Exploring the experiences of male caregivers caring for a partner with Alzheimer's dementia: An Interpretive Phenomenological Analysis.

"A strange thing about dementia is that it doesn't make sense sometimes. […] It's a horrible feeling"

by

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THESIS

A thesis submitted in partial fulfilment of the requirements of Edinburgh Napier University, for the award of Doctor of Philosophy

DOCTOR OF PHILOSOPHY

School of Health and Social Care
Edinburgh Napier University

Edinburgh, Scotland

October 2020

Declaration

I declare that this work is submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy.

I confirm that the work has not been submitted for any other degree or professional qualification.

I confirm that this thesis is the result of my own independent work under the supervision of my director of studies and supervisor.

Signed: Gwenne McIntosh

Print:

Date: 05/10/2020

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Approved by:

Director of Studies: Dr Norrie Brown
Supervisor: Dr Adele Dickson

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Abstract

Introduction

Dementia is a global health issue. The role that family members adopt to support people to remain at home has an impact on caregivers, communities, health services and the wider economic climate. This thesis presents an exploration of male caregivers' experience of caring for a partner with Alzheimer's dementia. The aim is to uncover the experiences of male caregivers and identify factors that encourage or inhibit decisions to access support services. The perspectives of men caring for a partner with dementia are underexplored, resulting in a lack of insight into the individual caregiving experience.

Method

The study adopts a qualitative phenomenological approach offering close examination of the lived experience of caregiving leading to deeper understanding of the concepts, values and meaning men draw from their experiences. Semi-structured interviews with seven men caring for their partners provided the data for this study and was analysed using Interpretive Phenomenological Analysis (IPA).

Findings

Three themes were identified: 1. Lack of Influence; 2. Changes and Losses and 3. Protecting Others. Findings provide increased understanding of the individual experience of caregiving in the context of being a male partner. Men's experience is complex as Alzheimer's dementia brings about substantial change in roles, responsibility and relationships. Decisions about caregiving and accessing support are related to men's view of their sense of duty and the desire to protect others. Perceptions of support services influence men's decisions to access support, and the consequences that arise from interactions with service providers are often unexpected, unintentional or unwanted. The lack of involvement and power in making decisions adds to the emotional impact of caring resulting in a spiral of disengagement from services.

Conclusion

This study offers new insights, providing opportunities for health and social care staff to better respond to the needs of men through improved engagement and will be of interest to those working with caregivers and those providing support for people with dementia.

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Acknowledgements

I would first of all like to acknowledge the male caregivers who agreed to share their experiences with me in order to better understand their experience of caring through their eyes. I trust that I have given justice and significance to the experiences, thoughts feelings and insights they shared with me.

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Abbreviation Key

CASP	Critical Appraisal Skills Programme
CBT	Cognitive Behavioural Therapy
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CPN	Community Psychiatric Nurse
DOH	Department of Health
DSM	Diagnostic and Statistical Manual of Mental Disorders
GP	General Practitioner
ICD	International Classification of Disease
IPA	Interpretive Phenomenological Analysis
LMIC	Low and Middle-Income Countries
MEDLINE	Medical Literature Analysis and Retrieval System Online
NCD	Neurocognitive Disorders
NES	NHS Education for Scotland
NHP	Nursing Home Placement
NHS	National Health Service
ONS	Office of National Statistics
QOL	Quality of Life
RCT	Randomised Controlled Trials
UC	Unintentional Consequences
UK	United Kingdom
US	United States
WHO	World Health Organisation

Preface

I started my nursing career in 1998, as a student mental health nurse in Scotland, having had some limited summer volunteering experience in an older people ward in a local mental health hospital. Once qualified, I worked initially in an in-patient rehabilitation service then moved into community day care provision. Working as a community mental health nurse for four years, I first realised the psychological and emotional demands on family members when a man, who had been attending a community based mental health resource, arrived at the clinic with his clothes and possessions. He informed me that his mother has "had enough" and had told him to leave and that he had nowhere else to go. I contacted his mother and I arranged to visit her at home later that afternoon. When I arrived at her home, we sat in her living room and she narrated her experience of caring for her son. She described his unusual behaviours, including believing he was in contact with the royal family and how he spent many hours in the late evening and during the night pacing the house talking to himself and shouting at members of the royal family. This had been interrupting her sleep and causing issues with her next door neighbours.

Prior to this incident, I had followed policy and processes related to the inclusion of families and caregivers. At that time this included a telephone call prior to an annual review, invitation to attend the review and a summary of the annual review and outcomes from the review being sent out by letter. However, listening to this woman and hearing first-hand how caring for her son at home was impacting on her emotional, psychological and physical health so significantly that she felt she was unable to continue, had a transformative effect on me as an individual and as a mental health nurse.

This experience led me to adopt a new way of working with families and to integrate improved communication and contact with family members within the community mental health service. It also encouraged me to take on a new role out with the National Health Service (NHS), working as a Carer Support and Development Officer for the National Schizophrenia Fellowship. In this role, my focus was on supporting family caregivers of people affected by psychosis and meeting their information needs. In addition to this role, there was a responsibility to develop family caregiver awareness training for mental health nursing and social care teams. Following the end of this charity funded project in 1999, I moved into a three year pilot project in the NHS, working within general practice as a Carer Coordinator. Again, this role focused on family caregivers with a specific remit of supporting primary care services to identify, support and meet the information needs of family caregivers (Jarvis & McIntosh, 2004, 2007). This post offered the opportunity for me to work more broadly with caregivers as it was not limited to mental health. Over the first year of the project, it was clear that there was a significant support and information need for caregivers of people with dementia. Recognising this, I developed, in partnership with specialist dementia nurses, a range of support groups, information sessions and educational courses for families providing care for someone with dementia at home. In addition, I developed enhanced specific health and social care staff training courses. The aim of these was to improve the awareness and recognition of caregivers.

The pilot continued and I remained in this post until 2006. My work increasingly centred on individual support, group support and education events for families and training events for staff who were in contact with families caring for people with dementia. It was during this time that I first became interested in male caregivers of people with dementia. I recognised that men appeared to access and engage with particular types of services, for example those that were focused around dementia specific information sessions, practical advice and information, short courses and training events. Men appeared to be less likely to access individual support, attend informal support or mutual self-help groups. However, I observed that the men who attended the courses and training events engaged with sharing stories relating to their caregiving experience and the emotional impact of caring.

At the end of 2006 I moved into higher education and became a mental health nurse lecturer. Given my experience working with families, I was given the specific remit of increasing the inclusion of family caregivers and people with lived experience of mental health issues in the education programmes we provided. In this role I was able to continue with my interest in working with families through the caregiver networks I had. I continued to contribute to caregiver support services as the chair of a caregiver advocacy service and as an advisory member of a caregiver support organisation. I also continued to run caregiver events and dementia specific training.

As I progressed as a lecturer, I began to engage with research, completing a small-scale research project exploring students' perspectives of service user and caregiver involvement in education as part of my MSc dissertation. When I was encouraged to apply for my PhD I wanted to build my confidence and completed a further study exploring family caregivers experience of contributing to nurse education.

When I considered the potential topics for my PhD, I returned to the early experience I had with caregivers as a nurse and then as a Carer Coordinator. It was through these experiences, and my genuine interest and passion in exploring the perspectives of caregiving men, stemmed. When I was given the opportunity to undertake my PhD, I was keen to pursue this area of interest further and developed my proposal for the application process. The interest and passion has been an essential component throughout this journey and has helped to maintain my momentum and focus.

Chapter 1 - Introduction and Background

"The impact of dementia is not only significant in financial terms, but also represents substantial human costs to countries, societies, families and individuals" (World Health Organization (WHO), 2017)

1.0 Introduction

The global impact of dementia is outlined in the above quote by the WHO in their action plan driving forward the challenge for member states to work collaboratively to meet the needs of people with dementia and their families towards 2025. This quote demonstrates the significant impact dementia has from an individual to a global level transcending personal, family, community and social constructs.

The focus of this thesis is on the exploration of male caregivers experience of caring, specifically those caring for a partner who has a diagnosis of Alzheimer's dementia. The ageing population, increased prevalence of dementia and the role that family members adopt to support those closest to them to remain at home, has an impact that is far reaching. This impact can be felt personally, in the communities we live in, the health services we have and the wider economic climate we exist in.

When first developing an interest in family caregivers in the mid 1990's, caregiver awareness training and education was new on the health and social care agenda. My role at the time was to work with service providers to identify and meet the information needs of family caregivers. The training then often started with statements like: "Family caregivers are the backbone of health services" or "if all family caregivers stopped caring today, it would require a second NHS workforce to replace the care they provide". Now in 2020, the recognition and attention given to family members who provide care at home seems to have gained little momentum, yet societies continue to rely substantially on this informal type of care provision.

The knowledge and understanding of the experiences of male caregivers is relatively limited in the literature, despite males contributing to the 'informal', unpaid caregiver community. When employed as a mental health nurse and while working directly with family caregivers in both the third sector and statutory services, I noticed differences in the types of support, information and respite services that were accessed by caregivers. I observed that the type of support accessed appeared to be related to, among other things, the gender of the caregiver, their relationship with the person receiving care and the diagnosis of the person receiving care. Yet most caregiver support was homogenous in nature. It was this observation that sparked my interest in exploring the experiences of male caregivers and to focus on my study today.

The aim of this research study is to identify which factors encourage or inhibit male caregivers of people with Alzheimer’s dementia decision to access respite and support services and to explore the perceptions of accessing support. This chapter will contextualise caregivers of people with dementia from a global to local perspective. It will define key terms and concepts related to and connected with caring for someone with dementia. The key terms will be defined and an overview of the recognition of family caregivers from a policy perspective will then be given as a way of creating a shared understanding of the topic and why it is significant. The recognition of family caregivers in health and social care policy will then be explored as a way of offering an overview of the United Kingdom (UK) policy perspective relating to caregiving and dementia and why it is important in relation to health, health care, well-being and society.

1.1 Population, ageing and dementia

There is global recognition that the population is ageing. People are living longer due to advances in medical science and health care as well as the increased knowledge relating to healthy lifestyles (Gilbert, Teravainen, Clark, & Shaw, 2018). As the population of older people increases, the prevalence of non-communicable diseases like dementia has grown (Touhy & Jett, 2017). This has led to increased focus on dementia and its impact on individuals, families, communities, services and the economy. This is evident in the development of global policies and strategies aimed at preparing for this anticipated rise in both older people and dementia (United Nations, 2015; WHO, 2017), but it is less evident in the local policy perspective.

As people continue to age, the range of health-related conditions associated with ageing will increase, resulting in a growing number of older people with ongoing, complex health conditions being cared for at home (Touhy & Jett, 2017). In addition to this, these older people will be supported and cared for by family members who themselves are ageing.

The Office of National Statistics (ONS) (2017), predict that there will be an ongoing increase in the number of people in the UK over the age of 65 over the next two decades. By 2035, for example, the number of people over the age of 85 is likely to be 2.5 times more than in 2010. This will account for around 5 per cent of the UK population (WHO, 2015).

1.2 The contribution of caregivers

Family members are known to contribute significantly to the care and support of people who have dementia living at home. This forms a substantial proportion of the care provision worldwide but more so in low-income and lower-middle-income countries, where family caregiving currently predominates (WHO, 2012). However, as the population demographic changes, family members, specifically adult children caring for a parent, who may not continue to provide care for older relatives with dementia leaving a worrying deficit for countries to address. This is of particular concern to low and middle income countries (LMIC), where families currently provide the majority of care for older people (WHO, 2012). Family caregivers are critical to meeting the health needs of people with dementia and this provision of care enhances quality of life of the person receiving care (Brodaty & Donkin, 2009). Brodaty and Donkin, (2009) state that it is only with the contribution of family caregivers that people with dementia can remain at home.

In the UK, caregivers are recognised for providing an essential contribution to community care (Lin, Macmillan, & Brown, 2012). An indication of how reliant the statutory care services are on the contribution of families to meet health and social care needs to enable people with conditions like dementia to remain at home.

1.3 Defining dementia

Dementia is described by the WHO (2012), as:

> *"...a syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities."* (WHO, 2012:2).

Definitions of dementia often refer to it being a generic term, or a word used to describe a group of symptoms. These symptoms can include memory loss, confusion, cognitive impairment and mood changes and can result in difficulties with managing day-to-day tasks (Alzheimer's Research UK, 2019). Dementia is often seen as an umbrella term that encapsulates a number of diagnoses like Alzheimer's, Dementia with Lewy Bodies, Vascular Dementia and Frontotemporal Dementia, most of which are associated with, but not limited to older people (WHO, 2012). The type of dementia diagnosed goes some way to identify and common symptomatology and to predict progression (WHO, 2012), although it is recognised that the individual experience of dementia is unique. As we age the likelihood of developing dementia increases however, dementia is not a part of "normal" ageing (Touhy & Jett, 2017).

1.4 Biopsychosocial explanation of dementia

Dementia is known as a multifactorial disorder, in essence meaning that there are many factors that are linked to the likelihood of developing dementia (Qiu & Fratiglioni, 2011). When considering the determinants of dementia, it can be helpful to align these to biological, psychological and social influences or biopsychosocial determinants, as these capture the genetic, environmental and lifestyle factors related to dementia. However, the explanation of dementia is further complicated due to the increased likelihood of co-morbidity, when people have more than one health condition, in older adults.

From a biological perspective, age is the most powerful determinant of dementia (Touhy & Jett, 2017). Growing older results in physiological changes within all body systems. In normal ageing, the plasticity (the ability to alter structure and networks) of the brain reduces (Maurer, 2006). Normal functioning is reliant on the effective communication within the nervous system. With advancing age, the grey matter and number of dendrite spines decreases and this impacts on the speed of information processing, attention and memory (Touhy & Jett, 2017). Alois Alzheimer described the condition first; he identified the microscopic changes in the brain known as amyloid plaques (deposits of proteins surrounded by nerve cells) and neurofibrillary tangles (proteins inside neuronal cells). Post mortem findings also showed atrophy of the cortex of the brain with some parts were more affected than others (Maurer, 2006). The origin of these plaques and tangles is still unclear and many explanations have come to the fore and none have been confirmed but what is clear is that these changes result in degeneration of the interconnections between the neurons resulting in cognitive impairment (Maurer, 2006).

Genetic factors are also known to influence the development of dementia with evidence supporting gene mutation in some people who develop dementia under the age of 65 (Camicioli, 2013). Although relatively few cases (2-5%) of dementia, early or late onset, are related to gene mutation (Qiu & Fratiglioni, 2011). Increased likelihood of developing Alzheimer's dementia specifically has been shown when there are first degree relatives with the condition, indicating genetic component (Qiu & Fratiglioni, 2011).

There are also modifiable risk factors that are known to be associated with dementia that, although have a biological basis, for example high blood pressure and diabetes, are influenced by environmental and lifestyle factors (Camicioli, 2013). These risk factors are of interest due to the potential to reduce the risk through health improvement strategies including the cessation of smoking, reduction in Body Mass Index and increase in physical activity (Touhy & Jett, 2017). Many interventions are targeted at improving cardiovascular health which is closely aligned with dementias that develop due to interrupted or reduced blood flow to the brain (Touhy & Jett, 2017).

Psychological factors include an individual's resilience, coping strategies and behaviours that can influence a person's knowledge, skills and motivation to attend to their wellbeing (Cromby, Harper, & Reavey, 2013). There is evidence to suggest a potential link between depression and dementia (Mansoor, Misra, & Ganzini, 2013), with a twofold increase in the risk of developing dementia in people who experience depression. However, it is unclear if depression is a risk factor or an early sign of dementia due to the high incidence of people experiencing depression in the years before dementia is diagnosed (Mansoor et al., 2013).

Social interaction, intellectual engagement and support networks are indicated to be protective factors in that they are thought to reduce the risk of developing dementia and in slowing down the progression of dementia. Research indicates that those with good social networks are less likely to develop dementia (Wilson, 2009), indicating that social interaction could be a protective factor. Intellectual achievement in formative years has also been linked to reduction in likelihood of developing the condition (Camicioli, 2013) adding to the evidence that dementia is not solely biologically determined.

1.5 Prevalence of dementia

The worldwide prevalence of dementia in 2011 was estimated to be 35.6 million (WHO, 2012). The increasing number of people who are living with dementia is currently considered to be one of the major public health challenges worldwide (WHO, 2012, 2017, 2018). It is expected that the number of people living with dementia worldwide will double by 2030. The concern about the issues relating to the increased prevalence of dementia, including the burden on family caregivers, stigma, quality of life, as well as the wider economic impact on communities, is shared worldwide (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016). The largest increase in prevalence is estimated to be in LMIC's, however dementia is likely to be the leading reason for needing care in older age in both high-income countries and LMIC in the future. It is the associated costs of which, that has made dementia a major health concern worldwide (WHO, 2015, 2017, 2018).

1.6 Progression of dementia

The progression of dementia is dependent on many factors, including individual factors such as health status, age and lifestyle as well as factors including the cause and type of dementia (Prince et al., 2016). The most common type of dementia is Alzheimer's dementia, accounting for approximately 60% of cases worldwide. Alzheimer's type dementia is known to progress slowly often over 10 years or more. The symptoms include forgetting new or recent information, disorientation, confusion, and lack of awareness of harm. However, there are several other known types of dementia, including the second most common, which is vascular dementia. Vascular dementia can progress more quickly and can present with sudden more noticeable periods of deterioration (Touhy & Jett, 2017).

1.7 Diagnosis of Dementia

As noted above, there are a number of types of dementia, stemming from differences in aetiology, progression and symptomatology. The diagnosis of a specific type of dementia is usually clinically determined via observation, presentation, physical examination and significant clinical history, and neuroimaging (Barkhof, Fox, Bastos-Leite, & Scheltens, 2011a). Due to the reliance on clinical examination, Barkhoff, et al (2011a) note that diagnostic certainty is related to the expertise of the clinician and that early and reliable diagnosis is needed to inform evidence-based treatment decisions. Quinn (2013) considers specific dementia diagnosis is still in evolution and therefore requires clearer documentation of individual presentation and effective use of clinical criteria to improve classification and accurate diagnosis.

Diagnostic criteria set out by the Diagnostic and Statistical Manual of Mental Disorders (DSM) version 5 (Simpson, 2014), includes dementia in the neurocognitive disorders (NCD's) classification. This is subdivided into mild, where the deficit does not significantly impact on daily functioning, and major NCDs. Due to the significant impairment, dementia is referred to as a major NCD. In this criterion, the mild to major NCD classification is said to be a continuum based on the impact of the impairment on the person's level of functioning (Simpson, 2014). The International Classification of Disease (ICD), version 11 (WHO, 2019), classifies the main dementia diagnoses under section 8, "Diseases of the nervous system", where similar to the DSM description, referring to neurocognitive impairment as a "major feature" (WHO, 2019).

1.7.1 Alzheimer's Dementia

Alzheimer's dementia, frequently referred to as Alzheimer's Disease, is a form of dementia initially described by Alois Alzheimer in 1906, when giving a presentation to psychiatrists in Germany (Maurer, 2006). Alzheimer's dementia is referred to as a disease or syndrome and is described as neurodegenerative due to the chronic and progressive deterioration of neurological function. Alzheimer’s dementia is known to be the most common form of dementia, accounting for between 50% and 70% of dementia diagnoses (Lau & Brodney, 2007). Frequently classified as mild, moderate or severe, Alzheimer’s dementia presents initially with memory loss and mild cognitive impairment and progresses in the moderate stage to include difficulty with reasoning, recognition and sequencing. In the latter, severe stage, people can experience a loss of functioning in relation to speech, daily activities and mobility (Lau & Brodney, 2007).

1.7.2 Vascular Dementia

Vascular dementia is usually associated with stroke (Barkhof et al., 2011b). The diagnosis is made when the clinician connects the vascular events to the decline in cognition (Barkhof et al., 2011a). The onset of vascular dementia is usually sudden and the progression of the condition is often described as “stepped”, rather than the slow progressive decline seen in Alzheimer’s dementia (Camicioli, 2013).

1.7.3 Dementia with Lewy Bodies

Less common dementias for example Dementia with Lewy Bodies, is usually characterised by the presence of Parkinsonism, but without the resting tremor and fluctuations in level of consciousness. In addition to these, there is often spontaneous auditory hallucinations (Camicioli, 2013) uncommon in other types of dementia.

1.7.4 Frontotemporal Dementia

Frontotemporal Dementia is associated with changes in personality, people affected by Frontotemporal dementia often show uncharacteristic behaviours, including disinhibition, social withdrawal and lack of empathy (Barkhof, Fox, Bastos-Leite, & Scheltens, 2011b). There are often progressive difficulties with language, for example aphasia and a lack of fluency in their speech (Barkhof, Fox, Bastos-Leite, & Scheltens, 2011b).

1.7.5 Other Dementia

There are several other diagnoses that are described as dementia due to the symptoms and presentation including include Huntington’s disease, Creutzfeldt-Jakob disease, and Korsakoff syndrome. There are also those related to the progression of other conditions including Down's syndrome dementia and Parkinson's Disease associated dementia and those related to infections and toxins (Alzheimer's Research UK, 2016; Quinn, 2013).

The diagnosis of dementia can be complicated due to the changes related to ageing and increased likelihood of co-morbidity as well as the presence of mixed dementia (Camicioli, 2013), where an individual is affected by two different types of dementia. The different presentation and related symptoms associated with the types of dementia and the way that it affects the individual, will result in variations in experience of caregiving. For those with Alzheimer's dementia, the onset is often slow and progression lengthy, resulting in the need for prolonged caregiving at home.

1.8 Dementia and gender

Dementia affects both men and women and although there are variations in specific regions of the world for example, East Asia, Western Europe and Latin America, where there is an expected increase in percentage of women with dementia (Prince et al., 2015), most will see an equal incidents of dementia for both men and women. This is mainly due to the increasing population age and levelling out of life expectancy between men and women (Prince et al., 2015).

Global Alzheimer's and Dementia Action Alliance, in partnership with the Alzheimer's Society, published a report in 2017; "Woman and Dementia: A Global Challenge", in which they note that mainly due to the increased life expectancy of women, there are more women with dementia than men. Women are also more likely to adopt primary caregiver roles within families and it is estimated they make up two thirds of those caregivers looking after someone with dementia. Therefore, men account for one third of those caring for someone with dementia. In this report, Global Alzheimer's and Dementia Action Alliance and Alzheimer's International encourage that the "gender-perspective" should be incorporated in any dementia specific local or global policies and plans (Erol, Brooker, & Peel, 2015), thus indicating the importance of recognising and responding to the different needs of male and female caregivers. Erol et al., (2015) also propose that these policies and plans should come with the required resources to support effective and sustained implementation, something that is further encouraged by Age International (2018).

1.9 Defining caregivers

Caregiver is a term that is used broadly in international literature, relating to family members and others who provide care to a loved one who has a health condition, disability, or who is frail. Definitions of caregivers differ, but generally include descriptions of providing care, support or help to another. In the UK, the term “carer” is used predominantly and describes *“someone of any age who provides unpaid support to family or friends who could not manage without this help”* (Carers Trust, 2016). The term “carer” can present some confusion as this term is also used within health literature to describe an employed, paid individual who provides care to people in residential, nursing home and people’s homes. As the term caregiver is used more broadly in international literature and provides some clarity and differentiation between informal caregivers and paid caregivers, employed carers, “caregiver” will be the term used throughout this work.

Brodaty and Donkin (2009) describe caregivers as either care providers or care managers. They note that family caregivers are more frequently female and are usually the spouse or daughter of the person with dementia. Brodaty and Donkin (2009) report that the spouse is more likely to adopt the care provider role and the daughter the care manager role, indicating the potential different role adopted depending on the relationship with the person with dementia. Recognizing the individual caregiver experience of different family members. The role adopted by the caregiver may therefore lead to different needs and information requirements to support them in this role.

1.9.1 Partner caregivers

The term “partner” is used in the context of life-partner and encompasses terms such as “wife” “husband” and “spouse”. The literature surrounding caregivers in this specific relationship use a number of different terms. Individuals who care for their partners with dementia experience caring in a unique way that is different from other family members or informal caregivers due to the nature of a partner relationship (Pretorius, Walker, & Heyns, 2009; Shanks-McElroy & Strobino, 2001). With the increase in ageing and the prevalence of dementia it is likely that those in a partner relationship will come to provide care and support to each other as they age. Partners tend to provide more care and support to their partner following a diagnosis of Alzheimer's dementia and generally consider it their duty to provide this increasing level of care (Bronner, Perneczky, Mccabe, Kurz, & Hamann, 2016).

Relationships change with the advent of caring and partners are often reluctant to seek external support, due to a sense of responsibility and respect for their partner. However, they often neglect to take into consideration the degenerative nature of Alzheimer's dementia and increased caring this brings (Bronner et al., 2016). There is therefore potentially a fine balance to ensuring that the autonomy of the individual is maintained and the caregivers support needs and views are valued when dementia progresses and specifically when capacity for decision making changes (Chrisp, Tabberer, & Thomas, 2013).

1.10 Gender, masculinity and caregiving

The way that gender is conceptualised in the literature is complex and has generated from enquiries spanning many decades (Magnusson, Marecek, Magnusson, & Marecek, 2012). Essentially, gender studies relate to how males and females differ, if at all (Kray, Howland, Russell, & Jackman, 2017). Connell (1987), a key author in relation to gender, stated that gender was socially determined in the moment, indicating the fluctuating nature of how gender is understood. Kray et al. (2017) state that the interest in gender continues today due to this fluctuation and its significance in relation to equality.

Exploration of the differences between men and women frequently stem from qualities and traits associated with genders, offering biological, behavioural or psychological explanations of gender (Magnusson et al., 2012). Although often criticised due to the potential reductionist view in which these perspectives are generated (Kray et al., 2017), people hold implicit theories that help them to make sense of the social world (Ferree, 2016). When applied to gender roles, these lay theories attribute specific roles to gender. For example, "caretaker" as a female role and "provider" as a male role.

This emphasis the role of caregiver is not considered to be a male trait or quality. Kray et al. (2017) propose that although there are women who frequently adopt the provider or “breadwinner” role, people with fixed beliefs about gender will continue to view the provider role as male. However, those with a more flexible view of gender, view these roles more broadly (Kray et al., 2017). Magnusson et al. (2012) however, questions the value in searching for clear and fixed differences or similarities between men and women, if femininity and masculinity are socially and culturally determined, and therefore ever-changing.

Gender, masculinity and caregiving are theoretically and empirically important due to the assumptions made about those that take on caregiver roles. Media portrayal of caregivers and care providers in general, continues to be predominantly female. Spendelow, Adam, and Fairhurst (2016) highlight that caring is gendered within society, with the general view that more women than men provide care and that caregiving is related to nurturing which is *“inherently feminised”* (Spendelow, et al., 2016:134). This could then result in uncertainty in the minds of people who take on caregiving roles through a sense of duty and loyalty to the person requiring care.

Additionally, the way in which men are perceived and understood in society is linked to masculinity, although there is no single origin of masculinity (Reeser, 2010). Reeser (2010) goes on to suggest that masculinity can be considered as an ideology, a set of ideals that form the basis on which we understand masculinity. The way in which people understand masculinity is influenced by media, sport, education, business and politics which are said to design, promote and sustain the ideology of masculinity (Davis, 2015), often to create masculinity in a way that serves a purpose. Masculine norms, the roles, behaviours and ideals society attaches to masculinity are said to reduce men’s potential, leading to psychological distress and can ultimately limit the way in which men are able to express themselves, specifically the way that they are able to express feelings of distress (Caperton, Butler, Kaiser, Connelly, & Knox, 2019). The societal perceptions of caregivers, men and masculinity could, therefore, marginalise men who take on caregiving roles and create tensions for men taking on this role in relation to their identity.

1.11 Caregiver burden

There is recognition in the research surrounding caregiving, that supporting someone at home who has dementia has both an emotional and physical labour, often referred to as burden, that can impact on the well-being of both the caregiver and the cared for (Mcintyre & Reynolds, 2011). However, and despite this, there is still a sense of commitment and responsibility from a personal, societal and emotional perspective that often drives family members to continue to provide care (Lin et al., 2012). The burden of caring encapsulates both the physical and emotional demands of caring, as well as the economic impact on individual caregivers and families (van der Lee, Bakker, Duivenvoorden, & Dröes, 2017). Family caregivers are emotionally connected to the individual in a way that is different from those who are employed as care staff (Lin et al., 2012). It is this complex, emotional burden, often linked to feelings of guilt, anxiety and responsibility that could create barriers when accessing support networks and make engaging in services like respite challenging (Pretorius et al., 2009).

However, there are risks with conceptualising caregiving in relation to caregiver burden. The majority of the literature surrounding caregiving is set around the concept of caregiver burden, which may restrict or prevent this experience from being understood from other perspectives. For example, in relation to the value it brings, the benefits it offers to individuals, families and society and the positive aspects of caring for a loved one (Donovan & Corcoran, 2010). Caregiving can bring about feelings of achievement and satisfaction (Tornatore & Grant, 2004), as well as generating a sense of purpose and fulfilment however these positive aspects of caregiving are frequently overshadowed by research surrounding burden (Yu, Cheng, & Wang, 2018).

1.12 Caregiver support

Within the UK there is a broad range of support, both formal and informal, local and national for people with dementia and their families (Carers Trust, 2020). This ranges from National organisations. including the Carers Trust providing information and support to caregivers via their website and through their 14 centres across the UK, and Carers UK who are a campaigning organisation meeting information needs of carers and lobbying to increase awareness and provision for caregivers (Carers UK, 2020). Some caregiver support, however, emerges from local need, for example mutual support groups, information networks and community hubs and are often provided by non-statutory services and facilitated by people who have had similar caring experiences. Other, more formal services emerge from policies or strategic plans and have specific aims and target groups and related outcomes for example those that were put in place following legislation for example the Carers (Scotland) Act (2016) (Scottish Government, 2018b). These formal services are frequently provided by health and social care services and would include day hospital and assessment services and respite provision. Much of the support for caregivers does not recognise the different and unique experience of different caregiver groups. Rather there is a tendency to offer broad brush, homogenous support for caregivers or in relation to specific diagnosis. The diverse range of support networks, both local and national, in my view can make navigation and identification of appropriate support difficult without effective communication and partnership working between organisations and networks. Lack of effective coordination of carer support resources and good information sharing could result in people not being aware of the available support networks around them.

1.12.1 Respite care

Respite care is considered a valuable resource for family caregivers, to ensure that people get a break from their caring role. Respite is described as any intervention that is designed to give caregiver a break from their caring role (Maayan, Soares-Weiser, & Lee, 2014).

In Scotland the need for regular respite care was first highlighted in the 2010 strategy where there was emphasis on the provision of *“flexible, personalised short breaks provision to carers”* (Scottish Government, 2010:10). The central tenets of personal choice and flexibility was to be enhanced by the introduction of direct payments (UK Government, 2019). This early recognition that caregivers require tailored respite services to meet their individual needs was a shift away from traditional, service led, resource determined provision.

1.12.2 Education and training

The WHO (2012) recommend that caregiver education, including information and training related to caring for someone with dementia, must be enhanced. WHO (2012) state, however, that this will be a challenge, specifically for LMIC, who need to address the attitudinal issues and stigma surrounding dementia before people will be confident to access education. The WHO highlight some of the educational programmes in the UK and Scotland as good examples of valuable psycho-education and support for caregivers (WHO, 2012). Prince et al. (2016) also support the importance of caregiver education and suggest that this is effective when offered at an early point in the caring role and it is tailored to the needs of the caregiver.

In Scotland, caregiver training and workforce education was a key aim of the 2010 Carer Strategy. The Scottish Government (2010) set out plans to support boards and national caregiver organisations to extend caregiver training and workforce education. Caregiver awareness training was introduced to the core induction of new health and social care staff and in education curricula to enhance the knowledge and awareness of health and social care staff about the role of caregivers and the issues they face. The Scottish Government, in partnership with the National Health Service (NHS) Education for Scotland (NES), have since introduced an education package for all health staff called *“Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers”* (NHS Education for Scotland, 2011). This document sets out the knowledge and skills people need to work well with people with dementia and their caregivers at informed level through to skilled and expert levels, as a way to better meet the needs of people affected by dementia. The introduction of this framework generated an online Knowledge Network, where developments, awards and further educational opportunities, for example the Dementia Champion training, are shared (NHS Education for Scotland, 2019).

1.13 Global policy perspective

Due to the anticipated impact, the WHO identified dementia as a public health priority in 2012 and published a report that aimed to increase awareness and outline a public health approach that countries could use to minimise barriers and stigma surrounding dementia and to improve the quality of life for both people with dementia and their caregivers (WHO, 2012).

The WHO (2012) report detailed the vital role that family caregivers play in the provision of care to those affected by dementia in our communities. The WHO report (2012) outlined clearly the physical, emotional and economic burden caregivers face and guides countries to develop policies or integrate strategic aims and related policies that support caregivers to continue to care as long as possible. The WHO describe the support that caregivers should have includes: *"information to aid understanding, skills to assist in caring, respite to enable engagement in other activities, and financial support"* (WHO, 2012: 4). Prince et al. (2016) summarised international dementia specific research for the 2016 World Alzheimer Report and stresses that dementia care should be continuous, holistic and integrated in order to meet the needs of people with dementia and their caregivers.

Following this, the WHO produced a Global Action Plan (2017:5) that aimed to *"improve the lives of people with dementia, their carers and families, while decreasing the impact of dementia on communities and countries".* Due to the nature of dementia, people with the condition are more likely to come into contact with hospital services. It is estimated that at least 25% of the hospital population at any given time will have dementia (Alzheimers Disease International, 2018). Although the numbers in relation to people in hospital with dementia are increasing, and whilst this is not a new phenomenon, this has been the case for many years. However, hospital services are still frustratingly ill equipped to meet the needs of people with dementia and subsequently they have poorer outcomes, higher mortality rates and longer stays in hospital (Alzheimers Disease International, 2018).

1.14 The UK policy perspective

The people who provide care informally to family members and friends have been recognised in the literature and in the policy perspective in the UK since 1999, when the first strategy for caregivers, "Caring about Carers" (Department of Health (DOH), 1999), was launched. This strategy set out three core aims for caregivers; Information, Support and Care (DOH, 1999).

A decade later the DOH launched the 2010 Carer Strategy titled: Recognised, valued and supported: next steps for the Carers Strategy (DOH, 2010). The priority areas in this strategy mirror the core aims of the 1999 strategy in relation to the information and support needs of caregivers, while giving further detail to the financial hardship caregivers can face and the impact on their own health and well-being. Although this second strategy changed focus from meeting information and support needs of caregivers to recognising the contribution they make, it was evident that people who provided care often remained isolated, unrecognised and unsupported, perhaps indicating a lack of impact of the first strategy had eleven years before.

1.15 The Scottish policy perspective

The 1999 UK wide strategy (DOH 1999) directly influenced the development of the Community Care and Health (Scotland) Act in 2002 (Scottish Executive, 2002), which gave recognition to caregivers as "*key partners"* in the provision of care. It also recognised the specific needs of caregivers and the importance of providing services to support them to continue to care. Although this Act had limited impact in relation to provision of support services for caregivers, it did recognise that the first step in meeting the needs of family caregivers was the provision of information and therefore directed all health boards in Scotland to develop an information strategy for caregivers.

In 2010 the Scottish Government launched their first strategy for caregivers called "Caring Together" (Scottish Government, 2010). Informed by the landmark report "Care 21: The Future of Unpaid Care in Scotland" (Scottish Executive, 2006), this strategy set out rights based aims to ensure that the needs of informal caregivers in Scotland were identified and responded to. The measures identified in the strategy included caregiver health checks and flu vaccinations, as well as access to training. The strategy (Scottish Executive, 2006), also set out the requirements for health and social care services to have the involvement of caregivers at the heart of planning, procurement and delivery of services.

1.16 The importance of caregivers

Family caregivers are pivotal in relation to supporting people with dementia to remain at home (Brodaty & Donkin, 2009). This care provision is a substantial economic contribution to the societies we live in (Carers UK, 2011). Developing strategies to respond to the increased demands that the ageing population and the related increase in prevalence of dementia will bring, need to include the ways in which family caregivers will be supported and how their quality of life and health can be maintained (Prince et al., 2016; Wimo, Jönsson, Bond, Prince, & Winblad, 2013; WHO, 2012, 2017).

Caregivers provide a significant proportion of the total care that people with dementia need. In the UK, caregivers have taken up the increased caring role since the policy shift from institutional care to community care (Carers UK, 2011). Since 1999 there has been acknowledgment within UK policy that family caregivers require recognition for the care they provide. Added to this caregivers need information, support and services to ensure they can continue to care (DOH, 1999). In the UK, both north and south of the border over the past two decades, there has been strategic and legislative reference to the needs of caregivers (Department of Health, 2010; Scottish Executive, 2003, 2006; Scottish Government, 2014). The aforementioned strategies and reports recognise the need to enhance the support for caregivers and to provide improved access to respite care and other services. These documents have also noted that consideration should be given to the general health and well-being of caregivers, as well as the provision of adequate training opportunities. However, despite three decades of rhetoric, there appears to be little progress in meeting the information and support needs of family caregivers given the recurrence of these basic requirements in current policies (Scottish Government, 2017).

In 2013, for example, the Scottish Government made a commitment to ensure that the needs of people with dementia and their families were met. Specifically, this related to early diagnosis and support that people with dementia and their families receive. The Dementia Strategy (Scottish Government, 2013) outlined the need to promote the quality of life people with dementia and their families have through protecting rights and promoting wellbeing. The strategy set out these aims over the duration of the strategy which was between 2013 and 2016. Since then the 2017 strategy has been in place (Scottish Government, 2017), which aims to continue to strive to provide timely, person-centred support, build on the provision of post-diagnosis support and respond to the increased incidents of dementia in older age groups. The key outcomes of this current strategy (Scottish Government, 2017) demonstrate the intention to identify and diagnose dementia earlier to allow for more participation from the person with dementia in planning care and increased dementia-enabled communities (Scottish Government, 2017).

The 2017 strategy highlights a person-centred approach as a way to ensure that the support and services offered meet the needs of the individuals and their families, rather than meeting the needs of the service providers. The strategy also recognises that the increase in demand for services due to the increased incidents of dementia in the older age groups will require a review of current health and social care provision. This is due to the complexities of meeting the needs of older people who are more likely to have concurrent long term conditions in addition to dementia, it is this co-morbidity that brings challenges for the coming years (Scottish Government, 2017).

The emotional and physical demand on family carers, who are often spousal carers of a similar, and increasing age, remains high (Phillipson, Jones, & Magee, 2013). Although there are studies that explore the needs of caregivers and their burden (Cairns, 2012, Stirling, Andrews, Croft, Vickers, Turner, & Robinson, 2010), few studies have been undertaken to uncover the facilitators and barriers that impact on the decision to access services and other support networks for people who are caring for someone with dementia at home. Added to this, there are few studies exploring the specific needs and experiences of male caregivers caring for a partner with Alzheimer’s dementia, which is something that is highlighted in the review of literature in Chapter 2. With the need for more individual and person-centred services, tailored to meet the specific needs of people now at the core of all health and social care policy, this personalised approach needs to be extended to male caregivers.

Studies that consider the caregivers experiences of deciding to use services like respite and residential care, have shown that there is engendered feelings of regret and guilt (Cairns, 2012) indicating potential barriers to accessing long term care options. This adds to the recognised barriers that family caregivers face when seeking support, such as lack of information, issues with access and limited education (Bruce & Paterson, 2000, Stirling et al. 2010). In addition, there is the burden of making decisions alone and often for the individual with dementia, as the condition progresses (Samsi & Manthorpe, 2013). There are also indications that attitudinal issues relating to health beliefs about dementia, stigma and embarrassment that prevent family caregivers accessing support, even when the burden and psychological impact of caring is high (Phillipson et al., 2013).

Improved understanding of the factors that influence male caregivers decision to access support and services and the experience of the initial interaction and engagement could be beneficial in developing strategies that break down barriers leading to timely, targeted information and support specifically for male caregivers.

1.17 Chapter Summary

The impact on communities due to ageing will require major alterations to health and social care systems globally. The related increase in people living with dementia and therefore reliance on family caregivers will mean strategies to support and sustain family caregivers will need to be identified, introduced, and maintained. Understanding the way specific caregiver groups experience caregiving, perceive and access services will provide opportunities to develop targeted and flexible support to better meet the needs of caregivers. This study aims to develop an understanding of the way in which male caregivers of a partner with Alzheimer's dementia experience and perceive caregiving and support services and explore the factors that contribute to and influence decisions to access services. The generation of new knowledge in this area could provide valuable information about the nature of support required by male caregivers and the points at which support and services are offered, potentially providing opportunities to target and align responsive caregiver-centred support.

Chapter 2 - Literature Review

2.0 Introduction

This chapter will detail the literature review process starting with an outline and rationale for the search strategy adopted. It will then offer a narrative account of the current knowledge surrounding male caregivers caring for a partner with Alzheimer's dementia. The core elements of research include systematic and planned processes; the search for new or deepening knowledge; logical approaches to answer a question and the collection of data (Moule, Aveyard & Goodman, 2017). An essential part of the process is the review and appraisal of current literature. A literature review is described by (Aveyard, 2014:5) as a *"comprehensive study and interpretation"* of the literature surrounding a particular concept, issue or topic so that the phenomenon can be better understood. For this research, the literature review will identify and present relevant research and other published evidence surrounding male caregivers caring for a partner with Alzheimer's dementia. The review will identify key or relevant information surrounding this topic. The literature reviewed has also been assessed in relation to quality, approach and trustworthiness of the findings which as Thomas and Hodges (2010) note, helps to evaluate the evidence and identify potential gaps in what is known.

2.1 Literature Review Process

A literature review can inform the various stages of a research study (Thomas & Hodges, 2010), for example, in relation to this study, the early stages of developing the proposal, it helped to inform and refine the focus of the research question(s), identify where there may be gaps in knowledge around the experience of male caregivers are and the selection of research methods or approaches for the study. Aveyard, (2014) uses the analogy of a jigsaw when she describes a literature review; to see the whole picture, each related part needs to be seen and evaluated individually, then contextualised in relation to other pieces for new understanding and insights to emerge.

The design of the intended research will have an impact on the literature review approach and the point at which the review is undertaken. For example, in quantitative research studies there is a rather fixed research process that clearly sets out when the literature review would take place. While in qualitative research there tends to be a more flexible approach and processes are often determined by the nature of the topic to be explored and the researchers epistemological stance or perspective (Horvat, Heron, Tancredi-Brice Agbenyega, & Bergey, 2013; Parahoo, 2014).

The topic and scope of the review is not only defined by the research question(s) to be addressed, but the review of literature can also help to refine and solidify the research aim and questions (Parahoo, 2014). In order to ensure the relevant literature is identified, the approach to the review needs to be methodical (Aveyard, 2014; Bryman, 2016) to demonstrate the logic in how the landscape of knowledge, in this case surrounding male caregivers of partners with dementia, appears.

The focus of the research and the methodological approach will also determine, to some degree, the type of literature that should be explored and its relevance to the topic. As this research study has adopted a qualitative approach using Interpretative Phenomenological Analysis (IPA), the literature search and review ideally follows the data gathering and interpretation process (Smith, Flowers, & Larkin, 2009). This is different to the process followed in other research methods, where for many, the literature review is the first step in the research process (Bryman, 2016). The rationale for this is related to the nature of the data gathering and analysis process.

IPA methodology sets out to minimise any avoidable potential bias stemming from preconceived ideas, concepts and relationships to maintain a *“...a degree of open-mindedness...”* (Smith et al., 2009:42). Search and critique of the related literature prior to data gathering and analysis could influence the emerging narrative in interviews and the way in which the researcher engages with the transcription analysis (Smith et al., 2009). The risk being that findings and conclusions from existing research, once in the researcher’s head, could influence the narrative and flow of the interview, thus moving away from the participant leading and exploring their own experience of caregiving. For example, the interviewer intentionally or unintentionally could influence or guide the interview by asking questions based on the themes that have emerged from existing literature, rather than allowing the participant to lead the narrative. Delaying the review of literature until after the analysis process minimises this risk and is in line with the IPA approach, therefore, reducing bias and increases the trustworthiness of the interview data and analysis. It also ensures that the focus remains on the lived experiences as the individual perceives it, maintaining the core principles of phenomenology (Finlay, 2014), which will be discussed in more depth in Chapter 3.

Having said this, and in order to develop the research proposal and gain ethical approval, a preliminary scoping of related literature was required. This initial, preliminary review of the literature provided an opportunity to not only develop and focus the research questions, it also allowed for an examination of the literature to create a picture of the knowledge and the gaps in this particular area. This approach also helped to contextualise the current knowledge base as a *"body of research",* rather than seeing each piece of research individually in isolation (Aveyard, 2010: 6). This preliminary search also proved to be valuable in identifying key terms and phrases that are used by authors and researchers in the field. This then formed the foundation of search terms to be used in the main literature search strategy (See Table 2.1: Key Word/Search Terms). It is therefore important to acknowledge and consider any influence from the preliminary review. To do this, the reflexive diary was used during this early scope of the literature. This then allowed me to draw out and consider the impact of the review alongside my own perceptions and ideas about male caregivers in a more open and transparent way.

Thomas and Hodges (2010) identify four main stages in the literature review process, although note that these can at times overlap. Following on from the steps in the development of the search strategy outlined above by Moule et al. (2017), Thomas and Hodges (2010:3) say that these literature review stages consist of:

- *Developing and refining the topic and scope of the literature to be reviewed*
- *Searching for and retrieving copies of relevant research material*
- *Reading through the studies located and assessing them*
- *Writing a report summarising the key information found*

Thomas and Hodges (2010) go on to acknowledge that the searching, reading and writing stages are frequently repeated for the duration of the study. Parahoo (2014) also suggests a stepped process for reviewing and synthesising the literature around a specific subject. Parahoo's (2014) process offers more detail than Thomas and Hodges (2010) and includes reference to selection, appraisal and synthesis:

- Formulation of the research aim and questions
- Define the outcomes/intervention
- Set the inclusion and exclusion criteria
- Search the evidence
- Select items to be reviewed
- Appraise the evidence
- Synthesise the evidence
- Conclusion (Parahoo, 2014:125)

The detail offered in Parahoo's (2014) approach is helpful for the novice researcher, as it highlights specifically the appraisal and synthesis of the evidence identified. The use of these terms indicates higher order skills in relation to analysis of the evidence, where Thomas and Hodges (2010) specify a rather vague "assessment" of the sources identified. It is important to note, regardless of the process, a review of literature goes beyond a description of the literature surrounding the subject. Rather, it is the deep critical analysis and appraisal of the research process, arguments and propositions made (Aveyard, 2014; Bryman, 2016; Moule et al., 2017; Parahoo, 2014).

2.2 Types of Literature Review

There is said to be some confusion surrounding types of literature review and which best fits the purpose for which it is intended (Noble & Smith, 2018). In 2009 a typology of literature reviews that included 14 different types of review, including Scoping Review, Critical Review, Systematic Review and Mixed Methods Review (Grant & Booth, 2009). Grant and Booth report that although many of the reviews identified did not possess an explicit and prescribed methodology and many could not be used exclusively, they did offer that the typology provides a point of reference for those selecting which type of review best fits the purpose and those who aim to interpret and evaluate reviews (Grant & Booth, 2009). Since 2009, Narrative and Integrative reviews can be added to this list (Noble & Smith, 2018) offering further scope to select the type of review that best meets the needs of the research proposed. Here, three types of literature review: a general conceptual or narrative review systematic review and a integrative review.

2.2.1 Narrative Review

The narrative review usually provides a conceptual overview or narrative around a specific topic or phenomenon (Morris, King, Turner, & Payne, 2015). This type of review is often used as a preliminary search for the development of the research proposal or for thesis or dissertation purposes (Aveyard, 2014; Coughlan, Cronin, & Ryan, 2013). The narrative review provides the landscape associated with a subject and includes a broader range of literature including the policy and legislative backdrop, experiential narratives and discussion papers, as well as primary research studies. Due to the breadth of sources, a narrative review does not always present the method by which the sources were selected, which limits the reproduction of the search (Noble & Smith, 2018). This wider review does not attempt to combine or amalgamate data which requires a significant level of comparability in the studies, rather it aims to synthesise data through interpretation. Usually presented in a user-friendly format, this type of review aims to present a broad perspective on a subject, and its development (Noble & Smith, 2018). Hence a narrative review is more aligned to qualitative studies (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005). Dixon-Woods, et al. (2005) go on to posit that a narrative review can integrate evidence from both qualitative and quantitative research and other diverse forms of evidence alongside each other, but note the risk of this less formal approach may be open to criticism due to the lack of transparency.

The narrative review offers this study a valuable approach for consideration. It best fits this research in the main, due to the challenge of establishing a shared view of the phenomenon: male caregiving experience, and the related concepts. The lack of research specifically relating to men caring for a partner with Alzheimer's dementia limits opportunity for comparability across studies. The broad ranging related concepts for example, health, caregiver burden, isolation and partner relationships are inter-connected with male caregivers caring for partners with dementia and their decision to access support and services. It is due to this that a narrative review approach would be considered suitable. The narrative review also provides the opportunity to include wider related literature that may be missed if a more restrictive and prescribed approach was taken (Aveyard, 2014).

2.2.2 Systematic Literature Review

A systematic literature review aims to provide a structured, planned and repeatable search and synthesis of related research surrounding a specific topic. Systematic reviews and specifically those which are focused on Randomised Controlled Trials (RCTs) are seen as the pinnacle of the hierarchy of evidence (Moule et al., 2017). This type of review includes the selection of comparable research studies through the assessment of the quality of the research methodology in relation to the particular criteria. For example, research design, population and type of intervention or outcomes. Systematic reviews usually follow a set framework or guidelines on which to conduct the review (Grant & Booth, 2009). Often used for quantitative research, systematic literature reviews tend to focus on RCTs or experimental studies, where statistical data can be reviewed and synthesised (Thomas & Hodges, 2010). A systematic review provides clearly articulated and repeatable approach to show what is known about a subject and what remains unknown (Grant & Booth, 2009).

A meta-analysis, although shown by Grant and Booth (2009) as a separate type of review, is when a systematic literature review gathers related data, usually numerical, from smaller studies and re-analyses the data in order to provide more precise results and presents this as if in a larger study. Systematic reviews including the meta-analysis are significant in health and social care as they allow the researcher to establish patterns, make links and identify outcomes that may not be identified in single, isolated studies (Aveyard, 2014). In relation to health particularly, findings from these types of reviews impact on the evidence (or lack of) for treatment and interventions and can directly influence practice. In principle, the systematic literature review should be comprehensive, rigorous and transparent, otherwise the conclusions drawn may not be reliable (Aveyard, 2014; Bryman, 2016; Moule et al., 2017).

A systematic review, although regarded as the highest in relation to the hierarchy of evidence, is not a good fit for this study which sets out to examine the personal meaning and perceptions of individuals. The related published literature is most likely to be quantitative and focusing on specific perceptions of individuals. Added to this, there is limited sources that focus on male partners who are caregivers, further limiting the value in selecting this approach to reviewing the literature. However, the systematic approach for example, the detail and clarity of terms, the well-articulated inclusion and exclusion criteria and the defined critical evaluation of the research undertaken in the studies identified, would be valuable in the initial exploration of the research findings available and could form a valuable account of what is known about the topic and clearly identify gaps in the knowledge.

2.2.3 Integrative literature review

An integrative literature review, like the systematic literature review, offers a systematic approach to reviewing the available literature surrounding a given topic. This approach uses a non-experimental design and detailed search strategy to identify sources that relate to answering usually specific targeted clinical questions (Noble & Smith, 2018). Different from the systematic literature review, the integrative review can include RCTs, observational studies, qualitative research, clinical experts and any other relevant evidence, the evaluation of which forms a systematic categorisation and thematic analysis of the studies included. The integrative review is set around six steps, which include; preparing the question, searching the literature, data collection, critical analysis, discussion and presentation of the review (Souza, Silva, & Carvalho, 2010).

The integrative literature has become valued particularly in health care research, as it offers a unique tool for the synthesis of research available on the given topic and which can be used to guide practice based on clear evidence and scientific knowledge (Souza et al., 2010). Souza et al. (2010) advocates the use of integrative reviews, particularly for health professionals for example nurses, due to its value in promoting evidence-based practice to inform health care and related policies, protocols and procedures.

The integrative literature review would be a valuable approach for this study, due to its inclusion of a broad base of literature. The clear steps and well-articulated search approach would enhance the trustworthiness and transparency of the approach. However, the review of the literature for this study does not set out to provide generalisable findings to develop protocols or procedures. The intension is to identify both what is known about the experience of male caregivers caring for a partner with Alzheimer's dementia and identify any the gaps in what is known.

2.2.4 Literature review for this study

A thematic narrative literature review has been selected for this study. This is due to both the purposes and focus of the research. Given the aim of the research, there is clear benefit to the inclusion of "grey literature", which includes broader literature, for example government reports, local and national policies and discussion papers (Bryman, 2016), sources that are not usually included in systematic literature reviews. For example, it is important to capture the concept of family caregivers and caring in relation to dementia as understood by policy makers and service providers. The inclusion of personal narratives, case studies and reflective accounts relating to male family caregivers of people with dementia, will add to detail and depth of understanding of the range of perspectives available in the literature. The policy and legislative backdrop is also important to include in the review of literature, as the emergence of caregiver recognition in the early 2000's and related priorities will help to provide context to this study. These valuable sources would be omitted if a systematic literature review approach was undertaken.

Regardless of the type of literature review adopted, the demonstration of a methodical, systematic approach is considered essential, as it allows the researcher to clearly show the way that the sources of evidence examined in the review have been selected, based on clear criteria (Aveyard, 2014). Thus minimising selection bias (Coughlan et al., 2013), where selections are made based on the view or preconceptions of the researcher. This is a risk for this study, as the data collection and interpretation take place before the literature review. There are many protocols published to support the transparent and systematic approach to a literature review to minimise bias (Lovink, Persoon, van Vught, Koopmans, Schoonhoven & Laurant, 2015; Shamseer, Moher, Clarke, Ghersi, Liberati, Petticrew, Shekelle, Stewart, Altman, Booth, Chan, Chang, Clifford, Dickersin, Egger, Gøtzsche, Grimshaw, Groves, Helfand, Higgins, Lasserson, Lau, Lohr, McGowan, Mulrow, Norton,Page, Sampson, Schünemann, Simera, Summerskill, Tetzlaff, Trikalinos, Tovey, Turner, & Whitlock, 2015), but these mainly focus on reviews of quantitative literature. In recent years, there has been a rapid growth in qualitative systematic reviews, particularly in health and nursing research (Kable, Pich, & Maslin-Prothero, 2012). This increase has highlighted a lack of literature review protocols specifically to guide qualitative researchers in ensuring trustworthy, high quality reviews that minimise selection bias and facilitate transparency (Butler, Hall, & Copnell, 2016). However, Moher, Tetzlaff, Tricco, Sampson, and Altman (2007) report that most completed systematic reviews (89%), do not mention a review protocol, which in their view calls into question the results.

2.3 Critical Appraisal

When evaluating literature, critical appraisal of the type of review used and the way that the literature review was carried out is now commonplace. This is due to the introduction of tools and guidance around systematic literature review approaches. For example, Critical Appraisal Skills Programme (CASP) (CASP, 2018). Coughlan et al. (2013) assert that one of the first steps in critical appraisal of research is the evaluation of the literature review undertaken. They propose that there should be congruence between the type of review that the author said they were going to undertake and what they actually did.

