, 2 years maybe at the most. The time goes very quickly so it could be 2 years. But prior to that it was just me looking after _____ (wife's name) myself, full time, '*all*' the time..... (Pauses)....

Interviewer: Okay. And I suppose other sources of support as carer to your wife, that you feel could assist you or perhaps...?

P11: Well I don't know if there's anything else out there that can do more... The district nurse has said to me on a couple of occasions 'have you considered respite care?' Eh...something similar, something like _____ (wife's name) going somewhere for a week. I haven't really thought about that...

Interviewer: Had you not?

P11: No I hadn't really because eh... We'd been away eh... Last year, my two sons organised a long weekend in Florence you know which eh, a place I always wanted to visit, and we had a great, great time. And the plan there was if I wanted to go off and visit some of the museums with say my young boy, who is also a graduate of Trinity, we could do that and my older fella would take _____ (wife's name). But in the event we kind of all stayed together eh... from the hotel to the various museums and places of interest and dinner in the evening... And we're going to repeat the same in May, we're going to Rome...

Interviewer: Oh lovely.

P11: Yeah we're going to Rome in May from a Thursday to Sunday, I've been to Rome a couple of times but eh...the same will apply. Now we'll be going with their partners as well, so extended family, so if I wanted to go off to the 'Vatican' say I'll get tickets on line, you know _____ (wife's name) just would not be interested, and she would go with one of the other and we'd meet up later. That's the plan going forward. But eh in terms of well respite in that regard, I haven't '*fully*' considered it and I would feel, well I was very upset when she went off first on the bus to the HSE place, so I wouldn't altogether at '*this*' point relish her, going in somewhere when I '*swanned*' off for a week you know just..... (Pauses).....

Interviewer: Do you mind me asking why is that, you were upset, you talked about the day care initially?

P11: Well I eh suppose because the attachment is so strong eh...And I'm kind of happy that she's there with '*me*', even though (Laughs) in inverted commas 'She's not with me' some of the times, and like when she knows '*me*', and she'll know our two sons. She would be slow to ehm put a name even on her brothers and sisters. When her sister came this morning, I knew she was coming, I was upstairs to brush my teeth and I heard her coming in and I came down and I said 'Who came to visit you?' And she wouldn't answer and she said 'Who is it you?' (Laughs). But curiously '*physically*' she looks quite well and you wouldn't readily recognise that there's anything wrong with her unless you were talking to her for a short time or and just notice the strain. But eh a cursorily glance wouldn't tell you anything. You know people comment that she looks very good and, she '*eats*' quite well..... (Pauses) ...And eh I'm also in, there's also eh a respite grant as well...

Interviewer: That's right, yeah.

P11: ...which eh I sent off, I sent the form off a 'year' ago and I heard nothing, and I said that's well because of cut backs and I just let it go. And then a year lapsed and I still hadn't heard anything so I rang them again and told them I'd sent in the form, some place over in ____ (place name) and they told me it must be lost, they hadn't got it, we didn't get it. So they asked me to apply again and I had to go through about getting the doctor to sign forms and somebody else had to sign something... And luckily I had kept copies, copies weren't available. So I was given a eh two year remit. Now again I had to follow it up by 'phone' in order to 'get' it. And I think on the third phone conversation I was told 'Oh that's just landed on our desk and you'll have it in a few days...' I'm delighted to get it, now I see that as something specific for her. It's helping to pay the charges on ____ (organisation name)...Eh other costs involved because when the lady comes out from ____ (organisation name), there's a payment there. Now it's, its 'nominal' enough but you know, it builds up you know over the weeks and the months. And the same applies to the centre in ____ (place name). Now the rate is slightly reduced because she doesn't go by bus but eh so...I'm, I'm not bothered by the costs there, I think that's good.... (Pauses)....

Interviewer: Okay. Eh and when you talk about the lady who comes in from ____ (organisation name), how do you find that then, having somebody coming in?

P11: Well eh the lucky thing is ____ (wife's name) seems to know the lady quite well, with this lady, that's the lucky thing. She comes in and sits with her and chats to her. Now she's fairly chatty when I'm there, and she's asking her how she is and she's commenting on her clothes and hair and (Laughs) ... I'd be hoping, I'd be hoping I'd have her 'dressed' properly you know to merit these comments (Laughs) but however. And I would tend to watch telly. And yesterday I believe they went out to the garden because it was nice and sunny, I left sunhats for them and put cushions on the chairs. But I'm not sure how long they stayed out there because this lady is quite fair and probably the sun wouldn't appeal to her too much, I don't know, maybe you might understand. But eh she seems happy to sit with her but, ____ is her name, but she tells me that after an hour or so ____ (wife's name) becomes agitated, fidgety, getting up and walking around the house. Now 'I don't notice' any of that agitation when I'm there. I come back from bowls and she will say well ____ (wife's name) was agitated now and she's calmed down now that you've come in (Pauses)..... So that eh, that works reasonably well. Now they may be able to give me more time, a lady that's she's looking after is gone into a home and it gives her more time, and she says that I should consider taking up the option because these options won't be available in another 12 months,

but if they're once established, there's a better chance of maintaining them. So eh again you might say I'm lucky in that respect. How are people going to manage you know in the future, with eh reduced services available (Pauses)..... But eh there you go is there anything more I can add?

Interviewer: Eh no, I think you know like I said eh I've been trying to encourage your story, and you've been excellent. I suppose in trying to show me or explain to me your own situation so thank you very much. But just one or two things from your own initial narrative that you've spoken about, I just I was wondering eh in caring for your wife, would you see any challenges in caring for her at all?