There is a range of critical appraisal guides and tools developed to support reviewers (Moule et al., 2017), with many offering a generalised tool in the form of a set of questions that can be asked of any research, regardless of design. In essence these include a list of questions that encourage a “yes” or “no” answer, the more “yes” responses indicate a higher quality (Polit & Beck, 2012). However, the development of specific critical appraisal tools by CASP, offers reviewers templates and guidance relating to evaluating the quality of specific research. These include primary qualitative, quantitative and mixed methods research as well as literature reviews and RCT. The templates provided and the prompt questions included, are set to encourage close examination of the literature and the evaluation of the overall quality of the research, based on the measures related to the type of research being reviewed. Given the review of literature for this study includes a broad range of literature the CASP tools were selected as were particularly valuable. The CASP tools for qualitative studies, literature reviews and randomised control trials generate a score that indicates quality and is helpful in the appraisal process, while the tools for mixed methods studies and quantitative research generate yes/no answers which then are more challenging to synthesise alongside the scoring system.

2.4 Search Strategy

The literature review begins with the search strategy (Parahoo, 2014). The search strategy should be aligned to the research questions and the aim of the study to clearly articulate the core concepts and phenomenon related to the study. A review of the literature is not only to explore and better understand the topic, but also when used for research purposes, to ensure that the same research has not already been undertaken (Parahoo, 2014) and therefore to avoid duplication. The search strategy adopted for this study was to ensure that the most closely related and relevant sources of evidence surrounding the topic being explored were identified. The approach taken was based on the stages identified by Moule et al. (2017:41):

- Confirming the research topic or question
- Identifying which literature to include
- Identifying inclusion and exclusion criteria
- Identifying key terms
- Performing a search
- Revising the search, as necessary, and replicating it in other sources.

2.4.1 Confirming the research topic or question

A preliminary scoping review of the literature was undertaken at the proposal development stage of the study. This search was conducted to ensure that there was both a need for the research and to refine the scope of the study. The outcomes of this review indicated a gap in knowledge around male caregivers' perspectives and limited research around male caregiver decisions concerning accessing support services. This preliminary search helped to refine the research aim and questions, as well as to reinforce and better align the research approach.

The initial analysis of the literature provided an opportunity to not only develop and focus the research question, it also allowed for an examination of the literature to create a picture of the research in this area (Aveyard, 2010). The process undertaken in this preliminary review of the literature was systematic and structured to ensure that the body of research included relevant research was explored. This does however create some tensions with the IPA process and the intension that the literature review is carried out after the analysis is complete, to minimise bias and pre-judgement that may come from reading. It was, therefore, essential to be aware of how this initial review of the literature and the findings from it, integrated with my beliefs and understanding of the experience of male caregivers. It also increased the importance of early engagement with reflexivity as discussed in Chapter 6.

Search terms used to identify relevant literature for the preliminary scoping review, were relatively broad in relation to the caring terms used were a combination of “carer”, “caregiver” and “family carer”. To search specifically around the relationship to the cared for: “spouse” and “adult child” were also included. Terms used to search the literature in relation to decision making were “decision making models”, “decision-making theory”. For the literature relating to the condition: “dementia”. The preliminary scoping review used the following databases: AMED, CINHAL, MEDLINE and PsycINFO.

The results were limited in that they included unrelated sources through the use of the term “carer” and few were related directly to the area of study. This was valuable as it helped to shape the aim and focus of the study proposal. It was also valuable as it allowed for consideration of search terms and led to some wider perspectives which helped to tease out some related findings. The literature identified through the initial search were, in the main, focussed around six core themes linked to caring for someone with dementia:

- The impact and experience of caring
- Caregivers needs

- Barriers to accessing support and respite services
- Uptake of respite services
- Decision making processes
- Relationships (adult child/spouse/partner) to the cared for
- Mental health and well-being of the caregivers

As mentioned, studies using IPA tend not complete a review of the literature until after the analysis stage of the research (Smith et al., 2009), however, this preliminary scoping review was helpful and informed the development and refinement of the research proposal.

The clear articulation of the aim of the review of literature is the first step in the process (Butler et al., 2016). The aim of this narrative review is to synthesise the best available evidence that explores the experiences and perceptions of male family caregivers of a partner with Alzheimer's dementia and their decisions to access support services.

2.4.2 Identifying which literature to include

The main way of searching the literature is through computer-based search technology. The databases used in the primary search for this study were Cumulative Index of Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval System Online (MEDLINE) and PsycINFO, as these databases were most closely related to the disciplines; nursing, social care and psychology that would be interested in exploring the core topics linked to the study: caregivers, decision making, and Alzheimer's dementia. The way in which the literature was identified is detailed in Table 1: Key Work/Search Terms.

2.4.3 Identifying key terms

The key word approach provides opportunities for the user to search a broad range of subject specific literature sources, while incorporating a variety of terms and phases. The use of key word "strings" for example: Carer and Alzheimer's, along with and/or options known as "Boolean logic" (carer or caregiver or family) and (Alzheimer's or Dementia or memory loss), can significantly increase the range of highly related literature identified (Thomas & Hodges, 2010).

The search terms used for this study were identified through the words and language used in the research aim and the research question. These were then refined by reviewing the terms used in sources identified in the preliminary literature search and the examination of the minor and major subject terms identified by the authors. An account of the Key Word / Search Terms used and the rationale for their use are detailed in Table 2.1.

Table 2. 1: Key Word/ Search Terms

Key Word / Search Terms for Literature Review			
Core Concept	Key Words	Rationale	Relevance to Study
Male Carer	(MM "Caregiver Burden") OR (MM "Caregivers") OR (MM "Caregiver Support") OR (MM "Caregiver Strain Index") OR "caregiver*" or "carer*" or "spouse*" or "spousal*" or "partner*"	Preliminary search for male carers offered no results. Preliminary search showed a difference in language depending on author/publication source. US term “caregiver” did not come through in the search when “carer” term was used on its own. “Burden”, “strain” and “support” were used widely and noted in the database indexing system.	Indicated a potential gap in the literature. Male carer perspectives not explored. “or” selected to capture sources that focussed on carers generally as well as spousal carers and those that focus on carer burden and support.

Alzheimer’s Disease	(MM "Alzheimer's Disease")	The inclusion of the range of conditions that come under dementia would explode the results beyond the scope of the researcher.	The focus was to ensure the homogeneity of the group in line with the methodological approach. Limitation to this type of dementia increased the similarity of duration and likelihood of caring role.
Decision Making	(MM "Decision Making") OR (MM "Decision Making, Clinical") OR (MM "Decision Making, Ethical") OR (MM "Decision Making, Family")	Preliminary literature search and subject key words within the database results showed the use of “clinical”, “ethical” and “family” as frequent terms used alongside “decision making”.	In line with the research questions the process of decision making within clinical settings or out with to explode the possible results ensured that the scope of decision making was maximised before combining with the other terms.

An example of the search using these terms within the MEDLINE database is available in Appendix 1, in order to better demonstrate the approach adopted, the design of the search and links to the inclusion and exclusion criteria and for replication.

2.4.4 Identifying inclusion and exclusion criteria

Inclusion and exclusion criteria were established to ensure the sources selected for review were clearly aligned to the research aim and questions and avoided review of unrelated sources (Aveyard, 2014). The inclusion and exclusion criteria for the literature review are detailed in Table 2.2.

Table 2. 2: Inclusion and Exclusion Criteria

Literature Search Inclusion and Exclusion Criteria	
Inclusion	**Rationale**
Primary Research (Qualitative, Qualitative and mixed methods)	To broaden out sources and to capture related findings where mixed methods were used
Literature Reviews	To capture previous synthesis of related sources
Carer/caregiver policy and related legislation	To examine the key drivers and legislative backdrop to caring
Published >1990	To capture relevant accessible sources and some seminal research and policy
Full text available	To evaluate trustworthiness of the research process and findings
Carer/caregiver of people with Alzheimer’s dementia perspective	Link to research focus and questions
Carer/Caregiver of people with Alzheimer’s dementia and decision making	Link to research focus and questions
Spouse as carer	Link to research focus and questions
Written in English	Accessibility and time/cost of translation
Exclusion	**Rationale**
Articles not available in English language	Accessibility/time available for translation
Other family not spouse	Link to research focus and questions to maximise homogeneity of participants.

No full text available	Unable to evaluate and examine trustworthiness of research process
Professional carer/caregiver (paid)	Unrelated to research question.
Published <1990	Unlikely to have research related to this prior to the late 1990's
Service user perspective only	Not linked to caregiver focus

Decisions on what to include and exclude in the search strategy is described as a *"vital step"* (Aveyard, 2014:42) in the literature review process. This is in part due to the vast amount of literature available, as well as the overall growth in health research due to the increased focus on evidence-based practice. The growth of available literature and the varying degrees of quality has increased the need for a clear and focused approach for reviews and aligned inclusion and exclusion criteria for selection (Moule et al., 2017). Setting the criteria facilitated and enhanced the literature search process adopted for this study and helped to focus and capture the related literature available. The process of establishing the criteria also supported the researcher in examining and defending her own view of the literature, interpretation of key terms and scoping broader literature sources. For example, clear articulation of the range of terms and words used helps to defend the depth of the search.

2.4.5 Performing a search

Once the inclusion and exclusion criteria and key terms were established, an electronic search was performed. This search can be then replicated in a number of different search engines and databases, thus ensuring that the best attempt possible to identify and locate relevant sources (Moule et al., 2017). The search using this process produced a focused range of well related sources that was manageable in relation to number of sources.

2.4.6 Revising the search

The initial search resulted in a moderate number of related sources. Revising and refining the literature search, if the number of sources is overwhelming, can be accomplished using limits in relation to date of publication, type of literature and review of the terms used (Coughlan et al., 2013). However, this was not required for this search, as the parameters set around the search were clearly articulated via the inclusion and exclusion criteria for the search and a clear rationale can be provided to support each element of the criteria.

Language difference is significant in relation to terms and key words. For example, the term “carer” is widely used in the UK, while “caregiver” is used in the United States (US). Not including “caregiver” would significantly reduce the scope of identified literature and limit the literature review and potentially the study.

Publishers now encourage authors to set out the related key terms into both major and minor subject terms prior to publication. These are then used to ensure that related sources can be discoverable. This helped to develop the list of search terms and aided the search via databases. Using the subject terms, which can differ between databases due to the different target professions and subject, can avoid sources being missed.

Once the specific, focused database search was completed, further screening stages were followed in line with Butler et al. (2016), who describe a number of stages from the initial title and abstract screening to full text review, all based on the inclusion and exclusion criteria. Further measures were followed to ensure there has been a robust and appropriate search for related sources. This included an examination of the reference lists of identified articles that can be used to locate further sources. Consideration of other or similar key terms can be noted, as can specialist authors who regularly publish on the topic. In addition to this, specific journals related to dementia, for example Dementia, The Journal of Dementia Care and those related to gerontology Gerontologist and the Journal of Applied Gerontology, which were targeted to locate further relevant literature that met the inclusion and exclusion criteria.

Research related to caregivers is not limited to health and psychology. Other disciplines, for example social care and education may also have an interest in male caregivers; for example, in relation to gender, work, and wider socioeconomic aspects. To ensure no key sources were missed, the “related article” pop up options within search engines were used along with the aforementioned reference list review. This snowballing approach towards exploring the literature helped to broaden out the sources identified as relevant to gaining a view of the knowledge surrounding male caregivers of spouses with Alzheimer's dementia. Some well related sources did not result from the original database search for example, Brodaty, Mittelman, Gibson, Seeher and Burns (2009), Mittelman, Ferris, Steinberg, Shulman, Mackell, Ambinder and Cohen (1993) and Russell (2006), so this approach was of value.

2.4.7 Critical Appraisal of Identified Literature

The aim of critical appraisal in a literature review is to assess rigor and evaluate any methodological issues that may impact on the quality of the findings (Butler et al., 2016). However, Butler et al.(2016) state that although traditional qualitative literature offer direction for what would be considered as rigor in qualitative research, including Holloway and Wheeler (2010), and Polit and Beck (2012), few have resulted in the development of usable appraisal tools. The contention and lack of consensus regarding what makes a good qualitative study have been problematic in relation to literature reviews. It is due to this that the critique and evaluation of qualitative research has been scrutinised for many years (Elliott, Fischer, & Rennie, 1999; Kable et al., 2012). There have been frequent assertions relating to the inflexibility of processes and perceived usefulness of procedures and frameworks used to critically evaluate qualitative research methodology (Levitt, Motulsky, Wertz, Morrow, & Ponterotto, 2016; Northcote, 2012). Levitt et al. (2016:2) report on the findings of a task force and propose the concept of *“Methodological Integrity”* within which are two related aspects: fidelity and utility. The notion of fidelity relates to the closeness and connection to the subject/topic being explored and how this is maintained throughout the research process while utility relates to the procedures and processes chosen and undertaken to achieve the research goal/s. Levitt et al. (2016) go on to propose a framework that can be used to assess the methodological integrity in relation to fidelity and utility of qualitative research. This is encouraging and a move away from using standardised processes to evaluate rigor to using a framework to evaluate trustworthiness (Northcote, 2012).

Regardless of the debate and discussion surrounding quality measurement in qualitative research, the published evidence surrounding the topic to be explored needs to be critiqued and sysnthesised. As with all stages of the research process, this needs to be systematic and transparent. For this study, the referencing management system Mendeley© was used, which offers additional features including allocation of folders for specified literature, notes page and comment and highlight functions that allow for notation directly on the document (Mendeley, 2020). These functions allowed for critical review of the papers included in the literature review which then was transferred into a table for clear reference and documentation of the critical appraisal process.

Butler et al. (2016) encourages the researcher to adopt a clear protocol that outlines the critical appraisal process and recommends that it should include the following:

- Which appraisal tool to be used and why
- The adoption of a clear scoring system relating to the quality of the study
- How the results will be used

For the purposes of this review, the CASP (2018), ten question qualitative checklist will be used as the appraisal tool due to its wide use in health and social care research and its clarity and ease of use. CASP is internationally recognised as a valuable tool for appraising both qualitative and quantitative literature (Kable et al., 2012). CASP will be used alongside the simple scoring system identified by Butler et al. (2016):

Scoring system for each question:

- Yes: 1 point
- Unsure: 0.5 points
- No: 0 points

A review should not summarise the literature, it should be *“a critical synthesis of the literature”* to inform or make recommendations for future research (Kable et al., 2012: 879). Presented in table form, the summary and appraisal of the identified literature, along with the scoring will clearly demonstrate the transparent appraisal process, while helping to avoid writing a summary of the literature (Kable et al., 2012). The summary of the literature reviewed is in Table 2.3, examples of the CASP scoring results can be found in Appendix 2.

2.5 Review of literature

Research evidence surrounding caregivers of people with dementia experience includes studies from the UK, Denmark, Belgium, Germany, South Africa, Netherlands, USA, Canada, Spain, Brazil, Singapore, Hong Kong and Australia demonstrating global interest in the topic. Although there has been research surrounding informal caregivers and their experience of caring since the 1990’s, perhaps due to the first mention of the significance of family caregivers in the policy rhetoric (Department of Health, 1999), there are limitations to these sources in relation to considering the male perspective (Mc Donnell & Ryan, 2011; Robinson, Bottorff, Pesut, Oliffe, & Tomlinson, 2014; Shanks-McElroy & Strobino, 2001).

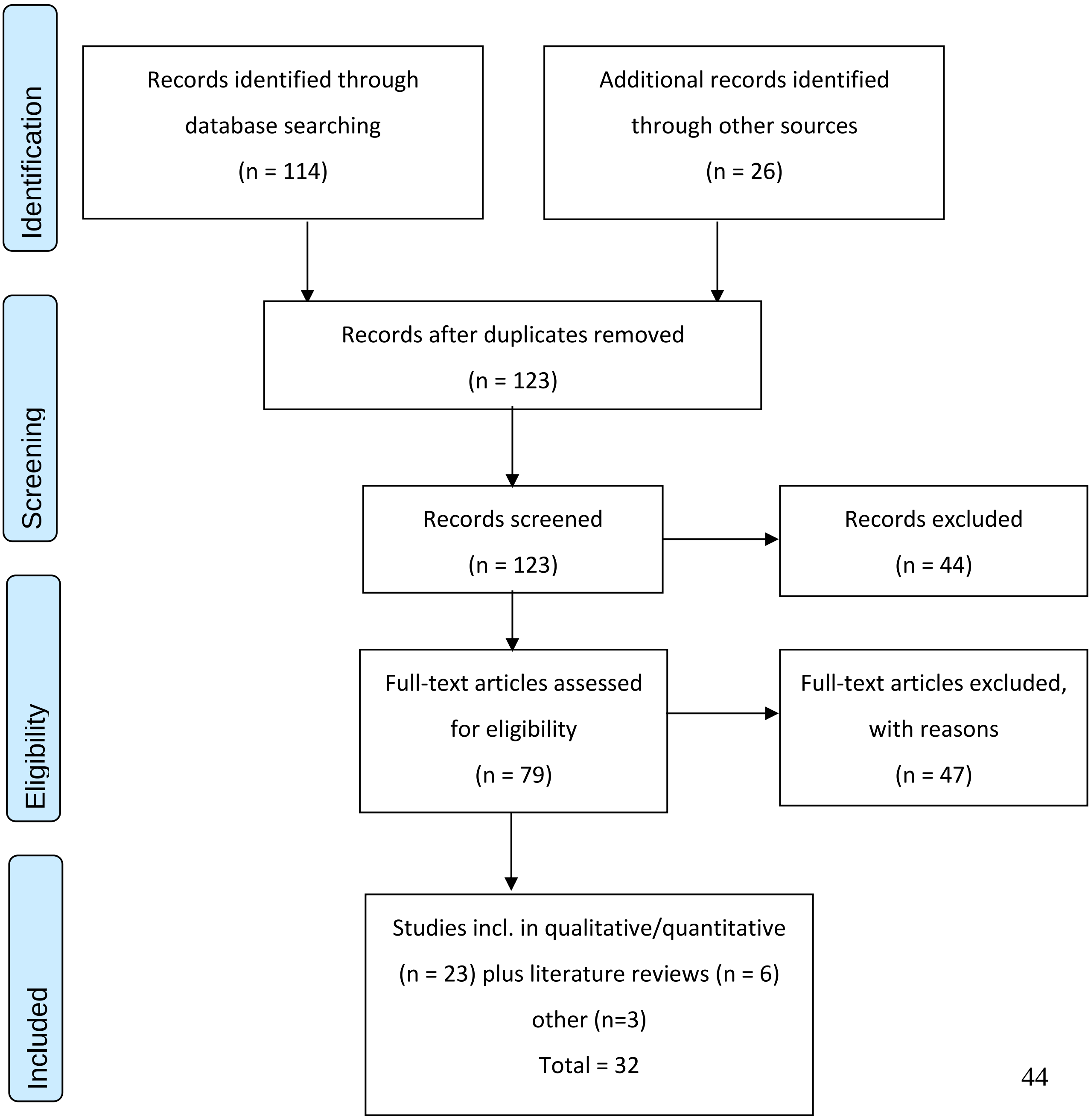
2.5.1 Identification of literature

This initial database search identified 114 sources with only a few studies directly related to male caregivers and their experience of deciding on accessing support. Further sources were identified through the snowballing approach described earlier and through wider reading. The lack of specific research around this topic encouraged a broadening out of the search to capture dementia caregiver experience more generally. The search is detailed in PRISMA (Moher, Liberati, Tetziaff, Altman, & The PRISAM Group, 2009) diagram Figure 2.1. This diagram maps the number of sources identified, included and excluded.

The literature search identified 32 articles that focused on the caregivers of people with dementia that met the inclusion criteria. The sources identified showed a varied approach to exploring this topic. Twenty-three of the articles identified were presenting findings from primary research studies. Two of these used secondary analysis of data gathered from previous studies (McLennon, Habermann & Davis, 2010; Shanks-McElroy & Strobino, 2001) and one, Karlin, Bell and Noah (2001) who carried out a follow up phenomenological study from a previous qualitative study to refocus specifically on male caregivers. There were 15 qualitative studies and 6 quantitative studies and 2 that used mixed methods (Karlawish et al., 2003; Stirling et al., 2010). The remaining sources included six literature reviews (Etters Goodall, & Harrison, 2008; Farina, Page, Daley, Brown, Bowling, Basset, Livingston, Knapp, Murray, &

Banerjee, 2017; Mc Donnell & Ryan, 2011; Robinson et al., 2014; Schoenmakers Buntinx & DeLepeleire., 2010; Yu, Cheng & Wang, 2018) and three discussion papers (Brodaty & Donkin, 2009; Brodie & Gadling-Cole, 2004; De Vugt & Verhey, 2013). Each included as they offer some perspectives of the knowledge around the core concepts related to caregiving and dementia. Review of policy and legislation including Carers UK (2011); Scottish Government (2017); Scottish Government (2010); UK Government (2019) and WHO (2012, 2015, & 2017) have also informed this review. This range of sources are in line with a narrative review, in that they draw from a range of sources that illuminate what is known about the topic (Dixon-Woods et al., 2005).

Figure 2. 1: PRISMA Diagram



Much of the primary research literature surrounding caring focused on the impact of caring on caregivers, the likelihood of caregiver burden, and the subsequent uptake of residential or nursing home care (Arcain Nass, Ferraz Teston, Emilia Peruzzo, Luiz Mincoff, & Silva Marcon, 2016; Bruce & Paterson, 2000; Hirschman, Kapo, & Karlawish, 2006; Karlin et al., 2001; McLennon et al., 2010; Mittelman et al., 1993; Picco, Subramaniam, Prince, Jeyagurunathan, Sambasivam, Chong, Chua, Zhang, Ng, Abdin & Vaingankar, 2015; Russell, 2006; Schoenmakers et al., 2010; Stirling et al., 2010). This perhaps indicates the potential economic value of well supported, able caregivers, given the demand on services if family caregiving stops. For example, the increase in care at home services and nursing home provision. The earlier publications identified between the early 1990's and the mid 2000's, coincide with key caregiver acknowledgement in policy, particularly in the UK, where caregivers were first mentioned (DOH, 1999; Scottish Executive, 2002) indicating the point at which caregiving became of interest to both policy makers, practitioners and researchers.

Primary research related to caring frequently focuses on specific conditions like dementia, but with only a few (Black, Schwartz, Caruso & Hannum, 2008; Harris, 1993; Pretorius, Walker & Heyns, 2009; Sanders & Power, 2009 and Shanks-McElroy & Strobino, 2001) offering perspectives of male partner (relationship-specific) caregiver experiences. From these, only Harris (1993) specifically focusses on men caring for a partner with Alzheimer's dementia. This suggests a lack of current and specific research in this area, with a gap in years since the male experience has been examined, indicating limitations to the current knowledge relating to this population.

The broader literature tended to report on caregivers generally, drawing together experiences from male and female, partner, adult children caring for a parent or grandparent, son and daughter-in-law caregivers and siblings (Cheng, Lam, Kwok, Ng & Fung, 2013; de Labra, Millán-Calenti, Buján, Núñez-Naveira, Jensen, Peersen, Mojs, Samborski & Maseda, 2015; Karlin et al., 2001; Meichsner & Wilz, 2018; Picco et al., 2015; Stirling et al., 2010). This generalised, homogenous approach reveals researcher's assumption that all caregivers, regardless of the relationship between the caregiver and the cared for, will have a common or shared role and experience. A more nuanced and specific perspective would present opportunities to better support individual caregivers in their specific context.

It is acknowledged, that a significant percentage of caregivers are partners and around 40% of partner caregivers of older people are male (Bruce & Paterson, 2000; Mc Donnell & Ryan, 2011; Robinson et al., 2014). Bearing in mind, due to the ageing demographic touched on in Chapter 1, the longevity gap between men and women is predicted to continue to reduce, resulting in an increase in the numbers of older men taking on caring roles at home. This challenges the stereotypical view of caregivers being predominantly female (Neufeld & Kushner, 2009; Russell, 2006) and may generate more attention being paid to men's experience of caregiving.

Changes in relation to the number of men who provide care and the context of caregiving due to advancement in knowledge and awareness of Alzheimer's dementia, has led to the development of global and national policies and strategies. These documents aim to improve the experience of people with Alzheimer's dementia and their caregivers. If the strategic aims, like early interventions and improved access to support and services (Scottish Government, 2017; WHO, 2018), are to be actualised then enhanced understanding of the factors that encourage and inhibit specific caregiver groups like men caring for a partner with Alzheimer's dementia, to access services is needed.

2.6 Critical Review

The review of the literature is presented in Table 2.3 Summary of Reviewed Studies. Through the critical evaluation of the sources, five key themes relating to caregivers of partners with dementia emerged:

- Assessment of need and identification of risk
- Positive aspects of caregiving
- Targeted interventions
- Role relationships and identity
- Caregiver health and well-being

This review of the literature will be presented in relation to these five themes.

Table 2. 3: Summary of Reviewed Studies

#	Author (year), Title Country	Study Design	Sample size and sites	Key findings	Value and contribution	Limitations
1	Arcain Nass, et al. (2016) “The Institutionalization of the Elderly With Alzheimer As a Difficulty of Consequence in the Treatment of the Elderly.” Brazil	Qualitative: Exploratory and descriptive study Aim: to gain an understanding of the experience of handing care over. Purposeful sample SSI, recorded and transcribed. Content analysis using a thematic mode (three steps outlined) Ethical approval sought	6 family members of elderly residents in a long-term care setting Interviews held in the care facility when the family member was visiting	Gives an account of those behaviours that contributed to the decision to move to a care facility: risk, safety, family fear, aggression. A sense of being overwhelmed led to decisions about long term care Use of direct quotes to demonstrate analysis process	Loss of being part of the persons life, the loss of history "perception that family with AD is physically present but mentally absent"	All female participants, one wife Lack of reflexivity and no acknowledgements of the limitation of the sample and being interviewed in the care environment may limit/inhibit responses
2	Black, et al. (2008) “How Personal Control Mediates Suffering: Elderly Husbands’ Narratives of Caregiving” USA	Qualitative: Phenomenological case study approach Aim: To explore the experience suffering in men (older age) caring for a spouse Four narrative accounts of men caring for wife with dementia	4 older men caring for a partner, identified from a previous study (n=120) 60 of whom were men Each man was interviewed in their own home	Main findings related to the strategies men adopted to mitigate the suffering experiences and related to 4 strategies: power of the “little” aspects, preservation of self, identity and	Value in exploring the experience of the older old age group as this is a gap in the literature. Relationship between older men sense of power and masculinity	Clarity needed on how the themes emerged from the narrative as they seem to be linked to the “themed” approach to the three interviews. Detail of how the themes of the three

		Data gathered by ethnographic open-ended interviews and informal conversations (X3 each themed) Recorded, transcribed and analysed with field notes Ethical approval sought		relationship, finding purpose Data analysis was discussed in weekly meetings and clearly outlined. No reference to researcher influence		interviews were decided. Context of suffering assumes there is some – and could lead to bias
3	Brodaty & Donkin (2009) “Family caregivers of people with dementia” Australia	Discussion paper where the background to caring is given in the context of ageing and dementia and from the perspectives of developed and developing countries, families	N/A	Links to the need for partnership approaches to meet the needs of the person with dementia and targeted interventions for caregivers	Theories of caregiving are presented in relation to strain and CB that focus on adaptation, “wear and tear” and NHP. Recognition that NHP removes caregivers from cross-sectional research relating to caregivers	N/A
4	Brodie & Gadling-Cole (2004) “The Use of Family Decision Meetings When Addressing Caregiver Stress The Use of Family Decision Meetings When Addressing Caregiver Stress.”	Discussion paper exploring the literature around decision making	N/A	There is value for both the individual, caregiver and service providers when decisions about care are made jointly. Highlights the reluctance of some caregivers to seek out and take up support particularly	Advocates a shift from professional centred to family centred models Role theory - male family role, adoption of new roles, difficulties in performing roles or role ambiguity can lead to distress	Family Decision Making originate from child services and would require adaptation for the use with families of adults with AD

	USA			by caregivers of people with AD		
5	Bronner, et al. (2016) “Which medical and social decision topics are important after early diagnosis of Alzheimer ’ s Disease from the perspectives of people with Alzheimer ’s Disease, spouses and professionals?” UK	Qualitative study Aim: to explore medical and social decision topics that emerge after early diagnosis of Alzheimer’s disease. Purposeful sampling criteria briefly outlined Participant detail clear SSI recorded and transcribed. Content analysis of data Coding and themes discussed between two researchers Ethical approval unclear	Included people with AD (5), their family carers (6) and health care staff (14) Interviews conducted by physician in the memory clinic	Spouses set out to provide care to the end - without knowing the AD progression and impact Spousal caregiver want to carry on as normal Early diagnosis opportunity to encourage engagement with services Spouse main person to initiate contact health and social care and main person providing support Analysis presented and discussed at a workshop	Professionals anticipate need rather than working in a person/family orientated way Recommends the development of a specific decision-making tool for people with AD to aid involvement in decision making post diagnosis so caregiver feel more comfortable with making decisions that are not solely their responsibility	No discussion of researcher influence – being a physician within the memory centre interviewing the participants could impact on the responses. As a Memory treatment service the findings support their purpose –diagnosis and engagement with services
6	Bruce & Paterson (2000) “Barriers to community support for the dementia carer: A qualitative study.”	Qualitative study Aim: To understand how caregivers access to community support and potential barriers Semi structured interviews using open	24 caregivers 40% were male Interviews in participants own home	Timing of support and the quality and accessibility of support services is a key element to preserving carer health and wellbeing	Recommends early recognition of carer stress and burden to help accessing support. GP knowledge and recognition of levels	Lack of detail as to how major themes were identified. Three participants did not want to be recorded so field notes taken – could

	Australia	ended questions to gather data, GHQ30 and Family Burden Interview standardised tools Thematically analysed, content analysis using QSR. NUD. IST computer package Ethical approval gained		The impact on health through lack of sleep, sadness, depression and guilt. Key role of the GP identified. Transcripts were read by both authors to identify themes	of distress is key to identify those at risk of breakdown	impact on depth of data, recall and interpretation
7	Cheng, et al. (2013) "Self-efficacy is associated with less burden and more gains from behavioral problems of Alzheimer's disease in Hong Kong Chinese caregivers." Hong Kong	Quantitative study Aim: to test if different beliefs about ability to achieve goals - exploring positive and negative appraisal A second wave of a longitudinal study relating to caregiver well-being Confirmatory factor analysis Measures- ZBI, Neuropsychiatric inventory, multi-dimensional Functional Assessment, and depression rating scale & reduced self-efficacy scale Inclusion and exclusion criteria clear Ethical approval gained	Sample n=99 caregivers of people with dementia 35% spouse Interviews in the home or clinic environment	Described the multidimensional structure of caregiver self-efficacy. Efficacy in controlling upsetting thoughts was most important in buffering the effects of dementia related behaviour problems Factors relating to positive aspects of caregiving: Role fulfilment, effective emotional regulation and finding meaning in caring	Recommendations: investment in the psychological interventions related to recognising and addressing negative thoughts could have benefits for caregivers	No explicit focus on male carers as a variance. Adjustment for age required

8	de Labra et al. (2015) “Predictors of caregiving satisfaction in informal caregivers of people with dementia” Spain, Denmark and Poland	Quantitative study Aim: to explore the predictors of caregiver satisfaction Recruited via Alzheimer’s society Inclusion criteria clear and aligned Relative burden using the ZBI, Global Deterioration Scale, Caregiver Competence Scale, Social Support Q and Carer Satisfaction Scale Ethical approval gained	Sample n=101 Those with 6 weeks of primary caring for someone with dementia 30% male	Exploring the positive aspects of caring, highlight the predictors of carer satisfaction Framed around Pearlin’s Stress process model Explores the experience of stress, actual stress and the mediators of stress Caregivers more likely to experience negative outcomes if they feel less satisfied with the caring role	Link to severity of dementia increased the level of satisfaction. Recommends that psychological interventions designed to increase the positive aspects of caring and the condition targeted for those who are not kin and those in the early stages of dementia	Limited focus on male spousal relationship and satisfaction. Lack of clarity around satisfaction of support – perceived by caregiver
9	De Vugt & Verhey (2013) “The impact of early dementia diagnosis and intervention on informal caregivers.” Netherlands	Discussion paper related to the value of early diagnosis and the benefits and potential drawbacks	N/A	Explores stigma and caregivers keenness to keep things normal in the pre-dementia phase. Benefits and risks related to early diagnosis specifically of support in not available	Urgent need for more research into the impact of early diagnosis and availability of tailored interventions, maximise involvement of the cared for and illicit the caregivers strengths before burden	N/A
10	Donnellan, et al. (2015)	Qualitative Study	20 spousal caregivers of	Resilient caregivers were younger and	Value is related to the focus on	Limitations include the sample all

	“What are the factors that facilitate or hinder resilience in older spousal dementia carers?” UK	Aim: To assess whether dementia spousal caregivers can achieve resilience and what assets and resources they draw on. Purposeful recruitment of caregivers from 2 local carer support groups SSI Thematic analysis was completed using a three-stage grounded theory approach. Then conceptualised in relation to the definition of resilience Ethical approval sought	people with dementia (13 female and 7 male) Interviews face to face while attending carer support group	had cared for longer More men than women were resilient Factors that support resilience include continuity, remaining positive, enjoyment in the role, humour and sense of identity Downward comparison to those who are worse off may support self-efficacy. Community based factors incl. connections with others, shared understanding of caregiving. Resilient caregivers take up informal support Reflexivity reported in the data analysis	resilience which is under-researched. Caregivers drew less on the societal aspects that are said to facilitate resilience suggesting a different experience for those who are caring. The identification of those who are resilient and those who are not may allow for interventions related to promoting resilience The multi-dimensional and operates at individual, community and societal levels	being those who use carer support groups therefore may indicate there are elements of resilience in that population, difficult to apply to wider caregiver population Some interviews were very brief which may limit the depth of data gathered
11	Etters, et al. (2008) “Caregiver burden among dementia patient caregivers: A review of the literature.” USA	Literature review with an aim to identify the factors influencing CB for those caring for people with dementia, patient and carer characteristics related to CB. Evidence based	No details of inclusion and exclusion criteria for review Databases: CINAHL, MEDLINE, and Psych Info.	Family support reported as significant in relation to CB – positive support and carer recognition within families supportive	Offers definition of coping and male/female strategies. Recommends specialist nurses to fulfil carer assessment role	No detail of the criteria used to identify literature – key word search in core databases with minimal terms used – carer burden, dementia

		interventions that lessen CB	Search terms used – carer burden, dementia Year range: 1996-2000	in reducing CB while conflict increases CB. Use of assessment tools to identify those at risk can aid nurses. Caregiver and family focused psychoeducation interventions to increase the knowledge of family could lead to reduced CB and fewer early NHP	working within geriatric teams, nurse practitioner role should include the assessment of CB risk and then selected individualised interventions could be implemented	Not specific to male carers Interesting exploration of tools and CB but limited in the systematic approach to exploring the literature with no detail offered. No critical review framework detailed
12	Farina et al. (2017) "Factors associated with the quality of life of family carers of people with dementia: A systematic review." UK	Systematic review Aim: to explore the factors that link to QOL Both qualitative and quantities primary research was included and strategies were adopted: snowballing, and related article searches (lateral) Mixed methods appraisal tool used. Narrative analysis used to describe the findings and themes were identified using inductive approach	41 articles PubMed, PsycINFO, Scopus and WoS Databases used for search. Key word search clearly articulated. PRISMA included	A total of 10 themes were identified: demographics; carer–patient relationship; dementia characteristics; demands of caring; carer health; caregiver emotional well-being; support received; carer independence; carer self-efficacy; and future. links to caregiver health and QOL and its link to the person	Increased QOL for those with purpose and meaning Value of increased opportunity for carers to have independence and time to use for themselves Financial security enhances sense of QOL = lack of security may increase sense of burden Felt need significant but the uptake of	Vast variation in studies and their focus – caregivers in general

		A carer with lived experience of caring for someone with dementia reviewed the themes that emerged		with dementia noted with caution due to the subjectivity and transference of QOL perceptions onto the cared for	services remains low for some Recommends that more research is needed to establish what factors predict QOL and how it can be measured	
13	Harris (1993) “The misunderstood caregiver? a qualitative study of the male caregiver of alzheimer’s disease victims.” USA	Qualitative study Aim: To gain an in-depth insight into the experience of men caring for their wife with AD Purposeful sample of male caregivers recruited through an AD association. SSI with interview guide which was pre-tested with 2 caregivers Transcribed interviews were analysed thematically Ethical approval not mentioned but reference to protocol being followed	15 male caregivers	Findings included: commitment, social isolation, coping, problem-solving, outside activities, accomplishment, need for specialist help and limited expectations of help from children. Generation of a typology of male caregivers: The worker, the labour of love, the sense of duty & at a crossroads	Adds valuable detail around the experience of men The typology offers Recommendations include: Targeted carer programmes delivered by nurses and people with experience of caring along with alternatives for those who do not engage with group support are needed Increased outreach programmes to improve the knowledge of lay people who provide support for family caregivers	There are limitations to the generalisability of the sample due to the use of participants who already access support which may result in some bias. The lack of reflexivity detailed in the article limits the evaluation of quality and researcher influence
14	Hirschman, et al. (2006)	Qualitative study Aim: What standards of decision making	30 caregivers (15 recruited from an AD	Caregivers were in two key groups related to making	Recommendations: early intervention to be aware of	Limitations include the variation in the relationship with

	“Why Doesn ’ t a Family Member of a Person With Advanced Dementia Use a ...” USA	caregivers use when making medical decisions for their relative SSI with family dementia caregivers in a long term facility Purposeful sample inclusion criteria well described Interviews recorded and transcribed and analysed using theoretical saturation Thematic analysis then two others completed coding based on the themes Use of QSR*NUDIST Participants were coded for type of decision making and demographic data applied Ethical considerations and approval not mentioned.	centre and 15 from a long term care centre) Interviews were either face to face in the caregivers home or over the telephone	decisions about treatment: substituted judgement or best interest Little indication that there were differences in the way that specific family members made decisions Fewer than half had engaged with discussions about preferences pre dementia Spousal caregivers are more likely to include the person in the decision 10 random selected transcripts were re-examined with the final codes	decisions prior to reduced capacity Caregivers struggle with considering the person “then” and “now” and their preferences, advanced planning should be about treatment decisions and to identify what is important and valued by the person, offering flexibility for the surrogate to make decisions Non-spousal caregivers need support to have health care decision discussions with their relatives	the cared for between the two groups with 12/15 being spousal in AD clinic population and 1/15 spousal in the long term care group. Assumption about knowledge of the participants, those using the clinic having unique knowledge due to their participating in the clinic, but this not tested Difference between telephone and face to face not noted The offer of only two ways of deciding influence or limit the opportunity for participants to describe alternative strategies
15	Karlawish et al. (2003) “Why Would Caregivers Not Want to Treat Their	Mixed Methods: Cross-sectional survey interviews. Purposeful sample.	102 caregivers of people with AD	Findings show that caregivers are less likely to allow for treatment if the dementia is	Differences in decisions relating to age and ethnicity are worthy of further study	Small number of participants and lack of inclusion of those who have limited knowledge

	Relative ' s Alzheimer ' s Disease ?" USA	Aim: to assess caregiver willingness to allow cared for to commence AD slowing medication Measures: Geriatric Depressive Scale & Screen for CB Caregiver rating of cared for QoL Cared for: (MMSE) & Dementia Severity Rating Scale Interviews explored the medication option benefits and risks and were transcribed and thematically analysed Logistic regression analysis used for statistical data Ethical approval gained		advanced and where functional deficits are present Caregiver mental health influenced decisions particularly where there is depression Inter-researcher reliability checked by sharing initial coding of interview analysis	QoL measure is a key element that caregivers use to decide on treatment options for those they care for Particular value in relation to caregivers being the people who frequently make decision about treatment	and understanding of dementia and treatments limits the generalisability of findings Limited detail on thematic analysis of interviews to meet the quality for qualitative study
16	Karlin, et al. (2001) "Long-term consequences of the Alzheimer's caregiver role: a qualitative analysis." USA	Qualitative phenomenological study, a follow up study from a previous quantitative study Aim: to examine the experience of caregiving by family members with AD Questioning style in line with	51 family carers (from previous (8 years) study with 174 participants) 22 (43%) of the 51 were male	Themes (7): Role issues and role reversal; problems and burden of being a caregiver; support sources and resources; support group issues; protection, nursing home placement, and guilt;	Recommendation: implementation of carer training and intervention programmes, accessibility of support services and value of services, recognising the impact on caregivers	There is a lack of detail in relation so the gender and relationship - 28 caregivers were spousal but no reference to which were men. Lacks analysis of the male spousal perspective specifically

		phenomenological approach undirected and using prompts Data transcribed and thematically analysed. No ethical approval mentioned		research awareness and participation; and additional contributions as a caregiver Extensive use of quote to demonstrate themes		No mention of bias or researcher influence, no reflexivity indicated No detail of recruitment of those identified from original study
17	Mc Donnell & Ryan (2011) “Male caregiving in dementia: A review and commentary” Northern Ireland	Literature review Aim: to address the gap in the literature relating to men as carers of people with dementia. 56 sources explored, number of which were qualitative in nature	Databases: CINAHL;MEDLINE; PsycINFO; Key words: Key words: Well related key words listed. Year range: 1999 - 2010.	Key findings relate to men in caregiving role, sons as carers, support services, gender differences in CB. Identification of unhelpful relationships limiting engagement in services. Reference to different support needs of men practical and problem solving and lack of willingness to take up emotional support. Men have alternative strategies for coping	Recommends avoiding one size fits all approach to support service. Link to crisis being the point when men engage with services. Also longitudinal studies and more depth of diversity – more quantitative studies. Advocates focused examination of interventions to reduce CB and the effectiveness of these	Good clear outline and method for review. Year range may miss some early sources. No critical analysis framework detailed
18	McLennon, et al. (2010) “Deciding to Intritutionalize: Why do family members	Qualitative Study Aim: To identify common themes in those that decided to use long term care facilities for their	inclusion of 11 carers mixed (Parkinson and AD)	Two themes: Anticipating the inevitable and Reaching the limit. Recognition of time between considering	Link to the institutionalisation of the PWD being directly related to the decline and	There are limits to how the experience for caregivers will be the same – the inclusion of memory loss in AD

	cease caregiving at home?” USA	relative with AD or PD and unrelated crisis/events leading to NHP Secondary use of data – content analysis of transcribed interviews Purposeful selected sample – those who withdrew from original study having due to NHP Original study purposeful sample of caregivers accessing a training programme Descriptive thematic analysis Ethical approval for original study		institutionalisation and actual NHP Increased likelihood of dementia carers reaching this point before the those caring for someone with Parkinson’s Caregiver health an indicator for NHP Use of second reviewer verification in data analysis Use of direct quotes to demonstrate themes	increased demand for care. Also notes the value of transition to care facility Recommendation of tailored targeted interventions Physical and mental health monitoring is required to identify those at risk.	is significantly different. Only 2 PD caregiver, limiting findings Participants had withdrawn from the original study due to NHP – unclear if this was explored in relation to ethical approval to use this data gathered from someone who withdrew. No mention of reflexivity
19	Meichsner & Wilz (2018) “Dementia caregivers ’ coping with pre-death grief : effects of a CBT-based intervention.” Germany	Quantitative: RCT Aim: to examine if a telephone-based CBT intervention and grief module could increase caregiver coping, maintained over 6 months. Intervention: 12 therapy sessions over 6 months. Plus a psychoeducation manual (10 modules)	273 caregivers allocated randomly an intervention (n=139) or control group (n=134). Allocation based on 1:1 allocation and gender	Findings showed that there were small to moderate effects from the intervention on caregivers grief experience and indicates caregivers able to come to terms with their grief more than the control group	Recommendations: Health care professionals should identify if pre-death grief is a factor and significant for the caregiver and intervene Value of telephone CBT intervention due to the flexibility offered to caregivers	Requirement for literacy skills and motivation for CBT engagement and manual completion Screened for acute physical and MH issues – as high proportion of caregivers experience both this may be a

		Control group given general written information on dementia and caregiving and financial compensation Measures: pre-death grief measure. Pre randomisation, following intervention and 6 months post intervention Analysis using latent change model. SSPS Subsequent analysis used variables including caring situation and sociodemographic data Ethical approval sought		Increased pre-death grief was experienced by spousal caregivers when compared to adult child caregivers	who often cannot attend groups due to caring role.	limitation to the intervention Ethical consideration given to those with mental health issues resulting from grief being excluded 32% data missing at 6-month assessment limiting findings
20	Mittelman et al. (1993) “An Intervention That Delays Institutionalization of Alzheimer ’s Disease Patients: Treatment of Spouse-Caregivers.” USA	Quantitative: RCT Longitudinal comparison study Aim: to examine the effectiveness of a caregiver intervention for carers of people with dementia Randomly assigned to an intervention group or a control group. Intervention: individual	206 participants: 120 female and 86 (42%) male Interviewed by researchers in the treatment environment	Findings one year on was to look to see if there was a difference in the two groups in relation to seeking and taking up residential care options. Initial results showed that there is reduced NHP in the intervention group. Results show that	This study offers comparison of likelihood of NHP in the context of the sample population and reports that there were no differences in NHP in relation to variables like gender, income, AD related behaviour and ADL support and age	Although there was random allocation to the treatment and control group there were more female carers in the control group this may have impacted on the findings This was acknowledged and considered in the analysis

		and family psychological support Purposeful sample clearly articulated inclusion and exclusion Tools included: SPES scale, Depression scale, CB scale. Memory and behaviour Checklist, Social network scale among others (initial, 4 & 8 month) Mention of ethical considerations but no mention of approval Informed consent was gained		increased and ongoing emotional and practical support reduces the uptake of NHP. Clear account of the coding variables and the analysis process		
21	Neufeld & Kushner (2009) "Men family caregivers' experience of nonsupportive interactions" Canada	Qualitative: Ethnographic study Aim: Exploration of male caregivers of family members with dementia perceptions of non-supportive and supportive relationships with family and professionals Data gathered from individual interviews, diaries & focus groups	Sample: 34 men, 24 of whom were spouses, paid caregivers (5) and 15 professionals Five additional men who were on the waiting list for the study included in a focus group Choice given for setting for the	Unhelpful interactions resulted in lack of orientation to caregiving, inadequate support and hurtful interactions The range of data was well in line with an ethnographic study and offered a wealth of detail	The ecomap was valuable to consider the relationships and support networks and the importance placed on these by the men. Recommendations focussed around the potential for family and professionals to be more aware of the complex nature of men in caregiver roles and ways to	The use of language shifted from supportive and unsupportive interactions to "helpful and unhelpful" these terms may be perceived as different Significant differences in the relationship between the caregiver

		A men's social network in the form of an ecomap constructed from analysis of first interview data Diary entries over a 2 week period (n=13) were also used. Thematic analysis used throughout Ethical approval gained	individual interview	Advisory committee including male caregivers guided the study Use of direct quotes to demonstrate themes	avoid unintended negative interactions	(partner/son) and cared for and the domestic arrangements – living with/living apart, own home/assisted living limiting the generalisability to population
22	O'Shaughnessy, et al. (2010) "Changes in the couple relationship in dementia care: Spouse carers' experiences." UK	Qualitative study Aim: To explore the experience of caregiving. Recruitment through Alzheimer's Society. Methods SSI with spousal caregivers of people with dementia Analysis: IPA Ethical approval gained	7 (2 male) spouses caring for partner with mid-stage dementia	Findings: 4 themes including connectedness & separateness, Tension between own and spouses needs, knowing and not knowing the future, seeking control First two interviews were pilot interviews and transcripts were shared and discussed Initial themes were shared with participants. Direct quotes used to illuminate themes	Recommendations include the assessment of caregiver need and emotional impact of becoming a spousal caregiver in the context of relationships Caution over "professionalisation" of caregivers will minimise the recognition of tensions between roles	Lack of homogeneity in sample is out with focus for IPA, no linkages to the linguistic and language elements of IPA Researcher reflexivity and influence on research is under described
23	Picco et al. (2015) "Care participation and burden among	Quantitative Study Aim: to establish carer burden for those	693 participants (dyads older person and carer)	Those caring for a person with behavioural and	Recommendations: targeted carer support	The older adult identified the caregiver – this may

	informal caregivers of older adults with care needs and associations with dementia.” Singapore	caring for older family members with care needs Interviewed via cross-sectional national survey Measures: behavioural and psychological symptoms of dementia, Zarit Burden Interview Participants via the national survey of > 60 years: a probability sample was randomly selected using a disproportionate stratified sampling the frame, defined according to ethnicity Ethical approval gained	12 strata defined according to ethnicity (Chinese (38.5%), Malay (30%), Indian (30%),	psychological issues related to dementia expressed higher levels of burden Identification of those who are at higher risk (carers who are married, those caring for people with dementia, older adults with multiple care needs) Increased interventions that alleviate carer burden are required for these groups	programmes specifically for those caring for someone with dementia Identified and for those in high risk groups This study found the CB score lower than other studies and suggests that cultural differences in country may be an explanation	or may not be the main or sole caregiver No exploration of male/female carers Limited examination of spouses
24	Pretorius, et al. (2009) “Sense of coherence amongst male caregivers in dementia: A South African perspective.” South Africa	Qualitative study Aim: to explore carers experience of caring for a wife with dementia Convenience sample Data gathered from transcribed SSI and From the GHQ, Carer Burden Inventory (CBI), Satisfaction with Life Scale (SWLS),	10 white, middleclass males caring for a spouse with dementia Most interviews conducted in participants own home	Qualitative data using the Sense of Coherence model divides into three headings: comprehensibility, manageability and meaningfulness giving a clear structure Men adopted a task and problem	Reports on the value of improved services to maximise free time for spousal carers and the impact on men specifically around caring	Unclear of the value in including the quantitative data Some inconsistencies in the survey scores and narrative accounts not explored

		Sense of Coherence Scale (SOC) and the Fortitude Questionnaire (FORQ) Descriptive analysis of quantitative data was used to explain the qualitative data SSI transcribed and analysed using orientational analysis and coded using NUD*IST programme. Qualitative findings were compared to the quantitative measures. Ethical approval not mentioned, informed consent gained		focussed coping aids resilience and the sense of meaning and achievement Direct quotes used to illuminate analysis. Use of Antonovsky's sense of coherence as a framework		
25	Riedijk et al. (2006) "Caregiver burden, health-related quality of life and coping in dementia caregivers: A comparison of frontotemporal dementia and Alzheimer's disease." Netherlands	Qualitative Longitudinal study Aim: comparison study between caregivers of people with FTD and AD with respect to CB, QOL and coping Compared caregivers of people with FTD and AD Demographic data, results from survey tools including coping	29 FTD caregivers and 90 AD caregiver participants Existing data from a previous study was used for the AD carer group 35 (39%) were men	Findings: no significant differences detected between the caregivers in relation to HQoL (physical scale) or between the coping strategies used Increased felt burden of caregivers of FTD when compared to AD carers, particularly in	Recommendations include potential for the need for diagnosis aware interventions - targeting those with FTD caring roles due to the increased disinhibition and social isolation due to behaviour This study offers valuable findings in relation to specific	There would have been value in mixed methods to extrapolate more detail around the concept of burden and how this is felt by caregivers Other aspects of live can add to sense of burden that this data would not capture

		skills (Utrecht), HQoL, CB (single question rating) and a Neuropsychiatric inventory assessment tool. Statistical analysis using ANCOVA. Regression analysis to assess predictors of CB HQoL Ethical approval gained		the short term, those who cared for longer term HQoL was improved, suggests adaptation Lack of specific support for FTD caregivers Statistical analysis is well described and clearly set out	symptoms and behaviours that caregivers find troublesome The comparison between FTD(home) and FTD(Care) showed that where the person stayed did not have a bearing on caregiver burden	"Passive coping" was referred to frequently but under defined
26	Robinson, et al. (2014) "The Male Face of Caregiving: A Scoping Review of Men Caring for a Person With Dementia." Canada	Literature Review: Scoping review related to male carers and health. Review outlined well and offers clarity in process although is not addressing the quality of the studies explored Reports to be a more systematic approach to a scoping review.	Broad range of databases explored Search terms clearly detailed 30 studies included in the review Inclusion and exclusion criteria and selection process is systematic and clear Year range: 2007 - 2012	The review captures the literature on male caregiving and the context of masculinity There was no interpretation of the articles explored, rather the authors themed the literature into main categories: men's experience of caregiving, relational factors and outcomes of caregiving Theme: "Men's experience of caregiving" was the focus for 14 articles	Recommends the inclusion of masculinity theory as a context Recommends that research is undertaken with the focus on gender and masculinity as a factor that will impact on care decisions and carer experience	Although noted as a scoping review, the inclusion of quality measure would have added value to this paper

				Indicates growing interest in the topic		
27	Russell (2006) “The Work of Elderly Men Caregivers.” USA	Qualitative research Aim: to explore the way in which older men who leave work to care for their wife’s with dementia manage the change Social constructivist view using in-depth open unstructured interviews Purposeful sample via the home care and other organisations. Thematic analysis No ethical approval noted	30 men who care for their wives with dementia 23 were retired 8 of whom retired to care and two worked part time. Time and place of interview as determined by the participant.	Two themes: Coping with the isolation & Invisibility of caring The adaptation of a managerial and nurturing approach to care seems to help with these two stressors Family either not around or tendency to “ambush” caregiver. Direct quotes used to illuminate themes.	Explored in the context of masculinity and the social constructs of men as caregivers - stereotypes and assumptions are mentioned Men making sense of caring role in relation to work and previous “identity” Recommendation – to consider the challenge of long held views of men in caring roles	No examination of potential bias or mention of reflexivity or ethical considerations
28	Sanders & Power (2009) “Roles, Responsibilities, and Relationships among Older Husbands Caring for Wives with Progressive Dementia and Other Chronic Conditions,” USA	Qualitative study: Phenomenological Aim: To explore that changes that men experience in relation to role, responsibility and relationships. Method: individual SSI (2), four months apart Data analysed using a content analysis approach to identify	17 male spousal caregivers Choice of setting for SSI give, three chose office of researcher Interviews conducted by researchers	Two themes: adapting to new role and changes in relationship. Men had to shift between the role of partner and carer to adapt to changes in their relationships External researcher reviewed transcripts Both researchers completed analysis independently	Recommendations include the role of the social worker in supporting men through the changes in the relationship Men need a safe space to express the emotional impact of the caregiving experience	Authors recommend further longitudinal studies to capture the experience of men over the duration of the condition

		"meaning units" or themes Ethical approval was gained		Reflexivity journal maintained Categories given to participants Good use of quotes to demonstrate analysis and themes		
29	Schoenmakers, et al. (2010) "Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review." Belgium	Literature Review: Systematic review of clinical trials aims to identify the triggers for depression and burden in family carers of people with dementia Clear outline of criteria and method for identification of sources Quality measure – Delphi Criteria checklist for RCT Meta-analysis via Review Manager Software	26 articles selected Identified through data base search and included grey literature Key words clearly outlined Year range: 1990 - 2009	Depression is more common in older caregivers, women and in those caring for people with dementia when compared to other LTC The results were inconclusive due to the population bias of caregivers recruited to studies. Lack of evidence that interventions to support caregivers alleviate depression or burden	Links to the need to be person centred in approaches to supporting carers "Felt" needs to be established - rather than a normative approach based on care needs of the individual with dementia	Limitations to the review stem from lack of clear data and wide variety of measures used. Search terms did not include variations in terms for caregivers nor alternatives to "dementia" potentially missing sources
30	Shanks-McElroy & Strobino (2001) "Male caregivers of spouses with Alzheimer's disease: risk factors and health status"	Quantitative descriptive study Survey Aim: to describe caregiving role and identify risk factors in relation to health.	Original study: 616 both male and female 66 responses of which 29 were male = 44% of the respondents overall	Male caregivers associate stress with providing personal ADL based care and limitations of leisure activities Stressfulness of care provision and	Recommendation: more education and training, increased funding for in-home and day care services and health monitoring	AD behaviours list and family/friend help list/leisure list – unclear what this is, how it was compiled and how it was interpreted

	USA	Subset of wider study using purposeful sampling: male spousal caregivers Standardised measures used: Inventory of physical symptoms of ill health Subjective rating of physical health in the past year and the year (Likert scale) validated Depression scale and CB scale Ethical approval not reported		frequency of behavioural dysfunction are potential predictors of burden, physical health and depression Recognition of increased likelihood of carer health being affected by ageing	Links to care context, lifestyle and history Encourages more qualitative research into the impact of caring on male caregivers and longitudinal studies on impact on health and wellbeing over the duration caring	Subjective rating of physical health one year prior to caring may be challenging due to recall Little interrogation of the findings and some assumptions made that male caregivers would access increased training/education opportunities
31	Stirling et al. (2010) “Measuring dementia carers’ unmet need for services--an exploratory mixed method study.” Australia	Mixed method exploratory study Aim to explore the link between CB, service user and carer felt need Objective and subjective measures of CB, caregiver stress and service use Individual interviews at three time points to assess the context of service use and caregiver need, and to reflect the cultural context of the	20 caregiver /cared for dyads recruited via a dementia specific organisation	Findings include a relationship between caregivers use of services and cognitive and functional status of the cared for. No significant relationship between CB and service use Use of direct quotes and triangulation with the quantitative data added value Analysis completed by two researchers and used peer	Recommends that more attention should be paid to notion of “felt” need rather than CB and the general assessment of normative need made by service providers	90% of the carers in the dyads were female no reference to difference in gender Limitations due to numbers and generalisability is noted

		caregiver/cared for relationship, service use diary entries Data analysed using Bivariate descriptive analysis Ethical approval gained		debriefing to explore potential bias and examine process of interpretation		
32	Yu, et al. (2018) "Unravelling positive aspects of caregiving in dementia: An integrative review of research literature" Hong Kong	Literature Review: Integrative literature review Aim: to exploring the positive aspects of caregiving and identification of conditions that relate to positive experience 5 stage method data synthesis and clearly presented	Appropriate data bases searched 41 sources reviewed Key words clearly identified No year range given CASP checklist for qualitative (n=18) and quantitative (n=25) cohort studies used	Key findings of the include four key domains: a sense of personal accomplishment and gratification, feelings of mutuality in a dyadic relationship, an increase of family cohesion and functionality, and a sense of personal growth and purpose in life	Recommendations: Encourages a shift from considering CB to looking to enhance positive aspects of caring as a way to sustain and support caregivers	Recognition of limitations related to language use to describe positive experiences

2.7 Assessment of need and identification of risk

There was significant attention paid to the recognition of caregiver need in the literature reviewed (Brodaty & Donkin, 2009; Brodie & Gadling-Cole, 2004; Bronner, Perneczky, Mccabe, Kurz, & Hamann, 2016; De Vugt & Verhey, 2013; Donnellan, Bennett, & Soulsby, 2015; Etters et al., 2008; Karlin et al., 2001; McLennon et al., 2010; Meichsner & Wilz, 2018; Neufeld & Kushner, 2009; O'Shaughnessy, Lee, & Lintern, 2010; Picco et al., 2015; Robinson et al., 2014; Russell, 2006; Schoenmakers, Buntinx, & Delepeleire, 2010; Stirling et al., 2010). With many, for example; Bruce and Paterson (2000), Karlin et al. (2001), McLennon, et al. (2010) and more recently Meichsner and Wilz (2018), recommending the formal assessment of caregivers as a way to identify those at risk of not being able to continue to care. Caregiver needs that were identified, were frequently contextualised in relation to discontinuation of caregiving and included; increased burden, isolation, physical and/or emotional health deterioration (Donnellan et al., 2015; Etters et al., 2008; Karlin et al., 2001; McLennon et al., 2010; Meichsner & Wilz, 2018; Schoenmakers, Buntinx, & DeLepeleire, 2010; Stirling et al., 2010). While other studies warn against assumptions that all caregivers have similar needs, reporting the importance of understanding the specific, individual needs of men who care for family members with dementia (Neufeld & Kushner, 2009; O'Shaughnessy et al., 2010; Picco et al., 2015; Robinson et al., 2014). Further, they note the value of a planned transition to care home facilities, based on the mental and physical health assessment and needs assessment of caregivers, rather than solely on the needs of the cared for.

O'Shaughnessy et al. (2010) recommend the assessment of caregiver need. Through interviews with seven spousal caregivers, two of whom were men, using IPA, they set out to explore the changes in the couple relationship in dementia care. O'Shaughnessy et al. (2010) identified four group themes: connectedness and separateness; tension between meeting own needs and meeting needs of spouse; knowing and not knowing the future; and seeking control – emotional and practical strategies. The focus O'Shaughnessy et al. (2010) was the relationship between the caregiver and their partner and how it changed due to caring. O'Shaughnessy et al. (2010) note how the experience of caring alters the couple’s relationship as they adjust to the increasing care required due to dementia. The study highlights the requirement for service providers to understand the unique needs of spousal caregivers, to be able to provide a flexible support network to accommodate the changing relationship and the “oscillation” between feeling connected and separate from their spouse and moving in and out of strategies that help caregivers manage loss and change. O’Shaughnessy et al. (2010) was a valuable study in relation to the context and the approach taken, however no separation between the experiences of the five women and two men is offered, indicating either that there were no perceived difference, or that the analysis did not draw out any variation between them. Mc Donnell and Ryan (2011) however, reviewed the literature surrounding male caregivers and identified that men have different support needs to women, due to their lack of willingness to take up emotional support and their alternative strategies for coping. In line with Harris (1993), Pretorius et al. (2009) and Russell (2006), Mc Donnell and Ryan (2011) posit that men tended to adopt task and problem focused coping strategies, indicating differences between the genders. This further reinforces the need for further and more contemporary research into the perceptions and experiences of male caregivers specifically in order to better understand their experience and perceived needs in a changing society.

The need for caregivers to have time to pursue their own interests and maintain their own identity was a strong theme in studies by Mittelman et al. (1993); Pretorius et al. (2009); and Shanks-McElroy and Strobino (2001). Equally, the need to gain a sense of purpose and achievement were also strong protectors in relation to minimising caregiver burden and nursing home placement (NHP) (Cheng et al., 2013; Karlawish et al., 2003; Pretorius et al., 2009; Yu et al., 2018).

Farina et al. (2017) and Stirling et al. (2010) report on the value of focussing on caregivers “felt” need, rather than assessed needs, due the potential differences. Farina et al. (2017) reviewed the literature relating to the Quality of Life (QoL) for family caregivers of people with dementia. Examining 41 sources, Farina et al. (2017) identified the disparity between assessed need and felt need, in relation to caregivers deciding to access support. Farina et al. (2017) encourage that more attention to be paid to felt need and QoL measures.

This mirrors the findings of Stirling et al. earlier in 2010, who conducted a mixed methods study, exploring the link between burden and felt need, finding that there was no significant relationship between burden and service use. Similarly, Stirling et al. (2010) recommend that more attention should be paid to felt need, rather than assessment of burden and the general assessment of normative need, which is usually defined by service providers. These findings indicate that there could be a lack of correlation between the measures used to assess caregiver stress and burden, the needs of the individual being cared for, and the perceptions of the caregiver, that drive caregivers to utilise support and services (Stirling et al., 2010). It is important therefore, that interactions with caregivers are carer-centred in the way in which needs are identified. These interaction significant in relation to identification of risk of burden. Better understanding of the perceptions of men and the support and services they feel they need to the continue caregiving, will be valuable.

Bronner et al. (2016) conducted a qualitative study including data from people with Alzheimer's dementia, their family caregivers and health care staff. Using semi-structured interviews, Bronner et al. (2016) found that spouses set out to provide care to the end, often without knowing specifically about Alzheimer's dementia, its progression and how it is likely to impact on them and the person they are caring for. Bronner et al. (2016) also reported that professionals frequently anticipate needs rather than working collaboratively with caregivers. Based on this, they recommend the development of specific decision-making tools to support people working with caregivers, to do so in a more caregiver/family orientated way. Although Bronner et al. (2016) do not suggest any tools specifically, they propose that decision making tools would to be used by those who are in contact with caregivers, around point of diagnosis. Improved understanding of the factors that influence the decisions men who care for a partner with Alzheimer's dementia make, would be of value when developing these tools.

There are some assumptions made by Bronner et al. (2016), for example, that caregivers would engage in support and services at an early point and that this would be seen as positive by caregivers. The diagnosis of dementia can be challenging for individuals and families (Ornstein, Wolff, Bollens-Lund, Rahman & Kelley, 2019) and caregiver’s may need time to come to terms with the diagnosis before engaging with services. Negative interactions could also be seen as those where caregivers do not feel ready to make changes, or access services and therefore be harmful to the professional/caregiver relationship (Neufeld & Kushner, 2009).

2.6 Positive aspects of caregiving

Recognition of the positive aspects of caregiving was evident in the literature reviewed (Cheng et al., 2013; de Labra et al., 2015; Donnellan et al., 2015; Harris, 1993; Pretorius et al., 2009; Yu et al., 2018). With emphasis placed on the sense of purpose, meaning (Cheng et al., 2013; Yu et al., 2018), personal accomplishment (de Labra et al., 2015; Harris, 1993; Pretorius et al., 2009), satisfaction and role fulfilment (Cheng et al., 2013; de Labra et al., 2015; Yu et al., 2018) as aspects that contributed to positive experiences. Donnellan et al. (2015), for example, explored whether dementia spousal caregivers can achieve resilience and found that they draw from their connections with others, having a shared understanding of caregiving and through the use humour, remaining positive and finding enjoyment in the caregiving role. Donnellan et al. (2015) interviewed 20 spousal caregivers of partners with dementia and focussed on resilience, reporting that those who cared for longer, who were younger and who were male, tended to be more resilient.

The positive outlook and belief in ones abilities to meet the demands of caregiving were also noted by Cheng et al. (2013) who’s quantitative longitudinal study exploring caregiver well-being and beliefs about ability, known as self-efficacy, impacted on the success of caregiving. Cheng et al. (2013) reported belief and finding meaning in caregiving were associated with less burden and positive gains and is therefore significant in relation to caregiver resilience. Although not related specifically to male caregivers, this research shows the importance of a sense of achievement through setting goals and caregiver self-efficacy. Cheng et al. (2013) note the importance of self-efficacy in buffering the impact of behaviours that are associated with dementia, which were perceived as challenging. Similarly, de Labra et al. (2015) gathered data from 101 caregivers, of which 30% were men and found that there was a correlation between increased satisfaction with caregiving and late stage dementia. Like Chang et al. (2013), de Labra et al. (2015) recommend that more attention should be paid to the positive aspects of caregiving to reduce stress levels. However, later stages of dementia may bring about different care challenges, perceived as more manageable and therefore more rewarding. Also, the increased time caring may allow for caregiver adaptation to the role and increased engagement with services, which may account for the reduction in stress. Further research is needed to investigate, through the perspectives of male caregivers, the factors that influence the coping strategies men adopt, how these support resilience, and the ways in which support and respite services can complement the caregiving men provide to their partner.

Yu et al. (2018) examined 41 articles related to positive aspects of caregiving. Using a narrative synthesis, four key domains were identified: sense of personal accomplishment, increased family cohesion, feelings of mutuality and a sense of personal growth and purpose. Although this review did not draw out specific sources that examined male perspectives, its focus on the positive aspects of caregiving was refreshing and offers knowledge related to interventions that supports and sustains family caregivers. This review offered some similarities related to the value of a sense of achievement, reported by Cheng et al. (2013); O'Shaughnessy et al. (2010); and Shanks-McElroy and Strobino, (2001). Understanding these encouraging aspects of the caregiving experience, identified above, may illuminate strategies that maximise these protective elements, to better support caregivers. However, the lack of attention to the experience of male partner caregivers specifically, is a gap in the knowledge surrounding this and could add valuable detail when developing these interventions.

Caregivers ability to adapt to their role as caregiver was also recurrent in the literature reviewed and shown to be protective in relation to caregiver stress and burden (Black et al., 2008; Brodaty & Donkin, 2009; Harris, 1993; Riedijk et al., 2006; Russell, 2006; Yu et al., 2018). Black et al. (2008) found that men, in particular, adapted to their caregiving role as a way to mitigate the emotional burden. Russell (2006) found that men tended to draw from work related strategies to identify successes in caregiving, which helped to regain a sense of purpose, achievement and identity. Russell (2006) interviewed 30 men who cared for their partner with dementia, to explore the way in which older men who leave work to care, manage the change. Using in-depth, unstructured interviews he identified two themes: Coping with the isolation and Invisibility of caring. Russell (2006) concludes that it is through the adoption of a managerial and nurturing approach to care, that men adapt and cope with isolation and invisibility. Similarly, Black et al. (2008) analysed four narrative accounts from men caring for their partners with dementia and found that older men coped with the emotional aspects of caregiving through focussing on the small successes and preserving a sense of self and identity and finding purpose. These studies in particular shine some light on the experiences of men and offer some detail about the importance of tangible ways to show that caregiving is successful, and how this links to having purpose and meaning.

2.9 Targeted interventions

Many of the studies reviewed focused on the avoidance of NHP (Arcain Nass et al., 2016; Brodaty & Donkin, 2009; Etters et al., 2008; Hirschman et al., 2006; Karlin et al., 2001; McLennon et al., 2010; Mittelman et al., 1993), while others focused more on caregiver burden (Bruce & Paterson, 2000; Cheng et al., 2013; Mc Donnell & Ryan, 2011; Picco et al., 2015; Pretorius et al., 2009; Riedijk et al., 2006; Schoenmakers, Buntinx, & DeLepeleire, 2010; Shanks-McElroy & Strobino, 2001). Recommendations, unsurprisingly, centre on identifying interventions that would minimise burden or avoid or delay NHP.

One of the earliest studies that specifically explored interventions to support spousal caregivers of people with Alzheimer’s dementia, was published in 1993. Mittelman et al. (1993) completed a longitudinal, comparison study which explored the impact of increased psychological interventions between caregivers of people with Alzheimer’s dementia caring at home. The intervention group were provided with a comprehensive psychological support programme and the control group were provided with standard support services. The interventions included; individual and family psychological support, mutual support groups and ad hoc consultation. Participants (n = 206), comprised of 120 females and 86 males and was one of the first studies to examine the spousal perspective. The explicit aim of the study was to evaluate the success of the intervention, based on the postponement or avoidance of NHP. Measurement of caregiver burden, caregiver's physical and mental health, depression, social network and dementia related behaviour was gathered along with core demographic data including age, income, employment, religion and length of caring. Findings after one year, indicated that there were less than half the number of NHP in the intervention group when compared to the control group. The findings suggests that, among other things, the tailored psychological and practical support offered could equip spousal caregivers to care for longer at home, thus delaying NHP. Mittelman et al. (1993), rather disappointingly offers limited insights into the male perspective of caregiving. No greater risk of NHP was noted between men and women and both appeared equally reluctant to consider NHP. Equally, there was no exploration of perspective of quality of services when considering NHP, known to be of significance when making decision about service including NHP (Carers UK, 2014).

Mittelman et al. (1993) reported that participant's financial situation had an impact on NHP, with those who had higher income being more able to sustain care at home. This may be linked to availability of funds to pay for help at home, but this detail was not offered. Different socioeconomic landscape and variations in healthcare funding and provision of interventions would impact on this approach if adopted elsewhere and hence a limitation of this study.

The age of the caregiver in relation to the age of the spouse with dementia appeared to be of significance, with younger caregivers opting for NHP sooner when the cared for person was older. Mittelman et al. (1993) suggested that this could be due to the perceived impact on social and lifestyle choices of younger caregivers. Therefore, interventions to increase the opportunity for younger caregivers to maintain social engagement and lifestyle choices may reduce burden and avoid NHP. This was similar to the findings from Pretorius et al. (2009), who's study in South Africa gathered and examined quantitative data from ten male caregivers, who were caring for a wife with dementia. This research used Antonovsky's Salutogenic model (Antonovsky, 1996), which specifically focusses on health and the origins of health and places emphasis on coping well and well-being, rather than disease progression (Mittelmark & Bull, 2013), and the Antonovsky's Sense of Coherence framework (Antonovsky, 1993), that expresses health as a continuum, from ease to dis-ease and is linked to managing life's stressors. This framework proposes that the focus on disease prevents us from considering the individual, subjective experience of disease or illness (Mittelmark & Bull, 2013) and therefore, encourages a framework where salutogensis and pathogenesis are considered in parallel. The primary goal of Pretorius et al. (2009), was to obtain a picture of the psychological experiences of men caring for a spouse diagnosed with dementia within the South African context. This study drew on multiple published questionnaires related to general health and well-being, caregiver burden and life satisfaction, providing a vast amount of data from a small sample in terms of quantitative research. The data was then examined using Antonovsky's Sense of Coherence (Antonovsky, 1993) subcategories: comprehensibility, manageability and meaningfulness.

In line with Mittelman et al. (1993), the increased provision of interventions and improved services, that maximise free time for spousal caregivers and the experience of men specifically in relation to caring, was seen as significant (Pretorius et al., 2009). This was similar to findings from Shanks-McElroy and Strobino (2001), who explored the risk factors that influence the health of male caregivers of spouses with Alzheimer's dementia. As one of the key studies that focused on caregivers caring for a spouse with Alzheimer's dementia, this offered valuable insights. The research originated from a quantitative survey-based research study, in which 616 potential participants were approached and 66 agreed to participate, 29 were male, which is equal to 44% of the respondents overall in the original research.

As a subset of the wider original study, Shanks-McElroy and Strobino's (2001) descriptive study, used standardised measures including; an inventory of physical symptoms of ill health, which was completed subjectively from the year before caring started and the previous year; physical health rating; depression and caregiver burden scales were all used to gather data. The Burden Scale for Family Caregivers is used in a number of studies and has been shown to be a reliable tool to assess the subjective burden related to caregiving (Cil Akinci & Pinar, 2014). The scale was developed from two conceptual models, Pearlin's Caregiver Stress Model and Lazarus and Folkman's Transactional Stress model (Graessel, Berth, Lichte, & Grau, 2014). The original scale is a 28 item scale has been adapted and evaluated in a number of settings including cancer and head injury but is most commonly used to assess burden in caregivers of people with dementia (Graessel et al. 2014).

The Zarit Burden Interview (Zarit, Reever, & Bach-Peterson, 1980) is one of the most commonly used caregiver burden scale in clinical and research settings. Each of the 22 items in this scale is rated on a 5-point Likert scale. The overall scores are between 0 and 88 with scores over 17 being considered as an indication of high burden. The scale has been broadly scrutinised and has shown to demonstrate reliability and validity particularly in the dementia caregiver population and in wider populations of caregivers (Moore, 2010; Siegert, Jackson, Tennant, & Turner-Stokes, 2010). Shanks-McElroy and Strobino (2001) developed abbreviated Alzheimer's dementia behaviours list, family/friend help list and a leisure list however, it was unclear what these lists contained and how they were compiled and interpreted.

Shanks-McElroy and Strobino (2001) found that, because spousal caregivers are of similar age to the person they care for, there is an increased likelihood of their own health being affected by the ageing process. Male caregivers specifically, associated stress with providing personal care, which suggests this could be a potential predictor of burden. Frequency of behavioural aspects of Alzheimer's dementia were perceived as challenging and were linked to increased caregiver burden, physical health issues and depression, which correlates with findings from Mittelman et al. (1993). Shanks-McElroy and Strobino, (2001) note that caregivers "felt" need to supervise the individual with Alzheimer's dementia, resulted in a sense of being trapped in the home and increased the feelings of isolation. Developing tailored interventions, that take into account the relationship between the caregiver and cared for and the reason for care was also highlighted in a comparison study by Riedijk et al. (2006) who reported that those caring for a family member with frontal temporal dementia, face increased isolation due to the disinhibition of those they care for, resulting in increased isolation. Caring for people who develop behaviours that are challenging for others, result caregivers feeling trapped in the home and further minimised the sense of independence and the opportunity to attend to their own social or vocational needs (Shanks-McElroy & Strobino, 2001). The importance of independent and time to one's self was also recognised by Farina et al. (2017), Harris (1993) and Pretorius et al. (2009). Recommendations to design tailored psychological support for spousal caregivers, targeting those at increased risk of NHP with proposed by Bronner et al. (2016); de Labra et al. (2015); De Vugt and Verhey (2013); Donnellan et al. (2015); Etters et al. (2008); Harris (1993); Karlin et al. (2001); Picco et al. (2015) and Sanders and Power (2009). In order to ensure that these proposed tailored psychological support services meet the needs of caregivers of men caring for their partner with Alzheimer's dementia, the experience of this population and how men perceive and value support services, requires to be understood from their unique perspective.

The focus on avoiding or delaying NHP and supporting caregivers to care for longer at home, is seen broadly in policy and is indicative of the anticipated rise in the ageing population and the global need to prepare for increased incidence and prevalence of dementia (Touhy & Jett, 2017; WHO, 2015). The importance placed on maintaining caregiving, could therefore indicate a tension for health and social care staff to genuinely respond to the identified and felt needs of caregivers, when there is a policy drive to maintain people in caregiving roles in order to keep people at home.

Meichsner and Wilz (2018) studied the use of Cognitive Behavioural Therapy (CBT) interventions for caregivers of people with dementia, to establish whether there is value in using this intervention to support caregivers of people with dementia coping with pre-dementia grief. Following their Randomised Control Trial (RCT), they concluded that CBT along with grief specific interventions, could reduce the caregiver burden and help caregivers cope with loss and grief. They identified that increased pre-death grief, specifically associated with this population, due to the loss of memory linked to dementia, was experienced by spousal caregivers. Improved understanding of relationship-based caregiving could facilitate the identification of need and establish targeted and tailored caregiver-centred interventions. Meichsner and Wilz (2018) excluded caregivers who had acute physical and mental health issues from their study, limiting the generalisability of their findings to the proportion of caregivers who are older and who are likely to experience significant health issues (Touhy & Jett, 2017).

The prevention or delay of NHP, was the focus of two of the six literature reviews identified; Etters et al. (2008) and Mc Donnell and Ryan (2011). The former, although not focusing on male caregivers specifically, examined literature from 1996 to 2006 in relation to caregiver burden and the identification of factors that influence caregiver burden for those caring for people with dementia. Etters et al. (2008) considered the cared for and caregiver characteristics related to caregiver burden, along with evidence-based interventions that lessen caregiver burden and assessment tools to identify those at risk of increased burden. Etters et al. (2008) report that caregiver and family centred interventions, aimed at increasing the knowledge of family caregivers, would reduce caregiver burden for the primary caregiver. This increased knowledge, along with multi-focused interventions, including psychoeducation for family caregivers, could lead to reduction in caregiver burden and fewer early NHP. Etters et al. (2008) recommend that specialist nurses, working with geriatric teams, could fulfil this role and should include the assessment of caregiver burden risk to inform the selection of interventions to be implemented. The acknowledgement, and recognition of the relationship between the care recipient and the caregiver would strengthen this assessment, along with increased attention to the caregivers felt need. This would then be generating a more holistic assessment. However, without improved understanding of the experiences of male partner caregivers and their views of support and interventions, interventions cannot be tailored to the specific needs of men in this role.

There were limitations to Etters et al. (2008) review, no detail of the criteria used to identify literature was given and the key word search used limited terms, “carer burden” and “dementia”, which may not have captured the related breadth literature available. As previously stated, this overuse of caregiver burden as a measure of the caregiver experience, can be limiting as it does not allow for caregiving to be conceptualise in more positive ways.

Mc Donnell and Ryan's review in 2011, examined research published between 1999 and 2010, with an aim to address the gap in the literature relating to men as caregivers of people with dementia. Key findings related to, men in the caregiving role, sons as caregivers, support services and gender differences in relation to caregiver burden. Mc Donnell and Ryan (2011) make links to the different needs of men in caring roles, when compared to women. They reference practical and problem solving support as being valued by men, similar to Pretorius et al. (2009), while a lack of willingness to take up emotional support, suggested men placed less value on this type of support when compared to female caregivers. Recommendations made links to men requiring different support, due to the adoption of alternative strategies for coping, as well as the need to avoid a “one size fits all” approach to support services. Both Etters et al. (2008) and Mc Donnell and Ryan (2011) recommend that caregiver-focused education interventions are needed to improve the experience of male caregivers. However, the specific forms and types of education and the nature of support that men perceive they need, when and how, is not addressed in this review. These points further reinforce the need for new and additional research in this area.

For interventions to be successful, attention must be paid to the way in which professionals interact and engage with caregivers. Supportive and unsupportive interactions are shown to impact on caregivers perceptions and decision making (Bronner et al., 2016; Donnellan et al., 2015; Etters et al., 2008; Mc Donnell & Ryan, 2011; Neufeld & Kushner, 2009; O’Shaughnessy et al., 2010; Russell, 2006). Neufeld and Kushner in 2009, explored the supportive and non-supportive relationships male caregivers of family members with dementia have with family and professionals. Data gathered came from individual interviews, diaries and focus groups with men, 24 of whom were spouses and 10 sons. The findings show that men found unhelpful interactions with others, for example professionals and family members, resulted in lack of orientation to caregiving, inadequate support, and hurtful interactions. These resonate with the findings of Etters et al. (2008) who stated that positive, supportive family interactions and recognition of caregivers within families, was seen as supportive in reducing caregiver burden, while familial conflict and disharmony increase caregiver burden. Neufeld and Kushner (2009) offered new knowledge around the perceptions of men principally related to non-supportive relationships, which is an area that has not received significant research attention. Neufeld and Kushner (2009) considered social context, beliefs and values relating to relationships. Recommendations focused on the potential for family members and professionals to be more aware of the complex nature of men in caregiver roles, and the ways to avoid unintended, negative interactions (Neufeld & Kushner, 2009).

Partnership approaches to working well with caregivers, were recommended by Brodaty, Mittelman, Gibson, Seeher, and Burns (2009) and Brodie and Gadling-Cole (2004), in their discussion papers, and by Bruce and Paterson (2000), who highlight helpful interactions with the General Practitioner (GP) and their role in supporting caregivers, to explore service use. Working in partnership with caregivers, is a core principle in the policy rhetoric (Scottish Government, 2017; World Health Organization, 2017), for interventions to be effective, caregivers must trust the people providing services, see them as valuable and view the intervention to be related to their perception of need (Rolfe et al., 2014).

2.10 Role, relationships and identity

A number of key qualitative sources focused on the experience of dementia caregiving (Black et al., 2008; Donnellan et al., 2015; Harris, 1993; Karlin et al., 2001; Neufeld & Kushner, 2009; O’Shaughnessy et al., 2010; Pretorius et al., 2009; Russell, 2007; Sanders & Power, 2009). Within these there were significant reference to the role that caregivers adopt, the changes in the relationship with the cared for due to dementia, and how these relate to caregivers’ sense of identity.

Harris (1993) offered insightful interpretation of the lived experience of men caring for a partner with Alzheimer’s dementia. Through semi-structured interviews with fifteen men, Harris identified core the following themes: commitment, social isolation, and loss of companionship, coping strategies, problem-solving, outside activities, the need for specialist services for men and a sense of accomplishment. Based on the findings Harris (1993) described a typology of men who care for their partners. The caregivers interviewed, predominantly resonated with one of the following types of male caregivers, each with unique characteristics, The Worker, The Labour of Love, The Sense of Duty and At a Crossroads. This in-depth examination of the types of caregivers is unique in the literature, although has limitations in relation to generalisability to wider caregiver populations due to the limited numbers in the study. The typology however offers some scope to identify interventions for those caregivers that meet the description, for example, those who are At a Crossroads, were described as those who are new to caregiving and adapting to the new role and who may be *"floundering"* (Harris, 1993: 554). This could offer opportunities to develop interventions for men who are at this point in their caregiving experience, to better navigate this change in role and to support effective adaptation and strategies to cope with the challenges experienced. These findings and typology resonate with Neufeld and Kushner (2009) who found that partners tend to continue to care for longer, when compared to son's caring for a parent. This indicates differences in the perceptions and experiences of men who care and that better understanding of the relationship between the cared for and caregiver, and the role men adopt would be of value.

Hirschman et al. (2006) interviewed 30 caregivers to explore the decision making strategies caregivers adopt, when making medial decisions for their relative. Hirschman et al. (2006) found that caregivers tended to fall into two categories, those used *substituted judgement* and those that use *best interest* to make decisions. They also found that spousal caregivers were more likely to involve their partner in decisions, indicating the importance of understanding the relationship they have with their partner. Hirschman et al. (2006) analysis demonstrated that fewer than half of the caregivers interviewed had discussed preferences before the onset of dementia. Hirschman et al. (2006) note the importance of advanced planning, potentially minimising the sense of uncertainty for those caregivers who are at a crossroads and helping to increase their confidence in making decisions. Reduction in uncertainty may also support those caregivers who Harris (1993) describe as foundering as they navigate new roles.

Pretorius, et al. (2009) describe different coping strategies used by men, caring for partner with dementia; emotion focused and problem focused coping. Problem based coping was associated with more positive outcomes, like reduced feelings of depression and improved emotional health, and are in line with findings from Black et al. (2008); Cheng et al. (2013); de Labra et al. (2015); Russell (2007) and Yu et al. (2018). Men's use of problem focused approaches to caregiving could be helpful in building resilience and a stronger sense of achievement, hence their improved outcomes. Pretorius, et al. (2009) found the use of problem focused coping and a sense of manageability, was seen to aid resilience, finding meaning and achievement in caregiving, which were identified as important protective factors by Shanks-McElroy and Strobino (2001). This indicates the importance of understanding the relationship between the cared for and caregiver when working with families.

Robinson et al. (2014) explored male caregivers in the context of masculinity. This scoping review of the literature, relating to men as caregivers, drew on sources published between 2010 and 2012. Thirty articles were reviewed and three themes emerged: men's experience of caring, relationships, and outcomes of caring. Robinson et al. (2014) advocate the need for a framework to explain these themes in relation to masculinity. Robinson et al. (2014) note that exploration and understanding of caregiving, from a gender perspective, is in its early stage and encourage the increased in research in this area. Reference is made to men's reluctance to seek support, in particular emotional support, and that this may stem from masculine norms, where men are to be stoic and resilient. The way that men adopt the role of caregiver is also, according to Robinson et al. (2014), related to masculinity and aligned their caregiving role to that of protector, provider and taking control of the situation. Men caring for their partners were also found to be reluctant to accept help from their children, further supporting the masculine ideals of protector and provider.

Black et al. (2008) explored the narratives of four men who cared for their partner with dementia. Black et al. (2008) take a phenomenological approach to explore the experiences of the men, through the lens of masculinity. Black et al. (2008) identified that the men attempted to regain control of their lives, which were disrupted by dementia, through the use of routine and preserving self and identity. The findings related to relationships, role and marriage and how men strive to maintain these, while dementia takes over many aspects of daily life. Similarly, Russell (2006) explores the way in which older men, who leave work to care for their partner with dementia, cope with the transition from worker to caregiver. Also explored in the context of masculinity and within social constructs of men as caregivers, Russell (2006) posits that stereotypes and assumptions can be harmful to men, particularly when it is assumed that men lack the inclination and capacity to care. Russell (2006) suggests that men take a different approach to caregiving and draw from managerial strategies that encourage a sense of control and self-efficacy. Russell (2006) suggest that this could explain how men are sheltered from symptoms of burnout and emotional distress, but stress, that these managerial approaches are adopted in tandem with nurturing approaches as they transition into this new role.

Sanders and Power (2009) set out to explore changes that men experience in relation to role, responsibility and relationships. In their phenomenological study with 17 men, caring for a partner, they found two themes: adapting to new role and changes in relationship. Men had to shift between the role of partner and caregiver to adapt to and negotiate the changes in their relationships, resulting from progressive dementia or other long-term conditions. The lack of focus on one health condition limits the findings due to the varied experiences of caring for different conditions, however Sanders and Power (2009) offer some new understanding surrounding the change men negotiate, when adopting the role of caregiver. In line with Black et al. (2008), Robinson et al. (2014) and Russell (2006), Sanders and Power (2009) note the importance men in their study placed on protecting their partner, in relation to dignity and personhood. Also, the importance of the role of provider, in relation to providing care, home maintenance and daily plan/routine. The relationship the men had with their partner changed in many aspects, including intimacy and closeness and the loss of the person.

The unique caregiving experience of men, in the context of gender, is of value as it relates to men's sense of identity when they adopt this new role. How men negotiate changes in the relationship with their partner, are also significant. Improved understanding of this experience, specifically for men who care for their partner with Alzheimer's dementia, will help services to better target interventions, support men transitioning into the role and connect with men in ways that protect their sense of identity and need to provide for their partner.

2.11 Caregiver health and well-being

Within the review of literature, the health and well-being of caregivers featured regularly, both in relation to the negative impact that caregiving has on health and well-being (Black et al., 2008; Brodaty & Donkin, 2009; Bruce & Paterson, 2000; Meichsner & Wilz, 2018; O'Shaughnessy et al., 2010; Sanders & Power, 2009), and the impact of specific dementia related symptoms on caregivers health and well-being (Arcain Nass et al., 2016; Cheng et al., 2013; McLennon et al., 2010; Picco et al., 2015; Riedijk et al., 2006).

Caregiving has been associated with negative health outcomes (Mcintyre & Reynolds, 2011). Bruce and Paterson (2000) interviewed 24 caregivers, gathering data from General Health Questionnaire and found that caregiving negatively impacted on sleep and stress levels and brought about feelings of sadness, guilt and depression.

Depression was identified as a health issue for caregivers of people with dementia in a number of studies (Karlawish et al., 2003; Schoenmakers, Buntinx, & DeLepeleire, 2010; Shanks-McElroy & Strobino, 2001) and is reported to be exacerbated when there are behavioural and psychological challenges and increased personal care (Picco et al., 2015; Shanks-McElroy & Strobino, 2001). Depression was found to be more prevalent in older caregivers (Schoenmakers, Buntinx, & DeLepeleire, 2010) and was recognised by Karlawish et al. (2003) as a factor that impacted on older caregivers decision making, finding a correlation between depression and decisions not to commence with dementia slowing medication. Older spousal dementia caregivers were also recognised as a population that are more likely to be affected by pre-death grief, when caregivers of people with degenerative conditions experience loss of the person before death (Meichsner & Wilz, 2018). This may be potentially relating to the age, life stage and relational elements of this specific older caregiving population. This is in line with Picco et al. (2015) who identified increased risk of burden in older married caregivers of people with dementia.

Farina et al. (2017) report in a systematic review of literature, related to caregiver QoL when caring for someone with dementia. This review links to caregiver health and QoL and how the QoL of the person with dementia is perceived by the caregiver. In line with Karlawish et al. (2003) mixed methods study, Farina et al. (2017) note caution due to the subjectivity and transference of QoL perceptions of the caregiver onto the cared for. Themes identified by Farina et al. (2017) included: relationships, dementia characteristics, caregiver health and caregiver independence. The importance of independence and time to peruse own activities were highlighted as positive in relation to QoL, which further supports the findings of Shanks-McElroy and Strobino (2001) and Pretorius et al. (2009).

Robinson et al. (2014) review of the literature indicated that caregiving had a negative impact on men's health and advocated that more research into the relationship between caregiving and men's health was needed, now more than ever due to the ageing population, and the number of men adopting caregiving roles. More recently, Ruiz Fernández and Ortega Galán (2019) conducted a descriptive study with 225 caregivers and highlighted that spousal caregivers, caring for over 2 years, report increased anxiety and depression. Although this study does not draw out male caregivers' perspective specifically, they do highlight the need to consider the relationship and the length of time caring when considering the health risks for caregivers.

Schoenmakers et al. (2010) set out to examine the literature surrounding the triggers for depression in caregivers of people with dementia. Fourteen sources were included and Schoenmakers et al. (2010) found that depression was a significant factor related to stopping care at home and in line with Shanks-McElroy and Strobino (2001) recommend that professionals recognise the “felt” needs of family caregivers, rather than the needs of the cared for when offering support services. This comment highlights the importance of fully understanding the experience of specific family members who provide care without which appropriate and targeted health related interventions cannot be offered.

There is evidence to suggest that there are health implications for caregivers and that both the relationship to the cared for and the length of time caring influences caregiver well-being. As the longevity gap between men and women decreases, more men will take on caregiver roles, increasing the importance of research that provides improved understanding of male caregivers’ health and well-being.

2.11 Quality of literature reviewed

There were variations in the quality of the research papers reviewed, although there were no sources eliminated due to the quality score for this narrative review, emphasis was placed on reviewing the landscape of knowledge surrounding the topic (Kable et al., 2012), in this case, experience of men caring for a partner with Alzheimer’s dementia. Those with low CASP scores frequently did not include essential detail, for example, in earlier qualitative studies there was a lack of detail around ethical considerations, bias and reflexivity, seen in both Harris (1993) and Karlin et al. (2001). However the discussions around quality measures specific for qualitative studies did not emerge until the late 1990’s, with work from Elliott et al. (1999) signposting the way for qualitative researchers to increase the trustworthiness of their studies through the development of guidelines that aim to legitimise qualitative reporting. Therefore, authors of earlier studies can be forgiven for not being aware of the quality measures applied retrospectively to their publications. More recent work however, for example Hirschman et al. (2006), McLennon et al. (2010), and Riedijk et al. (2006) do little to demonstrate the quality of their work with limited clarity of findings, and minimal attention being paid to potential bias particularly when research is carried out in areas where the researchers are based. Overall, the studies reviewed scored well when the CASP (2018) criteria were applied

(Appendix 2), but more importantly this process allowed for closer scrutiny of the studies and a systematic approach to evaluating the quality of the work.

2.12 Results of literature review

Those who care for people with dementia and who are older are identified as high risk in relation to caregiver burden and physical and mental health issues due to the ageing process and the demands of caregiving. There is correlation with caregiver burden and the experience of managing and coping with the behavioural aspects associated with dementia and with being a spousal caregiver. In addition to this, men specifically require a level of adaptation that includes negotiating societal norms, related to those who provide care and their role and relationship with their partner, in the context of gender, masculinity and identity.

Globally, the increased emphasis on dementia and caregiver needs has been demonstrated by both the United Nations (2015) and the WHO, (2015) with the “Call for action” in response to the projected demands that ageing and dementia present communities globally. This call has mobilised member states to take action. It is likely that the increasing interest in this area is related to the growth in the older age group and the consequences of this ageing population on families, the workforce, communities, public services and the economy (United Nations, 2019). The geographical range of the literature in this review indicates a broad interest in supporting caregivers as a means to sustaining the caring population. This supports the view that caregivers provide a significant economic contribution to the societies in which we live.

Through searching and evaluating the literature surrounding male caregivers of spouses with Alzheimer’s dementia it is evident that there are gaps in knowledge and understanding about this specific group of caregivers and their experience of accessing support and services. Due to this gap in the literature, it was essential to widen the search criteria, both in terms of year range and focus, to include dementia as a more general condition and caregivers rather than specifically men. This gap was due to the stark lack of male-focused research in this area within the last 10 years, resulting in potentially stereotypical views of caregivers and a lack of contemporary perspectives. This lack of sources relating to male caregivers, indicates the need for more focused research in this area.

2.13 Relevance to this study

This review of the literature surrounding male caregivers has helped to provide an overview of the current knowledge related to the research questions of this study. It provides a landscape on which to explore my research questions, which relate to how male caregivers of a partner with Alzheimer's dementia experience and perceive their caregiving and make decisions about respite for their partner with dementia and support services that are designed to help. The studies that examined the relationships with those who provide support, which includes both family and professionals, have helped to highlight the enablers and inhibitors to accessing support in the context of helpful and unhelpful interactions. However, this literature review indicates a number of gaps in knowledge around the male perspective of caring for a person with dementia, including; the way in which men perceive and respond to adopting a caring role, and how these perceptions, their experience of caring, and their relationship with the cared for impacts on their decisions about support, services and respite care. Equally, there is a lack of research specifically related to men and the partner caring relationship, with most sources combining the experiences of all caregivers as if they were a homogenous group. This reinforces the research aim and focus and strengthens the significance and importance of this study.

This review of the literature highlighted the need for focused tools for assessment of caregiver needs and tailored, targeted interventions to support caregivers of people with dementia, frequently linked to maintaining caregiver health and wellbeing and avoiding NHP. It is, however, unclear how these assessments and interventions can be developed without understanding the experience of caregiving from personal perspective. The gap in the knowledge, specifically from the male, partner caregiver perspective is clear and is therefore worthy of further study.

2.14 Limitations

Potential limitations of this narrative review are related to extending out the perimeters of the search. Due to the lack of directly relevant sources, the initial search criteria needed to be exploded out in order to cast a wider net and capture a sense of the knowledge around the topic caregiving for people with dementia. As many papers included did not routinely focus on male perspectives only findings can only be loosely related to the experiences of men. In addition, this narrative review has been an individual pursuit, with support and feedback from my supervisors, and therefore is an individual interpretation. To mitigate any bias, the detail of how the literature was selected and the criteria, databases and terms used are provided, along with examples of the evaluation to demonstrate the strategies employed to increase transparency in the way that the literature included was selected.

2.15 Chapter Summary

This chapter has outlined the literature review undertaken taken to identify and examine the available literature surrounding male caregivers of people with Alzheimer’s dementia using a narrative style. A methodical and systematic approach was adopted to ensure that related sources were identified, providing an overview of what is known about the topic. There were five themes identified through this review:

- Assessment of need and identification of risk
- Positive aspects of caregiving
- Targeted interventions
- Role relationships and identity
- Caregiver health and well-being

Each of which are relatable to male caregivers of people with Alzheimer’s dementia. However, there was a need to broaden out the search due to the limited sources that related specifically to men caring for a partner with Alzheimer’s dementia thus supporting the need for more research into this topic.

Unsurprisingly, many sources identified were published at a point when the importance of caregivers was first becoming realised, both in societal and socio-economic terms, in the late 1990's through to the mid 2000's. What is surprising, however, is the apparent lack of progress from these dates to the current date, particularly when caregivers continue to experience caregiver burden to an extent where caregiving can break down, caregiver health deteriorates, and NHP is required.

As the landscape of caregiving shifts due to the ageing population and the increase in people living with Alzheimer's dementia (World Health Organization, 2015), research into this specific caregiver group is required. Added to this, as the longevity gap between men and women closes, more men are adopting caregiver roles for their partners, which is a role that has predominantly viewed as a female role (Russell, 2006). This specific caregiver group continues to be neglected in the available literature, with many of the studies exploring caregivers generally conducted regardless of gender or the relationship to the person being cared for.

There is a lack of detail surrounding the lived experiences of men in this caregiver role and the meaning they make from this experience. Yet it is this detail that is needed in order to fully understand the male caregiver perspective. Important to appreciate, is both the experience of caregiving from the male perspective and how men's' perceptions of this role and the support and services available to them, impact and influence the decisions that they make about using services. It is through this knowledge that tailored and targeted support services and interventions can be developed.

From the few sources of literature surrounding male caregivers of partners with Alzheimer's dementia, qualitative approaches tended to be used, but few adopted a phenomenological approach, with only one using IPA as a method for analysis. IPA provides the opportunity to closely examine the ideographic, personal and unique experience of caregiving and the way it is understood by the individual and could therefore add the depth and focus to the body of knowledge.

Overall, the literature indicates the importance of targeted and caregiver focused interventions in order to improve the experiences of caregivers of people with Alzheimer's dementia. What is needed, therefore, is an exploration of the experiences of specific caregiver groups who are likely to provide substantial care now and in the future. In addition, a better understanding of the interventions that could support caregivers in this challenging role.

In summary, this review of literature supports the aim of this research study, which is to identify the factors that encourage and inhibit male caregivers of partners with Alzheimer's dementia decisions to access respite and support services.

Chapter 3 - Research Design and Methods

3.0 Introduction

The aim of this thesis is to explore the experience of men who care for their partners with Alzheimer's dementia and to add detail to the knowledge surrounding this topic. The literature review indicated that there is a lack of knowledge particularly related to the unique experience of men, with no new knowledge related to how caregiving is perceived by men caring for their partners in recent years. Although there are studies that draw on qualitative research approaches to explore the experience of caregiving, there are none beyond 1993 that examine this experience from the specific gender, diagnosis and relationship perspective. As much has changed in relation to the knowledge and understanding of caregiving and dementia, with the increased emphasis on caregiving in local and national policy referred to in Chapter 1, further exploration of this is needed to capture the experiences and perceptions of men today.

This study aims to identify the factors encourage or inhibit male caregivers of partners with Alzheimer's dementia decision to access respite and support services and to explore the perceptions of accessing support. The review of literature indicates that there is debate around the types of support and coping strategies that men draw from, with indications that these are different to women and potentially reduce the opportunity for men to attend to the emotional demands of caregiving. However, there are also suggestions that men adapt well to caregiving and draw on positive experiences and achievements to emphasise successful caregiving. Better understanding of how men make decisions about accessing support will add to this knowledge and provide essential detail required to support and enhance the positive aspects of caregiving and minimise the negative.

The objectives of this study are to identify and interview men who are caring for their partners with Alzheimer's dementia, in order to provide detailed data surrounding this experience from their unique perspective. The objective of the interviews are to provide an opportunity for the men to define and draw meaning from their caregiving experience and how they view support and services in a way that makes sense to them, and to unfurl the idiographic perspective, to shine more light on this experience and draw increased understanding of the factors that impact on decisions they make.

The review of the literature has therefore refined the research questions for this study which are:

1. How do male caregivers of partners with Alzheimer's dementia experience and perceive respite and support services?
2. How do male caregivers of partners with Alzheimer's dementia make decisions about accessing support services?
3. What do male caregivers of partners with Alzheimer's dementia perceive as the enablers and inhibitors to accessing services?
4. What do male caregivers of partners with Alzheimer's dementia perceive as the benefits of accessing support services?

This chapter will provide an overview of the research paradigms associated with social and health related research and detail the rationale for the approach taken for this study. This will include the theoretical and practical reasons for the methodology of choice, as well as an exploration of the range of approaches used in qualitative research used in contemporary social and health related research studies. The chapter will then go on to outline the approach to participant recruitment, the approach taken for data collection and data analysis, along with a discussion on ethical perspectives and considerations.

3.1 Research Paradigms

In order to justify the methods used and the design adopted to address the research aim and to answer the research questions, it was deemed essential to examine the philosophical perspectives that underpin research and to determine the researcher's view of the world (Bryman, 2016; Creswell, 2013; Donmoyer & Given, 2016; Silverman, 2013; Sobh & Perry, 2006).

A paradigm is a shared set of assumptions and perceptions about a given phenomenon (Bryman, 2016). Within the original research context, a paradigm is a common, shared view of the phenomena studied and of the range of research methods that align themselves to the study of the phenomena (Donmoyer et al., 2016). Originally developed and described by Thomas Kuhn, the term paradigm was used when Kuhn noted that there was a radical shift in perspective that led to a change in thinking observed within his scientific discipline. For example, the shift from Newton's to Einstein's version of physics (Donmoyer et al., 2016).

In research terms there are three aspects or elements to a paradigm: Ontology, Epistemology and Methodology (Marshall & Rossman, 2006; Sobh & Perry, 2006). Bryman (2016) encourages the researcher to examine their philosophical stance when they approach a research study, as the methods chosen for an enquiry are directly linked to the views that the researcher holds, which relate to both how they understand the nature of the social world and how it should be examined (ontology), and how knowledge is gained and generated (epistemology).

Ontological perspectives can be classed as objectivism or constructionism (Bryman, 2016). This classification relates to how the researcher understands phenomena, as either dependent or independent of social actors (Bryman, 2016). In essence, from an ontologically perspective, qualitative research is underpinned by a constructionist view, while quantitative is underpinned by an objectivist view (Bryman, 2016). Therefore in philosophical terms, the debates and discussions about the proponents of qualitative and quantitative research approaches are related to the orientation of the researcher (Scriven, 2005) thus signifying the value in exploring this as a new researcher.

The epistemological stance of a researcher relates, not only to the way in which people consider knowledge is constructed, but also how it relates to the nature of evidence and how it is collected (Silverman, 2013). Researchers can use both deductive and inductive methods to generate knowledge. Deductive approaches, like testing theory and hypotheses, result in developing or revising theory, while inductive approaches are where the theory emerges from the data collection and analysis (Silverman, 2013).

It is generally agreed in the literature that there are four research paradigms: Positivism, Constructivism, Realism, and Critical Theory (Bryman, 2016; Silverman, 2013; Sobh & Perry, 2006), and that the paradigm in which the researcher works directly connects with the methodological approach chosen (Birley & Moreland, 1999). In this sense, there is a clear and transparent alignment between the research approach and the method(s) to collect and analyse data. Each paradigm will be considered in relation to this research study and how it is connected to the in which the researcher works.

3.2 Methodology

Methodology is the philosophical stance and general principles which guide the researcher and aligns with the methods or research tools used in the enquiry to address the research questions (Bryman, 2016; Clough & Nutbrown, 2007; Dawson, 2006). Methodological decisions should be constructed, rather than selected, for the purpose of the research to be carried out (Clough & Nutbrown, 2007). Whereas, and in contrast, research methods are the set of techniques or tools used in an enquiry to gather data (Markauskaite, Freebody, & Irwin, 2011). The research methods utilised should be seen as “required by the context and purpose” of a particular enquiry and therefore selected (Clough & Nutbrown, 2007: 19). The methodological approach should be constructed, based on how a researcher views the way knowledge is gained, and the epistemological stance of the researcher (Horvat et al., 2013). This epistemological stance of the researcher underpins the way in which they describe what they know and how this is justified to others (Clough & Nutbrown, 2007). Therefore methodological epistemology is related to how researchers convince others of their knowledge and therefore how the quality and value of the enquiry is judged (Horvat et al., 2013).

3.2.1 Positivism

Positivism has been the main underpinning philosophy for science from the 18th Century. Initially introduced by Auguste Comte (1798 – 1875), positivism is based on the assumption that knowledge can be gained objectively through observation and that a phenomenon can be universally understood by examining its component parts (reductionism) (Stern, 2005). The positivist is committed to the precise gathering and accumulation of facts that are expressed through measurable, statistical data (Rubin & Rubin, 2005), with the researcher remaining objective. This disconnection with the researcher is regarded as ensuring a value-free truth that is unaffected by social context (Polit & Beck, 2012). This philosophical stance is most closely aligned with quantitative research design, due to its measurable, generalizable and causal relationships. However, there are several limitations in relation to humanity and lived experience (Bryman, 2016). These limitations are due to the significant human variation, personal interpretation and individual meaning derived from experiences and perceptions and is thus considered unsuitable for this research study.

3.2.2 Constructivism

Often described in the literature as Interpretivism or Interpretive Constructivism (Bryman, 2016; Rubin, & Rubin, 2005; Stern, 2005) the constructivist values the individual perspective or view of phenomenon, and the personal meaning derived from it (Pringle, Hendry, & McLafferty, 2011). Constructivists work from the assumption that people interpret phenomenon differently and that this will result in many potentially conflicting views and understandings of the same event or object (Rubin & Rubin, 2005). Interpretive constructivists examine the specific and detailed perspectives of the other and construct understanding and meaning based on these (Bryman, 2016). In this view, the researcher is engaged and connected with the world being investigated (Sobh & Perry, 2006). Due to the level of engagement, the interpretative processes of the researcher needs to be understood within the context of their own existing assumptions, understandings and meaning-making, to ensure understanding of the other’s perspective (Rubin & Rubin, 2005). These perspectives are most closely aligned with a qualitative research design (Bryman, 2016) and would be methodologically in line with this research study, due to its focus on subjective experience and meaning. Male caregivers experience caring and making decisions relating caring in the complex context of their role, relationship and past experiences. The perceptions they have and meaning they draw from these experiences and therefore the actions (decisions) they take, is based on this meaning. By examining these perceptions and the meanings drawn from them, interpretations can be made (Rubin & Rubin, 2005). The focus on the individual and the personal meaning within this paradigm aligns to my view of how knowledge is gained.

3.2.3 Realism

Realism considers that there is an external reality and that this reality exists independent of peoples understanding, values and beliefs about it (Ritchie & Lewis, 2003). Sharing some of the features of positivism (Bryman, 2016; Creswell, 2013), this stance indicates that there is a distinction between the way the world is and the meaning and interpretation held by people and society. In essence, the way that people see the world does not shape reality, but individuals interpretations of reality shape their understanding of the world around them (Ritchie & Lewis, 2003). Reality is real, but in order to know it, the researcher needs to collect data and be "…value aware and triangulate any perceptions…" (Sobh & Perry, 2006: 1195). While the positivists consider that scientific conceptualisations of reality directly reflect reality, realists argue that this conceptualisation is *"…simply a way of knowing that reality*." (Bryman, 2016: 14).

Epistemologically this research study and the researchers view of the world and reality does not fit with this view, due to its focus on individual meaning-making through people's experiences of being in the world.

3.2.4 Critical Theory

Critical theorists set out to identify the ways certain conditions, like gender, ethnicity, political views and cultural perspectives, influence peoples' beliefs, behaviours and experiences (Ritchie & Lewis, 2003). The researcher is "transformative", in that they are seeking to change the social world within which the participants live (Sobh & Perry, 2006: 1195).

This research study does intend to consider people within set conditions, for example, gender. Therefore, theories relating to gender and gender roles within society will be related to this inquiry. However, it is not the intension to adopt a transformative approach or to influence change, but rather to gain knowledge and understanding of the perceptions and meaning caregivers have relating to their role and how these influence the decisions they make about accessing services.

Examining and recognising the way in which the researcher understands and makes sense of the world, and knowledge can help the researcher make sense of the approaches chosen and how the data generated is understood. Taking the time to examine these aspects will add to the reliability of the research process and express how this knowledge can be disseminated and translated to others (Bryman, 2016; Clough & Nutbrown, 2007; Sobh & Perry, 2006).

As stated, the aim of this study was to explore the individual perspectives of male, spousal caregivers of people with Alzheimer's dementia and their decisions to access support and respite services. The core of this research is to understand the individual experience of the caregiver. In order to illuminate the experience of caregiving, participants must be able to describe their own experiences via their senses and perceptions and in their own way.

From an epistemological perspective the researcher's stance is indicated in the research aim and questions. These demonstrate the belief that knowledge is constructed by peoples' experience and perception of a given phenomenon, and that different understanding and meaning will be held by individuals with similar experiences.

In health, and in particular medicine, research has a long history of generating knowledge via the positivist paradigm, through use of measurement and examining the "cause and effect" relationship between the elements being investigated, with the researcher being distanced from the elements being examined (Brocki & Wearden, 2006; Bryman, 2016). However, today there is a growing body of research using a naturalist, interpretative paradigm that is informing both social sciences and healthcare (Creswell, 2013; Dowling, 2007; Silverman, 2013; Smith, Flowers & Larkin, 2009; Smith & Osborn, 2004). This growth may be due to the aim of this approach, which is both to reduce the distance between the researcher and those being researched and maximise the value of the researcher and how they relate to the focus of the research and the research process (Creswell, 2013; Dowling, 2007; Silverman, 2013). However, this positivist approach also may be related to people who work within health settings having an innate interest in hearing others stories and learning about peoples experiences (Brocki & Wearden, 2006). People's perceptions of health-related experiences cannot be isolated or tested in component parts, due to the interconnected nature of human beings and the phenomena they experience, which provides a major challenge for the positivist approach. This along with a move to recognise and value the individual experience and person-centred approaches to studying healthcare could also be contributing to the growth in the use of positivist approach.