P11: Would I see any challenges? Well obviously the situation at the moment is a challenge in itself and it would appear that while I'm not perfect in this regard, I'm eh coping with the challenge... If you'd asked me ten years ago, I'm not sure how I would answer but I meet, I meet fellow, other men and they tell me there's no way they would eh do what I'm doing. Now one man said this to me, I was getting tickets for a concert from him, only two days ago, he said I just wouldn't be able to 'do' what I'm doing you know I said, (Laughs)... told him I'd just come down from washing her teeth, helping her to wash her teeth which isn't easy. She's a denture and sometimes she knows what I mean by remove the denture and other times she doesn't, so I take it out myself. But he said he wouldn't be able to do that. Now he's a very accomplished gentleman in musical circles and he said he couldn't do this. So I think maybe, maybe it requires a certain kind of person or maybe...

Interviewer: Do you think so?

P11: I'm saying '*maybe*', '*maybe*' it does or maybe anybody can grow into this situation. Because certainly the two boys I have are quite different in nature and eh but they're quite sympathetic and very very helpful to ____ (wife's name). And this has been noted by third parties, for example the younger guy who does the shopping on a Tuesday night when I play bowls... Neighbours have spotted them in Tesco and he would be taking her by the hand or she would be wheeling the basket because you don't, because if you don't have her wheel the basket she can drift off to another aisle... Or she sees something on the floor and you could be gone on ahead and we've lost her a few times, momentarily. She tends to walk behind me, if you're not holding her hand or linking, she tends to walk behind which removes the '*initiative for her*' for heading in particular direction... I remember walking out between two cars to go to my car and she continued to walk and I looked behind and... As the fella says

there she was gone, and so I had to call her name out loud and luckily enough I stopped her further on... But in the early stages she did eh leave the hairdressers and walked home, and left an optician actually in _____ (place name) and walked home when my son was inside having his eyes examined and she was in reception and she obviously got 'fed' up waiting (Laughs), and she left. And she walked home. And 'did' arrive home. But we're not sure if she would do that now because... Sometimes, we live in a semi-detached in _____ (place name), we drive into the drive way and she's looking at the number and says '---' (house number) and yeah I say 'That's our house And she says 'And there's ---' (house number). I say 'Do you know who lives there?' 'No'. She doesn't know who lives on either side.... Now when she'd see the person she would probably recognise them but she would be slow to take these eh... So she certainly has disapproved in recent times and it's not going to get any better I realise, presumably brain cells die off and they can't be rejuvenated. And I wonder sometimes the benefit of the patch I apply which is no great stress but she also takes two tablets, abiksit tablets and they are becoming more difficult to administer and the district nurse thinks I could discontinue them but the hospital have prescribed them and their attitude would appear to be, look they're not doing her any harm so I think we should continue with them. But I see myself now having difficulty getting her to 'take' them. I might just talk to the chemist who's very helpful in our area to see and see if he has any suggestions....

Interviewer: That might be a good idea?

P11: Yeah In fact the district nurse mentioned that the other day, so that's something I want to do..... (Pauses).....

Interviewer: Eh, and it's every 6 months that you have the hospital....?

P11 The hospital visit is every 6 months. _____ Department in _____ (Hospital name). We've kind of moved on from the eh _____ (clinic name). This is a clinic for the aged. I can never pronounce the words is it Geren...

Interviewer: Geriatric?

P11: No there's another one....

Interviewer: Gerontology?

P11: Yeah that's the one. Eh...also in recent years, _____ (wife's name) will, have a diagnosed tendency towards Osteoporosis and that caused her major difficulty in the early stages, her back and she's had dexis scans and x-rays and all that kind of thing. But her Osteoporosis by virtue of taking Protellus at night and calcium during the day, which I also take. I also take Foselosis for Osteoporosis...Eh but '*Hey presto*' she never complains about her back, and from a standing position she can almost reach down and tie and untie her laces in her runners without any difficulty, she just doesn't talk about it..... Now the figures have improved but the change there has been dramatic. She never complains about her back. And it's amazing, in the early stage she was on Ponstan and other things. Now whether it was a factor of mind as well which has been suggested to me by the people at _____ (hospital name) that pain takes different forms.... You know pain can be a concept in the mind. But all that is gone and thankfully I don't have to cope with that...No, she does have a slight curvature, but her dexis reads are actually showing an improvement eh..... (Pauses)

Interviewer: Ok and how are you feeling in yourself? (Laughs) If you doing mind me asking...

P11: No, no that's part of it. Eh...I have been diagnosed with Osteoporosis but men get it maybe a lesser extent than women so for that reason I am on Foselosis for the past six months, maybe more and I take two Calcium tablets like _____ (wife's name) takes. But I don't feel any great difficulty, just maybe the odd occasion I might find a '*strain*' there. It doesn't bother me you know so...I'm not really able to go and play golf because that would take me away too long from _____ (wife's name). But the _____ (group name) is more manageable, its '*local*', except when there's matches away but the people I play with realise I wouldn't be able to play, I wouldn't attend every match...(Pauses).....

Interviewer: Okay, so there's an important social aspect?

P11: Yeah well there is that, there is that. And I'm told by people who '*seem*' to know that it's important to keep these up, you know these activities up.

Interviewer And do you feel that yourself?

P11: Eh...I, I, I feel that I '*could*' actually, if I stopped doing _____ (group name), I could maybe do a bit more in the house (Laughs). But eh no it's good fun and when I get involved in it, I can put other things out of my mind. Eh...Another thing that I '*did*' engage in, in times past, during when I started my working life, I was working under a lot of pressure in previous jobs, I eh did TM, Transgenial Meditation and I found that very very beneficial. The ideal

application is 20 minutes in the morning and 20 minutes in the morning, I just 'can't' do that when _____ (wife's name) is around. Now occasionally she would go off on a Friday morning with my older son _____ (son's name), I could sit down for 20 minutes and do it and I actually find the benefit of it. But if I could do that more often it would be better for me, helps your clarity, thinking, organisation of what you have to do (Laughs). So that's something that I should probably get 'back' into, and I've said that lots of times. But I do feel the better of it when I do engage in meditation. But don't get the opportunity too much.....(Pauses).....