Following the exploration of the ontological and epistemological perspectives within the research paradigms, the author's choice of paradigm rests with a constructivist philosophical methodological view and therefore will be more aligned with qualitative approaches and methods. The rationale for adopting a constructivist methodological approach is multifaceted. The constructivist paradigm views the construction of reality, as a result of both the participants' and the researchers' perspectives, and their values along with their interpretation of phenomena. The constructivist paradigm conceptualises that individuals develop their own meaning from how they perceive and encounter the world and that this meaning evolves over time (Brocki & Wearden, 2006; Smith et al., 2009). This study aims to examine the perception of male caregivers in relation to how they view their role, the support available and how this view impacts on decision making. It will therefore draw on personal experiences, values and meaning. The study is explorative, in that it aims to bring to the fore the experiences and perceptions of male caregivers. These perceptions will have evolved during the caring experience, making the constructivist paradigm a good fit for the study. The study provides an opportunity to explore individual and various realities that evolve and change over time and experience, rather than having a fixed and objective, value free understanding of phenomenon that the positivist paradigm holds (Smith et al., 2009).

3.3 Quantitative Research

The positivist paradigm is predominantly evident in quantitative research approaches (Creswell, 2013). Quantitative approaches more often focus on measurable and quantifiable data (Bryman 2016). Bryman (2016) goes on to say that quantitative research is static and structured using hard and reliable data to test theory, often placed in artificial settings. Quantitative research tends to involve large, representative data, relatively speaking, with a view to gathering facts and data to generate new knowledge (Blaxter, Hughes, & Tight, 2006). As a research strategy, quantitative research is viewed as deductive in nature (Bryman, 2016) and it is described as controlled and measured, with an objective stance producing reliable and replicable data that supports generalisability, while assuming a stable reality (Oakley, 1998). This quantitative research approach does not align to this study, due to its focus on the individual experience and personal meaning made of it. The individual focus does not align with producing replicable data that is generaliseable.

Measures of reliability and validity are associated with quantitative research approaches where the structured, methodical, replicable, demonstrable objectivity of both the process and the researcher engagement with the data is essential (Maltby, Williams, McGarry, & Day, 2010). These factors, however, are not what qualitative researchers are interested in or how judgements should be made in relation to qualitative research. Qualitative research approaches use an alternative and more appropriate set of criteria against which to make informed decisions about the quality of the research.

3.4 Qualitative Research

Qualitative research relates to an interpretive or naturalistic approach and sits within the constructivist paradigm. Qualitative research sets out to study phenomena in their natural setting, in order to make sense of it and/or to describe, interpret and draw meaning from it (Donmoyer et al., 2016). Qualitative approaches are sensitive to the people and environment under study, the data, which is predominantly words rather than numbers, gathered and analysed to establish patterns or themes (Creswell, 2013). Qualitative research is complex and not easily explained, due to its interwoven assumptions, concepts and frameworks. Terms used to describe qualitative frameworks include constructivist, interpretive, post-modern and feminist, among others, and it is via these frameworks that the approaches to qualitative inquiry emerge (Creswell, 2013). Ethnography, Grounded Theory, Phenomenology and Case Studies are four of these key qualitative research approaches and will be discussed here.

3.4.1 Ethnography

Ethnography is an approach to research that can be both qualitative and quantitative. Ethnography has its roots in anthropology, its main feature is the way in which it differs from other approaches, with its focus on culture (Holloway, 2008). Ethnography examines the values, beliefs and norms of a given culture, sub-culture or social group and the power structure in which they operate (Holloway, 2008). A distinction is often made by considering two types of ethnography: descriptive and critical. Descriptive ethnography is the description and analysis of cultures and sub-cultures to uncover patterns. Critical ethnography is usually on a larger scale (macro-ethnography), where the researcher studies social factors, for example power to generate change (Hansen, 2006; Holloway, 2008). This study will focus on male caregivers of partners with Alzheimer's dementia and therefore is not likely to recruit a large sample of participants, therefore this approach is not best suited. Although there could be value in a larger scale study of male caregivers to bring about new understanding of this group and the socially constructed role of caregiver.

3.4.2 Grounded Theory

Grounded theory is a qualitative research methodology that aims to illicit issues of importance through inductive processes, and then goes on to develop related theory (Ghezeljeh & Emami, 2009). Meaning is created through the analysis and coding of the data collected (Ghezeljeh & Emami, 2009). Drawn and developed from the work of Glaser and Strauss, and then later Corbin and Strauss, grounded theory sets out to draw to the fore the important issues from the stories of participants via the analysis of data, with the researcher remaining neutral and with no pre-conceived ideas (Bryman, 2016; Ghezeljeh

& Emami, 2009). Once identified, a unified theoretical explanation (Corbin & Strauss, 2015) for a process, phenomenon or action is developed, hence the theory is “grounded” in the data gathered. In grounded theory, theoretical sampling is the process of gathering data to be used to develop and confirm the theoretical categories and to define the concepts, processes or phenomenon being studied (Silverman, 2013).

Historically, grounded theory has developed in different ways with Glaser and Strauss disagreeing about the meaning and processes of grounded theory (Creswell, 2013); Glaser’s view is that of a “critical realist” who assumes an objective and neutral stance as the researcher. Glaser considers Strauss’s view to be too prescriptive and structured (Creswell, 2013). In grounded theory, ontology and epistemology merge because the ‘knower’ becomes inseparable from whatever is known (Ghezeljeh & Emami, 2009).

Charmaz, (2006) first developed an alternative grounded theory approach: constructivist grounded theory in 2002, which she describes as between the two and examining people in their natural setting. Charmaz, (2006) goes on to note the reciprocal relationship and interaction between the participant and the researcher is key to the construction of the data.

Some of the challenges for researchers using this methodology come from the need to set aside any theoretical ideas and assumptions, to allow theory to emerge from the data (Creswell, 2013). There is also a potential lack of flexibility when using Corbin and Strauss’s approach, which is reported to be more prescribed (Ghezeljeh & Emami, 2009). Grounded theory would align well to the aim of this study and the research questions through taking a focus on the stories of the participants. However, the requirement to detach from the phenomenon being explored would in my view be challenging given my history of involvement with family caregivers and my reason for undertaking this study. Therefore, constructivist grounded theory would be a better fit. As the intension of this study is not to generate theory. Rather it is to bring into focus new understandings and illuminate the way men experience caregiving for their partner and the meaning they make of this experience. Hence, the uniqueness of a constructivist grounded theory exploration would not offer the data needed to develop and confirm new theory.

3.4.3 Phenomenology

Phenomenology, as a methodological approach, focuses on meaning through describing a common experience or phenomenon (Creswell, 2013). A phenomenological methodology reports on the experience of individuals and aims to draw common meaning or the essence of the experience (Silverman, 2013). There are two main schools of phenomenology that have generated different approaches that have been widely used in social science research (Bryman, 2016; Moran, 2000).

Drawing on the writings of Husserl (1859 – 1938), the key principle of phenomenological inquiry is that experiences are considered in the way the individual encounters them and the meaning the person draws from that experience (Smith et al., 2009). It is through the examination of these individual experiences and the meaning constructed from them, that Husserl believed individual meaning could then transcend to a common meaning used to illuminate the experience to others (Creswell, 2013; Smith et al., 2009). To examine an experience in a phenomenological way, Husserl suggests that the researcher needs to “bracket” out or disengage from the phenomenon and consider the consequences of “taken for granted” experience, to be able to consider the perception and meaning made (Smith et al., 2009: 15). This bracketing out of pre-judgement to avoid contamination of the meaning was articulated by Husserl and is a strategy to ensure the purest data possible is captured (Abalos, Rivera, Locsin, & Schoenhofer, 2016) and is referred to as reductionist or descriptive phenomenology. Although highly conceptual and generic, Husserl (1859-1938) recognised that his work focused on the inquirers perspective and first person processes rather than that of others, and it is suggested that this recognition is underdeveloped in his writings (Smith et al., 2009). Due to this, phenomenology is described as a philosophy rather than a research methodology, and has been described as complex and challenging to use (Dowling, 2007). Despite this criticism, Dowling goes on to note that phenomenological approaches in health which relate to research continues to grow. This has shown to be the case (Ivey, 2019; Morley, 2019), perhaps due to the ontological and epistemological backdrop and the value of the individual, lived experience that aligns well with those who work in health, where there is a focus on individualised approaches to working with people and an emphasis on being person centred.

Heidegger (1889 – 1976), who was a student of Husserl further developed this original philosophy. Heidegger's evolution of phenomenology was described as interpretive or hermeneutic (Koch, 1995). Hermeneutics is the theory of interpretation (Smith et al., 2009), and deviates from Husserl's original writings in relation to the subjective experience. Heidegger embraced the subjective experience through focusing on being a person in the world or "Dasein" (Dowling, 2007; Koch, 1995). Heidegger advocates that the philosophy is founded on the ontological stance that the lived experience is interpretive and consciousness cannot be detached from the experience (Dowling, 2007). Heidegger (1996) and later Merleau-Ponty (2012) and Sartre (1956), each established the view that a person is embedded within their world that includes objects, relationships, language and culture, all of which relate to our unique understanding of the world and how we interact with it (Smith et al., 2009).

It is considered that the growth in phenomenological approaches used in nursing and health related research, is due to the notion of the lived experience (Heinonen, 2015; Smith et al., 2009). The lived experience focus in phenomenology and the nature of nursing seems neatly aligned with examination of the individuals experience of health care and how it is perceived (Dowling, 2007; Heinonen, 2015; Smith et al., 2009). For this study, the examination is on the experience of men who care for their partners with Alzheimer's dementia and will take on a phenomenological approach to capture this experience from the individual perspective.

The research aim of this study is a good fit with a predominantly qualitative approach due to its focus on the individual experience and meaning making. As the aim of the research is to explore the perceptions of family male caregivers and the way in which their view of support services. Hence, the qualitative methodological approach taken is hermeneutic phenomenological in nature, as aim is to provide opportunities to examine the lived experience of male caregivers and to understand the concepts, values and meaning they make drawn from these experiences. Personal close connection with the topic and focus of the research and the years spent working with family caregivers, would make bracketing out pre-conceived ideas required for descriptive phenomenology challenging. More importantly, however, I consider value in the recognition of my engagement and what it might bring to the research and the way in which it informs the analysis process. This consideration offers closer alignment to interpretive phenomenology, where the involvement of the researcher is recognised and made transparent in the research process (Ivey, 2019; Morley, 2019; Polit & Beck, 2012). This approach of interpretive phenomenology, is in line with the way in which these researcher's view the world and the value placed on the individual, personal meaning derived from the experiences people have in their lives (Bryman, 2016). It also aligns with the researcher's constructivist epistemological stance.

The aforementioned evaluations of qualitative research require an alternative set of criteria from the traditional, positivist judgements of objectivity, validity, and reliability (Northcote, 2012). Northcote (2012) posits that the dominance of quantitative research and the view that it is superior, devalues qualitative research and at worse attempts to evaluate qualitative research based on its criteria. Northcote (2012) has gone on to argue that due to the diversity and complexity of the participants, qualitative research should be evaluated using an alternative criterion that aligns with the epistemological perspective of the researcher. The measures used to evaluate qualitative studies should therefore be based on the trustworthiness of the approach taken, the clarity of how it is communicated and the transparency of the process (Northcote, 2012). In relation to the interpretive phenomenological approach, this frequently involves reflexivity and clear accounts of each stage of the research process which offers clarity through documenting researchers thoughts, feelings and how they relate to the study as it progresses (Berger, 2013; Smith et al., 2009).

3.5 Research Design

The research design relates to the plan put in place to conduct the study, often described as a framework used for the collection and analysis of data (Bryman, 2016). In essence, the overarching methodological perspective is determined by the views and beliefs of the researcher. However, the chosen design must also be seen as the best “fit” for the study to show there is clear alignment (Blaxter et al., 2006). In order to achieve this alignment, consideration must be given to the type of evidence that is being gathered, sample size and data type (Silverman, 2013; Smith et al., 2009). Creswell (2013) suggests that designing any qualitative research requires three key components: Preliminary considerations, Steps in the process, and Elements in all phases of the research. Preliminary considerations relate to the nature and focus of the study, the questions to be answered, the theoretical perspectives, the researchers own background, and the literature surrounding the phenomena. Steps in the process relate to the “lens” in which the phenomenon will be viewed, the questions asked, and how data is to be analysed. Elements in all phases of the research, recognise the story that unfolds and the ethical perspectives and how the narrative that flows from the research is shaped (Creswell, 2013).

3.5.1 Nature and Focus of the Study

The primary consideration or aim of this study is to explore the perceptions of male caregivers of partners with Alzheimer’s dementia and identify the factors that encourage and inhibit decisions to access respite and support services. The research questions are: How male caregivers of partners with Alzheimer’s dementia experience and perceive respite and support services; How male caregivers of partners with Alzheimer’s dementia make decisions about accessing support services; What male caregivers of partners with Alzheimer’s dementia perceive as the enablers and inhibitors to accessing services? And what male caregivers of partners with Alzheimer’s dementia perceive as the benefits of accessing support services? These questions focus on the lived experience of men in this specific caregiving role, with a view to better understanding their experiences from their unique perspectives.

3.5.2 Data analysis

Qualitative data analysis is viewed in different ways, often seen as a continuum with reduction of data to only that which is relevant at one end and a more holistic approach that allows themes to emerge at the other (Holloway & Wheeler, 2010). Inductive approaches to analysis attempt to avoid rigidity and encourages the researcher to put to one side the research questions, with a view to allowing what the data is saying to emerge (Bryman, 2016). Although it is important to recognise and stay in touch with the research focus, it should not determine what is sought in data (Bryman, 2016; Holloway & Wheeler 2010).

Interview analysis is said to be complex, and due to this complexity, it has been informed by researchers in multiple disciplines working from diverse perspectives (Roulston, 2014). Although there is said to be no right way to analyse interviews, Roulston (2014) proposes that researchers can advance qualitative research by carrying out informed, thorough, and transparent analysis situated in particular theoretical traditions.

The nature of the data gathered will influence the selection of analysis method. For example, Discourse analysis is an analysis method that focuses on the language, written or spoken (Hansen 2006) and Thematic analysis, is where key themes are identified during the analysis process (Bryman, 2016).

3.5.3 Interpretive Phenomenological Analysis (IPA)

IPA is an approach to qualitative research design that offers insight into how an individual in a particular set of circumstances makes sense of the phenomena in question, or the focus of the enquiry (Maltby et al., 2010) and will form the steps in this research process. IPA has its roots in psychology and has been developing over the past 20 years as an effective research method in healthcare (Pringle et al., 2011; Wagstaff, 2014). Often described as an experiential qualitative research approach, IPA is considered a good approach for research that focusses on phenomena that is not fully understood, complex or where there is a lack of previous exploration (Maltby et al., 2010). This is precisely why IPA is important in the area of male caregivers of partners with Alzheimer’s dementia, where as demonstrated within the literature review, there is no research into the area of male caregivers and their perceptions of decisions to access support and services. The key task for the researcher using an IPA approach is to “interpret and contextualise that person’s views from a psychological perspective” (Maltby et al., 2010: 148). IPA provides a framework to examine human lived experience, in this studies case, the male caregiver, in fine detail (Smith et al., 2009) which is an essential first step in gaining insight into the male perspective.

3.5.4 Foundations of IPA

IPA is influenced by 3 core theoretical perspectives: phenomenology, interpretation, and ideography (Smith et al., 2009). Smith et al. (2009) argue that IPA is phenomenological in that its focus is on the individual lived experiences, which as far as possible is expressed in their own terms and not by a set of pre-determined definitions. IPA recognises that individuals draw meaning from the experience of being in the world and it is from this meaning that reality is constructed. Smith et al. (2009) note that the challenge for researchers using IPA is how to translate phenomenological philosophy into a logical and coherent method of collecting and analysing third party data. Jonathan Smith is recognised as key author in the development of IPA, stresses that the different emphases of philosophers; Husserl, Merleau Ponty, Sartre and Heidegger shift from the focus on the experience and perception described by Husserl to the view of the person immersed in the world by Heidegger, should be seen as complementary rather than competitive (Smith et al., 2009).

Thus, Smith et al. (2009) consider these different philosophical views as collectively leading to a *“…mature, multi-faceted and holistic phenomenology”* (Smith et al., 2009: 34). Smith et al. (2009) go on to state that IPA is influenced by the core phenomenological philosophy and operates within the intellectual sphere of phenomenology, although clearly aligns to the interpretative rather than descriptive school of thought. However, Pringle et al., (2011) argues that there are challenges in relation to applying phenomenology appropriately due to these historical differences but suggests that IPA offers greater “ease of use” while maintaining its philosophical roots. However, (van

Manen, 2018) challenges Smith’s work, stating that IPA is out of kilter with the phenomenological tradition, which in the main is existential and therefore in direct contrast to the “physiological interpretation” of biographic data that van Manen describes IPA to be (Van Manen, 2017). This debate is unresolved and, in my view, appears to be related to the adherence to the founding principles of phenomenology, given that each person creates their own meaning and the double hermeneutic cycle in IPA. In essence, the researcher makes meaning of the participants’ meaning, which is a process that fundamentally shifts the focus onto the lived experience.

It is clear however that IPA is heavily influenced by hermeneutics, as it involves a significant level of interpretation in order for the phenomenon to come to the fore, or appear as it is seen as the researchers’ role to facilitate this unfurling process. Smith et al. (2009) notes that this drawing out process involves a close engagement of the researcher. To address this close engagement, a process of reflexivity is required for the researcher to be aware of their preconceptions. Smith et al. (2009) goes on to suggests that if attention is given to the cyclical process of reflexivity, positive engagement and recognition of the influence the close engagement has had on perceptions, researchers are able to, as far as possible, recognise prejudgment and preconceptions through the process thus supporting the trustworthiness of the approach. The attention to reflexivity in IPA literature is said to help to further address the issue of preconception, which is different compared with other qualitative approaches (Brocki & Wearden, 2006; Pringle et al., 2011).

Smith and Osborn (2004) describe the IPA approach as involving a double hermeneutic; with the researcher making sense of the participant who is making sense of the phenomena. This, and the interpretation of the meaning drawn out through this reflexive and cyclical process, can then be judged as appropriate and therefore goes beyond the standard thematic analysis, due to the depth of descriptive and interpretive analysis (Pringle et al., 2011). In essence, the quality of the research is said to be enhanced, as researchers who choose this approach set out to openly reflect on their role in the dynamic process of analysis, which is via the reflexive cycle and thus demonstrates transparency and openness (Brocki & Wearden, 2006; Pringle et al., 2011; Smith et al., 2009).

A significant influence on IPA is that of ideography. Ideography is concerned with the particular, which in IPA relates to both the particular phenomenon and the specific fine detail related to the phenomena, as it is understood by a specific group within a specific context (Smith et al., 2009). This is in contrast to nomothetic inquiry, which is concerned with group or population level perspectives to bring about the establishment of general laws or principles of human behaviour (Smith et al., 2009). Idiographic inquiry is said to be unsuitable for theory development, due to its focus on the individual. While nomothetic inquiry develops generalities based on averages in which the individual perspective is lost (Pringle et al., 2011; Smith et al., 2009). Therefore, it appears when considering this that idiographic inquiry is better suited to phenomenology, while nomothetic inquiry is better suited to grounded theory.

3.5.5 Rational for research design

This study adopted a phenomenological approach and used Smith et al. (2009) IPA step guide for the analysis, informed the elements in all stages and the narrative that flows from the research. It is clear that there is some debate about the potential loss of the unique individual perspective through this interpretive process and so it was essential that I adopted some caution to maintain a phenomenological stance and stay true to the focus on the unique meaning for the individual (Van Manen, 2017). This design was chosen due to the researcher's philosophical paradigm and methodological alignment previously discussed. The rationale for the selection of this design is related to the research aims and questions and is considered to be the best fit for the study for a number of reasons. The research aim was to examine and explore the perceptions of male family caregivers of a partner with Alzheimer's dementia, with this requiring exploration of how an individual, in a particular set of circumstances, makes sense of their experiences in line with IPA. The study is not setting out to identify an objective, generalisable statement about this experience. Rather it is exploratory in nature, due to limited understanding of male caregiver perspective in the current body of knowledge. The study therefore aimed to gain understanding of the individual experience and meaning drawn from caring as this perspective was not fully explored and understood.

The decision to adopt IPA was also linked to the sample and context. The role of caregiver is complex, and each person will perceive this experience differently, therefore constructing individual meaning from the experience, making the study ideally suited to an IPA approach (Smith et al., 2009; Wagstaff, 2014). As the researcher, I have an interest and experience of supporting family caregivers of people with dementia. Due to this experience it was essential that the research design chosen allowed for any potential preconceptions to be transparent. IPA, with its focus on hermeneutics and the importance of reflexivity, helped identify the potential preconceptions, explore and be aware of them in order to minimise bias (Smith et al., 2009). This is demonstrated through the open examination of researcher perceptions, thoughts, feelings and self-awareness.

Due to the complexity of the lived experience of caregiving, selecting a research design that allows for a highly detailed examination of the specific or particular experience was needed. The population targeted can be considered ideographic due to their gender, caring role and who they care for, as well as the condition which affects the individual receiving care. Having an ideographic sample fits well with IPA (Smith et al., 2009) and so further supports the choice made in this study.

3.5.6 Sampling strategy

The “sample” refers to the research participants used in a given study and are considered so as they represent a “sample” of the population (Bryman, 2016). The “population” is relative to the study, for example a population could be nurses within the United Kingdom, or nurses within one specific ward or unit. For quantitative research, the aim is to produce a sample that is representative of the population targeted and that this sample is statistically representative (Green & Thorogood, 2014). A probability sample strategy would often be used for this purpose, where there is an equal chance of individuals being selected to participate. In qualitative research design, the sample strategy hinges on other considerations, for example the aim of the research and research questions being asked, the method of data collection proposed and the number and access to potential participants (Bryman, 2016; Green & Thorogood, 2014).

Decisions about sampling are not straightforward; there is no definitive answer to questions about sampling. Often the decisions made about the sample size (number of participants) and strategy or scheme (how to select the sample members) are affected by practical issues concerning time and cost, rather than being made upon methodological considerations (Bryman, 2016; Collins, Onwuegbuzie & Jiao, 2006).

Sample scheme or strategy falls into one of two main classes: random or non-random sampling. Collins et al. (2006) identified 24 sampling schemes available to researchers when she explored the range of schemes used for sampling within four key psychology journals. Included in Collins et al. (2006) overview was the minimum sample size recommended for the *"most common quantitative and qualitative research designs"* (Collins et al., 2006: 86). Phenomenological studies, due to their depth and focus on individual experience, recommend either less than 10 interviews or more than 6 interviews being undertaken (Finlay, 2014; Noble & Smith, 2015; Smith et al., 2009). Hence, a maximum of 10 was set for this study, although at the time it was identified that this population may be hard to reach.

Sampling is closely related to the issue of generalisability (Higginbottom, 2004), which is often not a concern of qualitative studies. However, Higginbottom (2004) proposes that sampling is important for qualitative researchers and particularly in health care for two reasons; first that health research often relates to people who are individual, complex and unpredictable and the second reason is the potential significant population size. Higginbottom (2004) also notes that no research design is without criticism, but it is up to the researcher to ensure that an effective sampling strategy provides the firm grounding for honest and reliable conclusions to be drawn. Higginbottom (2004) summarises that qualitative researchers need to be open and transparent in relation to sample strategy as a way to increase the credibility of qualitative research. However, notes that few researchers give this level of detail. Due to this requirement, it is stressed that qualitative researchers should clearly articulate the sample strategy in order to demonstrate “validity” and “credibility” (Higginbottom, 2004; Topping, 2006; Tuckett, 2004). Although, questions have been asked about the pressure on qualitative researchers to be assessed against quantitative research quality measures (Northcote, 2012), with clarity about the sample and manner the participants were selected, ensuring openness and trustworthiness of the process. Qualitative sampling techniques are noted to be complex and therefore should be guided by frameworks or principles (Higginbottom, 2004). These sampling techniques are said to be further complicated when a mixed method design is employed (Collins et al., 2006). For this reason and the potential challenge of reaching appropriate numbers in this population, a solely qualitative approach is chosen for this study.

As the focus of this study is on specific detail and rich data, qualitative sample strategies are more often derived purposefully, as opposed to randomly (Bryman, 2016; Higginbottom, 2004; Tuckett, 2004). Smith et al. (2009) agrees and notes that sampling method must also be theoretically aligned to a qualitative paradigm but adds that this is particularly important in studies that adopt IPA. Smith et al. (2009) goes on to say that participants selected for an IPA study should be identified as they *“have access to a particular perspective on the phenomenon under study”* (Smith et al., 2009: 49). Due to this study having a focus on male caregivers of a spouse with a diagnosis of Alzheimer’s dementia, the sample strategy needs to be purposeful. The criteria of male caregivers, specific diagnosis of Alzheimer’s dementia, and specified relationship between caregiver and receiver, means that this sample strategy needs to be criterion based to increase the homogeneous nature of the participants (Collins et al., 2006). In addition to the criteria set for this study, the issue of access to family caregivers, and specifically male caregivers, could prove to be challenging. Therefore, the sample strategy needed to consider the way in which the potential participants could be identified. As such, a Snowball or Chain approach (Collins et al., 2006) was adopted for this study, so that the researcher could identify through initial contacts and groups, further potential participants for the study. This approach maximised the opportunity to reach potential participants. Tuckett (2004) suggests that for qualitative research, the approach to sampling should be flexible enough to allow for changes in the criteria, as the study unfolds. This flexibility allowed a range of sample strategies to be adopted.

3.5.7 Sample

As stated, close consideration needs to be given to the sample, as there are a number of potential barriers to accessing male caregivers, and particularly those caring for a close relative. Partner caregivers frequently do not identify themselves as “caregivers”, and adopt a caregiving role as part of their “partner” role (Chrisp, Tabberer, & Thomas, 2013). In line with the principles relating to sample size for a phenomenological study, a maximum of 10 male caregivers of partners with Alzheimer’s dementia were sought to participate in this study. The purposeful criterion based, snowball approach taken to identifying this specific group of caregivers for the study, resulted in 9 potential participants being identified. This sample size was appropriate for the nature of the study, the aim and research questions, and the practical aspects of the study.

Although there is some debate surrounding the ideal number of participants in an IPA study (Vasileiou, Barnett, Thorpe, & Young, 2018), Smith et al. (2009) encourage that there is no right answer, and that the importance should be placed on gaining a homogeneous sample to ensure that the study is relevant and significant for the participants, and to aid the researcher in capturing the essence of the phenomenon. The more specific the experience, the more challenging it may be to reach participants (Vasileiou et al., 2018). However, the more homogenous the sample would be (Noon, 2018), thus providing the rich detailed personal account of the experience, required for IPA studies. Noon (2018) reports that IPA studies can include as few as four participants and up to 10, but the emphasis should be on the detailed data and depth of the analysis. Vasileiou et al. (2018) argue that the more “useable” the data collected from each person; the fewer participants are required. Reference has also been made to the use of saturation, originating from grounded theory, saturation is considered the point where no new themes or codes are arising from the data being analysed (Morse, 2015). The demonstration of saturation has therefore become a quality measure in relation to qualitative research. However, according to Morse (2015), this is a quality measure that little is known about. Added to this, saturation is reported to be less applicable for phenomenological research due to the smaller sample size (Vasileiou et al., 2018), therefore highlighting the importance of ensuring depth and detail are gained in the data gathered for an IPA study.

Specific consideration was given to the recruitment of the sample for this study. Men caring for their partners could be a group that is hard to reach, particularly given the indication that men are less likely to seek support (Bronner et al., 2016). Men may also be reluctant to talk in depth about their caregiving role, due to the personal and emotional nature of caregiving (Robinson et al., 2014). To maximise the recruitment of participants, and to reduce the potential barriers for men participating, only one interview per participant was sought. This was to minimise the perceived commitment and time dedicated to the involvement in the study. The recruitment strategy remained open over the duration of the study and throughout the initial individual analysis process. As participants were interviewed, reflexive discussions were maintained with the supervisory team. Discussions were held around the depth and detail that were captured in the early interviews. In addition, we explored the potential influence of initial analysis on later interviews. The two initial interviews generated rich data, with both men exploring their perceptions and experience of caregiving in depth. This indicated that the single interview approach was suitable to gain the detail required. All but one interview lasted over one hour, with most lasting well beyond (see Table 3.2: Biographical Details of Study Participants), offering a substantial amount of data to be transcribed and analysed. As the research progressed, recruitment was closed before the final analysis step was commenced to enable focus on the final stage that involves looking across the sample (Smith et al., 2009).

Information relating to the study was disseminated through caregiver networks, groups and organisations that have direct contact with caregivers. Using this approach ensured that the information was targeted to those support services that were knowledgeable about the target group, thus allowing for focussed identification of potential participants. This minimised invitations to participate in the study going out to people who did not meet the inclusion criteria. Once groups and individuals were identified a snowball approach was used to identify further groups or individuals who met the inclusion and exclusion criteria. This approach was successful at recruiting 7 participants, who were invited and agreed to be interviewed, which provided the data used in this study. Two further participants initially replied to the invitation to be interviewed but subsequently were not able to participate. One due to a significant deterioration in his wife's health and the other due to geographical issues and costs for travel.

3.5.8 Inclusion and exclusion criteria

The aim of the study directs the inclusion and exclusion criteria. In order to maximise the homogeneity of the sample, a requirement for studies using IPA (Smith et al., 2009), a set criterion was needed for this study. In order to identify men who have experience of caring for a partner with Alzheimer's dementia an inclusion and exclusion criteria was set and is outlined in Table 3: Sample Inclusion and Exclusion Criteria.

Table 3. 1: Sample Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
Male	Female
Currently caring for a partner with Alzheimer's type dementia	Former caregiver
Able to communicate in English	Currently caring for a family member (not partner) or friend
Able to participate in a spoken one hour interview	Currently caring for someone with dementia that is not Alzheimer's type
Caregivers who are accessing support networks.	Unable to communicate in English
Caregivers who have been caring for over 6 months	Unable to participate in a spoken interview
	Caregivers caring for someone with a recent diagnosis of dementia

The inclusion and exclusion criteria ensured that the sample was as homogeneous as possible, while acknowledging that perceptions and therefore meaning is individually constructed. A homogenous sample is in line with the inductive logic of IPA (Smith et al., 2009) and so by constructing the inclusion and exclusion criteria the researcher is maximising homogeneity. By setting criterion relating to diagnoses and gender, the sample population is further refined and therefore aids targeted identification of the sample population. The criterion also supports the identification of individuals who share common caring experiences, as the specific type of dementia diagnosed will determine the likely course and symptomatology of the condition (WHO, 2012), outlined in Chapter 1 (1.6).

Former caregivers and caregivers of people other than a partner were excluded from the study as the role and relationship is significantly different and therefore the not a good fit for an IPA study (Smith et al., 2009).

Individuals who were new to caregiving, for example, those who had a recent (within six months) diagnosis of Alzheimer's, were excluded. This was due to the potential emotional impact of the diagnosis, as well as the newness of the caregiving experience. Caregivers who are new to caregiving are less likely to be utilising services at the early point in caregiving. The age of the caregiver was not considered in the inclusion and exclusion criterion, as the age range was limited through the diagnosis, which is unlikely to affect younger people (WHO, 2012). Although it could have been valuable to consider the experience of caregiving from the old and oldest age groups as it may be experienced differently.

The remaining inclusion and exclusion criterion were set to overcome practical issues. For example, language barriers, accessibility and capacity to participate in a verbal interview (Bryman, 2016). These parameters were set due to time constrains of the researcher and to minimise additional costs and time, for example travel and translation processes. Biographical details of the 7 participants interviewed and included in the study are outlined in Table 3.2.

Table 3. 2: Biographical Details of Study Participants

Caregiver & Year interviewed	Age	Relationship with cared for	Length of time caring	Home environment	Family	Work / employment	Interview length
Andrew 2015	76	Husband	6 years	Own home, semi-detached house	One son and one daughter, not local	Professional, Retired before caregiving	97 mins
Bill 2015	72	Husband	5 years	Own home, terrace house	One son, local	Builder, Retired due to caring	92 mins
Cameron 2016	72	Husband	4 years	Own home, semi-detached house	Two daughters, local	Post Office worker, Retired before caregiving	106 mins
Eric 2016	70	Husband	4 years	Own home, terrace house	Brother and sister-in-law	Long distance driver, Retired due to caring	58 mins
David 2016	68	Partner	4 years	Own home, flat	Son from previous relationship	Electrician & Retail worker, Retired due to caring	88 mins
Frank 2017	76	Husband	3 years	Own home, detached house	One son estranged	Construction supervisor, Retired before caregiving	95 mins
George 2018	80	Husband (second marriage)	5 years	Own home, detached house	Two children from first marriage	Office manager, Retired	83 mins

						before caregiving	

3.5.9 Data Collection

Interviews are noted to be one of the main methods of gathering data in qualitative research (Bryman, 2016; Holloway & Wheeler, 2010; Vivilaki & Johnson, 2008). An interview is a dialog between the researcher and the participant, which aims to uncover data. It is a method used in qualitative research, both on its own and in conjunction with other methods (Holloway, 2008). Doody and Noonan (2013) explore the interview continuum and state that structured interviews are a useful way of ensuring consistency but can be limiting due to lack of elaboration. For example, when a participant requires prompting or additional explanations to bring about deeper and more meaningful responses. At the other end of the continuum, the unstructured interview offers an opportunity to gather a broad range of responses, but can be troublesome in relation to processing data and making linkages between respondents (Doody & Noonan, 2013), due to the quantity of unrelated data generated (Holloway & Wheeler, 2010). It is proposed that it is for these reasons that the semi-structured interview is currently the most popular method used for data collection in health-related research. This point is supported by Holloway and Wheeler (2010) who note that the semi-structured interview is the most common form of data collection in health-related research and is the method of choice for the novice qualitative researcher.

Other qualitative methods could be used to gather data to meet the research aim of this study. Qualitative data collection methods are wide ranging and can include questionnaires, observation or focus groups (Wagstaff, 2014). An initial focus group or a questionnaire could provide preliminary identification of core themes that relate to male caregivers and their perspectives of support and respite services, decision making and perceived benefits. However, the risk may be that male caregivers do not engage in group discussion about the emotional aspects of caring and decision-making approaches to caring, or that there could be practical and geographical issues with bringing groups of caregivers together. Observations of caregivers making decisions about care and support services would not be practicable for the study due to changing circumstances and events that caregivers experience, which can be sporadic and unpredictable. Individual interviews were therefore considered the most likely method of providing data required for this study.

IPA requires rich data, and this indicates that the participants should be given as much opportunity as possible to speak freely. This open dialogue offers the space required to reflect, explore and develop ideas and express them in ways that make sense (Grossoehme, 2014; Smith et al., 2009). This approach lends itself well to an unstructured approach to data collection. However, the researcher must be cognisant of addressing the research aim and questions and be able to “steer” the free flowing dialog to ensure it remains focused on the area of study. The value that IPA places on identifying a significantly homogenous sample, in the author’s view, helped to minimise a drift from the area of study while maximising the flow and personal meaning making of the participant. In addition to this, the use of a semi-structured interview schedule provided some guidance and prompts to ensure a consistent approach, while still allowing for a natural flow of the caregivers narrative and avoiding or minimising an overwhelming amount of unrelated data.

It is worth noting that individual interviews also have potential limitations that require consideration. Such limitations are dependent on the interpersonal and communication skills of the interviewer (Bevan, 2014; Doody & Noonan, 2013). Interviews as also time consuming to transcribe, with a one hour interview consisting of up to ten hours work, and requires planning, organisation and travel (Gillham, 2013). However, no research design is without its criticism, and the reason why space has been given in this chapter to show the clear rationale that informed the design and the methods adopted in this study.

3.5.10 Interview schedule

As discussed, there is a value in having some structure or plan for an interview when using an IPA approach (Smith et al., 2009). Both as a novice researcher and due to the need to limit the drift away from the research questions, an interview schedule was developed. Initially as part of the institution’s requirements for excellence in research practice, the schedule was included as part of the ethical approval submission. This process of gaining ethical approval, is to ensure that all potential issues that could have an adverse impact on the participants wellbeing in this study are explored and minimised (Edinburgh Napier University, 2018). The application to the ethics committee (See Appendices 3 - 6) included a Participant Information Sheet (Appendix 3) and a Participant Consent Form (Appendix 4). Alongside these, a clear and detailed interview schedule with prompts was developed and submitted (Appendix 5), and an additional post interview support information and contact sheet (Appendix 6). A list of post interview contacts was developed to mitigate against any emotional distress caused by the participant taking part in the interview. The interview asks the men to share their experience of caregiving, which can be a very personal and emotional experience. Therefore, it was vital that participants were given a range of support networks they could contact if the interview raised any difficult emotions, thoughts and feelings.

In line with the IPA approach, the interview questions are required to be flexible enough to allow for participants to tell their own story in a way that is meaningful to them. This requires careful consideration in order to construct questions in a phenomenological way. Bevan (2014) states that development of the interview questions and research interview process is often overlooked and under-reported in the literature that uses a phenomenological approach. Bevan, (2014) also notes that there is limited guidance or instruction relating to how to conduct phenomenological research interviews arguing that this is problematic given the need to obtain the deep level of detail needed for analysis. This issue is likely to be related to the core principles of phenomenology where the focus is solely on the individual exploring and finding meaning in the experience as they have experienced it and without the influence of the researcher. This has been a debate for some time and is suggested to be one of the core issues with IPA (van Manen, 2018). There are general guides on how to conduct a research interview that include, open ended, flexible and broad questions that illicit first the description of the phenomenon and then the reflection and the meaning from the experience (Bevan, 2014; Grossoehme, 2014). Grossoehme adds that there is value in utilising language that is accessible and in line with the given participant to increase connection and understanding. In essence, the quality of the data gathered is determined by the quality of the questions asked and the format of the research interview (Grossoehme, 2014). This process does, however, require some skill in the researcher to be able to adjust language used in the interview in relation to the given participant.

Gillham (2013) provides guidance to the development of semi-structured interview questions and states that they develop over time and the researcher must “prune” the questions to ensure that they draw out relevant detail. Also, the questions used need to be distinct from each other to address the different phenomena of the study. Gillham (2013) suggests that a pilot interview is helpful in determining the quality of the questions being asked. Guided by this recommendation and the supervisory team, an initial interview schedule was used in the first interview and notes simultaneously taken to identify any issues with the questions, their flow and perceived meaning. No issues were identified with these based on the first interview. However, as the interviews progressed, there were minor adjustments made to suit the individual and the particular circumstances of remaining interviewees. With a small sample, the value of a pilot interview appeared limited. Rather the approach was useful to evaluate, reflect and note the experience of each unique interview, which allowed me to build confidence and a range of resources I could draw from at points where interview questions or prompts drew little detail.

3.5.11 Data analysis

The analysis of the data gathered via the semi-structured interviews started with the transcription of the recorded interviews. IPA is an analytical process that is described as moving from *“…the particular to the shared…”* or from the descriptive to the interpretive (Smith et al., 2009:79).

When using an IPA approach, each transcript is examined line by line to identify the concepts, perceptions and meaning-making of each participant. As the analysis continues the similarities and differences in each interview are considered, which provides an opportunity to reflect on shared experiences or perceptions while keeping hold of the individual voice and variations in the themes that emerged (Smith et al., 2009).

As the analysis is iterative, it is important that the analyst is flexible with the data, which can be open to change throughout the process. The analyst in essence *“thinks about what the participant is thinking”* (Smith et al., 2009:80), this double-hermeneutic approach can sometimes be troublesome and difficult for the analyst. The process can be overwhelming, hence the step by step guide can be reassuring to researchers who are new to IPA.

Smith et al. (2009) goes on to say that due to the subjective analysis in IPA, truth claims are often tentative. However, the clear process and detailed dialogue between the data and the analysis process, along with the systematic, traceable nature of the analytical journey, increased the trustworthiness of how themes emerged. In order to enhance trustworthiness further, a reflexive log was maintained throughout to capture and tease out the researcher’s thoughts and feelings, while engaging in the analysis. Reflexivity is said to be the way in which the researcher can expose and examine the influence or potential impact they have on their research (Buetow, 2019). However, to be effective, this needs to be an authentic, transparent and thoughtful process, rather than a “tick box” exercise, as a way to signpost the reader to the ambition of the research (Jeanes & Huzzard, 2014). Reflexivity has the potential to explore both the ethical stance of the researcher and the researcher identity in context of the environment in which the researcher is based. The process of reflexivity can add to the way in which the researcher engages with ethical considerations and demonstrates the trustworthiness of the research process. Yet, it is said that an overemphasis on the reflexive process can overshadow the focus of the research itself (Jeanes & Huzzard, 2014).

Shaw (2010: 234) describes reflexivity as an *“explicit evaluation of the self”* and encourages that reflexivity is essential in experiential qualitative research, specifically due to the interpretive processes and co-construction of meaning. The phenomenological perspective is embedded in meaning making, being in the world, and what it means to be human. Humans experience the world and make sense of these experiences within the context of our environment. IPA is a complex process of exploring and examining the way participants make sense of their experiences with the researcher making sense of the way participants are making sense. As such, the resulting discourse is double hermeneutic (Smith & Osborn, 2004). It is this complexity in the interpretation of qualitative data that makes the reflexive process and its focus on the relationship between the researcher and the participants' essential in IPA (Shaw, 2010).

A clear and transparent process was maintained by the researcher in relation to the data collection, coding, emergent themes and professional knowledge used in the interpretation. During this process, reading, re-reading and examining each transcript in relation to descriptive content, language used and core concepts, and then re-reading to draw out concepts and meaning and how they are connected to the spoken word. Records of each stage were maintained and shared with supervisors for feedback and discussion. Smith et al. (2009) describe a set of 6 steps in the analysis of data described in Table 3.3: Stages of IPA. These steps informed the stages of each transcript analysis identification of emergent themes, super-ordinate themes and the final group themes, drawn across all participants.

Table 3. 3: Stages of IPA (adapted from Smith et al., 2009)

Step 1	Reading and re-reading the transcripts
Step 2	Initial noting
Step 3	Developing emergent themes
Step 4	Searching for connections across the emergent themes
Step 5	Moving to the next case
Step 6	Looking at the patterns across cases

The analysis process in IPA is completed case by case, with steps 1 – 5 competed for each transcript and the final step, step 6, encouraging the researcher to reflect on the similarities and differences in each transcript, while keeping the individual voice and variations at the core of the analysis (Smith et al., 2009).

3.5.12 Principles of IPA analysis

Drawing from the theoretical underpinnings of IPA; phenomenology and hermeneutics, the principles guiding the data analysis are set around a commitment to the participant's experience (Finlay, 2014), which in this case relates to caring. As the analysis progresses, the level of interpretation and therefore the involvement of the researcher, now analyst, develops. Hence, data analysis becomes a product of both the participant and researcher, hence the notion of double hermeneutic. During the process the researcher makes sense of what the participant is making sense of (Smith et al., 2009); in this case caregiving. Although this process undoubtedly influences the analysis, the core principle and requirement for the researcher is to transparently narrate the themes and specify the essence of the participants' experience (Finlay, 2014; Smith et al., 2009).

3.5.13 Process and strategies for analysis

The analytic process in IPA suggests that there is no single prescriptive method. In fact, literature surrounding the use of IPA values its flexibility (Cronin-Davis, Butler, & Mayers, 2009; O'Mullan, Doherty, Coates, & Tilley, 2019), as it offers opportunities for the researcher to allow the participant's narrative to bring to the fore themes. Smith et al. (2009: 79) state the essence of IPA is the focus on the individual participants' attempts to *"make sense of their experiences"*, thus maintaining true to the phenomenological roots; exploring common meaning and drawing out the essence of the experience. The set of processes, principles and strategies that Smith et al. (2009) offer to guide the researcher are of value, as the analysis process can be challenging and overwhelming. The creation of Smith et al. (2009) step by step guide, from my perspective, offers those new to IPA some reassurance that can help reduce anxiety and create a sense of manageability, while still allowing the rich depth of the phenomenon to emerge.

The findings presented in Chapter 4 follow the steps for analysis described by Smith et al. (2009). Each of the transcriptions were read through and listened to following the transcription process (Step 1). Having completed the transcription personally, the researcher felt immersed in the data at this stage. The initial coding (Step 2) of the transcripts was completed individually and in relation to the following: “Description/ content” “Language use” and “Interrogative/concepts/the logic”. This three-point process was completed by hand, with the individual’s initial analysis repeated while re-listening to the audio recording over and over again. This enhanced exposure to and maintained focus on the “voice” of the participant. Initial coding for participants 1 and 7 was shared with the supervisory team to ensure initial coding remained close to the participant’s explicit meaning. This action supported and enhanced the interpretation of the linguistic elements that I found particularly challenging to capture. The process, experience and learning taken from doing this can be found in the section of my reflexive diary (Analysis) in Chapter 6 and (Transcription) Appendix 8. Transcripts and initial coding were also “re-visited” at points following the initial analysis. The flexibility in the step process for analysis was helpful in allowing unanticipated themes to emerge and for the researcher to develop an insider’s perspective (Palmer, Larkin, de Visser, & Fadden, 2010). This is a vital step in the analytical process as it allows for attention to be paid to the participants’ unique perception of the experiences and the meaning they make in the context in which they experience the phenomenon. This attention includes interpretation of the words, phrases and manner in which the experience is narrated, thus giving depth to the analysis.

Re-listening to the spoken word helped to maintain focus on the experience. van Manen (2018: 1863) encourages researchers who use text based transcripts for analysis, to *"refer back to the lived experience that is being focused on",* to ensure that the focus is on how the text relates to the existential sense of the event or phenomenon, which in this case was caring. Examples of this initial analysis process can be found in Appendix 9.

Following the initial coding, is the development of emergent themes (Step 3). This was the point at which I felt a key shift in the level of interpretation. Smith et al. (2009) emphasises that the researcher will take a more central role at this stage. Emergent themes at this stage are phrases that represent the participant’s words and the researcher’s interpretation. In other words, the double hermeneutic cycle (Smith et al., 2009). This process is described in detail in Chapter 4.

Searching for connections across emergent themes (Step 4), is where the emergent themes are mapped, in chronological order through the participant's narrative (Smith et al., 2009) and across the whole transcript. Attention was paid to the experience being narrated, both in relation to the context and the function of the theme, and how it fits with the transcript as a whole. This stage encourages innovation in the analyst to organise the emergent themes. Themes are grouped or synthesised and renamed based on the connections between the themes, which is a process referred to by Smith et al. (2009) as 'abstraction'. Emergent themes can also be subsumed, which is a process called 'subsumption,' and where an emergent theme draws together a number of related themes. These groupings or clusters of themes are then grouped to form super-ordinate themes.

At this stage, I underlined quotes in the transcripts to illustrate or capture the essence of the super-ordinate theme and to highlight potential connections to final themes. This process also allowed me to capture the process and thinking behind the analysis and how it maintained true to the spoken word of the caregiver.

Step 5 in the process of analysis relates to moving to the next case and therefore repeating steps 1 – 4 within each transcription. The challenge for the researcher is being able to look at each transcript as if it were new and not allow pre-judgement based on the prior analysis. Smith et al. (2009) posit that if the analyst systematically works through each step, then the individuality of the next case will emerge, and IPA's idiographic commitment will be maintained. In response to this, during stage 4 of the analysis process, I set about capturing my thoughts and ideas on post-it notes, which I set aside and stored at the back of the analysis papers for each participant. This strategy both captured thoughts and ideas about the super-ordinate themes which could be helpful later in the analysis process. Physically setting themes aside minimised distraction from the caregivers' experience. This was helpful for me to recognise potential influencing thoughts. It also increased my self-awareness and ensured that my researcher knowledge and its potential influence was transparent. Although not a formal attempt to bracket knowledge or experience akin to Husserl's (1859-1938) philosophy, it was an effort to maintain focus on the subjective experience of each participant, yet not lose ideas and interpretation of the meaning as it came to me. This strategy was adopted to ensure that the themes arrived at arose from the data being analysed at that time. It also helped me to maintain focus on the participant's narrative. Step 6 is the point at which a theme emerges, through following the iterative and inductive cycle of analysis, first from a single transcript and then across transcripts (Palmer et al., 2010). It is through this cross-transcript analysis that recurrent themes emerged, although at what point a theme became "recurrent" is debatable. Smith et al. (2009) offer no direct rule for calculating when a theme becomes recurrent, but state that for this to be the case it should appear in "at least a third to a half of all participant interviews" (Smith et al., 2009: 107). From the initial singular experience, the researcher moves to the shared experience, through examining the data and themes across all participants, while maintaining a commitment to the experience of the individual. Step 6 was completed initially, followed by seeking reassurance around the super-ordinate themes, I repeated step 4 a second time for each transcript and then returned to step 6 to create the identified themes from the group (See Appendix 10).

Following this a process of abstraction and subsumption was undertaken and is outlined in Table 3.4.

Table 3. 4: Themes: abstraction and subsumption

→

Group Theme #1	Group Theme #2	Group Theme #3
Support and Services	Accessing Support and Services	Lack of Influence
Decision making	Influence, power, privacy and decisions making	
Loss	Change and Loss due to dementia	Changes and Losses
Health		
History		
Dementia/person with dementia		

Relationships	Changes in Roles and Relationships	Protecting Others
Caring	Caring and Coping with Dementia	

Eight preliminary super-ordinate themes were identified across the 7 transcripts:

1. Decision making
2. Loss
3. Person with Dementia
4. Relationships
5. History
6. Caring
7. Support and Services
8. Health

Following the re-view of the super-ordinate themes six group themes emerged:

Accessing Support, Help and Services. This captured the experience of deciding to use or not use services, the aspects that influenced the decisions, and how the men perceived the support or service.

Influence, Power, Privacy and Decision Making: the perceived impact and influence that the men had on decisions, specifically as they encountered aspects of Alzheimer's dementia that encroached on their normal day to day life, privacy and activities.

Change and Loss due to Dementia: aspects of their shared life that had changes and personal and joint loss.

Changes in Roles and Relationships: the changes men experienced due to Alzheimer's dementia and the influence it had on relationships with their partner and others.

Caring and Coping with Dementia: the aspects of caring, both positive and challenging, adapting and coping with changes encountered and helpful connections with others.

As the themes were explored further and refined by as a result of re-examining the super-ordinate themes from each participant and distilling the essence of their story, the representation of the theme across the group and then how they linked to the research aim and questions, the final common themes that recurred across the sample were:

1. Lack of Influence. This reflects making decisions that the impact and influence of decisions made.
2. Changes and Losses. This captures the scope of change and loss related to caregiving experienced by the participants.
3. Protecting Others. This encapsulates the participants perceived role and duty to protect others through developing coping strategies including adjustment, adaptation, problem solving.

3.5.14 Ethical considerations

Bryman (2016) cites Deiner and Crandell (1978) who broke down ethical transgressions into four main areas:

- Whether there is risk of harm
- Whether there is a lack of informed consent
- Whether privacy is invaded
- Whether there is deception involved

Working with people to explore their views and perceptions will bring ethical considerations relating to consent, invasion of privacy, and potential harm. For this study this would be primarily around the identification and recruitment of participants, clarity and storage of information and consent, anonymity throughout the study and dissemination. It is therefore essential that any risk is anticipated and guarded against (Bryman 2016). A way to ensure that a proposed study anticipates and guards against potential risk is via ethical approval. Edinburgh Napier University, like other universities has a robust and structured ethical approval process. Full ethical approval was sought and was approved by Edinburgh Napier University, School of Health and Social Care Ethics Committee for this study, to ensure that all risks or potential harm are considered and avoided or minimised, a copy of the feedback sheet with the requirements outlined can be found in Appendix 7.

In relation to the method of analysis used in this study, one of the challenges of refining and consolidating themes when the focus is on the individual perspective, is the potential loss of the idiographic element. It is however necessary to be both unbiased, and transparent in what is represented following analysis. For IPA, it is essential that the individual perspective and meaning making is not lost through the analysis process. This is something that can be difficult and is influenced by the sense of responsibility, both ethical and personal, the researcher has for ensuring that the depth of detail provided by the participants is acknowledged and represented in the final themes.

Edinburgh Napier University Code of Practice on Research Integrity (Edinburgh Napier University, 2018), was followed. This Code of Practice promotes the core guiding principles that support integrity in research, which includes promotion of honesty and openness, essential confidentiality, and respect of personal data and protection from harm. Exploring the potential harm related to this study, I identified the risk to participants from exploring their experiences of caregiving and thoughts and feelings related to these experiences. For most caregivers, sharing personal detail will be emotive. It was therefore essential that support and information about caregiver support services was made available to participants following the interviews, hence the use of the Participant De-brief Sheet (Appendix 6) and recommendations from the ethics committee (Appendix 7). This debrief sheet ensured that participants had a source of support if the interview brought to the surface strong emotions or difficult feelings. These concepts were also brought to the surface difficult emotions of researcher, captured in narratives taken from the Reflexive Diary (Interviews) in Chapter 6.

3.6 Chapter Summary

This chapter sets out the rationale for the methodological decisions made in this study. There has been an overview of the philosophical and theoretical perspectives and considerations that influence researchers and therefore the research methodology, which in turn underpin the research design employed. There is no definitive right or universally accepted and agreed research design for a given IPA study. Therefore, it is the role of the researcher to examine and explore the methodological perspectives within the context of their study, their beliefs about the world, reality and knowledge, and the skills and attributes they have and that which are required. Once the methodological approach has been decided, decisions need to be clearly aligned to the study and articulated to the reader to ensure that the validity of the study is recognised.

Chapter 4 - Findings

4.0 Introduction

This chapter presents the findings from the data gathered from seven individual face-to-face interviews with men who care for their spouse/partner with a diagnosis of Alzheimer's dementia. The interviews were carried out between July 2016 and March 2018. All of the participants had been caring for their female spouse/partner at home for more than two years. All couples were over the age of 65, and all were in heterosexual, long term (over 25 years) relationships with the person with dementia, six were married and one was not married. The participants were recruited from third sector caregiver support organisations in central Scotland.

The transcribed interviews provided the core data for this study, but it is through the IPA process in particular, that the analytical steps of IPA outlined by Smith et al. (2009) from which the themes were developed. IPA is underpinned by the theoretical perspectives of phenomenology and hermeneutics (as outlined in Chapter 3) and is centred on how experiences are understood by the individual. Adopting IPA with its principles of interpretation, ideography, gave me the opportunity to explore the particular phenomenon of male caregivers and how the experience is understood by this specific group and within this specific context. Smith's analytical steps of IPA were valuable, as they encourage an openness and transparency in the interpretation process which was helpful for me (See Appendix 9 & 10). Use of Smith et al. (2009) steps helped to give a level of clarity and depth of analysis that other phenomenological studies omit (Pringle et al., 2011). There continues to be debate surrounding the use of analysis steps, with some seeing this as a drift away from the core principles of phenomenology. These academic arguments potentially limit the appeal of using IPA. From my perspective, the steps of IPA offered an opportunity to relate the story of the analysis through the interpretation process. Although this double hermeneutic method is not without its challenges, I found that the steps helped to give some sense of structure to a complex and often testing process. One key benefit of using this approach, is the identifiable trail detailing how themes were arrived at, thus giving confidence in writing the narrative around the themes, the detail of which lies here in the findings chapter.

4.1 Group Themes

The common themes that emerged from the analysis process outlined in Table 3.4 were recurrent across the sample. The analysis of each transcript identified several themes, concepts and experiences, many of which were shared across the sample and some that were particular for individuals. As discussed in Chapter 3, there are challenges related to maintaining the idiographic element of IPA, while attempting to refine and distil the common themes to present here. A number of emergent themes are not presented here, as they were considered to be unrelated to the research questions or did not appear as recurring across the transcripts. An example of this would be: Diagnosis. Although this was touched upon by some participants, it did not appear to be as significant as the experience of early signs of dementia. For some, they had no recollection of a formal diagnosis. As the experience of diagnosis was not recurrent and did not align with the focus of the research questions, it did not emerge as a super-ordinate theme. However, all emergent themes and super-ordinate themes were re-visited and re-evaluated during the final step of the analysis process to ensure their significance or relevance had not changed. This openness and transparency related to how the themes were consolidated is seen as a key strength of Smith et al. (2009) approach and arguably gives IPA its clarity and depth (Finlay, 2014; Pringle et al., 2011). Keeping an open mind about the range of themes throughout the process is encouraged, as the relevance and importance of themes can change during the interpretation (Smith et al., 2009). Photographs of the analysis work showing the process of abstraction and subsumption can be found in Appendix 10.

The final themes (3) were arrived at through this process and are outlined in Table 3.4. The final themes capture the essence of meaning, identified through the analysis process. Each of the themes encapsulate the phenomenon of caregiving from the perspective of the seven men who cared for their partners with Alzheimer’s dementia that participated in the study:

Theme 1: Lack of Influence
Theme 2: Changes and Losses
Theme 3: Protecting Others

Each of these themes will be examined and illuminated by the direct quotes in this chapter.

4.2 Theme 1: Lack of Influence

The lack of influence was particularly experience in terms of decision making relating to caring, and was touched on by all participants, albeit in different contexts. The experience of decisions being made was significant due to its relationship with the perceptions of the influence the men had on the decisions being made and the drive to maintain some control. This appeared to be linked to a sense of control, power and the impact decisions made had on their experience. For example, a lack of influence over the decisions about services, was described in relation to the extent to which the men felt able to shape and have a say in the decisions being made. For example, in accessing respite and being referred to other services. Whereas, the impact of decision, linked more to the result or outcome from the decisions made. This was related to the way that the decision affected them, their caring role, or their partner. Interestingly, decisions relating to initiating care services were frequently perceived as being made by others. In the main, the decisions were perceived to be made by nurses, social workers and medical professionals and usually in response to changes or deterioration in the person with dementia or caregivers' health. For some, making decisions was a more autonomous process, although still influenced by changes related to Alzheimer's dementia. For example, a trigger for seeking support was linked to a sense of not coping due to deterioration in participants' partners Alzheimer's dementia. This highlighted the impact that dementia was having and the lack of influence the men had on dementia progression. For other participants, decisions made to access mutual support groups and dementia café type services were seen as positive and were perceived to be of value. Many decisions made were connected with maintaining the pre-dementia life, routine, relationship and roles, in essence to minimise the impact of dementia.

4.2.1 *"I am not the one that made the decision"* - *Influence and involvement*

Most of the participants described incidents where decisions were made by others, thus limiting the influence or power they felt they had. This can be seen in the account from Bill as he describes his experience of his wife being admitted for respite:

"I mean I am not the one that made the decision about respite but I am pleased I have it now. I did appeal it, at the time I was told I could not get information about my wife due to confidentiality. So I asked about how I could appeal it [the decision to admit for respite] and I was put up to the other level and it took three weeks. By then it was all in place[…]." (B1)

This example shows, even though the respite care is now valued, it was a decision Bill felt was made without his involvement or influence. He wanted his partner to remain at home. Added to this, his attempts to challenge the decision were ineffective due to the time taken for the appeal process. Note the use of the term *"…I was put up to the other level…",* which indicated a perceived hierarchy of decision making in care services and the reference to the timescales. The impact being that Bill was too late to challenge the decision. This experience could then be seen as reinforcing Bill's perceived lack of influence, which resulted in a sense that he was resigned to the outcomes:
"By then it was all in place […]"

Similarly for George (G1), when describing going to a respite care facility, offers an insight into how the initial decision to seek respite was driven by his own health needs, and his need for a hip replacement. This respite experience was not successful, as the service was not able to accommodate George's wife due to her response to the respite environment. The outcome of the visit impacted on the level of distress experienced by his wife and then led to the decision to seek respite in a mental health hospital. George perceived that these decisions were made by the respite manageress and the social worker and in response to his wife's reaction:

"…we went along there just prior to me going in for the hip operation and she [wife] exploded in there. The manageress [at respite service] said 'there was no way we can cope with this' [wife's distress], you know, so the social worker at the time said "well I think she will need to go to the [hospital service]", then she was transferred, I was told she was going to be transferred to [name of service] […] and that is where she has been ever since." (G1)

The above quote indicates a perceived lack of power when the manageress reported that there was *"no way we can cope"* and the social worker's subsequent decision to seek an alternative service: *"I think she will have to…".* The way that George describes what the manageress and the social worker said, suggests the lack of opportunity to discuss or explore alternatives and therefore a lack of influence on these decisions. This perceived lack of involvement can be interpreted through this description with the use of the word *"told".* This quote also suggests a level of acceptance that this decision has been made, he was not able to minimise the impact due to his own health needs. In describing this experience, George indicates a lack of control on many levels, and in relation to his own health needs, the requirement for respite, the choice of respite environment and his wife's distress and her reaction to the respite environment. The use of the term *"exploded"* offers an insight into how quickly his wife's behaviour changed and how unmanageable it could be.

George (G1) indicates the process of decisions being made, perhaps due to the need to find respite care quickly, which resulted in the reactive nature of the decisions made by others. Through exploring this experience, George indicates the significance of this event. In essence, the need for a hip replacement set into motion a sequence of events that resulted in permanent hospital care. The perceived lack of involvement and influence in significant decisions about respite and permanent care appears to draw to the surface strong emotions. For example, the use of "[…]" in the transcripts was a notation where the caregiver expressed or suppressed emotions. This was observed as prolonged pauses, tearfulness or voice changes that indicated an attempt to compose oneself or prevent crying. Where able, the observable non-verbal or sub-lingual communication were also noted. This can be seen in the transcript with Andrew (A1), who spoke about the decision for his partner to have an increase in respite care and then asking about the timescales for permanent care:

"…so I said 'sounds good to me' I can do other things that I wanted to do, so I said yes, ok. I said to her how long do you think it would be before permanent care […] somewhere else [….] and […] emm well […] (breath in, tearful)". (A1)

In all of the interviews, strong emotions were expressed and the men frequently used pauses, silence or a change of topic to limit the overt expression of the emotions felt. This emotion can be seen to demonstrate the impact that significant events had on the men. These frequently related to the consequences of decisions or unintentional outcomes of decisions that resulted in a move away from their pre-dementia life, relationships and routine.

4.2.2 *"One thing was a consequence of the other"- Decisions as a consequence*

The participants frequently described decisions, made by them or others about care and services as being inevitable, or as a consequence of either the progression of dementia or their health, rather than a planned informed process. This further illustrates and reinforces the lack of impact the men felt they had on decision-making. Andrew spoke specifically about the way that he perceived decisions being made and associated decisions as unplanned outcomes or results from changes brought about by dementia:

"So, decisions like that [respite] are almost inevitable it's like being on a treadmill" "I never made a conscious decision. One thing was a consequence of the other" (A2).

"…the consequences of the last decision are the community nurse turns up, I didn't ask for her but she turns up. I don't realise say that you made the decision to say "you keep coming here every seven weeks" but you have. So a lot of it is inevitable, but accidental, although you say yes you don't realise you have said yes" (A3)

Andrew (A2) was describing a decision to use respite care. He associates decisions to the feeling of being on a *“treadmill”,* indicating his perceived continuous, ongoing nature of decisions due to his partner having Alzheimer’s dementia. The use of the word *“treadmill”* indicates that Andrew feels he is unable to slow things down, let alone stop them. This quote also fuels the feeling of being powerless and lacking influence or control in this inevitable sequence of events. The interpretation of caregiving decisions being like being on a *“treadmill”,* gives a sense of a rather dehumanising experience, and not having any opportunity to influence the course of outcome and having no control of where it might be leading to. For Andrew, the lack of control and inevitability of dementia and its progression is significant. This association may also reflect Andrew’s lack of influence, as he is unable to stop, change direction or escape the situation. Here you can see that Andrew is potentially realising he did not make decisions. Rather, the decisions were consequential and inevitable, suggesting a lack of impact and influence regardless of the decisions made, which offers a fatalistic reflective view of his experience (A3).

Andrew (A3) reflects back over an experience when a community nurse visited and that resulted in her continuing to visit for a further seven weeks. Andrew feels these decisions were “*accidental”,* they were unintended or unexpected again indicating his perceived lack of control and the potentially unavoidable nature of this experience. There was a clear recurrence of experiences where one, often early, interaction with health or social care professionals, which resulted in a perceived detached, yet systematic sequence of events. This experience was described in relation to the introduction of services or interventions being presented to the caregiver without any recollection of discussion or agreement. This was perceived as a further example of lack of involvement and reinforced fears of others taking over. This lack of involvement seemed to perpetuate fears surrounding loss of control, often coupled with a strong sense of frustration.

Initial interactions with primary care services, specifically General Practitioners (GP) frequently led to visits from community nurses, social workers, other professionals and the provision of services. These encounters were often described as unexpected by the caregiver. Some described people arriving at their home, telephone calls from services or equipment arriving at the home, which included for example commodes and incontinence products. These unanticipated, out-of-the-blue and unannounced arrivals again related to the sense that they were unavoidable or unexpected consequences, which followed in from the decision to make an initial appointment with the GP. These experiences created a perception that caregivers are not part of these decisions and suggest that others are not only making decisions, but also selecting services on behalf of the caregiver without their knowledge or involvement. This observation serves to reinforce the view that caregivers often are not in control, do not have a say and not being consulted about the decisions that affect them, which results in a sense of disempowerment.

"One of them just phoned me up about three months ago. She said 'I see you don't have respite care', I didn't even know what that was." "As I said I didn't ask for it [support services]" (F1).

Here there is an indication that Frank perceived the offer and provision of services as something he did not request, this creating a level of suspicion. There is an indication that Frank felt others were making decisions for him. The statement *"I didn't even know what that was"* emphasises his surprise at being offered a service he did not ask for and was not aware of. The re-iteration of not asking for the service offers some insight into his need to express his lack of involvement and control being taken away from him. It also indicates his intention to maintain caregiving without respite. This could relate to a lack of communication from others about the services that are available or that he has been overlooked in the process of discussing and exploring the potential for respite care provision.

For Frank, these unexpected actions following an initial contact was an indication that GPs and other service providers were watching them, for Frank this was described as a sense of being monitored:

"There was a nurse here last week and she is going to come in once a month now" "…they are checking up without me saying anything." (F2).

Frank (F2) describes a visit from a nurse that has resulted in her on-going visits. He expresses concern that people are watching him, and perceived the nurse as holding some power to monitor him, *"checking up"* on him, which again was something he did not ask for. This experience had made Frank feel under surveillance and potentially evaluated in the way he was providing care. This experience, described by Frank, indicates that the manner and approach of contact with health professional impacted on his perceptions relating to the reason behind the contact. That is, being monitored brought about a sense of intrusion of privacy and personal space.

4.2.3 *"The things you take for granted become a big deal" - Influencing factors*

There were a number of factors associated with decisions caregivers made surrounding their decisions not to access support or services. These factors included a sense of duty and responsibility, (which is described in more detail in Theme 2; Coping and Being Connected), fear, protection and privacy, possibly linked to disempowerment, inability to maintain normality and lack of control previously mentioned. All participants spoke of concerns about the quality and reliability of people and services, as factors that influenced their decision to take up services. Fear of poor-quality services and people 'taking over' were common and potentially linked to early experiences of lack of control and the consequences of seeking help and support. There was also an inference from some, that decisions to access support services demonstrated a lack of being able to cope and dependence upon others. These factors were both seen as negative, suggesting that the caregiver was inadequate in some way and unable to cope with demands of caring.

Quality and reliability of services was a common issue for those caregivers who had used home care services. This aspect was closely related to protecting the person being cared for, as seen here, A4, where Andrew is describing the experience of using a home based sitter service:

“I found myself turning people away because somebody would be coming and you open the door to somebody else, comes in the door – it’s a stranger as far as I am concerned and a stranger as far as [Wife’s name] is concerned” (A4).

Here Andrew describes a service that did not maintain the continuity of the companion supplied by the sitter service. There was no notification by the service that the companion was not the usual person. The repeated use of the term *“somebody”* and *“stranger”* in this quote indicates Andrew’s perception of this person as being unknown or unfamiliar for them. This viewpoint is expressed in a way that shows a lack of trust in the service provider, which is unsurprising when Andrew is entrusting others to provide care for his wife when he is not there. Having a stranger in his home was clearly unacceptable to Andrew, with Quote A4 offering an insight into both the need to trust those who provide care and the perceived risk and sense of vulnerability he had when making decisions about using the service. Quote A4 indicates the value Andrew placed on having a trustworthy, consistent and reliable service and how caregivers assess the associated risks, for example his partners safety and distress, thus minimising the impact when deciding to use a service.

Andrew takes on a gatekeeper role, which is expressed through use of the phrase *“turning people away”* (A4)*,* shows the role he adopted as the protector for his partner, their home and the influence he can regain over their daily routine and activities, that are influenced by care related decisions.

For David, the impact of unreliable services resulted in frustration specifically related to the impact it had on the time he had to himself:

“It’s the things you take for granted and that you know they become a big deal, yea yea. Especially when they eh they say they will be here at 1 o’clock and maybe they are 20 minutes late. You call and they say “ oh they will be there, just relax” [laugh] and then I know… they are all very, very nice” (D1).

David indicates in quote D1, the unreliability of services and how they can compromise his commitments and free time. There is sense of frustration that the service provider is unaware of the importance of and value placed on time when relying on services to give you respite from caring. When David quoted their response: *“oh they will be there, just relax”*, there is a sense he felt patronised. The laugh that followed indicated a level of despair at the lack of awareness demonstrated by the person on the telephone. However, there is an indication that David feels uncomfortable for criticising the service, when he adds *“…they are all very, very nice”.*

Conversely, the enablers for caregivers’ decisions to access support and service related to being consistent, reliable, trustworthy and practical, and those that meet the needs of the caregiver and/or person with dementia. David describes the first contact with a Community Psychiatric Nurse (CPN):

“…are so nice and they put me at my ease the first time they came through the door. Maybe I’m lucky, I don’t know what it is. But eh …and the nurse phoned me for a check-up and to give me a date for when she will be back and she said you can phone me any time you like, and I phoned her…” (D2).

For David, the impact of that first interaction and the ability of the nurse to put him at “ease” appeared to positively influence his perceptions of the nurse. This description could give the indication or suggest that the basis of trust was formed when the nurse first arrived at the door. This factor could link to the pre-conceived ideas and values placed on those in specific professional roles, like nurses, or equally offer an indication that David did not anticipate this based on pervious experiences. The phrase *“…maybe I’m lucky…”* may indicate that David has known of or experienced previous encounters with service providers that did not engender this sense of “ease”. It also indicates that this aspect is perceived as not the norm. That is, not everyone is *“lucky”* or that this is a rare occurrence, indicating that it is not anticipated that service providers can easily put caregivers at ease. David goes on to describe the follow-up telephone call from the nurse that encouraged him to take up the offer of support, which indicates the value placed on nurses who show interest and concern and how this can be an enabler for caregiver decisions to access support.

In contrast, George spoke of the need to protect care staff. Specifically in relation to the way George's wife responded to personal care. When George's wife's dementia deteriorated, she became distressed and aggressive when being supported with personal care. George proceeded to share an experience when he stopped care staff from coming in to help with his wife's personal care, due to her reaction to that service:

"[Wife's name] was a difficult person to deal with [ ] she was out of control. They arranged when she came out of the [name of hospital] to have certain things here like carers to come, mainly to do female things, you know to wash and those sort of things, but they didn't last. They were nice girls actually, but [wife's name] just told them to clear off. It was a bit like that you know. So that was that, and I thought well the chap in charge said 'they will get used to this', but I didn't want them to put up with that, so that was pretty well it really" (G2).

George (G2) indicates that the caregiver wanted to protect the staff from his wife's behaviours but may also be linked to protecting his wife's dignity, or his sense of embarrassment related to others being exposed to the behaviours. *"I did not want them to put up with that"* could indicate that George did not want others to see his partner like that, or to see what he needs to deal with. This could be related to maintain privacy and a now allowing the outside world to see the changes Alzheimer's dementia has brought to their live. Note also in this quote, the perception of who made the decision to provide paid carers following hospital admission *"…they arranged…"* indicating the lack of involvement George felt he had in the initial decision. However, George clearly indicates that it was his decision to stop that care staff from coming in to provide personal care *"…I didn't want them to put up with that…",* suggesting he maintained power over some decisions.

Privacy was closely linked to protection and was a common influencing factor that arose from the transcripts. This aspect of privacy was usually in relation to services provided in the home and was linked to the reason why caregivers decided to discontinue or not to access services:

"I don't like everyone knowing my business, is that arrogance? Or is it another thing? A Scottish thing? I don't know if it was the way I was brought up, it's nobody's business but your own" (D3).

In quote D3, you can see the reflection on why David felt that he did not want people to come into his home. Herein, David explores his need for privacy as relating to a personal trait, cultural background or his childhood experiences and his beliefs about home-life being personal and private. David could also be concerned about being judged by others, exposed or fear of stigma relating to caregiving or dementia. Equally this perception could be attributed to self-preservation and a sense of increased vulnerability. David's exploration of why he feels this way is potentially an indication that he is questioning or expressing some doubt as to the basis of his judgement. He may be exploring what it is that he is using to inform his judgement, which relates to his need to maintain privacy within his caring role.

Potentially linked to the need for privacy, some decisions about care related to the person with dementia not accepting care. This, for some, appeared to be the caregiver believing that their wife would not like or want to receive services. Cameron described being given a list of "care at home" services to contact, following an accident where his wife fell and sustained a fracture that restricted her mobility:

"…she sent us a list for to pick carers to come in eh, a list of people who does the job, I didn't fancy any of them, you can always get the council – I didn't fancy them either." (C1).

When asked to say why, Cameron did not *"fancy"* them, he replied:

“’Cause [Wife’s name] did not want anyone in, she said ‘I don’t want anyone in’” (C2)

In Quote C1 and C2, Cameron gives different responses. The first indicated that Cameron did not want to select a care service, but when prompted this response changed to his wife expressing that she did not want the service. The notion of not wanting anyone *“in”* could be considered literally. For example, nobody physically enters private property or metaphorically allowing people to enter their life, links with the gatekeeping role that Andrew described (A4). There is also a drive for protecting personal boundaries and privacy, similar to David and George. Consideration could be given to the manner that the information was given to Cameron, with giving somebody a list not aiding their decision-making. Alternatively, it could suggest that being given a list and told to select a service could be a daunting prospect, particularly if the person has not done this before. Later in the transcript Cameron stated that he could not see himself accepting help unless things *“drastically changed”,* despite his daughters encouraging him to take the help he had so far refused.

For some, services were rejected by the person with dementia, usually by refusal to attend day care type services, this was highlighted by David in quote D4:

“So, the only guaranteed time I have got is when the two ladies come from the church for an hour and a half on a Tuesday and a Thursday, and if she goes to this eh Monday club I am guaranteed that I can, I don’t have to worry about her or anything else apart from that, that’s it.” “…she [Community nurse] had set up another club on eh, on a Wednesday and [Partner’s name] would have went there for maybe about four or five hours, but she completely refused to go” (D4).

David’s quote (D4) indicates his uncertainty surrounding his partners willingness to attend the newly proposed Monday club and indicates the importance of having a *“guaranteed”* (D4) service where he has an opportunity to relax. David accentuates the finality of his partner’s decision, through use of the terms *“completely refused”,* which shows his perceived lack of influence on this decision, which related to accepting her right to choose not to go or accepting his lack of influence to change this decision.

4.2.4 *"Didn't mean a thing" - ineffective decisions*

When caregivers spoke of decisions that they had made or were involved in making, they frequently offered accounts of the outcome or impact this decision had on their experience of caring. Caregivers perceived decisions made as either effective or ineffective. For Andrew, an example of this related to setting up welfare guardianship, which allows caregivers to have responsibility for key decisions for adults who are unable to make decisions for themselves. Andrew describes a point where his wife is detained in hospital, specifically when he had wanted his wife to return home:

"I'm thinking I did not have to do this, you know, I didn't have to get welfare guardianship I could have just made the decision, cause obviously getting welfare guardianship didn't mean a thing because they sectioned her [raised voice]." (A5)

In quote A5, we can detect Andrew's frustration at how futile the decision was, the lack of power and influence the guardianship status gave him in relation to his wife's care. Andrew's frustration and anger is clear in this quote. From Andrew's perspective, he sought guardianship to enable him to make decisions about his wife's care. When Andrew spoke of wanting to bring his wife home, he described being over-ruled and his wife being detained under a Short-term detention certificate, a section of the Mental Health (Scotland) Act (2003). Short-term detention certificates detain people who are at risk, unable to make decisions about medical treatment and have a mental disorder (Scottish Executive, 2005). Andrew's wife was in hospital during this interview Andrew was both tearful and angry as he recollected the experience, how it made him feel and his lack of influence despite holding welfare guardianship.

For Andrew, this perception of ineffective decision-making was also reflected in the description of use of welfare guardianship. Welfare guardianship allows caregivers to make key decisions for adults who are unable to make decisions for themselves (Mental

Welfare Commission for Scotland, 2014). The roles and responsibilities relating to welfare guardianship are set out in the Adults with Incapacity Act (Scotland) 2000 (The Stationery Office, 2000). Welfare guardianship requires additional reporting and audit, which resulted in frustration and additional stress:

"… they are due to come back well, quite soon, around the turn of the year and they will come back and say, "how have you been looking after your wife's money" and I'll be saying "get lost" and they will be saying "we have got authority" and stuff like that. And I will say I told you last year – [voice raised] I haven't got money [Wife's name] doesn't have money we've got money just like we've the house, it's our house. I don't live in one half – you know it's the same with money. But that is the consequence of going for financial guardianship you get people on your back that you didn't expect and you don't want and you can't shake them off." (A6).

Experiences that result in increased demands on Andrew, appeared to result in him perceiving the decisions as unhelpful, or worse resulted in more effort and complexity and may explain the sense that some decisions lack any impact, are ineffective, or do not provide them with the outcome that they thought would. It could also be linked to the quality and detail of information that caregivers receive to enable them to make informed decisions. For Andrew, his expression *"…you can't shake them off.",* indicates his sense of being pinned down or trapped by the administration or governance of these processes of having people "*…on your back…"*, which denotes a sense of being weighed down potentially adding to the challenges of caregiving that are inescapable and that he does not want.

In comparison, some participants noted the value of deciding to set up Power of Attorney, which is a document that includes a formal legal certificate that allows for another person to make decisions for a person when they become unable to make decisions for themselves (Office of the Public Guardian (Scotland), 2019). The decision was seen for most as providing a sense of security and reassurance that the partners were honest and trustworthy when making decisions about money and accessing their wife's bank accounts and pensions. Some of the practical ways this has met the needs of caregivers were outlined by Frank:

"I noticed the last time [Wife's name] was in getting her cataract done and they kind of said I wasn't allowed through with the patient and when I gave them the dementia Power of Attorney I got to stay with her all of the time." [ ] "… I go to the Post Office to lift her pension, she has to put in her pin number but she can't remember it and I just do it and nobody says a word. But you have that Power of Attorney so if anybody did question it then it is quite clear and that helps you." (F3)

This quote (F3) indicates the need for Frank to have legitimate reasons for his actions and that this reasoning is linked to people potentially questioning these actions now or in the future. This offers an insight into the complexity of caregiving and specifically when caring for someone who has reduced and deteriorating capacity, such as those with Alzheimer's dementia, making these decisions and the process for making them unique to caregivers of people with Alzheimer's dementia. This assentation also gives some insight into the need for others to see that Frank was doing the right thing, through showing some concern that people may think he was using his partner's money inappropriately. There is an ongoing sense of being scrutinised "*if anybody questioned it"* indicating some concern that people are watching.

4.2.5 *"I needed to have other people involved" - Triggers for accessing support*

For some, decisions to access support were related to feeling unable to cope. For Eric, not coping was associated with the practical caring tasks and in particular personal care aspects like washing and dressing. Eric talks about how challenging he finds dressing and undressing his wife, due to her level of confusion. He described experiences where he was not able to help his wife put on trousers and saw this as an indication of him not being able to cope:

"I was not really coping. I made the decision myself to go and get help [ ] I get annoyed, I canny help it, that's why I try to get some help from her sister coming in on a Monday

and it is bad at night" [ ] "…it is getting harder cause it's [the dementia] getting worse, it's happening more often type of thing, I can understand but I haven't got the energy, the girls come in and I just sit there and let them get on with it, I haven't for the patience for it, they have more patience than I've got" (E1).

Eric's quote (E1) indicates he is not coping. It offers some opportunity to see Eric's interpretation of how he came to make the decision to seek help with caregiving, as he speaks about getting *"annoyed"* and how caring for his wife is becoming more difficult. This quote shows awareness of feelings, and specifically increased feelings of annoyance. Strong emotions can impact on thoughts and behaviours, therefore feeling *"annoyed"* could have a potential impact on Eric's caregiving, something that he recognised and sought help for. Eric is aware that caregiving is *"…getting harder…"* and also recognised his lack of energy and patience and how this culminates in his inability to move *"…I just sit there…"*. This quote indicates that he feels Eric has no power to move and is essentially feeling overloaded. However, there also appears to be an acceptance and some relief, as Eric's partner's dependency is escalating, while simultaneously his ability to cope or to continue without help is decreasing. As such, Eric recognises his need for help. Quote E1 captures, not only the logic behind Eric's decision to access support, it also provides a clear demonstration of the physical, psychological and emotional labour of caring. There is a sense that Eric is overwhelmed by his experience of caring and that the decision to access help gives some control back to him.

George expresses a similar realisation that he needed to access some help and that he was not able to meet the needs of his wife without others help:

"Well I think it was becoming obvious, you know it was becoming obvious and I realised that I needed to have other people involved quite frankly." (G3)

For Eric, George, Frank and Bill, recognition that they were struggling to cope with caregiving triggered them to seek support. For each, the initial point of contact was the GP who provided information about local support networks or referred them directly to specific services, such as social care services and memory treatment clinics, where further information on services was provided. Reaching the point where it became clear that these caregivers were out of their depth in relation to caregiving, increased awareness of the need to access help.

4.2.6 *"That's the same as me" - Shared Experiences*

Most participants regularly attended dementia specific mutual support groups or a dementia café, and all spoke of the value of this network of support:

"…speaking to folk and hopefully giving them advice, 'cause their wives and partners have the same issues. It was an eye opener, they're friends now but some would say "I just can't cope" and some of them just say how things have been." [ ] "I was quite keen [to attend the group], cause things build up. Basically I needed it just to speak to someone to get away from the four walls, before the four walls caved in on you." (B2)

Bill indicates his surprise by the use of the term *"eye opener",* suggesting that the feelings of the walls caving in was not what he expected. The group offered him a space to be blunt and direct about how he was feeling due to the mutual experiences. Bill clearly had found the home environment oppressive and isolating, giving a sense of being trapped and buried by the walls caving in. This quote offers a sense of impending doom that Frank was feeling and that these experiences were enabling factors when deciding to go to the group for help.

For Frank, although he did not anticipate talking found the group helpful and encouraging:

"I found it good to talk, hearing the other ones talking, you didn't want to say anything but then you realise "oh! That's the same as me" then you get talking and it's quite good. Everybody talks to one-another so that makes it a bit easier" (F4)

The connection with shared experiences is a clear facilitator for Frank. For example, when deciding to talk in the group, this was highlighted by his clear reluctance to speak *"…you* *didn't want to say anything…"* and how the openness of the group and the sense of shared experience makes it easier: *"Everybody talks to one-another…".*

The positive experience associated with making the decision to attend the support groups or cafés and the helpful outcomes, for caregivers reinforced the sense that this attendance was an effective decision. These quotes highlight a number of factors that infer the helpful nature of the groups including not being the only ones in the situation, being welcomed and sharing experiences. The escalating levels of stress and emotion related to caring, along with the isolation that the men felt, could explain why the open space and welcoming environment of the group was valued. Talking to others in the same situation, provided the space and freedom to speak openly, perhaps without the threat of others taking over or making decisions because of talking about their experience of caring. This shared experience may also reduce the importance of portraying normalcy and coping.

Interestingly, this type of support was not viewed in the same way as other support services. This difference in view perhaps, is linked to support groups being out with the home and not replacing or taking over any aspect of the caregivers' role in the way that home care, sitter services and personal care services do. Additionally, consideration could be given to Bill's quote *"…they're friends now…"*, suggesting that new friends were an unexpected outcome of accessing the group and not something that would come from statutory services. This different relationship perhaps is of particular value to the men. For example, Bill describes the group as something that saved him from the overwhelming feeling of being trapped in the house, but acknowledges this was not something he would have previously considered:

"I wouldn't have done that [attend carers group], no. We would never have gone there. I didn't think we would have gone to that kind of thing" [ ] "we got word from [name of friend], he said 'come down to the café and we will go through to the dementia café', that's how it went. We have been every week since" (F5)

As support groups and dementia café style networks are frequently run by people with lived experience of caregiving, are non-statutory and are accessible to both the cared for and caregiver is worthy of note. These factors may be influential in encouraging men to engage with the service. There is, however, a risk that information about local groups does not reach caregivers, due to the informal nature of the information being shared and the isolation associated with caregiving.

Cameron, Bill and Frank regularly used accessible café areas within local supermarkets prior to getting groceries. As they became known to the staff, they established relationships with the café staff, who then offered to *"look after"* their partner while they completed their shopping. This unanticipated, community based, informal support was particularly valued by the men who spoke warmly about the care and compassion of the staff:

"…we go to [supermarket], em we go down there, it is usually a Wednesday and a Saturday there is a café, we will go up and have a coffee in there and a wee bit of shopping and what not. [ ] We were going down there for about three years now [partners name] was getting a bit slow with the walking so I thought tell you what, "you go up to the café and I will go and do the shopping". So that is what we do. When we go in I take her up to the café and get her a drink. [ ] We have been doing that for so long now the staff practically get everything ready for us when we go in." (C3)

Cameron goes on to talk about how he and his partner have come to know the staff in the café and how they sit with his wife, ensuring that she does not walk away to look for him while he does the food shopping. Cameron is reluctant to seek support from traditional services, but clearly values the informal support from the café staff and the group support offered in other less formal environments. This different attitude may suggest Cameron perceives these sources of support in a different way. The informality of the social spaces like a supermarket café perhaps do not generate the feelings of guilt that are common for caregivers when using respite and other statutory services. This type of community support indicates that for even those who are most reluctant to accept services may consider support from different sources depending on how they are perceived. The reassurance of routine and familiarity may also go some way to help Cameron have control in their life.

The experiences relating to maintain normality and minimising the impact of Alzheimer’s dementia, influences how men make decisions relating to caregiving. Detailed within the transcripts is a complex and multifaceted picture of this experience that can be interpreted in many ways. Through this analysis, the essence of making decisions appeared to be closely connected to protecting self, the cared for and others in a way that demonstrates coping, and as a way to minimise the impact that their partners deteriorating Alzheimer’s dementia. There was however a dominance of negative experiences expressed when exploring making decisions, specifically those decisions that were perceived as being driven by others. A lack of power or involvement in the decisions resulted in expressions of frustration, resentment and loss of control. For some, the exploration of making decisions related to their caring role appeared to result in a sense of inevitability, leaving caregivers feeling that they lack any power to influence what lies ahead. This sense of lack of power may be a factor that drives the need to maintain day to day routine and activities in order to hold on to some control. Decisions related to accessing services were frequently linked to health deterioration, either that of the caregiver or the person with Alzheimer’s dementia. Positive outcomes from decisions to access services like support groups were described as unexpected, with benefits like shared experiences and opportunities to talk valued. Likewise, positive outcomes of decisions to access services were linked to having more involvement, control, continuity, trust, and reliability. Essentially, it was felt that services should in principle meet the needs of the person with Alzheimer’s dementia and the caregivers, and not further complicate caregiving or create more issues. The perception of caregivers not making decisions, making ineffective decisions and being overruled by others are significant when understanding the experience of men as caregivers.

4.3 Theme 2: Changes and Losses

Throughout the interviews there was emphasis placed on the changes that were brought about due to Alzheimer's dementia. When people experience change, there are inevitably losses associated with that change. Dementia brings about substantial change in relation to both the person with dementia and the caregiver. It also brings about changes to daily life, future plans and relationships with others. The Changes and Losses theme captures the multifactorial aspects of change and its associated losses and sets out to illuminate the meaning the men made of the changes they identified in the interviews. This theme about changes and losses, closely links with the feelings the men expressed and relates to their role of caregiver and the feelings that arose from the changes in their lives and their partner due to Alzheimer's dementia.

4.3.1 "That's when I knew" - Changes due to *Alzheimer's dementia*

All the men interviewed spoke of changes to their day to day life, work, plans for retirement, holidays, health and independence. The associated losses identified were often around the plans they had made as a couple to promote enjoyment of their retirement years:

"We were looking forward to retirement and so that is sometimes we get a bit sort of God… ahhh […] (looks down). [Wife's name] worked up in [Name of Hospital] for 34 or 36 years or something." (C4)

Cameron experiences a wave of emotion when speaking about their retirement plans. There is a sense of pleading to God that his wife had deserved to enjoy her retirement. The mention of the length of time she worked appeared to emphasis this lack of fairness he expressed. In other words, his wife did not deserve to develop Alzheimer's dementia. The focus of the quote is mainly from his partners perspective, rather than his own again minimising his needs and sense of loss connected to this change. The anticipation of retirement planning and "*looking forward"* to retiring, indicates the positive feelings Cameron had when considering his retirement. He mentions *"sometimes"*, which indicates a fleeting nature of thoughts relating to their retirement and also the use of *"we"* suggesting that his perception of this change is shared with his partner. The anticipation and planning for retirement was then put on hold due to Alzheimer's dementia and results in an overwhelming surge of emotion for Cameron as he talks about this. This experience of loss of shared retirement planning is unique to partner caregivers, as couples share a history and potentially a shared view and plan for retirement. As the onset of Alzheimer's dementia is predominantly in later life, retirement may be closer therefore more prominent in the couple's thoughts. Plans and anticipation for retirement may be perceived as unattainable when one person developed Alzheimer's dementia. Reminiscent of Biographical Disruption first described by Bury in 1982 in the context of chronic illness. According to Bury (1982), chronic illness is a type of experience that disrupts the everyday life that brings about the recognition that pain, death and suffering is a reality rather than a distant possibility. Chronic illness, in this case Alzheimer's dementia causes a Biographical Disruption that brings to the fore the major issue of dementia and the impact it will have on future plans. Bury (1982) acknowledges that this disruption is felt by individuals with conditions and their families, however, for a person with dementia, this experience of disruption may be transient as the condition progresses, leaving those close to them to navigate this disruption.

For the men who were still working at the onset of Alzheimer's dementia, there was substantial change. They each spoke of giving up work earlier than they wanted due to caring responsibilities. This change in retirement plans was a significant one for all that spoke about it:

"I always thought I would work a wee bit longer than 65 but I couldn't. I ended up working the last 8 years with the council but I had to give it up, I got in touch with the council the next day, I need to know what I can do and what I can't do, I need to do this cause she looked after me" (E2)

Eric reflects on his plans to continue to work beyond 65 years old. In his quote (E2) Eric perceives a lack of choice *"…I had to give it up…",* which is touched on in Theme 1, and how this was linked to a perceived *"need"* to take on this caregiver role. While David notes the value and joy, he had in maintaining his work role, he too cites the reason for this change being related to his caregiver role:

“I had a little part time job which I loved like you know, eh.. and I had to give that up and eh.. because eh, she did not want to be by herself. So eh, I gave up that little job” (D5)

Major changes like giving up work is linked to a persons’ role and how they see themselves and how they identify themselves in relation to others. Giving up something that is valued, for example work, for another demonstrates the sacrifice that David made for his partner. David also considers the changes in their live related to not going on holiday and going out as a couple in the quote below:

“October, not the October this year, October last year I had five days, four nights and everything included, the hotel, I had to cancel last minute, and two weeks before, I had tickets for a show, a musical at the Kings, I had to cancel that. So you can’t really plan anything I thought maybe that was just a one off but maybe that had been building up, you know a pattern, no so you can’t really plan anything.” (D6)

This quote (D6) shows the disappointment felt by David when trying to plan and arrange things that he and his partner would have enjoyed, which has left him with a loss of planning and looking forward to social events. There is a lack of being spontaneous and looking forward to the things they used to enjoy. He also expressed hope that his partners refusal to go to events may not last *“…was just a one off…”*. However, there in an indication that he has accepted that it is a permanent change and that he cannot influence it by repeating the phrase: *“…so you can’t really plan anything…”*. This demonstrates the perception of uncertainty in his life and the lack of control he feels. This experience of not being able to plan social activities or to be spontaneous gives a sense that David feels his life is on hold, because they are unable to do the things they planned and wanted to do together.

The men interviewed spoke of changes in their partners, specifically around their ability to continue to do things they used to enjoy, resulting in them reducing or stopping social activities. Additionally, the men spoke of changes in their partner's behaviour, demeanour or manner that they perceived were linked to Alzheimer's dementia.

Most men spoke of a change in their partner's confidence and independence, each mentioning how this was one of the early signs of Alzheimer's dementia. Descriptions of their partner expressing increased anxiety when left at home alone, frequent calls to their work and tearfulness when the men were leaving the home were recounted. These were linked to feeling held back and trapped by Alzheimer's dementia as well as the impact these behaviours had on their ability to meet the demands of their work. Eric spoke of these changes and how they impacted on his ability to do his job. As a tour bus driver Eric was frequently interrupted by telephone calls from his partner, which caused him to be late for work. Added to this, his wife's reluctance to let him leave the house, resulted in him missing shifts and made him unreliable:

"That was when I knew she was not well. She took to phoning at night, I was in a bus and I had to say why I was coming in late and the service is for clients and we had a rota and we were on stand-by. I never got a good run cause I could not say I could be there." (E3)

In quote E3, it is clear that Eric found himself left out and perceived as unreliable, as he *"could not say I could be there"* due to his caring commitments and that he missed out on work. For George these changes in his wife were different:

"Well the two years prior to [partner's name] going into the hospital was quite fraught really. She could flare up very easily and she was becoming very, very difficult to look after. I got to a position where I couldn't really leave the house to do routine stuff shopping and that sort of thing and I played a certain amount of bridge and so a couple or one or two evenings a week I should say I would go and play bridge but I was never even sure if I was even going to get back into the house she would lock the whole house put the

deadlocks on or ram a chair under the thing so, you know, anyway in that situation it got completely out of hand” (G4)

Here (G4) George offers some detail around how unmanageable he felt the experience of caring for his wife at home could be. The use of terms like *“fraught*”, *“flare up”* and *“completely out of hand”* which were used when describing the changes in his wife’s behaviour, indicates that things were getting too much and were stopping him being able to do the most basic of things. For example, going out, shopping and attending his usual social groups. These omissions resulted in a loss of social networks and a loss of independence, which meant George became tied or trapped in the home. Frank also expressed many changes caused by his wife’s Alzheimer’s dementia although presenting very different reasons for him having to remain at home with his partner:

“Yeah about 2 years ago, but it was only the last 6 months that her memory has gone a bit. I have to be here all of the time now when I didn’t before so that is the difference. She wanders a lot through the house at nighttime, looking out the window she sees images out of the window and she sees people going up and down.” (F6)

Each of the men interviewed, expressed a number of different changes linked to or connected with their partners Alzheimer’s dementia and how it affected their partners and in turn them. Regardless of the nature of the change, whether it be distress, tearfulness or reactions to leaving the house, the men perceived this as an indication that they had to be at home. Which led to multiple changes related to role, identity and independence.

4.3.2 *“You’re the other Frank” - Changes in relationships*

As one person in a relationship takes on a caregiver role due to Alzheimer’s dementia, there are likely to be changes in the couple’s relationship. A feeling of being alone was, for some participants, particularly challenging. This was linked to the sense that they no longer had the person, their partner, alongside them. Some of the men described difficulties in making decisions without their wife’s input and agreement. Cameron touched on this issue of loneliness when describing decisions to buy a new car. He indicates the sense of being alone and having sole responsibility for decision making, rather than it being shared. Note the emotional pause in quote C5, which offers some insight into how challenging the decision about buying a car was. Cameron expresses the burden of responsibility through the statement *"it's all down to me".* Of note also, is that despite dementia, Cameron still seeks reassurance from his wife, which is potentially a way to maintain the norms of their relationship pre-dementia:

"…anything we wanted, it was always a joint decision you know, […]so it's all down to me now, even though I always ask [Wife's name]." (C5).

For some, particularly for Andrew, Frank and George, the changes in the relationship were substantial with the person being cared for no longer recognising them as their partner. This lack of recognition led to intense emotions, as well as changes in daily routine, in roles within the home, and in sleeping arrangements:

"I have got to be there all the time and if I am not there or even if I am there she will go through and when she comes back I say what you looking for and she will say she is looking for [Frank], I will say that is me and she will say no you are not you are the other [Frank]" (How does that make you feel when that happens?) "Horrible." (F7)

"She would say "you wait till [Andrew] gets home" you know […] and one night we went upstairs and [Wife's name] says who is that, she made such a fuss that I moved to the other bedroom and that meant that she wouldn't be getting up in the night and coming in shouting" (A7)

As all the men interviewed were in long standing relationships (over 20 years) with the person they are caring for, it is not surprising that the lack of recognition is connected with strong emotions. Throughout the interviews these strong emotions were touched on but most were reluctant to elaborate on the feelings and impact they had on them. This is seen in the quotes when Frank was asked about his feelings and he only used one word *"Horrible"* and did not expand further, perhaps as it is too difficult or painful to discuss.

Similarly, Andrew recounted the significant change of moving out of the couple's bedroom in a very factual way, which focused on the outcome – reducing the disturbance at night. The reluctance to explore the feelings associated with the move to another bedroom may be related to the personal nature of the topic, the intense emotional impact or the gender and age difference of the interviewer. Their partner being in another bedroom may also have been something that they had not discussed before.

All the men spoke of changes in the day to day living and the home care duties they took on. as they transitioned into a caregiver role. These changes tended to be related to practical roles and responsibilities, and included chores such as shopping, cleaning, washing, ironing and budgeting. Some men took on the role of providing personal care, while others did not. This omission appeared to potentially have some connection to the pre-dementia relationship for example, the time they spent together as a couple. Two of the three men who did not take on personal care for their partner, described relationships where they held jobs that took them away from the home for long periods, which involved long distance driving and specialist construction work. The third participant, Frank, felt that he was not the best person to provide personal care and that his wife would not have *"tolerated"* him taking on that role:

"Well you being a female, well probably for a man to do the hygiene, that is obviously much more difficult. I don't know how ladies would do sticking men into the tub and that sort of thing I have really no idea. [partner's name] would not have tolerated that sort of thing" "Well I would have found it difficult but it would never have worked out anyway" (F8)

This quote (F8) highlights how unappealing this is for Frank, how this was not something he would have contemplated or expected to have to do. The use of the term *"hygiene"* offers an insight into how he struggles to talk about and express the concept of personal care. He is clear that his partner would not have *"tolerated"* personal care provided by him perhaps that she would not have wanted him to provide this care or would have reacted pushed him away or would not accept it. He acknowledges that he would have also found this *“difficult”* and concludes by suggesting it would have *“never worked out”*, therefore no point in trying, without offering any reason why this would be the case. The men that did take on personal care tasks described close relationships with their partners spending most of their time together or as a family unit. Generally, these men described a reluctance to engage with services and intense feelings of guilt when help was needed from others thus offering some insight into the importance of the pre-dementia relationship and how this might impact on the perceptions of men adopting a caregiver role. It also offers insights into how vast the relationship changes due to Alzheimer’s dementia can be.

4.3.3 “I know that face” - Losses due to *Alzheimer’s dementia*

Any change will bring about associated losses and caring for a person with Alzheimer’s dementia brings about multiple changes, some of which are touched on in this theme. The impact of these changes highlighted a number of these losses experienced by the men. These losses manifested in a variety of ways including a loss of connections with friends due to caregiving. This included social networks, leisure activities, interests and friendships:

“I used to go about three or four times a week [the golf club] they were all pensioners. It was good because if you had anything you needed someone would have it. I have lost touch with them, sometimes I see them in the supermarket and I say – I know that face” (F9)

This quote (F9) indicates the broader value of going to the golf club, wider social connections *“all pensioners”*, sharing and helping each other *“…anything you needed…”*. Frank’s recollection of seeing familiar people offers some indication of his sense of loss and his feeling dis-connected with the group he identified with and with others. However, for some, the losses were more fundamental in nature, for example, sleep:

“I can handle everything if she could just get sleeping. When she is sleeping I can get sleeping. The other night four times she was up and down up and down. Three o’clock in

the morning, the only time I can get to sleep is when I can hear her heavy breathing I know that she is sleeping and I can go to sleep. Even when I am in beside her cause she has this restless leg syndrome as well, the twitching, I don't get a decent sleep. It's very important." (D7)

Quote D7 gives an insight to the intense feelings that David had in relation to being able to have a restful, unbroken sleep. His belief is that being able to sleep will help him to manage and cope with caregiving. The importance David places on sleep is significant and seems central to his ability to function and cope; the *"only"* time he can sleep is when she is sleeping, shows this sense of duty and responsibility and not being able to switch off and rest. The lack of sleep is the consequence of taking on this watchman role. David's description gives an insight into his intense focus on his partner, at the detriment of his own sleep. Consideration could be given to what David is fearful of if he were to be asleep when his partner is awake. This absence due to sleeping may be linked to David's sense of responsibility as caregiver and not being there when his wife needed him.

4.3.4 *"The strange thing about dementia is that is doesn't make any sense" - Feelings associated with changes and losses*

As previously noted, the men interviewed often did not express their feelings verbally and tended to hold strong emotions in check. This avoidance was done by pausing or changing focus or topic of the discussion. To aid the analysis, notations were used to highlight when strong emotions arose. These notations were used to capture the moments when strong feelings were expressed non-verbally, as perceived by the interviewer. All of the men expressed feelings connected with the changes and losses they had experienced due to their partners Alzheimer's dementia, both verbally and non-verbally to some degree. Frank, when sharing his experience of his partner no longer recognising their family home that they had shared for 35 years, stated:

"35 years, I suppose that is also hard when you feel that you are looking forward to going home and that is a strange thing about dementia is that it doesn't make sense sometimes.

[…] It is a horrible feeling. I feel really angry with myself when I think about it I really feel angry, but there is nothing I can do about it” (F10)

This quote (F10) offers some insight into Frank trying to make sense of dementia and the frustration that it does not make sense. Note the connections with his feelings, when he expresses looking forward to being in their family home and recognising that she does not share that attachment anymore. Frank describes this recognition as *“horrible”*, which offers a sense of how horrific this experience was for him. He goes on to say how angry he is with himself and about his wife’s dementia, emphasising this by using the word *“really”* which suggests the intensity of this feeling. Despite this acknowledgement, Frank has nowhere to direct this anger, due perhaps to the lack of sense or logic Alzheimer’s dementia seems to have.

Andrew communicated his intense feelings non-verbally and through para-lingual sounds indicated in quote A8. The strong feelings are expressed clearly when Andrew described the loss of his partner’s identity. These expressed emotions intensified when he described a sense of being complicit in the decision for his wife to be in respite:

“I’m watching this person […] [...] [gasp], you know I love gradually being stripped of identity and personality and.., and dignity and you are party to it and the fact that she is there [in respite]” (A8)

Andrew attempts to de-personalise the account by using *“…this person…”* to refer to his partner, perhaps in anticipation of this being particularly difficult to talk about. He used multiple pauses in an attempt to suppress his distress, by holding his breath at times. As he continues the “[gasp]” sounding like a deep sob, this demonstrates the depth of the emotions felt. Andrew describes the changes in his partner due to Alzheimer’s dementia, as a process of being *“stripped”* of her identity, personality and dignity, which are core aspects of her being ripped away. The person who she was is being lost in the progressive and enduring process of Alzheimer’s dementia. The intense emotions shared in this interview offers some insight into the complexity of caring, specifically for a partner with

Alzheimer’s dementia. The way in which for Andrew struggles emotionally with the way that Alzheimer’s dementia is taking away his wife’s identity, and how he feels responsible for the decision for her to be in the care environment, which is further contributing to intense loss. Andrew describes being *“party”* to the decision to use respite services and that he cannot escape this due to seeing her *“there”.* As an interviewer, this was a particularly challenging narrative to listen to, both due to the insightful level of self-awareness and the level of emotion expressed. This challenging experience was explored in my reflexive chapter (see Chapter 6).

4.3.5 *“You look rough” - Physical Impact of Caring*

Changes in physical health was something that all participants spoke about. Discussions were related to both the physical health of the person with Alzheimer’s dementia and the physical health of the men themselves. Physical health deterioration due to ageing was interconnected with the deterioration due to Alzheimer’s dementia and was linked to further losses. For example, when reduced mobility impacted on getting out of the home and maintaining some usual activities:

“If it is nice I take her up in the wheelchair cause she cannie walk, which is disappointing for us cause we used to walk for hours. We tried it a few weeks ago, got as far as the roundabout and had to come back, we were struggling.” (C6)

In quote C6, Cameron describes the loss of something that bound the couple together and identified them as a couple *“we used to walk for hours”* which was shared interest and something they enjoyed.

“…can’t walk around the shops the same, it’s nothing to do with dementia, it’s just getting old [….] we hardly go up to the centre and back down, that’s far enough.” (F11)

Frank in quote F11, indicates the limitations that poor mobility presents him and his partner and the restrictions this places on them. The phrase *“that’s far enough”* shows a sense of acceptance that this is part of ageing. More significant for most, was the impact that deterioration in their own physical health had on the men and its link to being able to continue with the role of caregiver. Five of the men recounted experiences of significant physical health issues, for example heart attack and hip replacement that resulted in them not being able to continue to provide care. Others recognised gradual changes in health due to caring, which included weight gain and reduced fitness due to lack of physical activity. In one case, Frank's need for surgery resulted in his wife's admission to hospital, which was something that he had not considered an option before due to her refusal:

"Well I needed the hip operation and I ended up in the [hospital] which ended up fine and that has not been a problem but it was because of that that [Wife's name] had to go into…, it was getting to the stage where she would have had to go to somewhere permanent anyway but this actually crystallised the whole thing." (F12)

In quote F12, Frank recalls the experience and lack of choice in decision in a way that suggests it brought about something that he had been anticipating. Perhaps this issue being related to physical need made the decision easier. His indication that he was aware that respite care was needed *"…it was getting to the stage…"* suggests that he might perceive the need for respite care due to physical health needs more acceptable than the need for support or lack of coping. There seems to be an acceptance that due to the significant change, this move to permanent care could not be avoided. The use of *"crystallised"* gives a suggestion that Frank's deteriorating health solidified his thinking and his own health needs suddenly became clear to him.

Andrew also spoke of his health impacting on his caring role. For example, he recounted a time when he had felt unwell and sought help from a neighbour:

"Like I said I felt a bit rough – Ha Ha – so, people cheer you up don't they – they say – "you look rough" oh thanks very much, Ha ha. I went round and they are really nice people [neighbour] took me down [to the hospital] thinking I had a stomach ulcer…I'd had a heart attack, they said we think you have had a heart attack I said to [neighbour] emm can you

call number 2 daughter to come up, cause they said to me do you want to call anybody. (A9)

Despite his significant health issue, Andrew was determined to maintain his caring role for his partner. There is an indication of him minimising his health needs, through *“thinking I had a stomach ulcer”* and only when this was more significant he called on his daughter. There appears to be a prioritisation of the partners needs over participants own, which resulted in health crisis. However, reflecting back over this experience, Andrew connects the intense physical caregiving role he had at the time of his heart attack and acknowledges he may understand this experience differently now when he goes on to say:

“Again I discharged myself – we all do stupid things don’t we – I don’t like depending on other people”. (A10)

Although the drive to return home for Andrew was linked to caring for his partner, there is clear indication that this was coupled with the desire not to be dependent on others. His statement *“I don’t like depending on other people”*, even when the *“other people”* were his children demonstrates this and will be explored in the final theme, Male Partner as Caregiver.

David expressed concern about his loss of opportunities to take physical activity to maintain his health, having previously enjoyed walking regularly and a recent improvement in fitness and reduction in weight:

“I used to walk every day for at least an hour and in my younger days I used to drink a bit, so I stopped drinking, lost all that weight and I felt great and I have had to give all that up and I feel resentful about that as well and I have put on about 30 odd pound since March [when he had to give up work] and all it is it’s all boredom.” (D8)

David in quote D8, clearly links the changes in his weight to giving up work and being at home for long periods of time. He associates feelings of resentment and bitterness related to this and perceived he had no choice but to give up feeling *"great",* which is a consequence of taking on a caregiver role for his partner. This sacrifice a further loss for him. This resentment and lack of control further demonstrates that David's life is on hold. The lack of stimulation, interest and opportunities to do the things he likes and enjoys has resulted in tedium. The *"boredom"* and inactivity in David's life now as a caregiver has impacted on his health and sense of identity. It also reversed all the health gains he had made before caring for his partner. David's sense of frustration, resentment and restriction was apparent throughout the interview. Consideration must be given to the impact of his perception of deteriorating general health and ongoing resentment may have on his emotional well-being and mental health.

4.3.6 *"The stress levels were through the roof" - Impact on mental health*

Physical and mental health are essentially symbiotic; however, one is more easily expressed by some than others. All the men spoke about their physical health directly, but not all spoke directly about the impact caring had on their mental health. Bill spoke openly about his mental health and how he recognised this as a signal that he was not coping.

"I just needed to get help and had questions to ask […] I was in a bad way. It was excellent how […], things that I found out about. I just needed help, sad. At that time I was not too bad but then she got aggressive. That was when I needed help […]. dreadful it was. I just knew the stress levels were through the roof." [How did that affect you?] "Well […] I just knew that I was stressed and ken, I wasn't sleeping." (B3)

Quote B3 demonstrates the challenge for Bill to find the words to say what he wanted to say about his deteriorating mental health is an indication of how difficult this is for him to talk about. His mention of needing *"help"* suggests at this point that he was not clear about what help he needed and where he might access it. The use of the word *"dreadful"* indicates how awful he was feeling at this time. Bill talks about stress and feeling that his stress levels were high, so high that they were *"through the roof".* Stress escalated so far that the levels were beyond control and intolerable. Later Bill returns to this when asked about the support he accessed following meeting with his GP and being referred to the CPN:

"I didn't think I was at the stage I was needing help and being depressed because of it. The [CPN] said that to me, 'are you feeling like you are not wanting to go on', and he was right I mean you would not have known. [ ] It was probably just that eh I didn't see that ….I would definitely recommend that anybody gets the help they need and get both the help for the combination of how you are feeling and to cope with all… the practical help." (B4)

Clearly this is a difficult topic for Bill to talk about. He touches on feeling depressed and not realising it was related to coping with caring. There is a sense that Bill was surprised that the CPN asked him about feeling suicidal and not being aware of these feelings: *"…I didn't see that…"* until he was asked directly by the CPN. When asked if it was a surprise that caring would impact on him this way he replied:

"It was, Yes it was aye, cause I mean, I have never […] I used to say that was the cowards' way out. I felt guilty after it ken cause I had thoughts like that myself, crying out loud! To find a way out." (B5)

Quote B5 demonstrates the significant impact caregiving had on Bill's mental health and how having the contact with staff who are mental health aware was of value when identifying his risk of suicide and deteriorating depression. Bill reflects on his perception of suicide and how this has changed due to this experience. Having accessed the support for his mental health, Bill went on to recommend that all caregivers get help for both the emotional impact of caring and the practical aspects. He described how his experience of needing help with his mental health led to accessing respite care. Similar to the experiences where significant physical health changes led men, for example Frank, to access support and services.