Interviewer: I suppose well, I'm just looking here like I had said at the outset, the objective of us meeting today was for me to be able to hear your story. So ehm I don't have any specific questions to ask you at this stage, but eh what I always do and I would like to give you the opportunity to do now as well, if you think maybe 'There's something you know that I haven't been able to refer to, or referred to' and you think is important to your own specific experience, and would like to mention something that perhaps we haven't talked about today?

P11: Eh I can't really, I can't really think eh I've too much more to add but maybe if I reflected on it later and if something occurred to me I could communicate to you in some way? I think I probably have your email somewhere...

Interviewer: I can even give you that, it should be on most of the...

P11: Oh that's it there...

Interviewer: That's it yeah, that's exactly it. So you know if there was anything additional yeah that would be a good way of contacting me.

P1: But I think the situation I have at the moment is, is a fact of life...

Interviewer: Do you think so?

P11: I think so, yeah you have no control over it. These things happen. It's eh, it's 'part' of life, yeah part of life. Eh I only heard, heard, just in the last couple of weeks of a former colleague of mine, you can correct me now sometime like 'Cardiovascular' dementia, is it, could there be Cardiovascular dementia?

Interviewer: There's eh a condition that would be eh, I'm not sure of the exact terminology; there is so many different but sorry go on...

P11: But he, he worked as an engineer with me in eh...if you like in the early form of computerisation, which was long before your time, you know punch cards? We worked on that...And he was quite a '*bright*' guy. And eh he's got this condition and his wife couldn't manage him and he's now in a home in _____ (place name) since...She said I could go in and visit him. 'He may know you and he may not.' 'And some days he's good and some day's he's not so good'... And he would be eh...Because he was of a technical background he's inclined to take for example the remote control, like _____ (wife's name) does too. But he's taking it because he wants to fix it. But he gets quite stressed out and upset ehm, and the only way they can calm down is to get his wife on the phone and she talks to him but eh that's extraordinary...There you are, I knew the fella quite well, amazing. And he played too, maybe _____ (group name) brings it on (Laughs)..... (Pauses).....

Interviewer: No, no... Okay well if you would like to contact me at any time that would be absolutely fine...

P11: I probably will contact you at some time just even to tell the other person what the study is...

Interviewer: Oh yeah if you would like to do that, that's fine...

P11: Ok

End

Appendix 10 Inventory of Narrative Elements under Three Parent Nodes – Theme, Tone and Imagery

Tree Nodes

Name	Sources	Reference	Created On	Created By
Images	0	0	23/10/2012 17:1	AS
Metaphors	17	92	10/01/2014 10:2	AS
Photographs and images	4	80	10/01/2014 10:2	AS
Patterns of meaning across men's caring experiences	0	0	14/11/2013 17:0	AS
Admiration and respect	0	0	14/11/2013 17:0	AS
All consuming nature of caring	0	0	14/11/2013 17:0	AS
Determination and pride	0	0	14/11/2013 17:0	AS
Future	0	0	14/11/2013 17:0	AS
Intimacy and closeness	0	0	14/11/2013 17:0	AS
Loss and sadness	0	0	14/11/2013 17:0	AS
Themes	0	0	23/10/2012 17:1	AS
Acceptance	13	46	14/11/2013 17:0	AS
Accustomed	5	12	14/11/2013 17:0	AS
Adaptations	15	43	23/09/2014 10:3	AS
Adjust	7	21	23/09/2014 10:3	AS
Admiration	12	113	23/09/2014 10:3	AS
Advocating	3	3	23/09/2014 10:3	AS
Affection	2	3	23/09/2014 10:3	AS
agressive nature of dementia	4	7	23/09/2014 10:3	AS
Animals	1	15	23/09/2014 10:3	AS
annoyance	12	53	23/09/2014 10:3	AS
Anxiety	15	70	23/09/2014 10:3	AS
Applying skills from work to caring role	4	17	23/09/2014 10:3	AS
Arrogance	1	3	23/09/2014 10:3	AS
Assertive	1	2	23/09/2014 10:3	AS
Attitudes to informal caring	3	4	23/09/2014 10:3	AS
Avoidance	6	10	23/09/2014 10:3	AS
Balancing	9	54	23/09/2014 10:3	AS
Balancing working with caring	1	1	23/09/2014 10:3	AS
Bitterness	6	12	23/09/2014 10:3	AS
Boredom	3	4	23/09/2014 10:3	AS
Burden	7	18	23/09/2014 10:3	AS
Calmness	9	22	23/09/2014 10:3	AS
Capabilities	9	14	23/09/2014 10:3	AS
Carers feelings towards dementia	3	3	23/09/2014 10:3	AS
Carers own health	14	83	23/09/2014 10:3	AS
Carers own needs	8	26	23/09/2014 10:3	AS
Cautious	2	4	23/09/2014 10:3	AS
Challenges in caring	14	76	23/09/2014 10:3	AS
changes in care staff	2	2	23/09/2014 10:3	AS
changes in caring roles and responsibilities	1	1	23/09/2014 10:3	AS
Christmas	3	6	23/09/2014 10:3	AS
Clarity	2	4	23/09/2014 10:3	AS
Climax	1	1	23/09/2014 10:3	AS