In relation to the experiences of changes and losses, it appeared to take a crisis to occur before services were accessed by male caregivers. The men interviewed only gave attention to their own health when it had deteriorated to the point where they were no longer able to provide care. Over the course of caregiving the men appeared to minimise their own health needs and prioritise the needs of their partners. The key perhaps is to identify how to better support men to consider and be aware of their own health before these significant physical and mental health issues arise. The lack of awareness of the impact of caregiving by both caregivers themselves and those who come into contact with them, however, may be a barrier to accessing support and support being offered. This will be discussed further in the next chapter.

4.4 Theme 3: Protecting Others

The relationship between the cared for and the caregiver is of significance and has been touched upon in relation to how the participating men attempt to minimise the impact of Alzheimer’s dementia and how this informs decision making (Theme 1) and the changes in the relationship due to Alzheimer’s dementia (Theme 2). As mentioned in the previous themes, the relationship the couple had prior to dementia seemed to influence the way male caregivers approached caregiving, particularly in relation to providing personal care. It also seemed to influence the caregiver’s willingness to seek and access support and respite. Within this theme, protecting others, is central to the way in which the men perceived their partner and caregiving role, how they adapted to and transitioned into caregiving and how they minimised risk and promotes safety through problem solving and prepared for the future. It also connects to how they view themselves and their identity.

4.4.1 *“My duty” - Roles and responsibility*

All participants spoke of how they viewed caregiving as an expectation or a responsibility they had as a husband/partner. Some of the participants elaborated on this expectation by connecting their beliefs, values, childhood experiences and perceptions of their parent’s relationship and their perception of their role as a partner and as a caregiver. Taking over roles within the home from their partner was viewed as part of being a couple, and something that their partner would do for them if they were the person with Alzheimer’s dementia. This reciprocal nature of being a partner was shared by all participants to some extent, and is shown here when Cameron described his caregiving role:

“…well I have got to do it [caring] […]. Well my main thing is to look after [Wife’s name]. Well, yes, I have been cared for all my life [laugh] […] by [Wife’s name] […] […]. I looked after the car and outside, even [Wife’s Name] did the garden and everything else” (C7)

Note the frequency of pauses in quote C7, which highlights the level of felt emotion when exploring the experience of caring. Cameron indicates how much he felt his wife contributed to their relationship and family life, in essence *“everything else”.* Cameron clearly expresses his current and main focus is caring for his partner, partly due to her caring for him *“all my life”* and thus fuelling the desire to pay back that care. The caregiving role was a change from his previous role and responsibilities which appeared to be linked with external maintenance. Looking after the *“car and outside”* offers an insight into the pre-dementia relationship, when his partner attended to maintaining the home, meals and family. This indicates that he has taken on or adopted the roles that his partner used to have, which included making the meals and other household activities that are often viewed as traditionally female roles. Nonetheless, Cameron sees that his priority remains looking after his partner with Alzheimer’s dementia.

Some men spoke of the early signs of Alzheimer’s dementia and how this was linked with both changes in roles they had and their sense of duty, which is described here by Andrew in quote A11:

“…there it was just small steps down hill, and I wouldn’t notice that [Partner’s name] stopped cooking, [Partner’s name] stopped putting the washing out. It never even struck me “oh I need to take on this job” you just did it” “I thought it was my duty to look after [Wife’s name]” (A11)

Initially Andrew barely noticed the gradual stepped decline in his wife abilities, resulting in his slow undetectable adoption of the caregiver role. The process of adopting the roles and activities that his partner was unable to maintain appears to be natural for Andrew, almost automatic. The phrase *“it never struck me”,* indicating the unconscious transition to caregiving.

Andrew reflected on this transition and later made connections to how he perceived his parents and their relationship. This offers insights into the way that Andrew makes sense of his experiences and his role as a caregiver. Note the intense emotional responses in quote A12:

“Wasn’t even a decision, it was a generational thing, I mean my mother died of cancer and my father looked after her at home and […] a generation ahead of me, you looked after each other and that’s what I grew up with and perhaps “in sickness and in health” and we made that vow and I feel guilty […] [sharp intake of breath] […] I am not doing it [tearful] [time lapse]. So, it wasn’t a question of […] just I have got to look after her on a daily basis.” (A12)

Quote A12, and more specifically the pauses within it, demonstrates the struggle Andrew had in expressing his sense of guilt that appears to be attached to not providing the care to his partner in the same way as his father had, and especially now that his wife had gone into care. The feelings Andrew is experiencing relate to his understanding of the role of a husband. His recollection of how his father cared for his mother until her death is fortified by his strong belief in marriage, and specifically the vow to care for each other. This emotional narrative shows Andrew making sense of his own caring role, through his recall of how his father cared for his mother. This parental role modelling appears to be intertwined with the powerful feelings of guilt now that he is no longer providing this daily care. Andrew struggles to come to terms with his wife’s admission to a care home and his inability to *“…look after her on a daily basis…”* and now that others are providing his wife’s care. Andrew’s guilt appears to be amplified due to not meeting his own expectations of caregiving and is giving rise to feelings of failure. For example, letting his wife down and not being able to emulate his father's ability to care for his mother. Andrew appears to be judging himself against either learned or self-imposed expectations, which is a powerful and unique experience.

For David, when asked to say more about his reason for taking on the responsibility for caring, he appeared to link this to his beliefs about society, contribution people make to communities and citizenship:

"Well that [responsibility] is one of the reasons and another reason, maybe this sounds, or call me stupid I don't know, but you can't just depend on the National Health Service or other people, you have got to do your part as well as best you can. Especially if people are trying to be eh helpful, and if you are not doing your bit you can't say it's nothing to do with me like, no. Yes, yes a big responsibility. You know" (D9)

David clearly views his caregiving role as a significant responsibility. In this quote (D9), there is an indication that he feels this is something that is linked with his view of the world. He describes a shared responsibility for providing care, which involved not *"just"* relying on others to step in when care is needed. David believes that those close to the person should also contribute and *"…do your part…",* which offers some insight into his view of others expectations of partners and also what the role of being a partner means to him. He indicates that he cannot say caregiving is *"…nothing to do with me…"* showing that he sees this as part of him and his role as a partner.

4.4.2 *"I asked her not to come to the house" - Protecting others*

Throughout the transcripts, participants touched on the issue of protection. This aspect of caring included the need to protect the person with Alzheimer's dementia, protecting others including family members and staff and protecting the relationship. For most of the participants, there was a strong drive to remain independent in their caring role. This desire for independence appeared to be influenced by their need to protect other family members, including children, from the demands of caregiving and is clearly linked to their perception of their role as partner. Returning to Andrew's experience of being admitted to hospital, in this quote (A13), he describes his daughter coming up to take over his caring role:

"I said 'look you have a job to go to and I can't depend on you, the neighbours I've got to go home and look after her', so there you go. […] I said… obviously I was the last one of the day [for surgery] 'so I'll be going home then', they say 'no you have to say overnight'. So I said that's ok [daughter's name] will come up she will stay overnight with [partner's name] and make breakfast, so I discharged myself against advice and all that sort of stuff" (A13)

Andrew indicates his desire not to be dependent on his daughter or his neighbours. His reference to his daughter having her own commitments *"…you have a job to go to…"* and his decision to leave hospital against the advice of the medical team, shows the lack of importance he places on his own health and his drive to be home to continue with his caring role. This indicates his sense of duty and role as a partner. Following this hospital admission, Andrew returned home to care for his partner until his next heart attack:

"I can't keep depending on other people, I can't keep going next door and saying I feel rough. I can't keep ringing the daughter up and saying you know, …emm…you know, I can't do it anymore" (A14)

Quote A14 demonstrates that Andrew clearly does not want to depend on others and rely on them the way that his partner depends on him. Andrew's second period in hospital resulted in his wife's first respite stay in a home. From quote A14, it seems that the increased frequency in which Andrew needs to call on the help of others, specifically his daughter, led to him accessing respite care and to the realisation that he *"…can't do it anymore…"* . Andrew it seems, aims to protect his daughter from having to take over the caring role, which was important to him as a father. Protecting his daughter from the burden of caregiving was more important perhaps than his own physical health. This sense of responsibility could be linked to both his sense of duty to be her sole care provider, which is intrinsic to his role as partner. In part also for his role as a father, which involves protecting his daughter from the demands of caring for her mother.

A sense of protection also appeared to be linked to maintaining normality in the caregivers' relationship, with their partner and life generally, and to preserve privacy, touched on in Theme 1. Maintaining privacy is peppered throughout the interviews in the way that the men act as gatekeepers, which involves keeping others out of their private home:

"…they are all part of a committee when they go back to the church they will be saying "oh and how was [Partners name] today…." I don't like it. There is people I hardly know, I'm not a churchy person but [Partners name] is. She hates to miss the church but I managed to take her on Sunday and that was the first church she had been in for about three weeks, I had people I hardly know coming up to me "how is [Partners name]" and that, "I hear [Partners name] wasn't very good the other day and you couldn't get out" and all that and I'm thinking I don't even know you lady" (D10)

This quote (D10) shows David's frustration at others knowing and asking him about his and his partner's life. He refers to them all being part of a group, *"all part of a committee",* giving a sense that he is an outsider and does not identify with this group. It also infers his belief that people are talking about them and sharing personal details about him and his partner within the church, giving a sense that he feels exposed and vulnerable. This quote shows how David perceives others who offer help as disingenuous and appears to fuel his desire to maintain some privacy. This is however at odds with his drive to maintain some usual activities that he knows his partner values, like going to church. This antagonism shows the ongoing tension between the needs of the person with Alzheimer's dementia and the needs of the caregiver.

For Frank, protection was in the form of protecting both himself and his partner, explored when he spoke about receiving support a social worker, whom he did not want to come to the house:

“I know one of the ladies came from [name of area] and I think their office is down in [place name]. She got me to write things that had happened that she should assess and we had these clandestine meetings as she didn’t come to the house, I asked her not to come to the house, I asked her not to come to the house, I met her at the harbour… we had had a chat about things.” “I couldn’t really take to narrate things when I was in front of [Partner’s name] I could only to it when she wasn’t there.” (To protect her from hearing that?) “Yes, so there we go.” (F13)

The use of the word *“clandestine”* in quote F13, offers some insight into Frank’s feelings about these meetings with the social worker. This acknowledgement indicates that he felt there was a need for secrecy due to feeling disloyal to his partner. This reaction could also be interpreted as a way to maintain his network of support and to protect him from his wife’s reaction to the meetings. Clearly Frank felt uneasy about speaking and describing the challenges he faced in the presence of his partner, indicating his need to protect her from that. Frank found a way to balance his need for support, while avoiding any distress his partner might feel having a social worker in the home. The connection with the social worker was valued by Frank but brought about engendered feelings of disloyalty when talking about his wife, her symptoms and behaviours to a stranger.

4.4.3 *“She can’t find the toilet” – Problem solving and practical solutions*

Most of the men interviewed recounted details of how they found solutions for difficulties or challenges related to caregiving. These included adaptions to the home, strategies to minimise distress, co-ordinating set daily routines and creating new networks of support and connections with others. As the men described finding solutions, it was apparent that these offered some sense of achievement and reward:

“I was worried about my wife falling down the stairs. So I asked for a stair gate. They said they could not ‘cause she may try to climb over it and fall and bang her head or something like that. What is the chances of that as opposed to someone walking up an open staircase and falling down? So, it ended up I had to buy a safety gate myself. It was not

the cost it I was after, it was just the practical help, you know if I am in the kitchen and you turn round and she has wandered out to the stair, it's just for safety." (B6)

Quote B6 shows how Bill arrived at a practical solution to minimise the risk of his wife falling downstairs. Although this stairgate was not able to be provided by a service, Bill took the decision to fit it himself and emphasised the practical nature of the solution.

Similarly, Frank has found solutions to a number of difficulties and takes pride in describing how he adapted the home to overcome potential risks of falls or disorientation:

"When she goes to bed at nighttime sometimes she will come back and ask me where the bedroom is. In fact just last week I put a ladies only sign on the bathroom door and there are about four doors all the way along and she will get up through the night and come back as she can't find the toilet." [ ] "It helps aye because I put two wee lights up as well that go on when you pass them and they are ideal." (F14)

For Cameron, it was important to create an environment that would enable him to continue to provide care for his partner at home, as her Alzheimer's dementia progressed, and she needed more care. His focus is also on the practical aspects of meeting his partners care needs, while also making caregiving easier:

"…it used to be what they call an en-suite [laugh] but it was a wee box shower could hardly swing a cat in it. So, eh, it was getting frustrating because I had to tell [partner's name] what to do cause I could not get inside beside her. So we have got the wet room now and I go in, get her all washed and that, back out dried, wrap her in the towel 'cause she is always cold." (C8)

The men often spoke at length about the practical solutions they found to address the difficulties they faced as their partners Alzheimer's dementia progressed. There appeared to be a value they placed on finding practical solutions that help. Finding solutions engendered a sense of pride and achievement and it also gave an opportunity to talk about the positive aspects of caregiving. In essence, something that demonstrates coping and perhaps something that they find it easier to talk about, rather than the emotional and difficult aspects of their caring role. Connecting with others and sharing solutions was also of value.

4.4.4 *“Fore warned is fore armed”* - *Knowledge, skills and capacity for caring*

There were mixed perspectives regarding the need for knowledge related to dementia. For some of the participants, an idea of what to expect and the opportunity to prepare for this was valued, while for others there was a reluctance to look beyond the present:

“I’m thinking to myself fore warned is fore armed, what can I expect next? and they are saying ‘we can’t tell you’ and I’m thinking wait a minute there is 100,000 people in Britain have got Alzheimer’s Dementia there is enough of the history and progression to be able to tell me what to expect?” (A15)

For Andrew, his approach was to be prepared for the invasion that is Alzheimer’s dementia and to be armed with the resources he needed to combat what is to come. He is frustrated by the lack of detail people are able to provide him with and struggles to see why they cannot give him a detailed account of what is to come given the prevalence of Alzheimer’s dementia (A15).

Whereas for Cameron, the opposite was described in quote C9. He struggles to answer these questions and to verbalise what is going to “happen” to his partner as Alzheimer’s dementia progresses. In contrast to Andrew, Cameron remains focussed on the moment and not allowing himself to consider what might be in the future:

“I don’t want to ken what’s going […] what’s further on.” (C9)

Those men that accessed peer or mutual support groups, like Cameron, did talk of attending information sharing sessions and presentations form organisations, and valued the connection with others. The information received in the support group context was viewed positively and often acted upon. For example preparing power of attorney. Even though this would have alluded to future progression of Alzheimer's dementia. Other information accessed in these sessions that the men found valuable included accessing funding for holidays or attending specific education/information based courses. Those participants who did not attend support groups were active in seeking out the information they needed to provide care individually. For example, finding out about services for home adaptations, or through identifying key people like mental health nurses, social workers and GPs, who could signpost them to services. Although this investigation would be dependent on the caregiver understanding of who is best to ask and what information they are likely to need.

Understanding how male caregivers of partners with Alzheimer's dementia perceive their role both as a partner and as a caregiver is important to identify the influence this has on their views about accessing support.

4.5 Chapter Summary

This chapter has outlined the three group themes identified through the analysis of the transcripts using an IPA approach. The themes presented offer an account of how the experiences of caregiving has been understood and interpreted by the male participant. The themes drawn from this interpretation and analysis process capture the lived experience of the men as caregivers, while maintaining clear focus on their own words and stories. The focus has also addressed the aim of the research, by drawing out the factors that encourage and inhibit male caregivers of people with Alzheimer's dementia decisions to access respite and support services within the interviews. The three themes identified: Maintaining Normality: minimising impact; Changes and Losses and Coping and Being connected, capture the meaning the men have made of their experiences of being a caregiver and how they understand this in relation to their perceived role and responsibilities, both as a man and as a partner. Also of significance, is the impact and influence men feel they have in relation to caregiving decisions and the changes they encounter due to dementia.

Chapter 5 - Discussion

5.0 Introduction

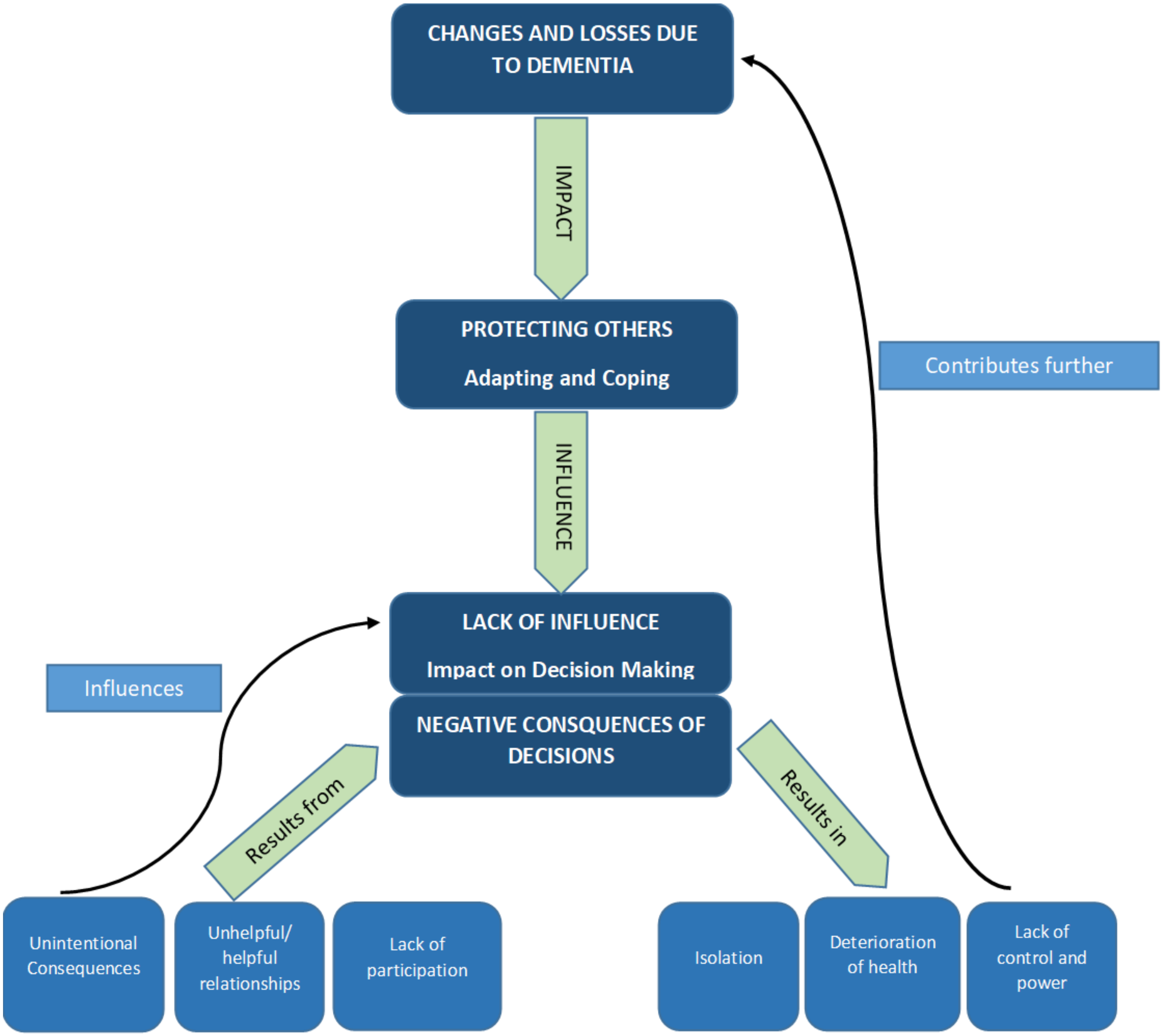
Following analysis of the transcribed interviews and in line with the Smith, et al. (2009) approach, individual super-ordinate themes were identified from the participant transcripts. After this, and looking across the participants' transcripts, three group themes were then identified: Maintaining Normality: minimising impact; Changes and Losses; and Coping and Being Connected. These group themes will now be discussed here in more depth and linked to what is known about the experience of male caregivers generally within the literature available. This discussion starts with an examination of the connections and relationships between the three themes identified and then goes on to explore each theme in more depth. The aim of this chapter is to interpret and describe the significance of the findings in light of what is already known about men caring for a partner with Alzheimer's dementia, and to explain and bring to the fore new understanding and fresh insights of this unique experience and how it is understood by the men interviewed.

5.1 Connections and relationships between the themes

The three group themes identified in this study are interlinked and influence each other. The relationship between the themes are outlined in Figure 1: Connections and relationships between group themes. The changes and losses related to the participants partners progressing Alzheimer's dementia impact on male partners and the way they perceive their role as both a partner and a caregiver. This is linked to their sense of identity, purpose and responsibility. The caregiver role men adopt, for example setting out to minimise the impact of Alzheimer's dementia, influences the decisions they make and how they perceive decisions relating to caring for their partners/wives.

The decisions made by the participants, arise from and are influenced by intentional and unintentional consequences and can bring about positive or negative outcomes (Pretorius et al., 2009). Equally, helpful and unhelpful relationships with care services and the level of participation experienced impact on experiences and perceptions of caregivers. The results of decisions can influence caregivers' isolation, health and a perceived level of power and control. These perceptions are linked to a sense of personal agency, or the ability to direct actions for specific purpose, is linked to and influenced by a person's belief about their capability (Chambers, 2008). When caregivers perceive these experiences as negative, this reduces their belief that they have the control or the agency to direct or influence the outcome. This then has an impact on the likelihood of caregivers deciding to access help and support or not which in turn, further increases the changes and losses felt by the caregiver.

Figure 5. 1: Connections and Relationships between group themes



5.2 Theme 1: Lack of Influence

Theme 1 encapsulates several concepts drawn from the individual narratives that relate to the experience lack of influence and control, particularly related to decisions to access support and services. The experience of decisions being made held importance for all the men interviewed. Dementia appeared to impact on all aspects of life for the men, presenting them with multiple, complex and unfamiliar experiences. These new experiences brought to the fore difficult decisions, many of which related to different aspects of their life, including work, home life, routine and health, as well as decisions relating to caring. These decisions frequently came as a result of deterioration in the health of the person being cared for. For example, the adoption of new roles and responsibilities when the participants partner with Alzheimer's dementia was no longer able to maintain their role and responsibilities. These changes intensified the perceptions that the men lack influence or control over their lives. There was a sense that these types of decisions were almost un-noticed, as caregivers adapt and transition from partner to caregiver. Overt decisions relating to caring, like the uptake of care specific services, including respite, home care and support services, were frequently perceived as decisions that were made by others.

Whether subtle or overt, the experience of care related decisions seemed to bring about perceptions of loss of control and the feeling that others were taking over, in keeping with findings from Mc Donnell and Ryan (2011) and Neufeld and Kushner (2009). This was particularly apparent when the decisions had to be made due to the deterioration in the caregivers' health, resulting in them being unable to provide the care needed to their partner. It was also apparent when caregivers first made contact with services, for example their GP, resulted, for some, in a chain of events that were unexpected and uncontrolled by them, from the caregivers' perspective. The perception that people were taking over generated feelings of frustration, anger and a sense of exposure, and seemed to be associated with a lack of control, something that is under-reported in the literature. This lack of control further exacerbated the losses and potentially damaging trust in the service provider and therefore impacting on future decision making (see Figure 5.2). This experience appeared to reinforce the lack of influence and control participants felt and thereby increased their reluctance to access services, continue with the service or to accept the offer of services or support. This may go some way to better understand the lack of linkages between caregiver burden and service use, reported by Stirling et al. (2010). Black et al. (2008) highlight that the lack of control and powerlessness experienced by caregivers as adding to the sense of suffering. This suffering may be linked to the tensions that lack of power and control create, in relation to the men's identity and from a gender perspective (Caperton, et al., 2019; Ferree, 2016; Kray et al., 2017). This lack of influence and control appeared to illicit a kind of negative self-fulfilling prophecy from which the only 'opportunity' that offered a sense of control, was a decision not to engage. This departure from service support would not be the intention of service providers, but with the result of alienating those for whom they were 'acting' for. Consequently, increased awareness of this reaction is essential if failing to use services is to be avoided. Farina et al. (2017) reported the disparity in relation to assessed and felt need when deciding to access services and supports improved measures to assess caregiver felt need. Attention should be paid to caregivers' sense of inclusion and influence when measures are developed.

McLennon, Habermann and Davis (2010), and Mittelman et al. (1993) reported on partners who were caregivers as being more reluctant to hand care over to others when compared to other family caregivers, for example children. Brodaty and Donkin (2009) propose that children caring for a parent often adopt a more "care manager" role, while a partner adopts a "care provider" role. This different role seemingly relates directly to the relationship between the caregiver and the cared for, with adult children caring for a parent taking on a role that includes organising and managing the care being provided. This recognition may be linked to the other responsibilities of children caring for a parent. For example, children are more likely to be of working age, may have their own family and also are less likely to live in the same home as the parent requiring care. Partners, however, are more likely to be living with the person being cared for and to be of a similar age. The relationship between the caregiver and cared for does appear to be of significance when considering the roles people adopt (Bronner et al., 2016; O'Shaughnessy et al., 2010). A child of the parent may be able to or need to adopt a more detached approach and be able to take a view of what needs to be done to ensure care is provided. In contrast, a partner may be more involved directly with their partner and have a different emotional attachment to the person with whom they have lived, loved and grown old with. This different experience relates to both the relationship with the person needing care and the age of the caregiver and cared for (Mittelman et al., 1993; Shanks-McElroy & Strobino, 2001). The closeness of a partner relationship may illicit a sense that they know the person best and therefore able to look after them better than others.

The adoption of “care provider” role was evident for Andrew, Cameron, Frank and George, who each asserted their desire to be the sole or main care provider for their partner. Equally, the participants showed a reluctance to have others, including wider family, friends and professional services to provide care, in line with findings from Neufeld and Kushner (2009). Bill and David, however, sought to identify and access support in their caring role, although for different reasons. For David the need to find day care services out-with the home was important to allow him time to himself, but these services and his partner’s lack of willingness to attend them presented a challenge. Finding by Pretorius et al. (2009) and Shanks-McElroy and Strobino (2001) support the importance of caregivers having time to pursue their own activities and how this can positively impact caregivers health and QoL, however do little to examine how this can be achieved when the cared for refuses to accept services. David, however, appears conflicted in his desire to have a break from caring, describing both a strong need to maintain their privacy by keeping others out of the home, while equally describing a strong drive to have a rest, get some sleep and have time to himself. Bill on the other hand is clear that there are aspects of the care provider role he cannot manage, feeling that this is beyond his scope. Through the recognition of his strong emotions and specifically frustration when negotiating personal care tasks like helping his partner wash and dress, led him to seeking support from others. This is in line with findings from Picco et al. (2015) who reported that caregivers of people with increased personal care demands and behavioural and psychological challenges are more likely to experience mental health issues. Picco et al. (2015) go on to posit that there is an increase burden specifically for older married caregivers of people with dementia. However, when considered from a gender perspective, Bill may be struggling to view himself as a care provider, an inherently female role, and potentially challenging his beliefs relating to being a man (Caperton et al., 2019; Kray et al., 2017; Magnusson et al., 2012).

Even within this small group of men caring for partners with Alzheimer's dementia, there were differences in the perceptions of being a caregiver, with beliefs about providing care for their partner and the value of support and services available to them. These differences indicate the need for a more considered approach to supporting caregivers and those they care for. Exploration into the experience of specific caregiver groups is therefore essential and something that IPA can offer, as it can uncover this kind of in-depth richer data and provide findings that can inform the approach taken to support caregivers. Williams, Moghaddam, Ramsden, and De Boos (2019) reported that there are benefits to having models and frameworks to inform support interventions to reduce caregiver burden. Based on their meta-analysis of thirty studies, Williams et al. (2019) endorse the use of frameworks and models, but caution that these need to be considered individually. This again indicates the need for enhanced understanding of the individual perspective in relation to assessing and meeting the needs of male caregivers.

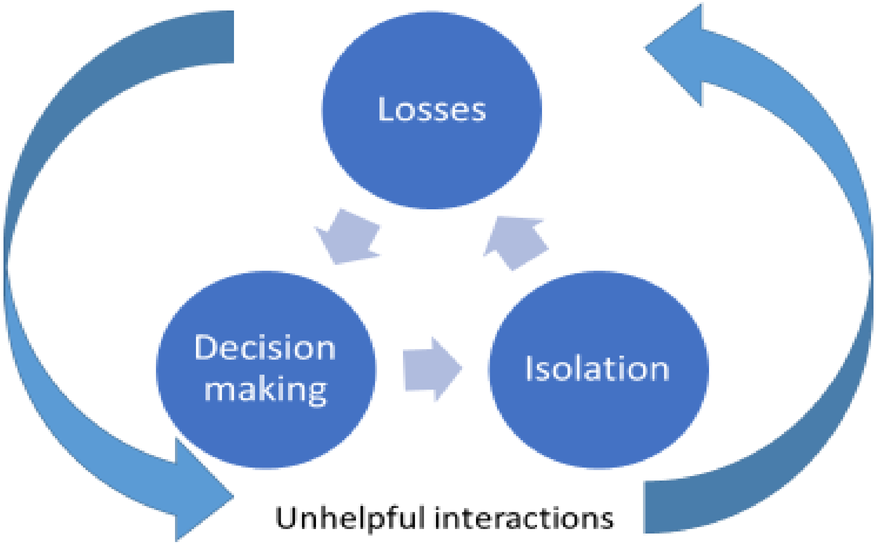
Adopting a caregiver-centred approach to providing support to people caring for someone with Alzheimer's dementia is something that is supported by Mc Donnell and Ryan (2011); O'Shaughnessy et al. (2010) and Phillipson, Jones, and Magee (2013). This would require a change, moving away from decisions made by health and social care staff that usually derive from the assessed needs of the person being cared for, to decisions that are informed by caregiver need. However, this is recognised as an area of tension as caregivers often focus on the needs of the person they are caring for (O'Shaughnessy, Lee, & Lintern, 2010) and therefore may find it difficult to engage in discussions about their own needs. This lack of attention to caregivers' own needs also may present a challenge for health and social care staff who may see the person with Alzheimer's dementia as their main focus and priority. The opportunity therefore could be for developing frameworks or models that encourage service providers to support caregivers to consider their own needs and make decisions that would be seen to benefit both the cared for and the caregiver. Care dyad assessment that incorporates the needs of the individual with Alzheimer’s dementia and their partner with equal weighting may be worthy of further study.

5.2.1 Unhelpful relationships

Neufeld and Kushner (2009) discuss caregivers experience of interactions, both with family and friends and with professionals, and propose that these relationships can be experienced as helpful or unhelpful. Unhelpful or un-supportive interactions including lack of support and poor signposting to support networks, are viewed as unhelpful and are said to create tensions. Professional relationships that lack trust, give the sense that people are not being listened to, lack of continuity or where there is a lack of confidence in the person providing support, were seen as unhelpful by the men in this study and in line with finding from Mc Donnell and Ryan (2011) and Etters et al. (2008). This can be seen in the experiences relating to decisions to use (or not to use) services described by Andrew. The lack of trust, continuity and poor interactions with professionals resulted in Andrew not using the services offered. Neufeld and Kushner (2009) link non-supportive relationships to a lack of understanding of the complex nature of man in caregiver roles and that this lack of understanding generates inadequate support and hurtful interactions. Conversely, professionals who demonstrate trust and who listen and maintain contact create helpful or more supportive relationships with the caregiver. Sanders and Power (2009) emphasised the value in social workers creating a supportive relationship with men who are caregivers to support them to navigate the transition to caregiver. The importance of trust can be seen in the response to the community nurse that visited David, whose interaction with David, left him feeling listened to and respected. The continuity through the follow-up telephone call engendered trust and resulted in David’s decision to maintain engagement with the service. These helpful relationships can create the potential to build trust and open the door for establishing an environment that meets the emotional needs of the caregiver. The establishment of this trusting relationship could form the bedrock for building a therapeutic relationship, where needs can be explored and the caregivers have the time to consider and discuss decisions and express emotions (Mc Donnell & Ryan, 2011; Sanders & Power, 2009).

Neufeld and Kushner's (2009) account of unhelpful relationships is of particular interest, as it resonates with the men interviewed in this study, who frequently spoke about interactions with service providers that were unhelpful. These interactions often resulted in negative outcomes from the caregivers' perspective (Mc Donnell & Ryan, 2011; Neufeld & Kushner, 2009; Pretorius et al., 2009). For example, when Andrew spoke about his reluctance to have an agency care worker, who he described as a "stranger" in his home and turning the care worker away when they arrived late. The lack of trust and dependability led to frustration linked to services not being consistent, sending "strangers" and being late, directly influenced to the decisions Andrew made about continuing to engage with services that he described as unreliable and is in line with findings from Etters et al. (2008); Mc Donnell and Ryan (2011); Neufeld and Kushner (2009) and Pretorius et al. (2009). The negative consequences of these decisions resulted in further isolation, which added to the losses felt by Andrew (See Figure 5.1) and which reduced his ability to continue to engage in his own activities, including walking, yoga and swimming. The link, therefore, to reduction in the caregiver's physical activity and wellbeing is clear. Looking more closely at this, and in the context of the relationship between the themes outlined in Figure 5.1, these unhelpful interactions resulted in a negative spiral, where Andrew's lack of trust resulted in disconnection and disengagement with the support networks available to him. This disengagement then leads to further losses and impacts on further care related decisions, as shown in Figure 5.2. Attention needs to be given to the significant impact of unreliable services and how this unreliability can bring about the drive for men to protect the cared for and minimise disruption to the daily routine.

Figure 5. 2: Spiral of Disengagement: The impact of unhelpful interactions



Creating helpful relationships and an improved understanding surrounding the complex nature of men in caregiving roles, could therefore minimise negative interactions and the related negative outcomes that add to the losses men experience. However, failure in regards to this could not only risk disengagement in services and increase isolation, it can also lead to significant reduction in caregiver wellbeing through further lack of time for caregivers to look after their own health and engage in social and recreational activities essential to wellbeing and reduction in caregiver burden.

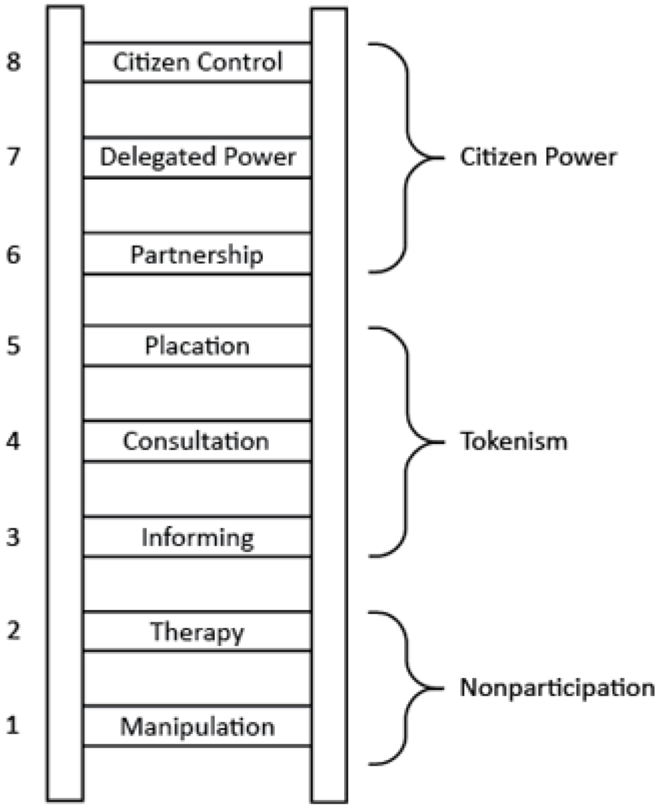
5.2.2 Unintentional consequences

Some of the negative outcomes described by the men appeared to stem from good intensions of professionals. There were accounts given that showed service providers making decisions about need and services that did not include the caregiver. The result of which was caregivers' frustration of being overlooked, not included and assumptions being made about their needs by others, which further contributed to the spiral of disengagement. These can be seen as Unintentional Consequences (UC), where the actions or plans made by people, intended to bring about improvement or facilitate changes in relation to development or growth have an unanticipated negative impact or outcome. For example, increased losses associated with caregiving. Oliver, Lorenc, Tinkler and Bonell (2019) explored the UC's resulting from public health policies and suggest that there are a range of reasons why UCs happen, including poor communication, lack of clear evidence and lack of well-articulated goals. Although not specifically related to caregivers, Oliver et al. (2019) go on to suggest that these UCs could be mitigated by better use of theory and improved involvement. Oliver et al. (2019) focus is at a more strategic and organisation level but can be applied as the principles of effective communication, evidence based approaches and improved levels of involvement, resonate with this theme with its links to "impact" and "influence" and therefore relates to the UC's experienced by the male caregivers. The difference is within the micro-level and people-oriented operational level. This new understanding provides evidence that can bring about opportunities to develop strategies that enable improved involvement at an individual level.

5.2.3 Theoretical frameworks for involvement

The notion of people's sense of being involved and participating in things that affect them first came to the fore in 1969 by Sherry Arnstein. Arnstein (1969) developed a theory that evolved from her research into service user involvement in social housing in the US. Although this theory can be applied in wider contexts, in fact in any area where there are people who hold little power to influence (Gates & Stout, 2004). The underlying concepts in Arnstein's (1969) theory are essentially shared, the "have not citizens" in several arenas trying to gain enough power to make the target institutions responsive to their views, aspirations, and needs. Arnstein (1969) observed and described specific levels of participation and presented them in hierarchical order, known as the "Ladder of Citizen Participation". Arnstein's (1969) work set out to induce social reform that would empower people (the have nots) to fully participate in order to share in the benefits of the affluent society (those that have). Presented as a framework in Figure 5.3, the theory is depicted in the form of a ladder, with each rung indicating a level of participation, Arnstein offers 8 levels with increasing participation, the pinnacle of which is citizen control (Arnstein, 1969). The theory can be applied to individual, operational and strategic levels to evaluate the level involvement experienced. The perceived lack of involvement in decisions being made, perceived by the caregivers in this study is significant due to its relationship with whether or not men engage with support services. If, however, service providers continue to make assumptions about caregivers needs, as reported by Bronner, et al. (2016), caregivers will continue to experience a lack of involvement and perceive professionals as making decisions without them. This is also in line with Brodie and Gadling-Cole (2004), who propose that there should be a shift from the established, service led professional-centred models of care to family-centred models, to maximise the shared decision making opportunities and reduce caregiver stress. It also resonates with Brodaty and Donkin (2009) who discuss the importance of partnership approaches to be successful in meeting the needs of the person with dementia and to target interventions to best support the caregiver.

Figure 5. 3: Ladder of Citizen Participation adapted from (Gates & Stout, 2004)



The first two rungs of the ladder include “manipulation” and “therapy”, which according to Arnstein’s (1969) theory, are defined as “Non-participation”. Non-participation is where there is no intended involvement or sharing of power or control. Rather, it is assumed that service users have inferior knowledge and understanding, therefore, it is the role of those who hold power. In this case in relation to service providers power to “educate” or “cure” those without power. The next three rungs offer people information: “informing” and an opportunity to voice views and have them heard: “consultation” but are framed in the “Tokenism” section of the ladder as the voice may be heard, but there is no influence or action following this. This Tokenism level offers some opportunity for involvement, but as it does not result in action “placation” is the best that can be offered, as those in power retain the right to decide (Arnstein, 1969). Progressing up the ladder there is a move to equalise power. The three top rungs describe “partnership”, where there are shared decisions and influence is apparent and “delegated power” where people using services negotiate taking on responsibility for decision making and have overall say for the decisions that have been negotiated. The final top rung; “citizen control” is where service users lead and take on all decision making or have full control. These rungs are described as “Citizen Power”. as they denote the scales of power tipping in favour of the service user.

Although there are clear limitations to this framework, for example the simplistic representation of a complex relationship between those in power and those who are not. Nevertheless, this framework is valuable for assessing the level of participation an individual has and in identifying the processes that are in place to maximise participation and could therefore be helpful when working with caregivers.

From this seminal work (Arnstein, 1969), many frameworks have been developed. For example, Goss and Miller (1995) who presented involvement on a continuum rather than a hierarchy. Goss and Miller’s (1995) framework present peoples’ involvement as having varying levels of influence and Goss and Millar suggest that the ultimate aim is to achieve partnership. Goss and Millar (1995) present five levels of involvement, including: “non-involvement”; “information collection”; “two-way communication”, through to “listening and responding” and ultimately “partnership”. Frequently used within health (Happell & Roper, 2009), policy rhetoric (NHS Education for Scotland, 2011) and education (Masters, Forrest, Harley, & Hunter, 2002; McIntosh, 2018; Stickley et al., 2016), this framework recognises that partnership is not always possible and that there may be times where the level of participation shifts depending on individuals and circumstances. For example, when the caregiver is unwell or does not have the required information on which to make informed decisions. Goss and Millar (1995) assert that people are given the choice about the level and extent of their involvement, although urge that this should be revisited frequently to ensure that partnership is maximised. Working with caregivers adopting strategies where partnership is maximised could therefore combat some of the UC and increase the impact and influence men feel that they have in the decisions being made. One of the closest frameworks developed from Arnstein’s work is Hart (1992), who developed a Ladder of Participation for children.

The influence that the original theory has had and the reach it offers to any arena where there are people who lack power, means that this theory holds value in exploring the level of participation caregivers’ experience. Using this theory could help to identify processes by which participation can be improved and at what point in the caregiving experience the levels of participation can be maximised.

5.2.4 Application of involvement theory

In the context of this study, involvement theory (Arnstein, 1969) offers an opportunity to examine the level of participation described in the narratives of men interviewed. Andrew, despite putting in place protectors to ensure he had a say in his partners care, described a lack of power and involvement in decisions. In keeping with findings from Brodaty et al. (2009) and Brodie and Gadling-Cole (2004), Andrew found that the protectors he put in place were ineffective when confronted with opposing views held by those in power. In his case the medical staff. Andrew’s experience could be described as Non-participation, Andrew was unable to take his partner home from an inpatient respite stay, with his demands to do so resulting in his partner being detained. According to Arnstein’s theory (1969), this could be placed on the “therapy” rung of the ladder, with the reason given for overruling his wishes, Andrew's deteriorating health and lack of physical capability to meet the care needs of his partner. Most of the participants described incidents and experiences that could be viewed as Non-participation or degrees of Tokenism. For example, when decisions were perceived as being made by others, thus limiting the influence or power the caregiver felt they had. This lack of power can be seen clearly in both Bill's description of the decision to engage in respite services *"…I am not the one that made that decision…";* and for Frank when he was offered services without being consulted or it being discussed. In both of these incidences, the men perceived a lack of involvement, which led to frustration and lack of trust in the service provider. Despite the intention to be helpful. These potentially unintended outcomes, or as Oliver et al. (2019) describes as UC, seem to arise from service providers making assumptions about the needs of the caregiver or the cared for, which led to decisions being made without their involvement. The UC for the men included loss of trust, loss of purpose and loss of agency. When added to the losses already experienced due to dementia (See Figure 5.1), the impact of these UCs could be significant due to the spiral of disengagement (See Figure 5.2) that can result. Based on Aronstein's (1969) ladder, the lack of inclusion in and influence on decisions could be assessed at best as Tokenism, as there was an element of information sharing and at worst Non-participation as the service providers actions were based on what was felt would be in the best interest for the caregiver and cared for, fitting the definition of "therapy" (See Figure 5.3).

The level of "manipulation" was evident in the account given by Andrew when describing the process of gaining welfare and financial guardianship. His intension was to ensure that he could have control over decisions about his partners care and to ensure he managed their finances due to her deteriorating capacity. There appeared to be limited information given to the Andrew that related to the power guardianship offered and how this could be overruled by others in certain circumstances. In essence, Andrew thought he had the power to make these decisions but found out that in particular circumstances he did not. Equally there were further UC that stemmed from these decisions, like increased reporting and administration that added to the caregiver's frustration and caregiver burden. Arnstein's, (1969) theory would suggest that although there was a degree of influence and a right to plan and make decisions about care and finances, ultimately these can be over-ruled by the power-holders right to judge the legitimacy or feasibility of the decisions made by the caregiver. As such, this would be in line with "placation" level of Tokenism on the ladder (See Figure 5.3). For Andrew, in particular, there appears to be a battle between him and the professionals, where Andrew strives to maintain control of the decisions being made that affect him and his partner.

Of course, there are many wider aspects of the application of this theory. For example, the potential barriers from the caregiver's lack of trust, previous experiences, negative attitudes to respite and accurate recall of the situation. Nevertheless, the negative impact these experiences had on the men and their perception of lack of power, remain and appear to negatively influence future encounters with health and other services (See Figure 5.2). The use of theory to identify and put in place strategies to maximise involvement through interactions with professionals from the earliest point in the caregiving experience, will help to minimise the UC and unhelpful interactions. Together they will improve communication and partnership between the caregiver and professionals, potentially halting the spiral of disengagement (Mc Donnell & Ryan, 2011; Neufeld & Kushner, 2009; C. Pretorius et al., 2009; Sanders & Power, 2009).

Improved understanding of the caregiver perspective and the use of involvement theory could offer some opportunities for improved relationships. For example, when Cameron described being given a list of care at home services to contact following his partner fall and shoulder injury:

> *"…she sent us a list for to pick carers to come in eh, a list of people who does the job, I didn't fancy any of them..."* (C1).

The provision of information sits at the bottom rung of the Tokenism section of the ladder (Arnstein, 1969). Giving information in this way for Cameron, resulted in him disregarding these services as an option and to decide to continue caring for his partner independently, adapting and managing to care for her with her shoulder injury that limited her mobility. This additional care would have increased the physical demands of caring and caregiver burden. Cameron described having a bed in the living room and him sleeping on the couch so as to be near to his partner, during the night. This example shows the limitations that information giving alone has. It offers an opportunity to consider how the level of participation could be enhanced. It also highlights the intense drive that some partners have to continue to care, despite increased care demands and burden, which is in line with findings from a number of studies (Lin, Macmillan, & Brown, 2012; Mcintyre & Reynolds, 2011).

Bronner et al. (2016) reported that caregivers often enter caregiving, with the intension to care to the end, without anticipating or fully understanding the impact that the deterioration associated with dementia brings about. This is valuable when considering the provision of information intended to support caregivers and the need to place it in context for the particular caregiver circumstances (Mc Donnell & Ryan, 2011). The complexity of the experience of men caring for their partner with Alzheimer’s dementia is highlighted here. For some, like Cameron, there was a clear determination to provide care potentially without fully understanding the impact that Alzheimer’s dementia would have on his partner. However, he also did not want to know more about the condition or what was likely to happen to his partner in the coming years. The dilemma for professionals, therefore, is to determine how men are supported to gain an understanding of the scope of caregiving, while respecting their wishes not to look too far into the future of their caregiving role.

Continuing with Cameron’s experience and by using involvement theory and aspiring to move to a more Partnership level of participation, the service provider could have worked more collaboratively with Cameron, listening and responding to his concerns regarding having people in his home to help care for his partner. Strategies could have been used to support Cameron to make an informed decision about utilising care services at home. Although this may not have changed Cameron’s decision, he may have felt listened to and have gained greater control relating to the decision being made. As a wider benefit, Cameron may then better understand the range and scope of support available to him, should he need it in the future. When Cameron gets to the point when he, as he described "really needed it", thus avoiding crisis interventions at a later stage. This staged approach may also lead to an improved relationship with the service provider minimising unhelpful interactions and preventing Cameron moving into the spiral of disengagement (Figure 5.2).

5.2.5 Quality and reliability

The quality and reliability of services were important to the men interviewed and related directly to the decisions they made about accessing support (See Figure 1). In recent years there has been a move to change the way that people access services. Direct payments to those with health and social care needs in the UK, has been reported to be a step towards increased choice, improved access and consistency and reliability of care provision (SEHD, 2019; The King's Fund, 2011). The widening market for care providers is also said to create the potential for improved quality of care due to the increased competition between services. However; there is known to be an economic impact relating to caregiving, both on an individual and societal level (van der Lee, Bakker, Duivenvoorden, & Dröes, 2017), that may contribute to the lack of availability or accessibility of care services and their quality and reliability. As countries adapt and respond to the increasing demands for services, due to increasing number of older people, reduced workforce and increasing costs (Touhy & Jett, 2017; World Health Organization, 2015) there will be challenges for services to meet individual needs while maintaining the quality of services.

The quality and reliability of care services are of upmost importance to caregivers (Carers UK, 2014). In their report titled: "Quality of care and carers", Carers UK (2014) surveyed over 2,000 caregivers who have used home care or respite services. The report summarises that good quality, reliable and affordable care services are essential to ensure that family caregivers are able to continue to provide care. However, 24% of people in the survey reported negative experiences of social care services, and 16% reported negative experiences of NHS services. The coordination of health and social care services was reported to be difficult. For those that reported negative experiences of help, this led to refusing care altogether or deciding not to accept care due to concerns about the quality. Reliability, continuity, skills and empathy were reported to be aligned with quality in relation to staff from the caregiver perspective. Confidence in the quality of care provided was noted to improve health through having more time to meet their own needs:

> *"Good care, that meets the needs of their loved one, can improve carers' ability to work, spend time with other family members, look after their own health and have a life of their own outside of their caring role"* (Carers UK, 2014: 12)

The influence that poor quality of care, or the assumption that care would be poor, was an indicator for decisions made by caregivers not to access or continue with support and respite services (Carers UK, 2014), which is in line with the findings in this study, however, the perceived quality of services and how this links to the decision to access services, did not appear in the review of literature. Preconceived ideas surrounding respite and care homes appeared to create a reluctance for men in this study to consider this as an option. There was increased value placed on NHS provision in comparison to private or social care services in the interviews with Andrew, George and David. These participants did not offer any accounts of why NHS care provision was valued more, other than the assumption that NHS services and staff are subject to ongoing education and training. The value the men placed on NHS services could be more related to familiarity and loyalty to the NHS in principle (Park et al., 2012). Park et al. (2012) also note that as the media is the public's main source of information on the NHS and other health care providers, personal stories have become the way in which people measure the quality of services they receive. This increased access to personal experiences therefore highlights how reporting of negative experiences within the media could add to the assumptions and pre-conceived ideas caregivers have about quality of care in services in all sectors. Focus on negative reporting of care services could also magnify the sense of guilt family members feel when realising they are no longer able to provide care at home. The anticipation of poor services may also negatively influence caregiver's confidence in seeking information about services, when they feel that they need support and help to continue to care. The potential delay or decision not to access services that could provide essential support is likely to add to caregiver burden, isolation and further losses, and in particular their own wellbeing leading to crisis (Pretorius et al., 2009; Robinson et al., 2014; Ruiz Fernández & Ortega Galán, 2019; Shanks-McElroy & Strobino, 2001). This aspect of wellbeing is shown in the accounts given by Frank, Andrew and David, who each describe deteriorating health, lack of accessing support services and crisis resulting in decisions for respite care being taken by professionals, which further enhanced the perceptions that the caregivers have little impact and influence on the decisions that are made.

5.3 Theme 2: Changes and losses

Dementia brings about substantial change, both for the person with dementia and the caregiver (O'Shaughnessy et al., 2010 ; Sanders & Power, 2009). Changes and losses experienced by the caregiver impacts directly on the role they adopt and the responsibilities they take on, as the person with dementia gradually loses their independence, role and capacity (van der Lee et al., 2017). Caring was described by some of the men interviewed as a process of responding and reacting to a sequence of events brought about by changes. Changes experienced were far reaching and touched on all aspects of life, from the day to day routine, to their plans for the future. The losses encountered included among other things, their identity, their partner and their work and social support networks (Arcain Nass et al., 2016; McLennon et al., 2010).

5.3.1 Changes in the day to day

All the men spoke of changes in their day to day life, but for some there were significant changes, for example giving up work, taking on new roles and changes in the relationship they had with their partners. Associated losses in relation to these changes, included both personal and financial elements, which will be discussed later. The loss of work due to the decision to no longer continue with employment, because of their increased caring responsibilities, was explored by the men who were still working when their partner developed Alzheimer's dementia. For those men who described their experience that led to them giving up work for the purpose of providing care, there was an attempt to make sense of the decision they made. Reflecting back, the participating men spoke of the pull to be at home, as their partners were becoming increasingly anxious when they were out of the home. Russell (2006) found that men require a period of adjustment when they leave work to care for their wife and part of this adjustment is to the isolation and invisibility of caring. Joseph and Joseph (2019) explore the concept of employment as respite and note that assumptions are made surrounding caregiving, gender and employment. They suggest that there is a pressure on male caregivers, due to employers assuming that they will prioritise work over caregiving and that women would prioritise caregiving over work. The change in demographics, indicates that more men will take on caregiving for their partner as the population ages (Neufeld & Kushner, 2009). From Eric and David's perspective, there was an indication that they felt that their partners were vulnerable without them. Both noted that their partner had lost confidence and it was this that had intensified the pull to be at home. Although not explored in depth, the men who spoke of giving up work appeared to feel they had no option but to do so, although this was clearly a decision that they had made. This decision was linked to being perceived as unreliable employees, due to their caregiver responsibilities. For example, having to return home early due to distressed telephone calls from their partner, being late for work or not being available for shifts when needed, in line with findings from Joseph and Joseph (2019). Both Black et al. (2008) and Russell (2006) explored the experience of men who gave up work to care, however, neither examine the men's decision to give up work, or how caregiving impacted on their work, therefore little is known about this experience. For the participants in this study, the combination of being an unreliable employee and the need to be at home to alleviate their partner's distress, seemed to be at the core of their decision to leave work, although this experience would no doubt add to their perceived lack of power.

Giving up work changes, among other things, the daily routine for both the cared for and caregiver and also the men's identity and self-esteem (Black et al., 2008; Mittelman et al., 1993; Pretorius et al., 2009; Shanks-McElroy & Strobino, 2001). The change in relation to the connections and wider work-related network the caregiver has and the financial changes, add to the impact of this change. Joseph and Joseph (2019) propose that work can be seen to provide the space away from the caring role and time to be around others. Joseph and Joseph (2019) focus on caregivers of people with dementia and their high stress caused by the increased intensity of caregiving that is associated with this role.

Although, there are significant barriers that impact on caregivers ability to remain in work, for example, lack of support, feelings that they are not meeting the requirements of the job, pressure from family and employers, and feelings of guilt. These findings resonate with the experiences described by David and Eric and offer an insight into how driven the men are to care for their partners, and putting the needs of their partner ahead of their role, identity, connections, income and personal needs, in line with Bronner et al. (2016). However, it is demonstrated by Mittelman et al. (1993), Pretorius et al. (2009) and Shanks-McElroy and Strobino (2001) that the preservation of men's identity is essential to sustain health and wellbeing when in caregiving roles.

Caregiving is also associated with reduced social interactions. For example, giving up sports, hobbies and social activities (O'Shaughnessy et al., 2010; Pretorius et al., 2009; Shanks-McElroy & Strobino, 2001). This loss of recreational activity creates reduced opportunity for social interaction and can lead to isolation (Shanks-McElroy & Strobino, 2001). This finding is in line with the men interviewed, who all spoke about social activities and hobbies that they had to give up in order to meet the needs of their partner with Alzheimer's dementia. Pretorius et al. (2009) advocate for the development of support strategies to maximise free time for male caregivers, for the purpose of maintaining engagement in social activities, as a way of building resilience. However, this approach does not take account of the emotional impact of handing over caregiving to others, nor the challenges some face in finding the right type of support that is both accessible and acceptable to the person being cared for and caregiver (Lin et al., 2012; Mcintyre & Reynolds, 2011). The men interviewed in this study described complex experiences that brought about the decision to give up social activities, because of their sense of duty, responsibility and drive to meet the needs of their partner. Added to this, was the nature of the relationship before the onset of Alzheimer's dementia. For example, Cameron did not have social activities out-with his family. As a couple, Cameron and his wife spent their free time together and with their family. For Cameron, creating free time to take up social activities was unfamiliar and potentially difficult to consider. Therefore, the proposed family-centred approaches advocated by Brodie and Gadling-Cole (2004) and Etters et al. (2008), where attention is paid to the needs of both the care for and the caregiver, and partnership approach, encouraged by Brodaty and Donkin (2009), would be helpful in working well with Cameron to select strategies, that acceptable to him and how he views his role and responsibilities, when caring for his wife. There must therefore be more consideration of the pre-dementia relationship, when considering the range and scope of support and services that can help to maintain social interactions and connections. Such considerations can avoid unintentionally bringing about further changes and losses for the men to cope and adjust to.