Name	Sources	Reference	Created On	Created By
Closeness	12	118	23/09/2014 10:3	AS
Comfortable	4	11	23/09/2014 10:3	AS
Comforting tone	1	2	23/09/2014 10:3	AS
commitment	6	13	23/09/2014 10:3	AS
Company	8	24	23/09/2014 10:3	AS
comparing own situation with that of other carer	2	2	23/09/2014 10:3	AS
Complex	1	3	23/09/2014 10:3	AS
Concern over what others think	1	2	23/09/2014 10:3	AS
Confidence	6	24	23/09/2014 10:3	AS
Confusion	1	3	23/09/2014 10:3	AS
constant need for support	11	26	23/09/2014 10:3	AS
Constantly on mind	8	18	23/09/2014 10:3	AS
Control	4	11	23/09/2014 10:3	AS
Converse with others on own caring situation	4	8	23/09/2014 10:4	AS
coping	14	58	23/09/2014 10:4	AS
Cost of outside support	2	12	23/09/2014 10:4	AS
Criticism	10	43	23/09/2014 10:4	AS
Current needs	1	1	23/09/2014 10:4	AS
Cutbacks in support	3	4	23/09/2014 10:4	AS
Danger	1	3	23/09/2014 10:4	AS
Day by day attitude	4	17	23/09/2014 10:4	AS
Day care	11	31	23/09/2014 10:4	AS
Death	2	4	23/09/2014 10:4	AS
Decision making	6	20	23/09/2014 10:4	AS
Despair	1	1	23/09/2014 10:4	AS
Determination	17	72	23/09/2014 10:4	AS
Developing scenario	16	79	23/09/2014 10:4	AS
Devotion	4	10	23/09/2014 10:4	AS
diagnosis of condition	15	36	23/09/2014 10:4	AS
Difficult to pinpoint	1	5	23/09/2014 10:4	AS
Dignity	16	54	23/09/2014 10:4	AS
Disappointment	3	5	23/09/2014 10:4	AS
Disbelief	1	1	23/09/2014 10:4	AS
Disorientation	13	70	23/09/2014 10:4	AS
Distraction	2	2	23/09/2014 10:4	AS
Distressing	2	6	23/09/2014 10:4	AS
Does not want to think about	6	11	23/09/2014 10:4	AS
Dogmatic	1	2	23/09/2014 10:4	AS
Doing everything	2	3	23/09/2014 10:4	AS
doing too much	1	2	23/09/2014 10:4	AS
Duty	9	31	23/09/2014 10:4	AS
Early stages of dementia	1	2	23/09/2014 10:4	AS
Education on dementia	1	2	23/09/2014 10:4	AS
Embarrassment	7	15	23/09/2014 10:4	AS
Emotional bond	1	1	23/09/2014 10:4	AS

Name	Sources	Reference	Created On	Created By
Emphasis	18	406	23/09/2014 10:4	AS
Encouragement	6	11	23/09/2014 10:4	AS
Exchanging information and experiences with o	2	4	23/09/2014 10:4	AS
Faith	4	8	23/09/2014 10:5	AS
Family	15	145	23/09/2014 10:5	AS
Family history of dementia	1	4	23/09/2014 10:5	AS
Fear	4	13	23/09/2014 10:5	AS
Feelings towards caring	15	66	23/09/2014 10:5	AS
Fight	1	2	23/09/2014 10:5	AS
Financial issues and concerns	11	33	23/09/2014 10:5	AS
Financial support	8	19	23/09/2014 10:5	AS
Flexible	1	1	23/09/2014 10:5	AS
Fortunate	2	8	23/09/2014 10:5	AS
Friends	5	15	23/09/2014 10:5	AS
Frightening	2	3	23/09/2014 10:5	AS
Frustration	13	71	23/09/2014 10:5	AS
Future	17	86	23/09/2014 10:5	AS
Gaining information on condition	2	5	23/09/2014 10:5	AS
Gaps in support services	11	36	23/09/2014 10:5	AS
getting out	8	17	23/09/2014 10:5	AS
gradual progression	16	86	23/09/2014 10:5	AS
Gratefulness	12	31	23/09/2014 10:5	AS
Greive	3	6	23/09/2014 10:5	AS
Guilt	10	30	23/09/2014 10:5	AS
Healthcare Professionals	11	81	23/09/2014 10:5	AS
Hectic	1	2	23/09/2014 10:5	AS
Helpful for other people	4	7	23/09/2014 10:5	AS
Helpful to carer	15	129	23/09/2014 10:5	AS
Helping with work of dementia organisations an	1	6	23/09/2014 10:5	AS
Hiding	1	2	23/09/2014 10:5	AS
Hindsight	9	18	23/09/2014 10:5	AS
Holding on	11	32	23/09/2014 10:5	AS
Holidays	7	15	23/09/2014 10:5	AS
Hope	11	33	23/09/2014 10:5	AS
Household tasks	16	55	23/09/2014 10:5	AS
Identity	15	67	23/09/2014 10:5	AS
Ignore	2	2	23/09/2014 10:5	AS
impact of dementia on carer	14	78	23/09/2014 10:5	AS
Impact of dementia on individual with dementia	17	137	23/09/2014 10:5	AS
Inclusion	5	11	23/09/2014 10:5	AS
Incompetent	1	1	23/09/2014 10:5	AS
Independence	7	29	23/09/2014 10:5	AS
Individuality	1	2	23/09/2014 10:5	AS
information from dementia organisations	6	9	23/09/2014 10:5	AS
in-house support and care	5	32	23/09/2014 10:5	AS

Name	Sources	Reference	Created On	Created By
interest in learning more	3	3	23/09/2014 10:5	AS
Interests and hobbies	17	70	23/09/2014 10:5	AS
Intimacy	9	17	23/09/2014 10:5	AS
Invisibility of condition	3	5	23/09/2014 10:5	AS
Irritation	2	6	23/09/2014 10:5	AS
isolation	11	35	23/09/2014 10:5	AS
Joy	1	1	23/09/2014 10:5	AS
Juggling	6	12	23/09/2014 10:5	AS
Justification	1	2	23/09/2014 10:5	AS
keep going	4	7	23/09/2014 10:5	AS
Kindness	1	2	23/09/2014 10:5	AS
Laziness	1	1	23/09/2014 10:5	AS
Life before dementia	19	172	23/09/2014 10:5	AS
Limbo	1	1	23/09/2014 11:0	AS
Limited involvement	1	2	23/09/2014 11:0	AS
Live for the moment	3	5	23/09/2014 11:0	AS
Lonely	8	18	23/09/2014 11:0	AS
Long term care	13	35	23/09/2014 11:0	AS
Loss	17	183	23/09/2014 11:0	AS
Love and respect	11	121	23/09/2014 11:0	AS
Lucky	10	19	23/09/2014 11:0	AS
Making the best of a bad situation	1	3	23/09/2014 11:0	AS
Male carers	4	7	23/09/2014 11:0	AS
Managing role as carer	8	16	23/09/2014 11:0	AS
marriage	10	15	23/09/2014 11:0	AS
meaning of caring	4	10	23/09/2014 11:0	AS
men's ability to care	2	3	23/09/2014 11:0	AS
Neighbours	4	9	23/09/2014 11:0	AS
Night time care	1	3	23/09/2014 11:0	AS
normal	13	46	23/09/2014 11:0	AS
Not around to care for individual	10	19	23/09/2014 11:0	AS
Not living with care recipient	1	1	23/09/2014 11:0	AS
Not wanting others involved in care	2	4	23/09/2014 11:0	AS
Noticing individual may be unwell	6	20	23/09/2014 11:0	AS
Old age of individual with dementia extra burde	1	2	23/09/2014 11:0	AS
On my own	9	15	23/09/2014 11:0	AS
onset of dementia	4	7	23/09/2014 11:0	AS
Outside help	12	73	23/09/2014 11:0	AS
Parallels between caring for individual with dem	8	36	23/09/2014 11:0	AS
Part of being old	6	8	23/09/2014 11:0	AS
Patience	11	26	23/09/2014 11:0	AS
Personal care	14	64	23/09/2014 11:0	AS
Planning ahead	11	20	23/09/2014 11:0	AS
Positive	18	117	23/09/2014 11:0	AS
Post caring life	2	3	23/09/2014 11:0	AS

Name	Sources	Reference	Created On	Created By
Practical attitude to caring	9	32	23/09/2014 11:0	AS
Prejudice	1	1	23/09/2014 11:0	AS
prepared	3	5	23/09/2014 11:0	AS
Pressure	6	29	23/09/2014 11:0	AS
previous caring experiences	3	6	23/09/2014 11:0	AS
Priority	1	1	23/09/2014 11:0	AS
Privacy	2	2	23/09/2014 11:0	AS
Protection of dignity and independence of indivi	6	22	23/09/2014 11:0	AS
Protectionary role as carer	17	184	23/09/2014 11:0	AS
Protectionary role as father	5	6	23/09/2014 11:0	AS
Proud	13	115	23/09/2014 11:0	AS
Public attitudes to condition	7	19	23/09/2014 11:1	AS
Public attitudes to male caring	7	114	23/09/2014 11:1	AS
Public misunderstanding of condition	5	11	23/09/2014 11:1	AS
Rapid progression	1	1	23/09/2014 11:1	AS
Reassurance	10	43	23/09/2014 11:1	AS
record keeping	1	1	23/09/2014 11:1	AS
Regression	1	1	23/09/2014 11:1	AS
relax	7	9	23/09/2014 11:1	AS
Reluctant	3	4	23/09/2014 11:1	AS
Repititive	5	6	23/09/2014 11:1	AS
Resentment	5	6	23/09/2014 11:1	AS
respite	9	54	23/09/2014 11:1	AS
restlessness	1	1	23/09/2014 11:1	AS
restricted	3	6	23/09/2014 11:1	AS
Retirement	7	14	23/09/2014 11:1	AS
Reward	1	1	23/09/2014 11:1	AS
role reversal	9	21	23/09/2014 11:1	AS
Routine	12	28	23/09/2014 11:1	AS
Same thing every day	3	3	23/09/2014 11:1	AS
Satisfaction	1	1	23/09/2014 11:1	AS
Schedule	5	12	23/09/2014 11:1	AS
Selfish	2	5	23/09/2014 11:1	AS
Sharing caring role with other family members	3	33	23/09/2014 11:1	AS
Shock	6	12	23/09/2014 11:1	AS
silence	4	4	23/09/2014 11:1	AS
Sleep	11	41	23/09/2014 11:1	AS
socialising	6	8	23/09/2014 11:1	AS
Sole responsibility	6	17	23/09/2014 11:1	AS
son caring for father	1	3	23/09/2014 11:1	AS
Sources of tension between carer and other fa	5	17	23/09/2014 11:1	AS
Sources of tension in relationship between care	10	36	23/09/2014 11:1	AS
Spoilt	1	1	23/09/2014 11:1	AS
Stability	1	1	23/09/2014 11:1	AS
Stages of caring	5	15	23/09/2014 11:1	AS