The men interviewed; spoke of new roles they had taken on as a result of caring. These included home based roles like cooking, cleaning and laundry which were roles previously held by their partner. They also spoke of taking on roles out-with the home. For example, shopping and managing the couple's finances. For some the adoption of new roles gave a sense of purpose and pride in achieving new skills. This is in line with the findings reported by Yu et al. (2018) who noted the positive aspects of caregiving, which include a sense of growth and accomplishment which instilled a sense of purpose. However, when men felt that they were unable to cope with or manage new roles, this led to feelings of frustration, sadness and guilt, and appeared to relate to a sense of defeat. This finding can be seen in the quotes from Eric (E1), Bill (B3) and Andrew (A8). It is significant therefore to recognise and focus on positive aspects of caregiving as protective elements to mitigate against caregiver burden (Cheng et al., 2013; de Labra et al., 2015; Yu et al., 2018). It is also vital that targeted support is offered to support roles that are specifically challenging for male caregivers. For example, personal care and expressed distress for example aggression (Farina et al., 2017; Picco et al., 2015; Shanks-McElroy & Strobino, 2001).

5.3.2 Changes in relationships

Changes in the relationship between the couples were touched on by all of the men interviewed. O'Shaughnessy et al. (2010) report that there are ongoing changes and alterations to relationships is due to the increasing caring role and the deteriorating nature of Alzheimer's dementia. O'Shaughnessy et al. (2010) highlight the need for service providers to better understand the unique needs of partner caregivers and offer support that responds to these needs. Conceptualising male caregivers' needs in relation to changes and losses may provide a normalising approach to exploring the increasing caring role and the burden this places on male caregivers.

One key change touched on by the men interviewed was the connection they had with their partner, on an emotional and physical level. The physical connection was linked to the physical contact between the couple, with some of the men no longer being able to sleep in the same bed or the same room as their partner. The emotional connection with their partner was specifically expressed by the men, who perceived that their partner had lost the capacity to recognise them and to be considerate their emotional needs. Also, the lack of emotion expressed by their partner with Alzheimer's dementia was challenging. Specifically, shared joy, happiness and emotional engagement in response to things they would have previously enjoyed was seen as a major change. There is little mention of the changes in the relationship between the caregiver and the cared for in the literature, with only O'Shaughnessy et al. (2010) making explicit connections with relationship changes as dementia progresses suggesting a gap in knowledge surrounding this. From the interviews, it was evident that changes in the relationship the men had with their partners affected them deeply and drew to the surface strong emotions. Andrew, Frank and George struggled to verbalise the emotional impacts of their partner no longer recognising them, which fundamentally changed all aspects of their relationship. This is something that is unique to caregivers of partners with dementia touched on by Meichsner and Wilz (2018). The strong emotions connected with this experience of rejection, must therefore be recognised by service provides. For example, GP's, community nurses and dementia specific services. As such, targeted emotional support should be made accessible to men in a way that offers opportunities to express these strong emotions and recognise the impact they have on their well-being, mental health and their continued caregiving. Meichsner and Wilz (2018) recommend that professionals should specifically aim to identify pre-death grief in caregivers caring for people with dementia and support the use of interventions like CBT as an intervention to help caregivers cope with the unique grief experienced by this group of caregivers. Psychological interventions, including CBT, counselling and psychoeducation are highlighted as particularly valuable to dementia caregiver due to the emotional burden the symptoms and progressive nature of dementia presents caregivers (Cheng et al., 2013; de Labra et al., 2015; Donnellan et al., 2015; Etters et al., 2008; McLennon S M et al., 2010; Picco et al., 2015; Riedijk et al., 2006).

5.3.3 Changes for the future

Ornstein, Wolff, Bollens-Lund, Rahman, and Kelley (2019) asserted the need for increased support for solo caregivers, especially in the final years before bereavement. Using data gathered from a Health and Retirement questionnaire, they concluded that solo caregiving was more common for people who cared for a partner with dementia and that both isolation and depression were more likely, this is in line with findings from Bruce and Paterson (2000); Karlawish et al. (2003); Schoenmakers, Buntinx and Delepeleire (2010) and Shanks-McElroy and Strobino (2001). All of the men interviewed in this study were solo caregivers each having rescinded social activities previously enjoyed and many of their plans for their future post-retirement. Cash, Warburton and Hodgkin (2019) explored caregiving within the context of long-term marriage and refer to the social and financial interdependence of being in a long term marriage, with limited opportunities and choices about the future. Although not specific to men or Alzheimer's dementia, Cash et al. (2019) study interviewed a diverse group of older caregivers caring for a spouse with the focus on the *"intersection of marriage and caregiving"* (Cash et al., 2019:19). The findings indicated that caregiving, in the context of long-term marriage, is assumed and that this normative expectation that a partner will provide care in later life, impacts on both decision making and future planning. This is in contrast to findings from Black et al. (2008); Robinson et al. (2014) and Russell (2006), who focus is on caregiving men, and report that there is an added complexity due to gender norms and stereotypical views of men's ability to adopt and manage caring roles. There were strong emotions expressed, when the men interviewed spoke of the future, with some unwilling to look beyond the next day. The men who spoke of the plans the couple had made for retirement, describing failed attempts at realising these plans. For example, trips and holidays that were unsuccessful or had to be cancelled. There were expressions of sadness when the participating men spoke of the points when they realised that the plans they had as a couple, could no longer be actualised due to their partner's dementia.

It is recognised that ageing and retirement bring emotional burden, through the loss of role, identity and purpose (Touhy & Jett, 2017). For many, this can bring about challenges in adapting to these changes (Touhy & Jett, 2017). The exposure to change is potentially intensified for those who have partners with Alzheimer's dementia, which is a condition that usually develops in later life and potentially at a similar point to retirement. For the men in this study who commenced retirement in order to provide care, the changes they experienced were twofold, impacting on people's ability to remain connected with others, continuing with social activities, and striving to adjust to new roles. It is recognised that chronic illness can lead to Biographical Disruption (Bury, 1982) and that this disruption can be experienced by those caring for people with chronic illness, and specifically dementia (Hasselkus & Murray, 2007). Chronic illness forces significant changes onto the caregiver resulting in disruption in the day to day life of the caregiver and their identity (Black et al., 2008; Hasselkus & Murray, 2007; Russell, 2006). These multiple and substantial changes faced by men, specifically those caring for their partner with Alzheimer's dementia, require to be acknowledged by service providers, since this can increase risk of caregiver burden and emotional burden felt as the person attempts to navigate changes and adapt to new demands (Brodaty et al., 2009; Brodie & Gadling-Cole, 2004; Russell, 2006; Sanders & Power, 2009).

5.3.3 Adapting to changes

The men interviewed talked about finding alternative strategies to manage the changes they experienced, through finding practical solutions to difficulties encountered. These ranged from adapting the home to establishing new routines and successfully navigating new roles adopted as their partner's skills decline. These problem-solving skills are recognised as protective factors by Pretorius et al. (2009) and offer male caregivers a sense of achievement and purpose (Yu et al., 2018).

The use of informal support and help in the everyday environment was an interesting finding. Cameron, Bill and Frank all described how they established fixed routines that allowed them to adapt to the demands of caregiving, which included specific days and times for particular tasks. These schedules included routines set around specific walks, activities like shopping and going out to coffee shops and garden centres. It was these routines that brought about opportunistic support and social engagement with others, which then became part of the couple’s social network, this resonates with findings from Black et al. (2008). An example of this was the use of supermarket café where, as described specifically by Cameron, his partner would sit and have coffee while he carried out the weekly shopping. The café staff became a source of support for Cameron and his partner and provided informal respite to allow him to shop alone. With familiarity, relationships developed with staff in supermarkets, local coffee shops, garden centres, which all appeared to create a supportive community for the men (Bruce & Paterson, 2000). Set within the routine of their week, this regular informal support was unanticipated by the men, but highly valued. This was a significant finding within this study, as it offered insights into the establishment of new supportive social networks that emerged from routine and familiarity with local communities, something that is underreported in the literature.

Dementia friendly environments or communities are currently being promoted as a way to create increased awareness of dementia, to minimise stigma and maximise inclusion for people living with dementia (Alzheimers Disease International, 2018; WHO, 2012). These examples of local everyday environments, in which people recognise someone with dementia and connect socially with them and their caregiver, could be an example of ways in which inclusion can be promoted and caregivers supported in practical and accessible ways. Phillipson et al. (2019) encourage that there needs to be a societal change to embed dementia friendly community initiatives, and that this needs to begin with challenging people’s perceptions of dementia. Phillipson et al. (2019) suggest a range of approaches that support dementia friendly communities, one of which is the development of dementia cafés.

The Dementia café or Memory café, as they are sometimes called, is an initiative that offers people affected by dementia a safe and relaxing environment where they can meet people with similar experiences and gain mutual support, advice and build social connections (Alzheimer's Society, 2019). Usually provided by non-profit third sector services, these cafés are places which are recognised for the support they can offer both the person with dementia and their families (Greenwood, Smith, Akhtar, & Richardson, 2017). Running in the UK since 2000, the Dementia café's initiative originated in the Netherlands, with the key aim being to create an environment where people with dementia and their family can continue to live as normal a life as possible (Akhtar, Greenwood, Smith, & Richardson, 2017). Greenwood et al. (2017) report that caregivers and people with dementia feel accepted and welcomed when they attend the café and benefit from the wider social engagement opportunities they offer. The findings within this study support these assertions, with all of the men who attended the dementia café's reporting a sense of being among friends and feeling welcomed. Particularly interesting are the cases of Bill, Cameron and Frank, who did not consider using a dementia café prior to their partner developing Alzheimer's dementia. This change of perception and willingness to attend a support service like this, is worthy of further attention. The aim would be to draw out the reason for this change in approach and why this type of support service appeared more acceptable to the caregiver. Improved understanding of why men are willing to engage with support services will create opportunities, tailor information and focus marketing to develop strategies that ensure information about dementia café's reach male caregivers.

From those interviewed, the café appeared to give the men an environment to both offer support and receive support. The café created an environment where they felt able to express themselves and talk about their caring role. It also provided a normalised environment where there is a mutual understanding of dementia and how it affects people. These findings offer increased understanding of the factors that encourage men to continue to use dementia cafés. For example, the opportunity to help and support others. This finding provides more detail about the value of dementia café environments that is known to remove the anxiety caused by stigma and lack of understanding that other non-dementia friendly environments can perpetuate (Phillipson et al., 2019).

Maintaining a sense of normality and privacy was very important for some of the men and can be seen in some of the quotes relating to how they perceived respite services and other forms of support. Maintaining normality can be seen as a way to cope with the significant changes men face. Creating a routine, for example, appeared to help with providing a sense of manageability when immersed in significant change, while engaging with support and other services appeared to contribute to and intensify the changes experienced (Mc Donnell & Ryan, 2011; Neufeld & Kushner, 2009). David, Frank, Cameron and Andrew showed reluctance to accept support preferring to maintain the caring role independently, without others being involved. This desire for independence can be linked to many things, for example fear of others taking over, attempting to slow down or stop the changes and losses associated with dementia, or simply to try to have time to adapt to the new experiences. Cash et al. (2019) propose that the desire to provide care without depending on others, is linked to being in a long-term relationship and that caregiving is based on internal and emotional drivers, which include duty and obligation that is reinforced by external and social pressures (Harris, 1993; Ruiz Fernández & Ortega Galán, 2019). The intimate environment of marriage and similar long-term partnerships create interdependence in which commitment to care is normative (Cash et al., 2019; Ornstein et al., 2019). This commitment to care may include the need to protect one another from the impact of the changes experienced, in attempts to sustain a “normal” routine and life. This study offers unique insight into the lived experience of men and their sense of responsibility and duty to care for their partners, which is explored in the next final theme.

5.3.4 Psychosocial Ageing Theory

There are many theories of ageing that encapsulate the concept of change and how it relates to how individuals react and adapt to ageing. This adaptation is of relevance to this study, due to the age of the men and the changes that they are exposed to and required to adapt to.

First Generation (1940-1950’s) ageing theory has an emphasis on adjustment in later life. For example, Role Theory (Cottrell, 1942). In Cottrell’s (1942) theory, identity is defined by the roles people have in society. As we age, the roles we adopt change and are replaced by new roles. How people adapt to the loss of prior roles and the adoption of new roles is seen as an indication of successful ageing. However, it is noted that cultural norms, gender and society influence the roles people adopt (Neufeld & Kushner, 2009; Russell, 2006).

Second Generation ageing theory (1960 – 1970’s) expanded and questioned first generation theories, an example of which is Continuity Theory which was developed by Havighurst in 1969 (Touhy & Jett, 2017). Continuity Theory suggests that people have their own roles and activities that they maintain into older age. These roles are a continuation of the individual’s life patterns, the roles maintained and taken into older age are determined by the individual (Touhy & Jett, 2017).

Third Generation (1990’s onwards) takes a more phenomenological view, given that this theory sets out to understand the personal meaning and experience of ageing within the context of people life journey. This approach is particularly relevant to the men in this study and the focus on their personal experience. An example of this is Life Story Theory developed by Ramirez-Esparza and Pennebaker (2006) who propose that narratives and storytelling have become areas of great interest over the past two decades. The appeal of the life story is that it can capture the culture and history of people and communities (Bohn, 2010). There is a universal commonality around the telling of stories and this has become a prominent approach in older people’s care (Touhy & Jett, 2017). In Life Story Theory, ageing is conceptualised through storytelling, noting that it is important to look back, talk and make sense of our experience, and hence the connection with phenomenology. This need to make sense of change is particularly relevant when illness and health conditions bring about additional changes (Sampaio, Renaud, & Ponce Leão, 2018). The process of creating meaning and accepting one´s life through storytelling, can be a strategy by which individuals adjust to significant changes in their lives (Bohn, 2010; McAdams, 2001).

For men caring for partners who have Alzheimer’s dementia, change is vast and is a result of both ageing and caregiving and so presents a complex experience from which to draw meaning. It is through the process of meaning making and adjustment that people who are ageing cope with the changes they are experiencing. However, for caregivers of people with Alzheimer’s dementia, this change continues and is intensified with the cognitive decline of the person with Alzheimer’s dementia, who gradually places more demands on the caregiver (Bronner et al., 2016).

5.3.5 Application of ageing theory

Men caring for partners with Alzheimer’s dementia may not be able to follow the culturally determined path of ageing, during which they adapt to and adjust to day to day, life as they age, in line with Role Theory (Cottrell, 1942). The added complexity of adopting a role that was not anticipated, may limit choice and prevent caregivers from putting in place the activities needed to create continuity as they age. Having Alzheimer’s dementia and the adoption of the caregiver role, in essence, changes perceptions of self and interrupts the opportunity to plan for and put in place strategies that support successful aging. Russell (2006) considers the transitions men make from the *“public arena”* of work to the *“unseen world of caregiving”* (Russell, 2006: 299), and considers the way in which men navigate this transition. Russell (2006) comments on the stereotypes and assumptions made about male caregivers, which will be touched on in the following section. First and second-generation ageing theory do not encapsulate caregiving and therefore it is challenging to apply them to people in this role. Rather than considering how people may hand over roles and responsibilities to others as they age, caregiver are taking on new unanticipated roles and navigating experiences that are unfamiliar and challenging.

Third generation ageing theory, for example life stories (Ramirez-Esparza & Pennebaker, 2006) offer some scope to support caregivers to gain some sense of the changes they are experiencing through exploring their life and relationship and deriving some meaning from this to their current context. More research into ageing theory and how it articulates with caregiving may offer some insights into these concepts. In particular, the relationships between them and how they are connected to better understand this experience. This study offers some new understanding of the value men place on opportunities to talk about their experience in environments where they feel a sense of connection and where they see their experiences are of value to others. Such environments appear to offer a place for men to express themselves and give and receive support from peers, which is a process that offers a sense of purpose and meaning.

5.3.6 Losses associated with change

The changes the men in this study experienced, for example, day to day life, relationships and future plans, resulted in multiple associated losses. These losses were broad ranging and included loss of role, identity, purpose, social networks, as well as the loss of their partner. Many of these losses are identified within the literature surrounding caregiving (Graneheim, Johansson, & Lindgren, 2014; Lin et al., 2012; Maria Garcia-Alberca et al., 2013; Riley, Evans, & Oyebode, 2018). In addition to these losses, there was also specific losses, such as loss of sleep, time to oneself, enjoyment and shared history, and for some, a loss of income and pension contributions, with this highlighted by van der Lee et al. (2017) as an additional burden on caregivers.

The changes in role and particularly changes in day to day life, for example, becoming a caregiver and oscillating between caregiver and partner roles, along with no longer having a work role, resulted in many losses culminating in a loss of identity. This change in identity is significant and is in line with a number of key sources. For example, Brodaty, Mittelman, Gibson, Seeher, and Burns (2009); Pretorius, Walker, and Heyns (2009) and Shanks-McElroy and Strobino (2001), who all recommend that maintaining connections, interests and hobbies are vital for maintaining a sense of identity and supporting well-being.

The men interviewed spoke of losing connections with work colleagues, as well as social networks of friends, wider family and significant groups. For example, connections related to regular sports, activities and hobbies. These examples mirror the findings in the literature relating to caregivers generally (Farina et al., 2017; McLennon et al., 2010; O’Shaughnessy et al., 2010; Shanks-McElroy & Strobino, 2001). However, few go on to examine the combination of these losses for male partners specifically, which may result in a higher risk of emotional burden through increased isolation. The losses experienced by caregivers’ impacts negatively on all aspects of wellbeing, including physical, emotional and psychological health (Riley et al., 2018). If socially and economically societies need family caregivers to continue to care for their loved ones, attention must be paid to the losses that caregivers experience, with interventions put in place to reduce the impact on their health and wellbeing.

Considering the losses experienced by the men in this study and in relation to the increased isolation that stems from the spiral of disengagement gives an increased awareness of the risk of increased isolation male caregivers of partners with Alzheimer’s dementia may experience (Harris, 1993; Riedijk et al., 2006). The experiences shared in this study indicate that one of the ways in which men may combat against this isolation, is through establishing routines that include connecting with people within communities who provide social contact, interaction and friendship that is viewed as a valuable resource by some men.

5.3.7 Loss of health

One substantial loss highlighted in the findings of this study, was the loss of the caregiver’s health. This mirrors the findings of the Robinson et al. (2014) literature review which revealed that one outcome of caring involved a direct negative impact on men’s health and well-being. Robinson et al. (2014) go on to suggest that more research into men as caregivers and men’s health is needed. This recommendation is particularly important in the ageing population and subsequent increase in caregiving by men as the life expectancy gap closes (Neufeld & Kushner, 2009; Russell, 2006).

Accounts of deteriorating health were present in all of the interviews. Although this may not be surprising due to the age of the men, it was noticeable that the importance the men placed on their own health was minimised, disregarded or perceived as not important. This aspect will be discussed in the following theme, due to its link with male caregivers and coping. Ruiz Fernández and Ortega Galán (2019) reported an increased risk of anxiety and depression in spousal and adult child caregivers, who have been caring for over 2 years. Hence, Ruiz Fernández and Ortega Galán (2019) recommend that both the relationship and the duration of caring should be taken into account when considering and planning interventions. These considerations would be helpful when developing individualised and caregiver-centred approaches, recommended by (McLennon et al., 2010; Van Vliet, De Vugt, Bakker, Koopmans, & Verhey, 2010). The findings from this study mirror these recommendations and in addition, would encourage that the changes and associated losses were also considered.

Aside from the Robinson et al. (2014) recommendations, there is little mention in the literature of the reduction in physical activity out-with the home due to caregiving and how this impact on caregivers health. An example of this within the interviews was when Andrew gave an account of not having reliable care at home services that allow him to continue with his regular physical activity, which included swimming and yoga. Regular physical activity is known to be of value in reducing and helping to prevent and treat non-communicable diseases, such as heart disease, stroke, diabetes and breast and colon cancer (López-bueno & Andersen, 2020; Scottish Government, 2018a). It also helps prevent hypertension, weight gain and obesity and can improve mental health, quality of life and well-being (World Health Organization, 2018). Findings from this study demonstrated that the lack of trust in services, due to poor reliability and continuity, resulted in the men either not engaging with or not continuing with services. The spiral of disengagement would not have happened if these services had afforded the participants time to access or continue to engage in physical activities they enjoyed.

David spoke specifically about health and lack of physical activity and described his frustration at not being able to manage his weight since taking on the role of caregiver for his partner. He attributed this to not having time to go for walks, which was something that he did prior to caring and having to give up work. David connected both of these changes to the loss of his health, and specifically his ability to go for walks and loss of work due to not being able to leave his partner at home alone. David recognised that prior to caring, his previous level of physical activity had helped him to maintain his weight. He also acknowledged that increased time in the home, boredom and tiredness due to lack of sleep all contributed to increasing his food intake, and this adding to his weight gain. Caregivers reduced opportunities to access and maintain physical activity can lead to health deterioration (Robinson et al., 2014). In relation to David, his lack of physical activity and subsequent weight gain would increase his risk of developing long term conditions, such as cardiovascular disease, diabetes and stroke (Greaves et al., 2011), thus impacting on his ability to continue to care. It is essential therefore to take cognisance of the broader and long-term impact of unreliable and poor quality services and the connection this has with caregivers' use of services.

5.3.8 Loss of their partner

A strong element that came through the interview analysis was the participants' loss of their partner, which included shared enjoyment and a shared history. Often described as pre-death grief (Meichsner & Wilz, 2018), and specific to caregivers of people with dementia. Due to cognitive deterioration over the duration of the condition, caregivers often find themselves in a position where they are grieving for the person whilst they are still alive (Black, Schwartz, Caruso, & Hannum, 2008). This experience can present as an overwhelming sense of loss of the person, their relationship and shared history (Meichsner & Wilz, 2018). All of the men interviewed touched on the loss of the person and their relationship, and some specifically spoke of the lack of shared joy and emotional responses to things that would have previously given them enjoyment and pleasure. Meichsner and Wilz (2018) recommend the use of CBT as an intervention for caregivers, which should include grief specific interventions to reduce caregiver burden. Thus, acknowledging the importance of developing relationship and diagnosis-specific tailored and considered interventions, that meet the needs of caregivers (De Vugt & Verhey, 2013; McLennon et al., 2010).

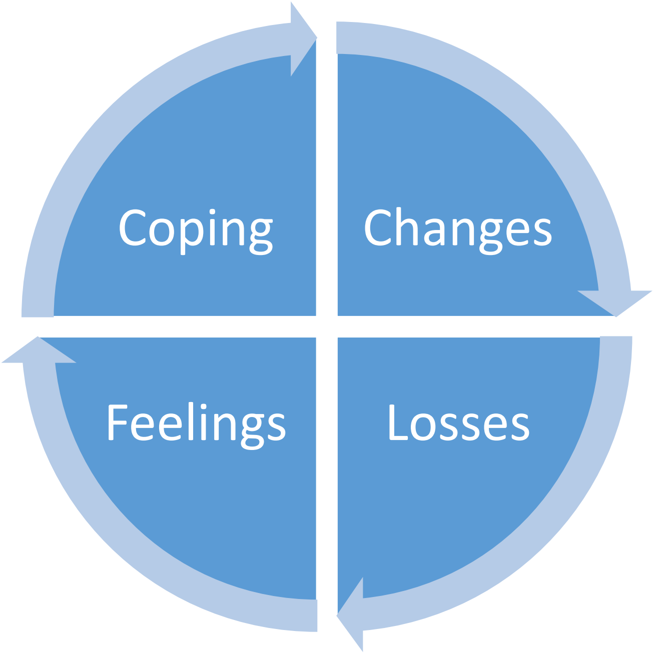
Loss of agency was also apparent in participants, whose perceived lack of control related to managing new and unfamiliar experiences and navigating services and support networks to identify ways to manage the difficulties they faced. Heckhausen, Wrosch and Schulz (2019) propose that self-agency is related to motivation and action for long-term goals, which are generated over a lifespan. This loss of agency appeared to impact on the sense of purpose and identity of caregivers interviewed. The sense of purpose is directly connected with beliefs about self-agency, therefore men who find themselves in unfamiliar and challenging caregiver roles may not believe that they have the capabilities to meet the challenges of this role. This aspect of care providing is potentially re-enforced when health and social care professionals are seen to take over or over-rule the goals and actions that are put in place by the men.

Caregivers are not able to change the outcome of Alzheimer's dementia, because people with Alzheimer's dementia deteriorate and the loss of the person through this progression is inevitable. It is a process, and it will happen regardless of what caregivers do. This lack of influence may intensify the feelings of not being in control and increase the desire for men to hold time still, to maintain the norm and to avoid the reality of substantial changes they are experiencing. For some of the men interviewed, there was a reluctance to access support and to let services into their home, which was particularly evident in the case of Cameron. This aspect of care providing appeared to be related to men maintaining a sense of control and coping and not wanting to expose the extent of the changes or their coping strategies to outsiders. Thus, distancing others from the home was not exclusive to service providers, and often extended to family members, friends and neighbours. This at times appeared to be a self-imposed isolation and may be linked to a sense of exposure and vulnerability to others taking control, this is in keeping with findings by (Riedijk et al. (2006) and Schoenmakers et al. (2010).

5.3.7 Emotional responses to loss

There is a clear connection between changes, losses, feelings and coping. Each of these factors influence the others and the emotional responses to these changes and losses experienced are significant to men who care for their partner with Alzheimer's dementia. Recognition of each of the change and loss elements of this cycle (See Figure 5.4) is required in order to illicit the emotional impact of caregiving and to enable identification of helpful strategies to support caregivers. As caregivers of people with Alzheimer's dementia experience frequent changes, they are continually responding to the losses they encounter with each change. The emotional burden required to manage the feelings associated with these changes and losses is significant. It is recognised in the literature that men are less likely to access emotional support and instead have a tendency to seek practical support and solutions to challenges (Cheng et al., 2013; O'Shaughnessy et al., 2010; Shanks-McElroy & Strobino, 2001). However, changes and losses generate intense emotions and for those caring for someone with dementia and these are often likened to the emotions associated with grief (Meichsner & Wilz, 2018).

Figure 5. 4: Cycle of Changes, Losses, Feelings and Coping



In this study, it became clear that for male partner caregivers of people with Alzheimer's dementia, changes and losses are significant; they encompass all aspects of participants day to day lives and their hopes and plans for the future. Despite this, there is often a reluctance for men to seek emotional support for themselves (Brodie & Gadling-Cole, 2004). However, this emotional support has, for some, been gained through more informal routes, for example, in mutual support groups like dementia café's, caregiver support groups, and unanticipated social community networks like garden centres, café's and supermarkets.

For some, the emotional impact of caregiving and its associated losses incurred significant mental health distress. This became evident in the interview with Bill whose caregiving role became overwhelming and resulted in him developing feelings of low self-worth and thoughts of suicide. O'Dwyer, Moyle, Zimmer-gembeck and Leo (2016) identified that 16% of 566 caregivers of people with dementia surveyed, experienced suicidal ideation regardless of whether they cared for the person with dementia at home or when the person was in care. Although the O'Dwyer et al. (2016) study did not differentiate between caregivers relationship to the cared for, it discussed the increased risk of suicide for those caring for someone with dementia, and offers recommendations to support the identification of those at risk. The authors go on to suggest that interventions that target a reduction in depression and increase reasons for living for example purpose, meaning and role could help to mitigate the risk of suicide. This finding is similar to those of Schoenmakers, Buntinx, and DeLepeleire, (2010). O'Dwyer et al. (2016) propose that there should be an exploration of suicide attempts and deaths by suicide in this specific caregiving population, with this data not currently captured. The recognition that globally men are more likely to die by suicide than women, and that a significant number of men who do take their own lives are older (WHO, 2014), gives more weight to O'Dwyer et al. (2016) recommendations.

As the men interviewed considered they had a primary role and purpose in providing care for their partner, this responsibility could be a viewed as a protective factor in relation to suicide risk. It is recognised that those who have dependants are less likely to act on suicide ideation (Scottish Government, 2018c), however, once caregiving comes to an end there could be a heightened sense of lack of purpose. Therefore, data around suicide attempts or suicide completion in this caregiver group, from the point where caregiving ends, could offer valuable insights and may provide additional detail that can inform risk assessment, strategies and policies. Interestingly, this links well with the Senses Framework (Nolan & Allan, 2017), which originally was developed in 2004. This Senses framework re-conceptualised older people care in a way that was no longer aligned to the biomedical model. The aim of this framework was to provide a clearer direction for staff to improve the quality and experience of care for patients, families and care staff. The framework is set around six senses that include a sense of purpose, significance and achievement, outlined in Table 5.1.

Table 5. 1: **The Senses Framework (Adapted from Nolan et al., 2006)**

Sense	Description
Security	to feel safe
Belonging	to feel part of things
Continuity	to experience links and connection
Purpose	to have a goal(s) to aspire to
Achievement	to make progress towards these goals
Significance	to feel that you matter as a person

Creating environments where people gain a sense of purpose, significance, achievement and establish a sense of connection with others, enhances self-worth and well-being (Nolan & Allan, 2017). The use of this framework helps health care workers and others who come into contact with family caregivers to identify strategies that maximise these senses and therefore increase the protective factors related to depression and suicide ideation. Environments like the Dementia Café's instil these senses, through café members sharing experiences, connections and providing opportunities to find purpose in supporting others in similar situations. Based on the interviews, the supportive and welcoming environment offers men the opportunity to express themselves, even when they did not intend to do so. The value of providing opportunities for men to talk to others, share experiences and develop strategies for coping, appears to be maximised when they arise in environments where they feel a sense of connection and security.

5.4 Theme 3: Coping and Being Connected

It is recognised in the literature surrounding caregiving, that caregiver burden and deterioration in the health of the caregiver are influential factors that relate to NHP (Bruce & Paterson, 2000; Karlin, Bell, & Noah, 2001; Mittelman et al., 1993; Robinson & Webber, 2013). It is known that partners are often the caregiver group that are most reluctant to hand over their caregiver role to others (Brodaty et al., 2009; Bronner et al., 2016; Harris, 1993). Brodaty et al. (2009) proposed that planned transition to services should be based on the needs of the person with Alzheimer's dementia and on caregiver needs. They posit that there is value in gaining a more detailed understanding of caregiver perspectives and that this would facilitate identification of their needs and therefore establish more caregiver-centred support, and supported by Phillipson et al. (2013) and Stirling et al. (2010). Based on the findings from this study, part of this detailed understanding needs to be in relation to the role the caregiver adopts, their gender and the relationship with the cared for, which to date has not been explored in the literature available. This gap in the literature demonstrates the value of this study's additional detail, which was examined through the experiences of men in a specific caregiving role.

5.4.1 Men and the role of caregiving

Russell (2006) recognised the lack of recognition that male caregivers generally receive in the literature and how the experience of male caregivers is marginalised, thus further reinforcing the stereotype that caregivers are female (Black et al., 2008; Neufeld & Kushner, 2009; Russell, 2006). Russell's (2006) work is one of the few studies that offers comparisons between male and female caregivers and specifically considers the way in which men transition from work to caregiving. Russell (2006) suggests that there are assumptions that men are not able to provide the nurturing element of care and rely on managerial styles of caregiving. This is in line with Black et al. (2008) and Spendelow et al. (2016), who posit that men in caregiving roles have the additional stress of coping with role and identity issues resulting from gender stereotypes. Russell (2006) reports that men draw on both management and nurturing skills when providing care, which is similar to the findings of Spendelow et al. (2016) who found that male caregivers who were able to be flexible in relation to these two aspects are more able to cope with the demands of caring.

The combination of managerial strategies that encourage a sense of control and self-agency, along with the nurturing skills, could explain how men are *"sheltered"* (Russell, 2006: 302) from symptoms of burnout and emotional distress. The adoption of a more solution focussed approach to caregiving, may in itself offer benefits like increased resilience, something that was supported by Cheng et al. (2013), Pretorius et al. (2009), Shanks-McElroy and Strobino (2001) and Yu et al. (2018), who all recognised this as a protective factor in relation to caregiver burden.

This present study indicates that the men interviewed gained a sense of achievement in identifying solutions to difficulties related to Alzheimer’s dementia. This experience could be related to a developing or growing confidence in caregiving, or an indication of increased resilience as the caregiver adapts to their new role. However, for some participants, these solutions did not bring about the benefits that were anticipated and therefore resulted in more distress and frustration. Russell (2006) notes that the men he interviewed found the invisibility of caregiving and not being able to see what they had accomplished as frustrating. Russell’s (2006) findings offer an insight into how men might seek visible and tangible evidence of coping and managing caregiving. This need for tangible evidence of successful caring was evident in interviews for this study. The men interviewed spoke at length about the solutions they had found in order to cope with issues arising from their partners Alzheimer’s dementia progression. Successful coping offered the participants some reassurance of successful caregiving and a sense of purpose and achievement. The men took pride in detailing the solutions they found to the interviewer, indicating the importance they placed on what clearly demonstrate the successes they have had to others. The reporting of successful strategies appeared to provide tangible evidence to confirm that they are coping with caregiving. This is aligned to Black et al. (2008) who also highlight that demonstration of coping and successful caring helped to sustain men’s identity and sense of purpose, which are concepts that are core to the Senses Framework (Nolan & Allan, 2017) (See Table 5.1). The reassurance that goals are achieved and changes due to Alzheimer's dementia are successfully navigated appear to have positive influence on caregivers' motivation. This is touched upon by Yu et al. (2018), who encourage that there should be more emphasis placed on the positive aspects of caregiving, rather than the focus being on caregiver burden, challenges related to caregiving, and stress. Although focussing on the positives can be of value (Pretorius et al., 2009; Yu et al., 2018), there would be risks associated with not acknowledging the more challenging physical and emotional aspects of the male caregivers' experiences, for example how caring related stress can impact on caregiver health (Shanks-McElroy & Strobino, 2001). Specifically, for men, the determination to care for a partner through love, duty and responsibility, as highlighted by Harris (1993) can lead to men overlooking their own health needs. This was evident for men in this study, for Andrew, Bill and Frank, who each developed health issues that impacted on their caregiving role. Lack of attention to stress and burden has this has the potential to limit the expression of feelings associated with the significant change and loss experienced by the men and the impact these have on their coping.

For men, physical caring tasks, like personal care, were seen as challenging. Brodaty et al. (2009) and Shanks-McElroy and Strobino (2001) recognised that personal care needs, as well as frequency of challenging behaviour, can increase the stress men experience, which adds to caregiver burden. In this study, the difficulty faced by some men appeared to be related to their sense of what is appropriate in relation to gender, their relationship and the perceptions of whether their partner would be comfortable with them attending to their personal care. This is unsurprising to a degree, as the provision of personal care is a very significant shift from the role of partner to that of caregiver. This study gives some increased understanding surrounding the influencing factors that determine men's view of their role in providing personal care to their partner and resonates with findings from O'Shaughnessy et al. (2010) who reports the change in relationship that spousal caregivers have to navigate as they transition into the caregiver role. Equally it links with Harris' (1993) "at a crossroads" caregiver, who is adapting and negotiating the move into the caregiver role. The increased understanding from this study leads to recognition that there is potential value in considering the point at which men perceive they shift from partner to caregiver. The shift from partner to caregiver is under-explored from a gender perspective and would be of value when considering the emotional burden experienced by male caregivers and the key points where emotional responses to changes and losses could be anticipated.

5.4.2 Masculinity

This study has focussed on men who care for partners with Alzheimer's dementia and therefore connects with men's perception of being a man, a male caregiver and a male partner. Caregiving can be viewed as a move away from the traditional gender role norms and this can result in men experiencing increased isolation and risk of depression (Caperton et al., 2019). However, despite caregiving being seen as a predominantly female role (Spendelow et al., 2016), the men in this study clearly viewed caregiving for their partner as their role and responsibility. Spendelow et al. (2016) recognise the importance of considering how men who are in caregiving roles adapt to the challenges that taking on a "feminised" role have. They report that those who adopt a more flexible approach to how they understand and combine traditional masculinity and nurturing roles benefit them psychologically. This was apparent for most of the men interviewed, who described their role of caregiving in the context of being a long-term partner. Through exploration of their caregiver role, the men described their drive to care as being related to the emotional connection with their partner, their time together and shared life, this is in line with findings from Harris (1993). The men also linked this to the way that they viewed the role of a partner or husband, which for some was described as stemming from their own parents relationship. Some, for example Andrew and Cameron, made sense of their role and their interpretation of caregiving through the role their father adopted. While others made sense of adopting the caregiving role by linking it to the care and nurturing offered to them by their partner throughout their life together. This was offered by quotes like *"…she has looked after me…", "…it's my turn to look after her…", "…she took care of me all my life…".*

Black et al. (2008) propose that the way in which men manage their caregiving role is a demonstration of who they are as a person, a husband and a worker. They suggest that men approach caregiving in a similar way to work. This perception relates to the findings of this study, specifically with regard to the attention given to the practical, solution focussed approach to the changes the men encountered. Black et al. (2008); Richardson et al. (2013); Russell (2006) and Spendelow et al. (2016) all reference the importance men place on demonstrating coping to others, with this linked to both showing outsiders their ability to provide care and gain a sense of achievement and purpose. From this study, it can also be linked to maintaining control and to hold back the progression of Alzheimer's dementia to mediate the impact of changes and losses linked to the deterioration in health of the person being cared for. Therefore, if caregivers are to be supported well in their role, there has to be better understating of the factors that influence the experience of caregiving. These factors must include not only the person, husband and worker, as defined by Black et al. (2008), but also in relation to the reason caregiving is required. It is the combination of these factors that will provide improved insights and better understanding of the unique experience and therefore the support and services that may be required.

The desire to care without depending on others was strong for some of the men interviewed. Their show of strength, resilience and coping can be aligned to the norms of masculinity, for example, being a provider as described by Spendelow et al. (2016). Also, as a way of keeping others at arm's length to preserve their and their partners privacy, identity and relationship (Black et al., 2008). This display of resilience and coping was apparent in the interview with Andrew, albeit at the detriment of his own health. Recognition that these societal norms relating to men who take on roles as caregivers need to be challenged to enable men to seek support and express distress without feeling this shows weakness or lack of ability. Harris (1993) goes some way in defining the role that male caregivers take on, when caring for their spouse with Alzheimer's dementia. Harris (1993) sets out a typology of caregivers that includes the worker, the labour of love, the sense of duty and at a crossroads. This study goes some way in further unpicking the way in which men adapt to caregiving roles as a man and as a partner and offers insights into the factors that they perceive as helpful and unhelpful in relation to their success of coping with the changes caregiving presents.

5.4.3 Problem solver: valuing practical solutions

As previously mentioned, problem solving and making things more manageable are seen as protective factors that aid resilience and mental well-being (Pretorius et al., 2009). Pretorius et al. (2009) propose that creative problem solving promotes a sense of achievement and hence improves outcomes for male caregivers. This is in line with findings from Cheng et al. (2013) who put forward the notion that the sense of achievement supports self-efficacy or agency and can act as buffer to the emotional burden of key behaviours associated with Alzheimer’s dementia, like repetition and seeking behaviour. Mc Donnell and Ryan (2011) also note that men value practical problem-solving support more highly than emotional support. This indicates that men seek different types of support than women, although there are clearly risks to assuming support preference based on gender alone.

The findings in this study in some way reinforces Mc Donnell and Ryan's (2011) observations that the men interviewed noted their reluctance to seek out and make use of emotional support. However, and at times to their surprise, the men found significant value in both receiving emotional support and offering support to others. Although there was a reluctance to express and discuss the strong emotions associated with change and loss in Alzheimer’s dementia in the interviews, this could be influenced by the type of the relationship between the researcher and participant and the transient nature of the interaction. As opposed to a reluctance to discuss feelings and emotions generally. Accepting the generalisation that men adopt a more practical, tangible approach to caregiving may result in a lack of attention being given to their emotional needs. This study provides evidence that men value emotional and practical support and that men identify and make use of both, particularly when it is associated with a sense of self-agency. An example of this is the new relationships the men developed with people, both those unconnected with formal networks of support and those which are. These relationships encountered both practical help and social interaction that positively impacted on their emotional well-being. When considering this in relation to the spiral of disengagement (See Figure 5.2), the enablers become the interactions that reduce disengagement and maximise engagement.

All of the men in this study expressed value in practical support that offered solutions to the issues they experienced due to caring for their partner with Alzheimer's dementia. There were clear links to finding solutions to the difficulties encountered and positive aspects of caregiving. Equally, the men in this study reported that they did not think that they would have sought out emotional support in the form of caregiver groups. This reflects the current knowledge surrounding male caregivers (Mc Donnell & Ryan, 2011; O'Shaughnessy et al., 2010; Sanders & Power, 2009). However, for most of the men in this study, identifying local support networks, that they were able to attend with their partner, were particularly valued, even for those men who were reluctant to use any other support service. Most men who accessed caregiver support groups, indicated that this would not have been something they thought they would have engaged with. Yet, despite their concerns about being asked to share experiences or talk to others within the group, they found that these welcoming environments and that the shared experiences of caring for a partner with dementia, facilitated their engagement in the group discussions. This is an indication of the factors that positively influenced their decision to access services and, more importantly, encouraged active participation in the interactions and discussions within the group. This therefore challenges the perspective that men reluctant to take up emotional support (Mc Donnell & Ryan, 2011) and place more value on practical support when compared to emotional support. It does, however, indicate that emotional support us accepted when offered in a way that is acceptable to men.

The focus on practical problem solving was very much related to dealing with and finding solutions to difficulties the men encountered due to the progression of Alzheimer's dementia. However, the willingness of men to look into the future and specifically consider the progression of Alzheimer's dementia is of significance. For some, the opportunity to be "armed" with the resources required to meet the anticipated needs in the future was valued, while for others considering anything beyond the present was challenging and emotional. Those who find this challenging may therefore be unprepared and lack the network of support needed to respond to the changes that Alzheimer's dementia progression brings. Improved mechanisms for opening discussion with male caregivers about their future needs is essential and these findings can inform these mechanisms. For example, interactions that acknowledge men's readiness for future planning that minimises disengagement would be of value to health care workers who have contact with caregivers. Improved understanding around this readiness for forward planning will support the development of caregiver-centred assessment that being about the tailored interventions recommended by De Vugt and Verhey (2013); Donnellan et al. (2015) and McLennon et al. (2010).

5.5 Promoting Engagement with Support and Services

The way in which men perceive support and respite services is related to their encounters with service providers and their preconceived ideas about services that can be reinforced by these interactions. Figure 5.2 outlined the way in which unhelpful interactions specifically can lead to a spiral of disengagement that can result in men being isolated further. Drawing on this knowledge along with the impact of changes, and losses and importance that men place on being actively involved in care decisions, highlights the ways in which service providers could maximise the opportunities to engage men with support services. Figure 5.5 outlines these enablers to create an environment that increases engagement opportunities. Adopting a positive framework where the factors that influence engagement and avoid disconnection will be of value when interacting with men, specifically at the early point of contact.

Figure 5. 5: Figure Spiral of Engagement

Service providers should place importance on ensuring that services are reliable and meet the needs of both the cared for and caregiver. To do this, the focus should be on establishing helpful interactions that involve caregivers as equal partners. Increasing staffs awareness of potential UC, that result from interactions, would improve the relationship between service providers and caregivers. This improved relationship is then more likely to promote ongoing connections and establish networks of support, thus improving the experience of male caregiver. The spiral of engagement (Figure 5.5) promotes the development of trusting relationships where men will be better connected and less isolated and offer increased opportunities to work collaboratively with them to identify and respond to the physical and emotional demands of this unique caregiving role.

5.6 Chapter Summary

Caregiving for men is a complex construct and is experienced in relation to values and beliefs, identity, gender roles and relationships, and is influenced by factors such as power, control, experience of services and changes and losses. Due to this complexity, men’s experience of caring for a partner with Alzheimer’s dementia is unique. Over emphasis is placed on caregiver burden within the available research, with many studies using this term to frame the caregiving experience (Arcain Nass et al., 2016; Bruce & Paterson, 2000; Hirschman et al., 2006; Karlin et al., 2001; McLennon S M et al., 2010; Mittelman et al., 1993; Picco et al., 2015; Russell, 2006; Schoenmakers, Buntinx, &

DeLepeleire, 2010; Stirling et al., 2010). The findings from this study indicate that caregiver stress is often related to lack of control and influence in the decisions being made that relate to caring and the ongoing changes in their partner due to Alzheimer's dementia. Lack of control and perceived powerlessness contributes to caregiver suffering (Black et al., 2008). Added to this the experience of a slow and distressing separation and associated grief as Alzheimer's dementia progresses are emotionally challenging (Meichsner & Wilz, 2018).

The experience of making decisions relating to caring would improve if caregivers were more involved in the decisions being made (Arnstein, 1969). In addition, caregiver experience would improve when those who are the first point of contact, for example nurses, GP's and Social Workers are able to listen and respond to the expressed needs of the caregiver, as well as the assessed needs of the cared for, in order to avoid UCs (Neufeld & Kushner, 2009; Schoenmakers, et al., 2010). The findings from this study indicate that male caregivers of partners with Alzheimer's dementia are more likely to consider accessing services that meet their own and their partner's needs, and if they are reliable and offer continuity. Equally, when interactions and relationships with service providers are experienced as unhelpful, caregivers often disengage (Neufeld & Kushner, 2009). The combination of which results in a "Spiral of Disengagement" leading to further losses and increased isolation. Conversely, when interactions are articulated in a way that facilitates engagement a "Spiral of Engagement" emerges.

Men who care for partners with Alzheimer's dementia experience substantial changes that transcend all aspects of their day to day life, their relationships and plans for the future. Those who are negotiating these changes, in addition to giving up work, require significant adjustment as they seek to establish a sense of identity and purpose. Men in long-term relationships with the person with Alzheimer's dementia view caregiving as an expectation, and something that forms part of the relationship agreement (Harris, 1993). This obligation to provide care for partners is a powerful motivator and for some men this leads to a drive to be the sole care provider, this is linked to perspectives men hold about their relationship, role and responsibility (Black et al., 2008; Harris, 1993; Russell, 2006).

This drive to continue to care and to take on sole responsibility for care provision at times results in the men overlooking their own needs, leading to deterioration in their health, increasing isolation and reduced support networks (O'Shaughnessy et al., 2010). Men adapt to these changes in a number of ways and frequently adopt practical, solution focused approaches to presenting difficulties (Mc Donnell & Ryan, 2011). This, however, does not infer that men do not value or seek emotional support.

This study shows that value is placed on formal and informal support networks, which are both emotional and practical, where there is shared understanding and experiences and offers space for men to talk about their caregiving role, as well as gain support and offer support to others.

This study indicates that men's experiences of caring are unique and is often a role that men feel they want to and should provide, regardless of their perception of gender roles or masculinity. There continues to be strongly held assumptions about men and caregiving that are perpetuated by media, employment and society (Russell, 2006). These stereotypes create barriers for men and increase the potential for isolation and psychological distress. Gender roles and difficulty in managing the transition between partner and caregiver along with the need to demonstrate strength and coping exacerbate the emotional demands on men caring for their partners (Black et al., 2008; Robinson et al., 2014). The increase in emotional demand, isolation and psychological distress could create increased risks for male caregivers.

Managing caring, problem solving and a strong sense of purpose, similar to that described by Yu et al. (2018), were positive factors that men valued, supporting resilience building and the continuation of caregiving. More emphasis on the positive aspects of caregiving and the enhancement of the sense of achievement, purpose and security, as described by Nolan and Allan (2017), along with the enabling factors linked to the Spiral of Engagement could offer an approach to better support and connection with male caregivers. There is value in viewing the experience of caregivers through the lens of gender, relationship and reason for caregiving in order to identify the factors that influence decisions to access and engage with support and services. This will enable targeted and considered approaches to working with male caregivers that avoids UC that can initiate a Spiral of Disengagement.

Chapter 6 - Reflexivity

6.0 Introduction

This chapter will present an overview of reflexivity and its use in establishing transparency and trustworthiness in qualitative research. It will demonstrate the application of reflexive processes and activities, which were employed throughout this study, in order to increase the quality of the research undertaken. I will present examples from my reflexive diary alongside references to discussions with my supervisors and peers, which have created opportunities for me to examine my role as a researcher. This examination includes the influence my perspectives have had on the research process, and my engagement in the IPA research approach. This chapter will highlight how these processes have allowed me to grow and develop self-awareness while becoming a practitioner-researcher. The value of engaging in reflexive activities throughout the research process is that it gives the researcher a documentary of the experience. In addition, it encourages exploration of the researcher's thoughts and feelings that can be used to inform and develop quality research outcomes and build confidence as a researcher.

6.1 Reflexivity in research

It is important to set out clearly the meaning of both reflexivity and reflection as these terms are closely related and can be used interchangeably in the literature. However, despite being used interchangeably, they are not one and the same thing (Mann, 2016). According to Mann (2016) reflection is an introspective process, a way of thinking about something, either internally or by using tools, in order to gain understanding or learn from the experience. For example, writing a diary or engaging in a collaborative discussion with another. Reflection can be transient or formal and is a way of re-capturing, thinking about and evaluating an experience. Critical reflection moves beyond thinking about and evaluating an experience. Critical reflection aims to critically explore and examine values and ideologies to *"challenge assumptions, interrogate the ideological status quo, question* *institutional norms and confront inequality, discrimination, gender bias, and marginalisation."* (Mann, 2016:10).

Reflexivity, however, is related to the way in which a researcher thoughtfully engages in the research design, development, analysis, synthesis and reporting of findings. In essence, reflexivity is the close examination of how the researcher's beliefs and values have impacted on the research outcomes and is achieved through a process of critical self-evaluation of the position of the researcher (Mann, 2016). Qualitative researchers, in particular, are required to develop self-awareness to identify potential cognitive bias that might unconsciously impact on the research process. Buetow (2019) describes this as *"Methodological Reflexivity"* (Buetow, 2019:10). The aim of reflexivity, in this context, is to bring potential bias to the consciousness of the researcher through strategies that encourage introspection. For example, internal processes of self-reflection and *"inter-subjective*" reflection, which is said to widen the researchers view by including a peer discursive process to recognising potential bias (Buetow, 2019: 11). Inter-subjective reflection encourages the researcher to view concepts and phenomenon for alternative perspectives.

Reflexivity has also been closely linked to ethics, as it requires the researcher to consider their own perspectives, including how risk and potential harm are framed (Jeanes & Huzzard, 2014). For example, encouraging the researcher to examine potential risks relating to unearthing sensitive or emotive data, use of language and terms that may cause offence to particular groups or individuals. Reflexivity, therefore, is a systematic process of examining the way in which researchers construct knowledge through each step of the research process. It is also a way to enhance self-awareness, awareness of ethical considerations, and consciousness of bias, in order to demonstrate openness (Buetow, 2019; Clancy, 2013; Freshwater, Cahill, Walsh, & Muncey, 2010; Jeanes & Huzzard, 2014). According to Finlay (2014), reflexivity can be understood as *"a process of continually reflecting upon interpretations of both our own experience and the phenomenon being studied"* (Finlay, 2014: 130), as a way to move beyond the bias of previous understanding. Thus demonstrating the way in which the researcher is engaging with, and thinking about the phenomenon being explored, and how this expands and introduces new ways of thinking about the concepts. Interestingly, Freshwater (2005) proposes that reflexivity is both a mode of monitoring research, as well as a research process in its own right, encouraging that the value of reflexivity is the enhancement of the trustworthiness of the research and so that it can be assessed and the quality measured.

Throughout the study, I engaged in a range of reflexive processes, both introspective and inter-subjective, to examine my relationship with the research process and become fully and thoughtfully involved. This included my understanding of caregiving and men in caregiving roles, as well as encounters I have had with people with dementia when working as a nurse. The strategies I adopted included; maintaining a written reflexive diary using Gibbs (1988) reflective cycle (see Figure 6.1), that allowed me to capture my experiences, thoughts and feelings, as well as learning, along each stage of the research process. In addition to this, I also engaged in inter-subjective reflexivity through dialogue with my supervisors, gaining feedback on my experiences. This included, for example, interviewing participants, the transcription process and the data analysis process. I also engaged in personal reflection following interactions with participant. This allowed me to capture my thoughts and feelings that have the potential to influence my understanding of these interactions. In order to widen my perspective further, I also engaged with an IPA researcher peer group within the university, where there were discussions and reflections on the research process and becoming a researcher. I identified learning needs with my supervisors and engaged in continued professional development activities including university led seminars, workshops and conferences, where research and reflexivity processes were presented and debated. The combination of these reflexive activities have enhanced the trustworthiness and transparency of this research study, and are in line with recommendations surrounding quality in qualitative research (Buetow, 2019; Mann, 2016; White, 2019). These reflexive activities have provided me with the reassurance and confidence that I have engaged with the research process in an open and honest manner, which is recognised as a core element for enhancing the overall quality of the qualitative research (Elliott et al., 1999).

The reflexive diary will be the main focus of this chapter and will explore the learning and self-awareness gained, as well as the opportunities it offered to examine bias, identity and role.

6.2 Reflexive diary

A reflexive diary has been maintained throughout the research study and forms a substantial element of the reflexive activities adopted to ensure the transparency and trustworthiness of the study. A reflexive account was written at each stage of the study forming a collection of collated reflective accounts, examples of which have been previously referred to, and will be presented in more detail here. There were a number of strategies used to capture experiences at the time, or as close to the time, of the experience as possible. These included voice recordings following interviews, handwritten post-it notes, hand written journal notes, mind maps and typed notes. These were then used as reference points for the formal typed diary accounts, set out in the order of the research process.

As a mental health practitioner and lecturer, I am accustomed to using the process of self-reflection to unpick and explore experiences and events, providing me with an opportunity to learn about myself and how I understand and perceive the world and people around me. Reflection has also helped to encourage me to think about experiences in other ways, or from other standpoints. For example, as part of clinical supervision and for professional development. Using reflexivity to examine my research journey, is however, slightly different. The purpose, although remains centered on self-exploration and learning, is re-focused to include the examination of the impact my previous experiences, knowledge, values and beliefs related to the topic being explored, has on the study and its outcome. Starting from the development of the research aim and questions, reflexivity has been used throughout, including the way I engaged with the interviews and resulting data. It is through the engagement in reflexive processes, and the documentation of these, that researcher's reflexivity is demonstrated (Freshwater, 2005).

The diary provided me with the space to capture and examine my experiences. It was a process in which I was able to take note of, and highlight, my thinking and responses to each stage of the research study, as I experienced them. The close critical examination of these experiences, and how they made me think, feel and react, became an important part of engaging with the experience of research. Thus, adding essential detail, specifically the self-awareness and self-monitoring, that is said to support the credibility of research findings (Freshwater et al., 2010).

However, to be effective, reflexivity needs to be a systematic, authentic, transparent and thoughtful process, rather than a “tick box” exercise or used as a way to signpost the reader to the ambition of the research (Jeanes & Huzzard, 2014). Reflexive models or frameworks can provide the structure for systematically engaging with an experience and encourage the depth of analysis and critique required for self-discovery and new learning. Models and frameworks are also said to be effective in handling the micro and macro detail of an experience (Mann, 2016). As a novice researcher, I was stepping into a role that was different to those that I had held before, changing from nurse to researcher changed the way I viewed my role and responsibilities. As such, I felt it was important to identify a framework to structure my reflexive accounts, to create a method for systematically capturing the experiences as they happened in a consistent way.