Name	Sources	Reference	Created On	Created By
Standing by	2	4	23/09/2014 11:1	AS
Strain	6	23	23/09/2014 11:1	AS
strange	1	2	23/09/2014 11:1	AS
Strong	7	17	23/09/2014 11:1	AS
Struggle	1	1	23/09/2014 11:1	AS
Subtle nature of caring	2	11	23/09/2014 11:1	AS
Subtle signs that individual may be unwell	6	11	23/09/2014 11:1	AS
supervisory role as carer	14	45	23/09/2014 11:1	AS
Support from family	16	109	23/09/2014 11:1	AS
Support from individuals other than family or frie	16	82	23/09/2014 11:1	AS
support group	7	44	23/09/2014 11:1	AS
supportive role as father	1	2	23/09/2014 11:1	AS
Surprise	6	8	23/09/2014 11:1	AS
Suspicious	4	8	23/09/2014 11:1	AS
Sympathy	7	19	23/09/2014 11:2	AS
Tense	1	2	23/09/2014 11:2	AS
The situation could be worse	10	18	23/09/2014 11:2	AS
Time management	9	22	23/09/2014 11:2	AS
Time to self	16	85	23/09/2014 11:2	AS
Tiredness	6	26	23/09/2014 11:2	AS
Togetherness	19	237	23/09/2014 11:2	AS
Total dependence	4	10	23/09/2014 11:2	AS
Training course for carer	6	16	23/09/2014 11:2	AS
Transition	1	7	23/09/2014 11:2	AS
Trivial	1	3	23/09/2014 11:2	AS
Trust	2	5	23/09/2014 11:2	AS
Turning point	14	40	23/09/2014 11:2	AS
unavoidable	3	7	23/09/2014 11:2	AS
understanding of condition	5	14	23/09/2014 11:2	AS
Unemployment	2	2	23/09/2014 11:2	AS
Upredictable nature of dementia	3	6	23/09/2014 11:2	AS
upset	17	71	23/09/2014 11:2	AS
verbal exchange or interaction	6	33	23/09/2014 11:2	AS
wandering	4	6	23/09/2014 11:2	AS
Weakness	2	6	23/09/2014 11:2	AS
Working at home while also caring	2	4	23/09/2014 11:2	AS
Working outside of the home	15	41	23/09/2014 11:2	AS
Worry	17	90	23/09/2014 11:2	AS
younger age with dementia	4	9	23/09/2014 11:2	AS
Tones	0	0	23/10/2012 17:1	AS
Acknowledging tone	15	208	10/01/2014 12:4	AS
Admiration tone	14	109	10/01/2014 12:4	AS
Annoyance tone	15	116	10/01/2014 12:4	AS
Anxiety tone	18	108	10/01/2014 12:4	AS
Arrogant tone	1	4	10/01/2014 12:4	AS

Name	Sources	Reference	Created On	Created By
Bitterness tone	5	19	10/01/2014 12:4	AS
Calm tone	6	9	10/01/2014 12:4	AS
Cautious tone	7	27	10/01/2014 12:4	AS
Comforting tone	1	2	10/01/2014 12:4	AS
Concerned tone	11	28	10/01/2014 12:4	AS
Confident tone	13	79	10/01/2014 12:4	AS
Conforming tone	6	7	10/01/2014 12:4	AS
Confused tone	3	8	10/01/2014 12:4	AS
Controlling tone	1	1	10/01/2014 12:4	AS
Determination tone	17	113	10/01/2014 12:4	AS
Disappointing tone	7	21	10/01/2014 12:4	AS
Embarassed tone	3	6	10/01/2014 12:4	AS
Emphasis	18	406	10/01/2014 10:5	AS
Encouraging tone	6	21	10/01/2014 12:4	AS
Enthusiatic tone	1	1	10/01/2014 12:4	AS
Excited tone	13	46	10/01/2014 12:4	AS
Frank tone	14	53	10/01/2014 12:4	AS
Grateful tone	16	82	10/01/2014 12:4	AS
Hesitation	15	51	23/09/2014 10:5	AS
Hopeful tone	14	44	10/01/2014 12:4	AS
Humour	18	133	10/01/2014 11:4	AS
Justifying tone	1	1	10/01/2014 12:4	AS
Laziness tone	1	1	10/01/2014 12:4	AS
Loss tone	17	226	10/01/2014 12:4	AS
Nervous tone	9	18	10/01/2014 12:4	AS
Nostalgic tone	17	137	10/01/2014 12:5	AS
Obliged tone	7	11	10/01/2014 12:5	AS
Open	3	9	23/09/2014 11:0	AS
Panic tone	2	3	10/01/2014 12:5	AS
Patience	11	26	23/09/2014 11:0	AS
pauses and silences	13	82	10/01/2014 10:2	AS
Positive tone	17	176	10/01/2014 12:5	AS
Reassuring tone	12	53	10/01/2014 12:5	AS
Regretful tone	16	69	10/01/2014 12:5	AS
Relieved tone	7	14	10/01/2014 12:5	AS
repetition	16	102	23/09/2014 11:1	AS
Safeguarding tone	17	139	10/01/2014 12:5	AS
Selfish tone	1	1	10/01/2014 12:5	AS
Shock tone	10	26	23/09/2014 11:1	AS
Somber tone	12	124	10/01/2014 12:5	AS
Strained tone	9	57	10/01/2014 12:5	AS
Supportive tone	2	2	10/01/2014 12:5	AS
Sympathetic tone	7	21	10/01/2014 12:5	AS
Tiredness	6	26	23/09/2014 11:2	AS
uncertain	16	76	23/09/2014 11:2	AS

▼	Name	▲	👤	Sources	Reference	Created On	Created By
●	Unease			4	8	23/09/2014 11:2	AS
●	Unfinished sentences			10	24	10/01/2014 10:4	AS
●	upset			17	71	23/09/2014 11:2	AS
●	Worry			17	90	23/09/2014 11:2	AS

Appendix 11 Additional Example of Turning Point in Men's Stories

David

David is 73 years old. He has been caring for his wife who has dementia for over the past three years. There are no other individuals living with them in their house and he has been retired from work for several years previous to her diagnosis. This interview took place in David's own home during the afternoon on a week day following a request made by him that it would be suitable to meet me here. The following quote is directly taken from the story he told me:

...Yeah. She started to get, she was a little bit incontinent, she had to wear these tena pants you know (David, P03)

Ok (Ann)

And she leaked a bit. But she did that for years anyway but it got a little worse. But then, she got diarrhea (David, P03)

Ah dear (Ann)

And it's very difficult. In a hotel now, to clean her, to clean the place. Afraid of the bed, putting towels on the bed, everything. We went on a small tour then to the south of Germany, to a kind of nature resort, nature forest and that. And she took bad and I had to get her to the toilet. Now granted it's not like here, the toilets were first class, even out in the wilderness. Of course I'd nothing to change her clothes. So between everything it was embarrassing aside from anything else, trying to get her home and all that, I thought the holiday would never end. And I just said well that's the end of holidays, I couldn't bring her anywhere. Now she got over that. You know, she just had the leakage problem then. And we started talking about it then. Like the eldest daughter is the closest to me. She lives in (place name). The other lassy lived in (place name)... She's the eldest married with two kids. And (son's name) lives down below, in (place name)... So we're talking about it, (daughter's name) and myself, and we started to look back. And there had been a 'couple' of incidences. One of the things that was always difficult was (wife's name) with the phone. It had been for years that if they rang up, and (wife's name) answered the phone and said is Dad there, because she could never make sense of phone conversations over the last few years. Few years 'before' anything happened her. She just, I don't know, she couldn't concentrate on the phone. And as for the mobile phone, I had to meet her several times in town. I used to go in early; she used to work as

(profession).... And eh, it was nearly impossible to meet her..... A couple of times I had to go looking for her around the centre of the city. She couldn't work out how to use the phone you know. This would be say 'the year' before. She read in the church with me, and she made one morning an absolute 'mess' of the reading, kept losing her place, couldn't find her place. And was very upset. And she said I'm not reading anymore. Now we just put it down to, you know, it's just one of those things. She had trouble reading and that you know. We left it at that. But in hindsight we could see it was the disease (David, P03)

Looking Back, ok (Ann)....

In the quote above, David tells me about several key incidences that stand out for him when recalling his wife's diagnosis. With a strong sense of loss and sadness, David tells me of the impact of dementia on his wife and how she became incontinent. He is extremely regretful as he remembers a holiday that they went on together following her diagnosis. This is in stark contrast to how he had excitedly recalled earlier in his story how they had enjoyed going on holidays together before dementia. It is as if this particular trip was a turning point for David in realising that he could no longer do things as he once did together with his wife. He displays a mixture of sympathy as well as guilt and slight embarrassment when telling me how she had diarrhea when they were away. This may also be reflection of the wider narrative that is taking place as David tells me his story – that of feeling judged, both by me and by wider society in his role as a male carer. For instance, it is as if he is almost balancing his feelings, thinking that he may be to blame for what happened. David's reference to his wife's leakage problem up to this point also acts as an important metaphor in his story in demonstrating how dementia only had a certain impact and could be dealt with. However, this incident is indeed a catalyst as he acknowledges that soon after he begun discussing his wife's condition with their adult children. Speaking with family members may have also provided him with a sense of togetherness - in not feeling that he was alone and clarifying that his wife was unwell. He recalls with a mixture of sympathy and guilt, how together they remembered specific incidences over recent years before his wife's diagnosis that unaware to them at the time may have been due to his wife's condition.

David then pauses several times as he remembers back to another specific situation of not being able to meet his wife. His pausing almost illustrates both his frustration and sadness that he felt at the time. It is then significant that the last incident David recalls relates to religion and the embarrassment he felt when his wife was confused in church when reading.

Thus, the influence of wider narrative also becomes apparent i.e. that of wider public attitudes surrounding dementia. Indeed, faith was important to David and his wife and this was evident through the visible signs of religious pictures hanging up around the downstairs of their house. This extended narrative also demonstrates minimal involvement on my part in which I tried to allow David tell his own story. However, I encouraged him through as above.

Appendix 12 Nvivo Coding Density from Excerpt of One Man's Story

P7 I mean it wouldn't be that she bathed every morning but and I had to, I had a new shower unit in, I've a new toilet in down here so that it's eh more convenient. And eh so that's all I have to work. At first, she didn't accept that at all, she didn't want it, and eh, it's got to the stage now where she accepts it, if I say come I'll have a shower first, you go in and have your shower...it will follow through, and, eh it's even getting closer to the stage where I actually have to be *with* her when she's showering, in case there's a problem.



Appendix 13 Interconnectedness Between the Patterns of Meaning in Men's Stories of Their Caring Experiences

All consuming Nature of Caring	Determination and Pride	Loss and Sadness	Admiration and Respect	Intimacy and Closeness	Future
Acceptance	Adaptations	Annoyance	Accustomed	Acceptance	Acceptance
Accustomed	Anxiety	Annoyance tone	Acknowledging tone	Accustomed	Accustomed
Acknowledging tone	Avoidance	Avoidance	Admiration	Acknowledging tone	Acknowledging tone
Adjust	Balancing	Balancing	Admiration tone	Anxiety	Adaptations
Anger	Being left alone	Behaviour of PwD	Advocating	Anxiety tone	Anxiety
Annoyance	Carers own health	Calm tone	Affection	Behaviour of PwD	Anxiety tone
Anxiety	Cautious	Carers own health	Calm tone	Challenges	Avoidance
Anxiety tone	Cautious tone	Clarity	Calmness	Closeness	Balancing
Balancing	Challenges	Closeness	Capabilities	Commitment	Bitterness
Bitterness	Commitment	Confidence	Cautious	Confidence	Bitterness tone
Bitterness tone	Confidence	Confident tone	Cautious tone	Confident tone	Carers own health
Burden	Confident tone	Confusion	Challenges	Confusion	Cautious
Calm tone	Constant need for support	Confused tone	Clarity	Confused tone	Cautious tone
Calmness	Controlling	Coping	Closeness	Controlling	Confused tone
Cautious	Controlling tone	Criticism	Commitment	Controlling tone	Confusion
Cautious tone	Coping	Day-care	Confused tone	Determination	Constant need for support
Challenges	Death	Determination	Confusion	Determination tone	Constantly on mind
Confused tone	Determination	Determination tone	Constantly on mind	Developing scenario	Criticism
Confusion	Determination tone	Developing scenario	Day-care	Dignity	Day by day attitude
Constant need for support	Developing scenario	Disorientation	Determination	Duty	Death
Constantly on mind	Duty	Emphasis	Determination tone	Embarrassment	Determination
Day care	Fear and apprehension	Fear	Devotion	Emphasis	Determination tone
Early stages of dementia	Feelings towards caring	Friends	Emphasis	Hesitant	Developing scenario
Emphasis	Frank tone	Frustration	Excited tone	Holding on	Emphasis
Exhaustion	Future	Future	Frank tone	Holidays	Family
Feelings towards caring	Gradual progression	Gradual progression	Feelings towards caring	Hope	Financial issues and concerns
Frustration	Holding on	Gratefulness	Gentle nature	Hopeful tone	Family
Gradual progression	Hope	Grateful tone	Guilt	Identity	Fortunate

Impact of dementia on carer	Hopeful tone	Grieve	HCPs	Impact of dementia on carer	Future
Impact of dementia on PwD	Identity	Guilt	Hindsight	Impact of dementia on PwD	Grieve
In-house support	Impact of dementia on carer	HCPs	Holding on	Intimacy	HCPs
Learning as you go	Isolation	Holding on	Holidays	Isolation	Hindsight
Metaphors	Just do it/ pragmatic approach	Hopeful tone	Hopeful tone	Just do it/ pragmatic approach	Holding on
Obliged tone	Keep going	Humour	Identity	Lonely	Hopeful tone
Outside support	Learning as you go	Impact of dementia on carer	Impact of dementia on carer	Loss	Impact of dementia on carer
Patience	Life before dementia	Impact of dementia on PwD	Impact of dementia on PwD	Loss tone	Impact of dementia on PwD
Pauses and silences	Loneliness	Interests/ hobbies	Independence	Love and respect	In-house support
Protectionary role as carer	Metaphors	Intimacy	In-house support	Marriage	Knowledge through experience
Relief	Nostalgic tone	Isolation	Life before dementia	Metaphors	Legal aspects
Repetition	Not wanting to place in LTC	Life before dementia	Loss	Normal	Learning as you go along
Repetitive	Pauses and silences	Lonely	Love and respect	Nostalgic tone	Life before dementia
Respite	Personal care	Loss tone	Lucky	Personal care	Live for the moment
Role reversal	Positive	Love and respect	Marriage	Photographs and images	Love and respect
Routines/ scheduling	Proud	LTC	Meaning of caring	Positive tone	LTC
Safeguarding tone	Proud tone	Making the best of a bad situation	Metaphors	Protection of dignity and independence of PwD	Lucky
Sole responsibility	Public attitudes to male caring	Marriage	Normal	Protectionary role as carer	Metaphors
Somber tone	Public misunderstanding	Metaphors	Nostalgic tone	Proud	
Strain	Regret	Normal	Not wanting others involved in care	Proud tone	Not around to care for PwD
Strained tone	Regretful tone	Nostalgic tone	Parallels with caring for child	Repetition	Not wanting to burden family

Stress	Relief	Outside help	Patience	Role reversal	Outside help
Subtle support	Resilience	Parallels with caring for child	Pauses and silences	Safeguarding tone	Pauses and silences
Supervisory role	Retirement	Patience	Personal care	Sexual relations	Personal care
Time to self	Role reversal	Pauses and silences	Photographs and images	Silence	Photographs and images
Tiredness	Routine	Photographs and images	Protection of dignity and independence of PwD	Socialising	Planning ahead
Unpredictable nature	Satisfaction	Positive	Regret	Togetherness	Positive
Worry	Strength	Pride	Regretful tone	Uncertain	Positive tone
	Stigma	Regret	Repetition	Upset	Post caring life
	Support from family	Regretful tone	Resentment	Worry	Practical attitude
	Support groups	Repetition	Respite		Prepared
	Support	Respite	Safeguarding tone		Previous caring experience
	Sympathy	Role reversal	Somber tone		Protectionary role as carer
	Tensions with family	Sarcastic tone	Supervisory role		Proud
	Time to self	Sexual relations	Sympathetic tone		Proud tone
	Togetherness	Silence	Sympathy		Regretful tone
	Total dependence	Socialising	Togetherness		Repetition
	Training courses	Sole responsibility	Uncertain		Respite
	Uncertainty	Somber tone	Upset		Routines/ schedules
	Unpredictable nature	Strain			Safeguarding tone
	Upset	Strained tone			Stages of caring
	Worry	Support			Strain
		Sympathy			Strained tone
		Tiredness			Support group
		Togetherness			Togetherness
		Total dependence			Total dependence
		Turning points			Uncertain
		Upset			Unpredictable nature
		Younger age with dementia			Upset
					Worry