Gibbs' Reflective Cycle was developed in 1988 to give structure to learning from experiences. This model was one that I had used before and is used frequently in health care and in education (Bassot, 2016). The model was chosen as it encourages a systematic approach, directing the user to unpick the experience and connect with the feelings and thoughts that emerge from it. The cycle takes the learner through a set of six stages, outlined in Figure 6.1, each posing questions that drill down and examine the experience and the sense made of it. Interestingly this resonates with IPA and the focus on the phenomenon, as it is experienced by person and the meaning that they make from the experience. The emphasis on feelings and learning in this model is what encouraged me to use this for my reflexive diary.

Figure 6. 1: **Six Stages of Reflection (adapted from Gibbs, 1988)**

From my perspective, the added value of this cycle, is the way that it encourages the learner to articulate the feelings associated with the experience and make connections with how these feelings impact on thinking and actions/behaviours. The inclusion of a "conclusion" stage was particularly valuable in exploring alternatives and different perspectives. It is this detail that helped me to closely examine these new experiences and provided me with the thinking space required to evaluate and monitor the relationship between me, my knowledge, my understanding, the experience and the influence it had on the research being undertaken.

An excerpt from the reflexive diary written following the first interview is a good example of how I used the model to identify feelings (Full details see Appendix 11). In the section below the range of feelings (presented here in bold text) potentially impacting on the interview are clear:

> *"Feelings: what was I thinking and feeling at the time? How have these changed?*
> *I recall parking the car in his street and making sure I had all the information and items I needed for the interview. I had some feelings of* ***anxiety*** *and some* ***trepidation*** *that I took to be related to this being my first interview and I had*

> *not carried out one as a researcher where the focus has been on experience of caregiving.*
>
> *Once in the man's house I was more* ***relaxed*** *and felt ease at drawing from my experience as a community nurse. I had a spike in my* ***anxiety*** *when I first prepared the recorder even though I had checked it and had spare batteries, and this remained for a while as the interview started.*
>
> *As the man began to talk, I tried to concentrate on his spoken word taking note of this non-verbal communication and his general manner and presentation. As this continued and there were no breaks in his narration, I started to become more* ***uncomfortable,*** *realising I was contributing nothing. However, there was some reassurance as he had a copy of the interview questions in front of him and he was following them as he spoke. This* ***reassured*** *me to some extent, but I was very aware of my anxieties showing and if I interrupted him I would be changing his direction and flow.*
>
> *I was* ***concerned*** *that I was missing key details and fine variations in his tone and non-verbal communication as he spoke very fast and did not break other than to attend to the telephone call and the dog. This gave me time to look at my questions and make some notes without looking distracted.*
>
> *There were a number of moments and at times with increasing* ***intensity,*** *where it was clear that the man was struggling with the depth of emotion attached to his account of the experience he had caring for his wife. The level of distress and emotion displayed made me feel* ***uncomfortable*** *and* ***guilty*** *at instigating this level of emotion by asking him about this very personal experience.*
>
> *I had some sense of* ***relief*** *when the interview was over and when the recording had been successful although I was left with the* ***uncomfortable*** *feelings and sense of* ***guilt*** *as I left the house and drove away."*

This account demonstrates the identification of the feelings and the range of emotions that came to the fore during this experience. It was through this first reflexive activity, relating to the interview process, that my struggle with role and identity were first revealed.

The experience and reflective process allowed me to consider how this interview went, and recognise how my emotions influenced my perceptions of the interview. I was able to identify how I was distracted, to enable me to identify how I could avoid this in the future. Paying close attention to my feelings, in this diary section, instigated the examination of my role and identity, demonstrating an increase in self-awareness, which is evident as I moved into the analysis section of the cycle:

> *"Analysis: What sense can you make of the situation?*
> *The sense I can make of this experience is twofold, first there are the practical and technical elements of the interview. I was attempting to gain some sense of control when really, I should be focusing on the depth of detail the man offered. I think that this was likely to be related to my lack of confidence in conducting the interview and my surprise when he held the interview questions and took control of answering each one in turn. I anticipated more involvement in the interview and was taken off guard when that role was taken away from me.*
> *My anticipation of the role of the researcher and way in which this role differs from the roles I have had in the past was of particular importance for me when reflecting on this experience. Formally as a nurse I would work with family caregivers to identify their support needs, access and provide required information, refer for services and provide emotional support. I would be there for the person, to meet their needs and to work collaboratively to improve their experience. As a researcher however, I was not there for the person, I was there with my own agenda and to meet the needs of the research study. This was a real issue for me both emotionally and professionally.*
> *The emotional impact of realising that I was asking the men in the study to explore and discuss the emotive and challenging experience of caring for their partners without any offer of intervention or support for them made me feel uncomfortable and ill at ease. I had an increased sense of guilt coupled with a disconnect with the professional identity I had as a nurse and now a researcher.*

> *I struggled with how to end the interaction due to this change in role, I would not be in contact with the man again following this, I can offer no interventions or ongoing support and was left with leaving contact information for support networks he could access following the interview."*

The significance of role and identity is evident through this reflexive diary account and is demonstrated in the way I made sense of the experience, and in my use of language. Note the statements *"…taken off guard…"* and *"…that role was taken away from me."*, these demonstrate my perceptions of my role as researcher, as well as my lack of flexibility when the participant took the lead. Capturing this early experience of interviewing allowed me to identify some of the struggles I was having adjusting to this new role. The process of engaging in this reflexive cycle, allowed me to identify the troublesome feelings I experienced and explore them in a way that helped me to connect them to underlying tensions I was experiencing in my new role as researcher, one of the key advantages of Gibbs (1988) model. This tension was unanticipated, as can be seen when I make reference to assuming my previous community mental health nurse role would support me in this research interview "*I was more **relaxed** and felt ease at drawing from my experience as a community nurse".* By recognising these feelings, I was able to highlight a significant difference in the role that I had in this interaction. For example, being there with my *"own agenda"* indicates a shift away from my role as a nurse, where the focus is on the needs of the person, to that of a researcher where the focus is on the aim of the study and gathering the data to address the research aim and questions. This change in role, and the adjustment required, is recognised in the literature (Mason-Bish, 2019, Noh, 2019, Dwyer & Buckle, 2009, Mendenhall, 2008). It was the process of reflexivity that offered an opportunity for me to examine the emotional impact of this change in role and subsequent "disconnect" with my professional identity.

The conclusion resulting from this was as follows:

> *"Conclusion: What have you learned, what else could you have done?*
> *"I have learned so much from this experience about myself and how I identify with my role as a researcher. I had not anticipated this reaction and the strong*

> *emotions that came to the fore. I would have benefited from reading around the experiences of researchers and undertaking interviews in more detail rather than assuming that this was a skill I had due to my previous role as a mental health nurse.*
>
> *I have thought about the feelings of guilt I had during the interview and how I was left floundering, trying to grapple with what I was there to do and how this differed from the role I would have adopted had I been there in my professional capacity.*
>
> *A conclusion I make here is that I am feel less able to manage my emotional reaction to hearing caregivers talk about their experience and that this is tied up with the way I perceive my role. As a nurse I have something to offer, a potential solution or an offer of support, while as a researcher this is not my role.*
>
> *The experience of this first interview and the way these thoughts and feelings caused a level of distraction is significant as it has the potential to impact on the way I engage in future interviews for example, if I do not resolve the tension with this new role then I may be inclined to avoid questions or prompts that illicit strong emotions from the participant."*

The conclusion section offered me space to consider what I have learned and importantly, to critically reflect on the potential impact this could have on the study. The resulting action plan included the increased use of supervision and peer support, in line with inter-subjective reflexive process (Buetow, 2019). Recalling the subsequent supervision session, around nine days following the interview, the discursive supervision session allowed me to further explore this experience, and the learning gained from the reflexive process. We spoke about the role of the researcher and the range of strategies that might help with the emotional aspects of the experience. An example of these strategies is the use of telephone contact with supervisors or peers following interviews. This is something that I went on to use as a strategy for future interviews. I later presented my reflection to the IPA peer group, which brought about a valuable discussion relating to researcher role, identity, and expectations of participants. The peer group also discussed ethical considerations relating to interviews, this created a support networks for novice researchers. Through the peer group discussions, it was clear that this was commonality in our experience, perhaps indicating the need for more attention to the transition from professional role into researcher role. Although the significance of these reflexive processes are broadly acknowledged in the literature (Clancy, 2013, Finlay, 2014, Freshwater, 2005), there remains little practical guidance on the process and use (Goldspink & Engward, 2019). However, guidance, if overly structured, may limit the researcher in exploring and identifying strategies that work for the individual, given the personal nature of reflexivity. This, for example, might be related to the specific needs of the researcher, their research approach or the nature of the data being gathered and analysed, or alternatively the method of reflection to bring about learning.

6.3 Practitioner – researcher

Transition from practitioner to researcher is complex and encompasses both ethical and professional dilemmas that create tension as the new researcher assimilates their new role (Noh, 2019; Skene, 2012). Mendenhall (2008) discusses the role of the practitioner and researcher and highlights the characteristics required for each are dissimilar, and that it is this dissimilarity that leads to conflict. Although related to social work, Mendenhall (2008) proposes that it is the shift in role or function, the context and expectations, which contribute to the disharmony between these two roles. However, Mendenhall (2008) offers that it is the shared core values and ethics of the profession, that bind these roles together, and therefore can offer some resolution to the tensions experienced by the novice researcher. Skene (2012) reflects on the nurse researcher's sense of responsibility and their duty of care for participants, linking this to professional values and ethics. Skene (2012) concludes that focus should be on who the research is about and who it will benefit, and to reflect on identifying and acting on issues as they arise. Skene (2012) also recommends the inclusion of a wide research team, who help maintain the focus and uncover researcher blind spots. This is in line with recommendations from Buetow (2019); Mendenhall (2008) and Noh (2019). Reflexivity, therefore, has the potential to explore the professional values and the ethical stance of the researcher and researcher identity, in the context of the environment in which the researcher is based (Jeanes & Huzzard, 2014).

For those who hold practitioner roles who transition into research roles, early engage with reflexivity processes is essential, not only as a way of demonstrating trustworthiness, but in order to allow time to navigate the shift in role and identity that becoming a researcher brings.

6.4 Reflexivity and IPA

Shaw (2010: 234) describes reflexivity as an *“explicit evaluation of the self”* and encourages that reflexivity is essential in experiential qualitative research, specifically due to the interpretive processes and co-construction of meaning. As the phenomenological perspective is centered on meaning-making, being in the world, and what it means to be human, reflexivity is essential (Shaw, 2010). IPA is complex, due to the double hermeneutic process (Smith & Osborn, 2004), it is this complexity that makes reflexivity an essential component to an IPA study. This is to ensure clarity and transparency is maintained throughout. The double hermeneutic process adds a layer of complexity, particularly at the data analysis stage, that makes the reflexive process and its focus on the relationship between the researcher, the participants and the data generated, of particular importance (Clancy, 2013; Shaw, 2010). Equally important is transparency in relation to the researcher’s perceptions, knowledge and experience of the phenomenon being explored. This transparency then allows for clear articulation of potential bias and clarity in the way that the researcher is both inside and outside of the research, that increased self-awareness brings (Goldspink & Engward, 2019). It is this increased self-awareness that has the potential to identify risks that could influence the IPA research at any stage (Smith et al, 2009).

Being a nurse, and having worked with family caregivers, gives me an insider perspective that may result in preconceived ideas about male caregivers, and how they perceive their role and their use of services. Nurses are said to be quick to look for patterns to explain complex phenomenon, and that this can result in unconscious bias (Buetow, 2019).

Therefore, nurses who undertake research, particularly research that employs qualitative approaches, may equally be predisposed to making assumptions and seeing patterns where none exist. It is this risk of unconscious bias, assumptions and pre-judgement that increases the importance of reflexivity, particularly at the analysis stage, given the potential impact bias could have on the emerging findings. Goldspink and Engward (2019) present the notion of *“echoes”* while engaging with IPA data analysis. Referencing Goldspink’s own personal experience of recognising that the process of analysis had brought to the fore connections to her own life and experiences, Goldspink herself set out to overtly evidence these interpretations, and how they were grounded in the participants’ narrative (Goldspink & Engward, 2019). Based on these experiences, Goldspink and Engward (2019) propose the inclusion of a sub-step to Smith et al. (2009) IPA six step process, where sub-step 3b is added. This is to encourage the researcher to *“Attend to the reflexive echoes”* (Goldspink & Engward, 2019: 229). This additional step aims to encourage the researcher to consider and capture their own understanding before moving on to the next stage of analysis.

6.5 Reflexivity and analysis

Reflexivity was maintained throughout the data analysis process, using a number of strategies. When engaged in the analysis of each transcript, I adopted a more introspective reflective approach, using regular breaks from the analysis to walk away from the transcript to think about the experience. At times, I struggled with the linguistic interpretive aspect of IPA, so when I was aware of this, I had a list of strategies to help re-focus my attention on language use. These included returning to the recordings and listening again, reading and attending to language and phrases in random page order, and using a notepad to capture as many different interpretations of the language/phrase used. Many of these strategies were introduced by linking with my peers and supervisors as well as the facilitated workshops and seminars I attended. Adopting a range of strategies is in line with the recommendations for using reflexivity as a quality measure in qualitative research (Freshwater et al, 2010). As I moved onto the latter analysis stages in IPA, stage 4 and 6, I used post-it notes more frequently, to note down thoughts and ideas, as well as mind maps, to visually set out the connections and patterns across the transcripts. The first, third and final transcript analysis were also shared with my supervisors and discussed in detail. Alongside these strategies, I also maintained my reflexive diary, the excerpts from the diary written while engaged in the analysis of the data, are given below:

> *“ Feelings: what was I thinking and feeling at the time? How have these changed?*
> *Having only completed one phenomenological study using an interpretive approach previously I was rather* ***concerned*** *by my lack of experience. I have been working with carers of people with dementia for over 18 years. I have a broad understanding of the factors that impact on the health and wellbeing of family carers. Due to this I was* ***worried*** *about whether it would impact on the way in which I conducted the interviews and therefore on the data gathered.*
> *I was* ***unsure*** *of how to approach the analysis in a way to show a logical and true interpretation of the transcription. Although I am aware that IPA is double hermeneutic I was still* ***concerned*** *that looking at the transcripts through my own lens would in some ways dilute or misinterpret the participants true meaning.”*

This diary entry demonstrates my insecurities and lack of confidence in the analysis process, however, recognising this led me to seek support and guidance. Attending a IPA workshop facilitated by Paul Flowers, co-author of Smith et al., (2009) was of particular value:

> *“Attending the workshop gave me an opportunity to both practice this process as well as speak to other researchers using IPA. My worries and concerns were mirrored in the discussions I had with fellow researchers and this gave me confidence that I was thinking critically about what I was doing and how I was approaching my research and that this in itself is part of the integrity of the research process.*
> *The practical aspects of the workshop opened new ways of analysing data that included a way of showing how you arrived at the concepts and themes, the road you took through the data and how the themes emerged.*

> *This helped to level out the worries I had with my influence and impact on the data gathered and how it was interpreted. It gave me confidence to demonstrate and provide a narrative at how concepts and themes emerged and the ability to articulate how I made sense of the carers experiences through their use of language, description and logic of talking about their experiences."*

The emphasis on telling the story of your analysis process, throughout the IPA workshop, highlighted the importance of transparency, and the need to engage fully in reflexivity. One area of particular difficulty for me, in relation to analysis, was the interpretation of language. As I used the diary throughout the process, I was able to return to this and re-connect with strategies that were effective for me. The reflexive process increased my self-awareness, as detailed here in the excerpt from the analysis section of the diary, and encouraged me to seek more guidance and support with this element of analysis:

> *"The analysis of language continues to be difficult for me, I have trouble seeing anything other than what is obvious – for example the meaning of the words or the phrase or what they are describing. The workshop encouraged us to look at the transcription line by line or by starting at the end and working backwards as a way to look at the words used rather the broader context they relate to. I am still finding this challenging. Seeking support and guidance can be challenging for me so this is something that I need to work on developing. Seeking support and connection with my supervisors and other researchers will help with this aspect."*

The use of the reflexive diary was of value during the process of analysis; however, it was the inter-subjective reflexivity that was of particular value. Exploring my challenges with the analysis with my supervisors helped me to tease out and explore these in more depth. These discussions led me to build confidence around articulating the challenges with analysis using IPA with others. For example, in 2017, I presented at the International Mental Health Nurse Research Conference, held in Cardiff (Presentation title: Emerging themes and personal reflections of using IPA). I sought to use this as a way to share my experience and to seek out new connections. Following my presentation, a valuable discussion developed around this topic that allowed me to make connections with other researchers who use IPA. These connections, that have continued, added to the peer group and support network I have gained.

Engagement in discussions with other researchers has supported the development of my research, through building confidence and the ability to articulate my research to others. This has led to improved ability to present my research journey in this thesis and challenge my own perspective, at each stage of the process. I have found that debate, critical discussions and willingness to interrogate personal assumptions has been of particular value. These processes encourage researchers to consider alternative views of phenomenon being studied and the way in which it is studied. These experiences have been transformative for me and aided my transition into a researcher role. It is this journey that that has enhanced my confidence in the study's findings and therefore the quality of work.

6.6 Chapter Summary

Reflexivity is an ongoing process and should be seen not only as an activity to demonstrate quality in research. Although it is essential to use a range of reflexive processes in order to illuminate potential bias, either conscious or unconscious, reflexivity offers the researcher much more. The added value of reflexivity for the researcher include increased self-awareness, examination of role and identity, as well as personal growth.

Although there is limited practical guidance on the use and application of reflexivity for researchers, this may serve as an advantage, as it does not limit the imagination or creativity of the researcher in finding and testing out a range of strategies that encourage critical self-reflection and pathways for inter-subjective reflexive discussion and debate. In my view, the active engagement in reflexive processes is essential so that novice researchers can successfully navigate the transition from practitioner to researcher.

Chapter 7 Conclusion

7.0 Introduction

Due to the predicted increase in ageing and the related rise in prevalence of dementia in the coming decades, dementia will have an impact at a global level, transcending personal, family, community, and social constructs (World Health Organization, 2015). The role that family members adopt to support those closest to them to remain at home, has an impact that is far reaching and includes health and social care systems and the wider economic climate we exist in. Strategies to support and sustain family caregivers will need to be identified, introduced and maintained. Therefore, understanding the way specific caregiver groups experience caregiving, perceive and access services, will provide opportunities to develop targeted and flexible support that better meets the needs of caregivers. The focus of this thesis has been the exploration of male caregiver's experience of caring, specifically those caring for a partner who has a diagnosis of Alzheimer's dementia.

7.1 Overview of Key Findings

This research set out to identify which factors encourage or inhibit male caregivers of partners with Alzheimer's dementia decision to access respite and support services and to explore the perceptions of accessing support. The research to date offers limited detail relating to the way in which men perceive and respond to caring, and how these perceptions, their experience of caring and their relationship with the cared for impacts on their decisions to use support, services and respite. Equally there is a lack of research specifically related to men and the partner caring relationship, with most sources combining the experiences of all caregivers, as if they were a homogenous group. Available sources indicate the importance of tailored interventions for male caregivers and report the value in recognising caregiver needs and the way in which initial interactions with service providers can be perceived as helpful or unhelpful.

The findings from this qualitative study has identified three themes: Lack of Influence; Changes and Losses and Protecting Others.

The experiences of men caring for their partners with Alzheimer’s dementia in this study, indicates the need for improved involvement of caregivers in care related decisions. There is also the need improve the reliability and quality of services that meet the needs of both the caregiver and the cared for, and the promotion of helpful interactions to avoid negative UC to avoid a “Spiral of Disengagement”.

The close examination of the lived experience of men in this specific caregiving role has added detail to what is known about the caregiving experience and offers opportunities for those who connect with male caregivers to better align support and services to avoid interactions that result in further isolation. As men appear to overlook their own physical and mental health needs, due to prioritising the needs of their partner. Hence, it is essential to work collaboratively with men to establish trusting relationships where men do not feel that decisions are made without them. Adopting strategies that enable engagement as outlined in the “Spiral of Engagement” will provide opportunities for service providers to work in partnership with men to encourage attention to be paid to their physical and emotional needs, as they navigate this challenging experience.

The study has shown that the male caregiver experience is complicated by social norms, gender and identity, and that the relationship between the cared for and caregiver adds to this complexity through the way in which it determines the way that men respond to and adopt a caregiving role for their partner.

7.2 Implication for policy and practice

This study offers improved understanding of the male partner caregiver experience, thus providing opportunities to target support to improve health outcomes for caregivers. For example, the provision of opportunities for men to recognise the changes and associated losses related to caregiving and dementia. Recognition of the emotional impact of caregiving and the support required to address the feelings associated with loss, would help to mitigate against the increased risk of emotional distress.

The three themes identified and the relationship and connections between them and the related concepts, give an overview of the impact and influence these have on men's care decisions. These findings should be integrated into key policies and guidelines to ensure those working with caregivers maximise interactions that are helpful and that maintain engagement with support services. The study also highlighted potential gaps in knowledge and understanding related to the experience of men caring for their partners with Alzheimer's dementia, which are noted in the next section.

To avoid UC there needs to be improved recognition of the experience of caregiving from the individual's perspective, which includes acknowledgement of the relationship of the caregiver/cared for dyads, gender and pre-dementia relationships and roles. The use of involvement theory to improve the caregivers experience of participation in decision making and effective communication strategies to promote the health and well-being of caregivers, could go some way to avoid UC (Oliver et al., 2019) which can result in disengagement from services.

7.3 Recommendations for further research

This study has highlighted some key areas that warrant further research. There is value in conducting further studies that relate to the transitions from partner to caregiver, for the purpose of better understanding the challenges faced by men as they move from being a partner to being a caregiver.

Identification of the protective factors that support men to continue to care while maintaining their own health and well-being, is also worthy of further study. This is because there are indications that men overlook their own health needs, as they prioritise the needs of their partners. The result of which is health deterioration, breakdown of caregiving and crisis interventions. Also, connections between mental health, suicide and male caregivers is generally underexplored and therefore further study in this area to establish if there are risks associated with loss, grief, guilt and caregiver burden specifically for men would be valuable.

7.4 Contribution to knowledge

Men who move into caregiver roles for their partner due to the onset of Alzheimer's dementia, do so in response to many influencing factors. The men involved in this study reported a sense of duty and responsibility centred on the role of being a partner in a long-term reciprocal relationship.

The experience of caregiving was unique for each of the participants, however, there were several aspects of this experience which were shared. Perceptions of decision making, and the lack of impact and influence men felt they had on the decisions being made, which related to caring, was just one of these aspects. This lack of involvement and power in decision making impacted on men's sense of purpose and resulted in frustration and led to disengagement from support and services that provide help.

This study offers improved understanding of the impact of caregiving, the significance of gender, and the relationship between the caregiver and cared for. The findings have the potential to inform the strategies that professionals can adopt to increase helpful interactions and bring about improved outcomes.

7.5 Strengths and limitations

The strengths of this study are the way in which it has generated sufficiently deep insights into the experience and perceptions of men who care for their partner with Alzheimer's dementia. The research approach adopted enabled this depth of exploration, using in-depth interviews and the IPA approach. The particular focus on men in this very specific caregiving role added to value, due to the lack of research in this area generally. The findings presented offer additional knowledge surrounding the perceptions men have of decision making that related to accessing support services, the impact of caring, the changes and losses they experience and their role as partner and caregiver.

The small sample (n=7) participants, although in line with using IPA and ideal for close, in-depth and comprehensive analysis of the lived experiences of people, does not allow for broader generalisation. However, it brings about understanding and adds to the existing knowledge to offer an ever growing and more refined picture of what it means to be a male caregiver.

Interpretation, specifically the double hermeneutic process in IPA, relies on the researcher making sense of the person making sense of their experience (Brocki & Wearden, 2006). As such, this is a complex and intense process and it is recognised that novice researchers using this approach can often limit their analysis resting within a more descriptive account, rather than embracing the creative nature of interpretation (Smith & Osborn, 2015). The good use of supervision, reflexivity and documentation of the way in which the individual super-ordinate and group themes were arrived at, has shown for me to be effective facilitators to interpretation.

Individual interviews require the researcher to hold significant interpersonal and communication skills that create a level of trust and that encourage participants to open up and explore the experiences, thoughts and feelings related to their caregiving role. Interviewing older Scottish men, some of whom struggled to articulate their feelings and emotions associated with caring for their wife/partner, was potentially a challenge in this research. Two participants clearly struggled to explore some aspects of the caregiving role and focused instead upon practical caring descriptions, sharing stories from their past, and recounting the chronological events following their wife/partners diagnosis of Alzheimer’s dementia. This evasion to discuss emotional aspects could be a way of protecting themselves (Pretorius et al., 2009) or a lack of skill on my part potentially missing opportunities to ask questions or request elaboration. Phenomenology encourages the enablement of participants to share their story in their way, without influence. However, the research process and the focus on addressing the aim and research questions do contradict this somewhat. The setting of a research aim and questions, defines the focus for the research to be undertaken, thus influencing the direction of the interview. It was therefore important to make use of the interview questions

(Appendix 5) to help ensure I covered the breadth of concepts that relate to the research aim, while also allowing the participant to tell their own story.

The emotional impact of the researcher must also be considered when undertaking the role of researcher. The preparation for early career researchers and the emotional impact of hearing people explore strong emotions and their roles and responsibilities are important aspects to also consider when planning research activity. Ethical considerations should include and outline the emotional demands of conducting an IPA study, to ensure researchers identify the support and guidance needed to ensure their own wellbeing is maintained. Engagement in research that involves interviewing people to gain understanding of their experience requires researcher openness (Finlay, 2014), and therefore, can be emotionally demanding, for both the participant and the researcher, particularly when the experience being explored is emotive. Through attending to the ethical considerations to ensure that no harm comes to participants, or researchers, the researcher is required to identify potential harm and offer strategies to mitigate these (Edinburgh Napier University, 2018). Closer consideration is required to ensure that potential emotional burden experienced by researchers is identified and supports put in place. The emotional impact of hearing people's stories, for me, were amplified due to the change in role from nurse to researcher. This change in role disrupted my sense of purpose as I had to transition into the new role of researcher. However, the use of a reflexive diary (Chapter 6 & Appendix 11) and support via supervisors and fellow research students have proven to be invaluable in building confidence in the new role and to make sense of the emotional aspects encountered.

Transparency and trustworthiness are valued in qualitative research (Elliott et al., 1999; Rodham, Fox, & Doran, 2015) with strategies adopted to maximise these. Given more time, a longitudinal study of male caregivers experiences of caring for a partner with Alzheimer's dementia would allow for continued connections with the caregivers and offer some opportunity for the men to review the transcripts and the analysis.

7.6 Chapter Summary

The key findings from this study offers new understanding surrounding the experience of men caring for their partners with Alzheimer's dementia. This new understanding identifies several specific experiences that influenced the men's perceptions about their role, responsibilities and purpose, and that informed their decision-making relating to caring and accessing support and services.

The literature surrounding male caregivers experience in general is sparse and is further limited in relation to male caregivers for partners with Alzheimer's dementia. However, authors call for the development of targeted interventions, for example psychological interventions, to improve outcomes for caregivers. It is, therefore, essential that the unique experience of men who care for their partner with Alzheimer's dementia is fully understood in order to inform the development of these interventions, and to maximise the uptake of support services and avoid or minimise caregiver isolation, burden and health deterioration.

This study has revealed that the strategies that service providers adopt can either help or hinder caregiver engagement. Thus, the findings offer opportunities to inform the practice of those who are in contact with male caregivers. Those who have contact with men at an early point in caregiving would benefit from an increased awareness strategies that avoiding disengagement in order to provide support and services that meet caregivers needs and actively involve them in any care decisions. It is, therefore, the intension to publish the findings from this research, targeting journals that are accessed by professionals who come into contact with caregivers as well as dementia specific journals.

This study identified a number of areas that warrant further exploration, including the impact that caregiving has on men's physical and emotional health and in the context of ageing, as well as how the experience of caregiving changes over time.

Consideration will also be given to the experience of undertaking this research, in particular the use of reflexive processes to aid the transition from professional to researcher. Increased focus on this would be valuable for novice researchers. Equally, attention to the emotional impact of qualitative research approaches on the researcher merits closer inspection and tentative guidance produced.

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Appendix 1: Example of Database Search (MEDLINE)

#	Query	Results
S9	S7 or S8	54
S8	S4 AND S6	41
S7	S4 AND S5	54
S6	S2 AND S3	2,017
S5	S1 AND S3	2,851
S4	(MM "Decision Making") OR (MM "Decision Making, Clinical") OR (MM "Decision Making, Ethical") OR (MM "Decision Making, Family")	31,888
S3	(MM "Alzheimer's Disease")	18,631
S2	(MM "Caregiver Burden") OR (MM "Caregivers") OR (MM "Caregiver Support") OR (MM "Caregiver Strain Index") OR "caregiver"	30,771
S1	(MM "Caregiver Burden") OR (MM "Caregivers") OR (MM "Caregiver Support") OR (MM "Caregiver Strain Index") OR "caregiver*" or "carer*" or "spouse*" or "spousal*" or "partner*"	122,427

Appendix 2: Examples of CASP Scoring

Qualitative Papers

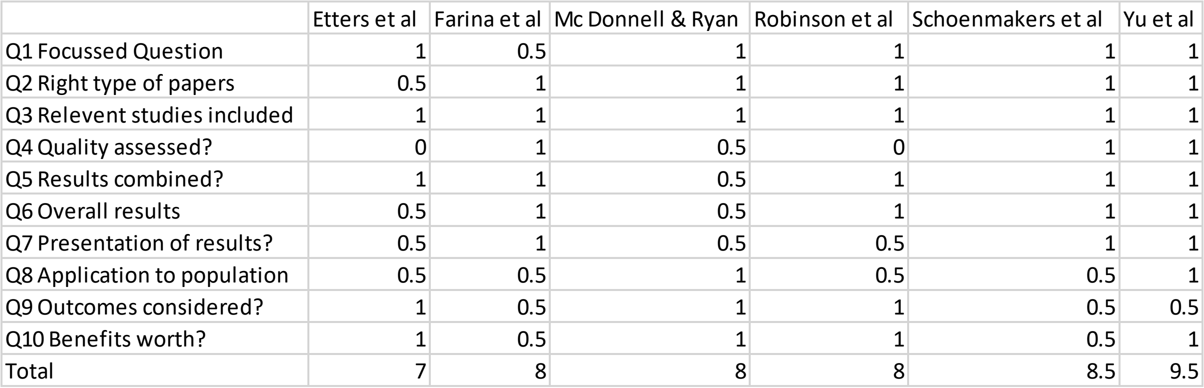
	Arcain Ness	Black et al	Bonner et al	Bruce & Paterson	Donnellan et al	Harris	Hirschman et al	Karlin et al
Q1 Clear aim?	1	1	1	1	1	1	1	1
Q2 Method appropriate?	1	1	1	1	1	1	0.5	1
Q3 Design appropriate?	1	1	0.5	1	1	1	0.5	1
Q4 Recruitment strategy	0.5	0.5	1	1	0.5	0.5	0.5	0
Q5 Data Collection	0.5	1	1	0.5	1	0.5	1	1
Q6 Relationship Researcher/participants	0	0.5	0.5	0.5	1	0	0.5	0
Q7 Ethical considerations	0.5	1	0.5	1	1	0.5	0	0
Q8 Data anaysis rigour?	0.5	0.5	1	0.5	1	1	1	1
Q9 Clarity of findings	1	1	1	1	1	1	1	1
Q10 Value	0.5	1	1	1	1	1	0.5	1
TOTAL	**6.5**	**8.5**	**8.5**	**8.5**	**9.5**	**7.5**	**6.5**	**7**

	Neufeld & K	O'Shaughn	Pretorius et a	Riedijk et al	Russell	Sanders &	McLennon, Habermann, & Dav	
Q1 Clear aim?	1	1	1	1	1	1	1	
Q2 Method appropriate?	1	0.5	0.5	0.5	1	1	0.5	
Q3 Design appropriate?	1	1	1	0.5	1	1	0.5	
Q4 Recruitment strategy	1	1	1	1	1	1	0.5	
Q5 Data Collection	1	1	1	0.5	1	1	1	
Q6 Relationship Researcher/participants	0.5	0.5	0	0.5	0	0.5	0	
Q7 Ethical considerations	1	1	0.5	0.5	0	0.5	0.5	
Q8 Data anaysis rigour?	0.5	0.5	1	1	1	1	0.5	
Q9 Clarity of findings	1	1	0.5	1	1	1	1	
Q10 Value	1	1	1	0.5	1	1	1	
TOTAL	**9**	**8.5**	**7.5**	**7**	**8**	**9**	**6.5**	

RCT

	Mittelman et al., (1993)	Meichsner
Clarity of focus	1	1
Assignment of participants random?	1	1
All participants accounted for?	1	0.5
Were people blind?	0	0
Homogenity of group?	0.5	0.5
Equality within groups?	0.5	0.5
Treatment effect?	0.5	0.5
How percise was the estimate of treatment effect?	0.5	0.5
Can be applied to local population or your context?	0.5	0
All clinically important outcomes considered?	0.5	1
	6	5.5

Literature Reviews



	Etters et al	Farina et al	Mc Donnell & Ryan	Robinson et al	Schoenmakers et al	Yu et al
Q1 Focussed Question	1	0.5	1	1	1	1
Q2 Right type of papers	0.5	1	1	1	1	1
Q3 Relevent studies included	1	1	1	1	1	1
Q4 Quality assessed?	0	1	0.5	0	1	1
Q5 Results combined?	1	1	0.5	1	1	1
Q6 Overall results	0.5	1	0.5	1	1	1
Q7 Presentation of results?	0.5	1	0.5	0.5	1	1
Q8 Application to population	0.5	0.5	1	0.5	0.5	1
Q9 Outcomes considered?	1	0.5	1	1	0.5	0.5
Q10 Benefits worth?	1	0.5	1	1	0.5	1
Total	7	8	8	8	8.5	9.5

Appendix 3: Participant Information Sheet

Information Sheet for Potential Participants

Identification of the factors that encourage and inhibit male caregivers of people with Alzheimer's type dementia decision to access respite and support services and exploration of the perceived benefits of accessing support.

My name is Gwenne McIntosh and I am PhD student from the School of Nursing Midwifery and Social Care at Edinburgh Napier University. I am undertaking a research study of the way male carers of a spouse with Alzheimer's decide to access support and respite services.

This study will explore the carer's view of accessing support and respite services and how they feel about their decision to do so. This research will provide much needed understanding about the nature of caring and decision making from a male perspective.

I am looking for volunteers to participate in the research. There main criteria for this research is that the participants are male and are currently caring for a partner or spouse with Alzheimer's type dementia.

If you agree to participate in the study, you will be asked to be interviewed in relation to your perceptions of your caring role and how you decide whether or not to access support services. The researcher is not aware of any risks associated with this research but does recognise that this may involve describing difficult and emotional experiences relating to caring. The whole procedure should take no longer than 30 - 45 minutes and will be held in a location that is suitable to you. You will be free to withdraw from the study at any stage, you would not have to give a reason and can choose not to answer any questions you do not want to answer.

All data will be anonymised as much as possible, but you may be identifiable from tape recordings of your voice. Your name will be replaced with a participant number or a pseudonym, and it will not be possible for you to be identified in any reporting of the data gathered. All data collected will be kept securely in a locked cabinet in locked room and once transcribed will stored on a pc that is password protected to which only I have access to. These will be kept till the end of the examination process, following which all data that could identify you will be destroyed.

The results may be published in a journal or presented at a conference.

If you would like to contact the supervisors of this project the contact details are below:

Dr Norrie Brown
Senior Lecturer and Subject Group Leader
Edinburgh Napier University
Sighthill Campus
Sighthill Court
Edinburgh
EH11 4BN

Email: [redacted]
Telephone: [redacted]

Or
Dr Adele Dickson
Lecturer
Life, Sport and Social Science
Edinburgh Napier University
Sighthill Campus
Sighthill Court
Edinburgh
EH11 4BN

Email: [redacted]
Telephone: [redacted]

If you would like to speak to an independent person, who knows about this project but is not involved in it, you are welcome to contact below:

Dr Barbra Neades
Senior Lecturer
Edinburgh Napier University
Sighthill Campus
Sighthill Court
Edinburgh
EH11 4BN

Email: [redacted]
Telephone: [redacted]

If you have read and understood this information sheet, any questions you had have been answered, and you would like to be a participant in the study, please now see the consent form.

Gwenne McIntosh
PhD Student

Appendix 4: Participant Consent Form

Consent Form

Identification of the factors that encourage and inhibit male caregivers of people with Alzheimer's type dementia decision to access respite and support services and exploration of the perceived benefits of accessing support.

I have read and understood the information sheet and this consent form. I have had an opportunity to ask questions about my participation.

I have been told that my responses will be anonymised. My name will not be linked with the research materials, and I will not be identified or identifiable in any report subsequently produced by the researcher

I understand that I am under no obligation to take part in this study.

I understand that I have the right to withdraw from this study at any stage without giving any reason. However, after data has been anonymised or after publication of results it will not be possible for my data to be removed as it would be untraceable at this point.

In addition, I understand that I can choose not to answer any particular question if I do not wish to.

I freely and voluntarily agree to participate in this study.

I agree that I give permission for my interview to be recorded.

Name of participant: ____

Signature of participant: ____

I have explained and defined in detail the research procedure in which the respondent has consented to participate. Furthermore, I will retain one copy of the informed consent form for my records.

Signature of researcher: ____

Date: __________________

Contact details of the researcher

Name of researcher: Gwenne McIntosh

Address:
PhD Student
SNMSC
Edinburgh Napier University
Sighthill Campus
Sighthill Court
Edinburgh
EH11 4BN

Email / Telephone: [redacted]

Appendix 5: Sample Questions for Interviews

Sample questions for interview.

The term “support services” include those services that support the carer and/or the cared for person and includes formal and informal support networks and statutory, non statutory and third sector services.

Interview Questions:

1. Can you describe your experience of caring?

Follow up prompts: when did you first see yourself as a carer? How did it feel when you first recognised you were a carer? What roles do you now have as a carer? What aspects of your own life have changed due to becoming a carer? In what way have things changed? What do you find most difficult about being a carer? What are the positive things about being a carer?

2. Do you access support services as a carer?

Follow up prompts: can you describe the time you first felt you needed support in your caring role? What kind of support did you need at that time? Were you able to access this support? Did your need for support change? If so in what way and when?

3. Can you describe the experience of accessing support services to help you or the person you care for?

Follow up prompts: what influenced your decision to access support? How did you find it? How did you access it? Where did you get information from? What do you recall about getting help as a carer for the first time? What would have improved that experience?

4. What helped you to make use of support services?

Follow up prompts: what did not help/discouraged? Did anyone encourage you to seek support? Who and in what way?

5. How would you describe the experience of deciding to use services?

Follow up prompts: what did you feel during the process of accessing support? What encouraged you to make use of a service and what discouraged you? What was the best timing for you accessing support?

6. How would you evaluate the impact of the support services you receive?

Follow up prompts: for you? For the person you care for?

7. What are your views of the support networks available for male carers?

Follow up prompts: do you think that male carers need specific support? Do you think having support directed at males is important? Why?

Appendix 6: Participant De-brief Sheet

De-Brief Sheet (Draft)

Identification of the factors that encourage and inhibit male caregivers of people with Alzheimer's type dementia decision to access respite and support services and exploration of the perceived benefits of accessing support.

Thank you for taking part in this research study to explore your perspective of caring and accessing support.

You contributions have been valuable to this study and they will go forward to provide a clearer view of male carers experiences of caring and making use of support.

Talking about your caring experiences can be difficult and therefore I have provided some contact details for services and support networks you may find useful if you feel you would like to talk to someone about your caring experience.

Contact Details of host organisation:

Contact details for carer support organisations:

Carer Counselling services:

Caring and Coping with Loss in Dementia training package:

If you would like to speak to someone relating to this research or have any further questions you can contact myself on [redacted] or telephone: [redacted] Alternatively you can contact the supervisors for the study:

Dr Norrie Brown

Senior Lecturer and Subject Group Leader

Edinburgh Napier University

Sighthill Campus

Sighthill Court

Edinburgh

EH11 4BN

Email:[redacted]
Telephone: [redacted]

Or
Dr Adele Dickson
Lecturer
Life, Sport and Social Science
Edinburgh Napier University
Sighthill Campus
Sighthill Court
Edinburgh
EH11 4BN

Email: [redacted]
Telephone: [redacted]

Or, you can contact the independent supervisor for the study:

Dr Barbara Neades
Senior Lecturer
Edinburgh Napier University
Sighthill Campus
Sighthill Court
Edinburgh
EH11 4BN

Email: [redacted]
Telephone: [redacted]

Appendix 7: Ethical Review Feedback Sheet

Ethical Review Feedback Sheet

Student Name:	Gwenne McIntosh
Supervisor:	Norrie Brown/Adele Dickson
Project Title:	Identification of the factors that encourage and inhibit male caregivers of people with Alzheimer's type dementia decision to access respite and support service and exploration of the perceived benefits of accessing support
Name(s) of Reviewer(s):	Anne Rowat; Janette Pow

	Yes	**No**	**Comments**
Section 1 – General Information			
Is all the required information provided?	Y		Update application to state B Neades will be the independent advisor as per participant information (PI) Updated
Section 2 – Consent & Care of Participants			
Are there any areas of concern identified in questions 1-10 (i.e. researcher has selected "No" to any of these items)?		N	
Are there any areas of concern identified in questions 11-14 (i.e. researcher has selected "Yes" to any of these items)?		N	
Section 3 – Box A/B			
1. Background Information			
Is adequate background information provided for the research?	Y		
2. Aims & Research Questions			
Are the aims & research questions clear?	Y		
3. Participants			
Are there any concerns about the nature and size of the sample?		N	
Are there any concerns about the inclusion/exclusion criteria?		N	
Are there any concerns about the recruitment strategy?	Y		You have stated that the research plan from the carer support

			organisations - could you please provide evidence of this. I have attached the email conformation from some of the orgaisations and group facilitators who will support me to access possible participants
4. Research Methods & Measurements			
Is the project outline sufficiently detailed to allow a decision about ethical aspects?	Y		
5. Risks to Participants			
Are there any concerns about potential risks to participants?		N	
6. Consent and participant information arrangements, debriefing			
Are there any concerns about the consent, participant information or debriefing arrangements?		N	
7. Ethical Considerations (Box B only)			
Are there any ethical issues that have not been addressed adequately?	Y		
Section 4 – Additional Information & Declaration			
Are all the required additional materials supplied?	Y		
Where applicable, are additional materials on headed paper?	Y		
Is the language on any additional materials appropriate?		N	Some minor typos in PI Reviewed and corrected
Are the contact details for the researcher, the supervisor and the independent advisor provided on the Participant Information and debrief sheets?	Y		
Has the declaration been signed?		N	Electronic version (Final version sent to ethics will require supervisor signature A paper copy with signature has been sent to Gill Napier.
Participant Information Sheet			
Is there sufficient information provided to enable the participant to give informed consent?		N	The application (section 6) needs to include detailed information of who will provide PI – is there someone from the care organisation in first instance (i.e to reduce coercion); how long will they get to digest PI before the researcher approaches and asks

			for consent (I assume this is face to face) etc. Section 6 now contains this detail
Is there information about the maintenance of privacy and confidentiality for the participant’s personal details?	y		
Consent Form			
Is the form structured appropriately, providing clear evidence of informed consent?	Y		
Debrief Sheet			
Are there any concerns about the debrief sheet?		N	
Other additional materials (e.g. questionnaires, interview schedules, stimuli, evidence of permission, recruitment posters/text)			
Are there any concerns about any other additional materials?	Y		

Recommendation of Reviewers:

Approved		
Referred	Y	Please update application and address the above comments.
Rejected		Rationale for this and action(s)

Appendix 8: Excerpt from Reflexive Account (Transcription)

Evaluation: what was good and bad about the experience – make a judgement

The good aspects of the transcription was adding to the detail – taking the notes and including them in the dialog particularly in relation to the non-verbal aspects of the interview. The experience allowed total immersion in the data at an early stage and supported the analysis process.

The time that the process took may have outweighed the benefits somewhat, I am slow at typing and listening to the recording is monotonous and I found it difficult to concentrate at times.

The mistake of long play recordings added to my frustration and irritation with myself for not checking the settings properly before starting the recorder.

Analysis: What sense can you make of the situation?

I feel that doing the transcription of the interviews myself was a decision I took based on what I thought was the right thing to do. I am aware that I am reluctant to let aspects of this research be in the control of others so think that I should be able to do it all myself.

I am also aware that getting interviews transcribed exposes you to others and they may make judgements about your interview style and approach – although I am aware this is an aspect that would not really interest anyone other than me. Having someone unconnected with the study in any way to help with the final transcription was helpful.

I think I am a little frustrated at not taking the opportunity to use a transcription service as it would have progressed my studies quicker allowing me to get into the analysis of the interviews much quicker and closer to the time of the actual interview in order to keep the interview fresh in my mind.

Appendix 9: Examples of Analysis (Stage 2-4)

Photographic evidence of transcription analysis using stages 2 – 4 of Smith et al. (2009) IPA steps.

	S/W		
Bloody useless you are. Good on benefits, you know your entitle to this and I will get the forms and you can get that, and invalid care allowance and all that sort of stuff, but, he would make suggestions and I would think "oh that's not bad, that's not a bad idea" like one of these tag things – not an alarm, and Identification a GPS thing so that if she wandered I would know where she was. And I thought oh that's not a bad idea - crafty I would be probably thinking that things were ok and then she'd slipped out the back and she would be up at the top of the road there or going next door or up the street lingering and doing the forms and it the guy in charge of the service said you are wasting your time can't have M put at risk because she is wearing one of these things that would be our responsibility, knowing that M had an ID or GPS tracker thing on and she stepped off the pavement and got run over I could say well if she had not have one of these GPS things I would have gone after her.	Un-helpful, of no use Helpful & knowledgable about benefits & entitlements SW making suggestions that would help with issues but are not accessible/available Value practical solutions Offered GPS tracking Suggestion of possible help with "seeking behaviour. Service providers cannot offer service due to risk. Service prov. responsib. Risk – who's? ← service / carer / person Perceptions of risk →	of no use 'sort of stuff' 'bad' 'good' idea. 'crafty' hidden smart, collusion slipped – sneek on purpose. un aware Waste – effort imaging [illegible]	Accessibility of services ↳ value & worth Meeting needs of carer/cared for. → Risk – perceptions – who's – +ve risk.

the next thing that happened - and I'm not saying to anybody I need any help and you know we are managing the carer role and M becoming a bit more mm, and the community nurse turned up and seven weeks of me saying to her, "I don't know why you are coming." I said "you I think you..." you know, she said "I want to see how you are getting on" and all this sort of stuff, and I said "fair enough, have another cup of coffee" like I said it was about every seven weeks or so, that emm by this stage M becoming, this is over, I can't remember how we went from next, emm but by then M was wandering, she is starting not to recognise me, starting to become incontinent. She said "oh, emm, would you like me to get on to council about a social worker" yes, " would you have the social work department and all that" and I said Yea, maybe I need to know what's available if anything is available and the next thing I know, is a social worker turns up, and an I am glad this is anonymous, couple of words:	next part of the experience not asking for help Recognised self as cover. Managing without help Community nurse started visiting. Un-sure of why visits were needed - ? purpose? Nurse wants to see how they were coping. Change in symptoms/wife Unsure of timescale Wife starts to 'wander'. Wife begins not to recognise him. Becomes incontinent. Accepted offer of SW ref. Recognises that there is value in finding out about services Accepting offer to help with lack of knowledge.	next - line of events Happening - life of its own 'We' managing - joint effort emphasis of time st 'turned up' repeated Q 'mm' lack of description of what was changing - flicking hand - dismissive disjointed "stuff" vague - clarity ?? dismissive ?? "fair enough" ownership of decision/acceptance dis-interest/ 'Stage' key points in progression of illness. *major symptom change* Although said Yes "Next thing I know" Sense of surprise "turns up" - not in control/choice - causation Nextthing - what is first thing,	Self agency Recollection difficult. disjointed Not listening going along with acceptance of people becoming involved Significant caring role Practical help valued. Information valued Ownership of decision

Consequence of decisions T1. Super-ordinate themes.

Financial burden

Acceptance of role - partnership
She would have done it for me.

Duty.

Family history of caring.

Marriage vows.

No real awareness of role - assumed it bit by bit.

No control. - ongoing rolling away. Can't stop it

Inevitability of change

hanges how you
ee yourself - I have
o look after her me to
rotect her. (Role)

ually act for her.

my role.

hallenge & speak up

essence
Protection.

Chronological story
Time

trust in services & people
quality
fear of challenge – repercussion. poor care.
fear of poor care
inconsistent/disorganised
continuity of people
no control
unsuccessful
↑ mistrust.

RQ

↳ stressful feelings
Results in
- frustration
- anger
- upsets
- fear.

Inevitability in dementia
treadmill No control
deterioration
loss of person
getting worse
increased work.

The role of Caregiving
not a conscious thing - part of marriage incepted?
never stops
independence ↳ copings.
Duty
responsibility
need to cope ↳ st demonstrate to others. ↓ if not?? care
own health
not valued.
protecting the person.
own health interrupts caring.

Non - Decision Making (NDM).
no control.
events, circumstances bring about decisions.
not my decision
S.Providers make decisions
RQ
carer overruled.
Decisions create more problems
family take over & overrule ↳ protection of carer
No power
~~The value~~
~~overruled.~~
If Services take over & fail to protect carer - how is this communicated

Transcript	Description/content	Language use	Interrogative/concepts /the logic
Okay so we have started recording, so I have got a list of questions here that I will refer to and as I said before we met that they are all about your experience and there is no right or wrong answer, it is generally how you think about the situation of caring for your wife. So the first question is generally what has your experience been caring for your wife?	superficial		
Well the two years prior to M going into the hospital was quite fraught really. She could flare up very easily and she was becoming very very difficult to look after. I got to a position where I couldn't really leave the house to do routine stuff… shopping and that sort of thing and I played	Pre hospital time was fraught. Before the admission Unpredictable, challenging fast paced Spontan.. really after hospital 2 Unable to cope got into - trapped No way to manage basics of living	History starting point fire, hot Flare driven 'very' intense rescue reality repeat word 'very' [illegible] stuck in a place position - race, place shape	Point [illegible] 2 years duration Unmanageable situation Deterioration too much failing to achieve basics of living. Trapped at home

powerful

Isolation

got to a point stuck

you know
— trust
— shared knowledge
— reassurance

Help her. parent - child shift in rel.[3]

in drinking. She would over indulge in wine so if I did get into the house, you know on the occasions that I got in, she would sometimes be lying on the carpet, you know. There were problems with wetting the carpet and those types of things she was very much out of control. What I did have and I can only praise them really was a series of Carers, well so social workers, I should say social workers who came and all of them were very very helpful, You know I cannot complain at all about the attention I have had from people like that you know, so I have been very lucky that way, but of course M was a difficult person for them to deal with. Two or three times she went into the [hospital] because I	Started drinking Not knowing what he would deal with Challenging. incontinence uncomfortable Un-managable could not control Input from SW Many different people helpful plenty of Attention from others plenty of help not complaining. as expected it did not work difficult person for me & others	involved - joined up with indulge - choice personal gratification over - too much on my side - you know - you can see my view. not all the time 'those types' difficult to speak about unpredictable, nobody able to control her Felt I had little but valued Many people, a number of people in a row Praise - value, reward recognition everyone helpful lucky in that way but not others To be expected. focus on me/us deal with, content with a challenge fuelled	Changes in behavior started using alcohol impacting on others incontinence Exposure - others seeing this SW services valued People who came were helpful I got help Sense of luck that help was forthcoming lucky - not everyone does? but it did not work - did not change Others found it difficult

Change.

Exposure.

SW valued

Got help

Chance luck

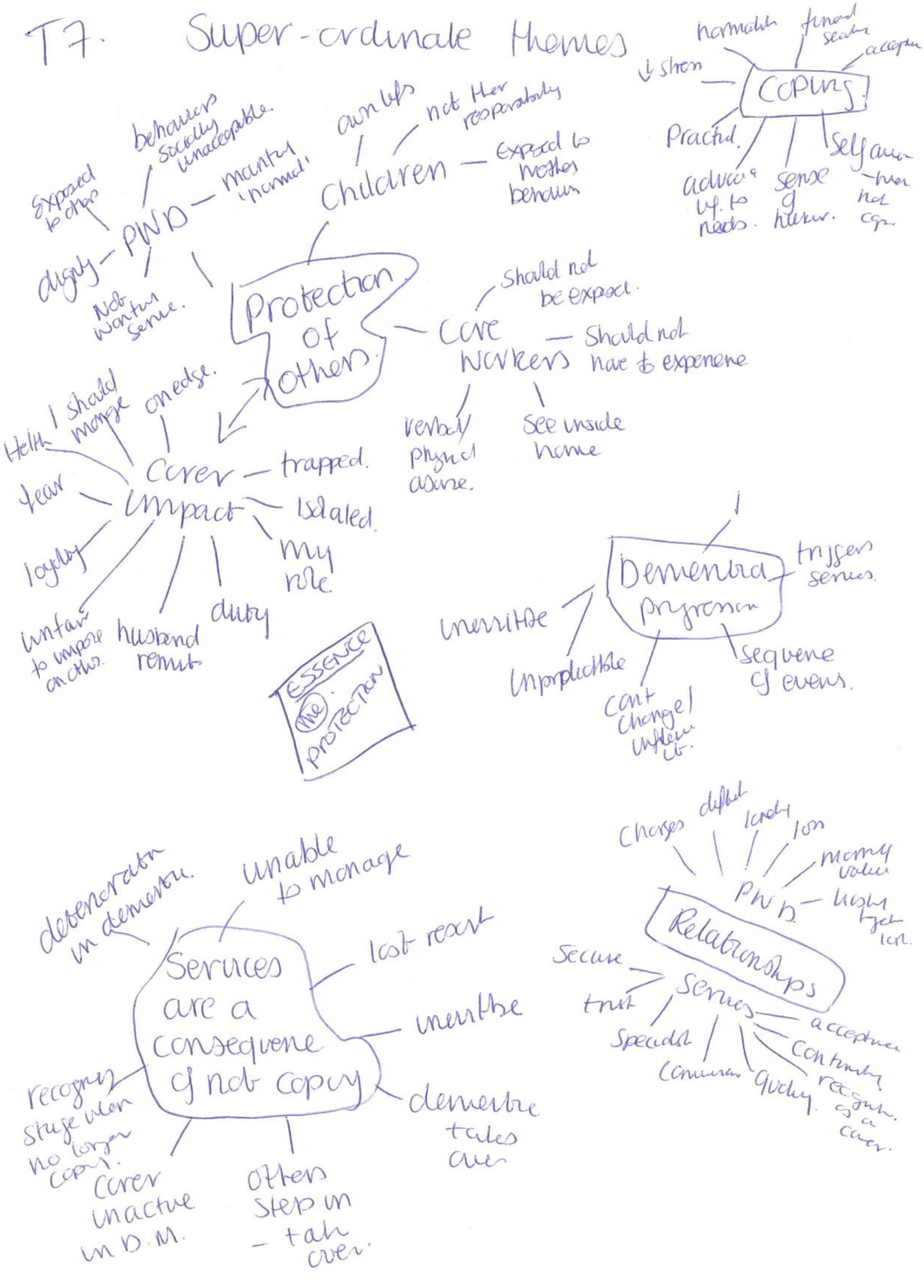
ineffective.

Q'

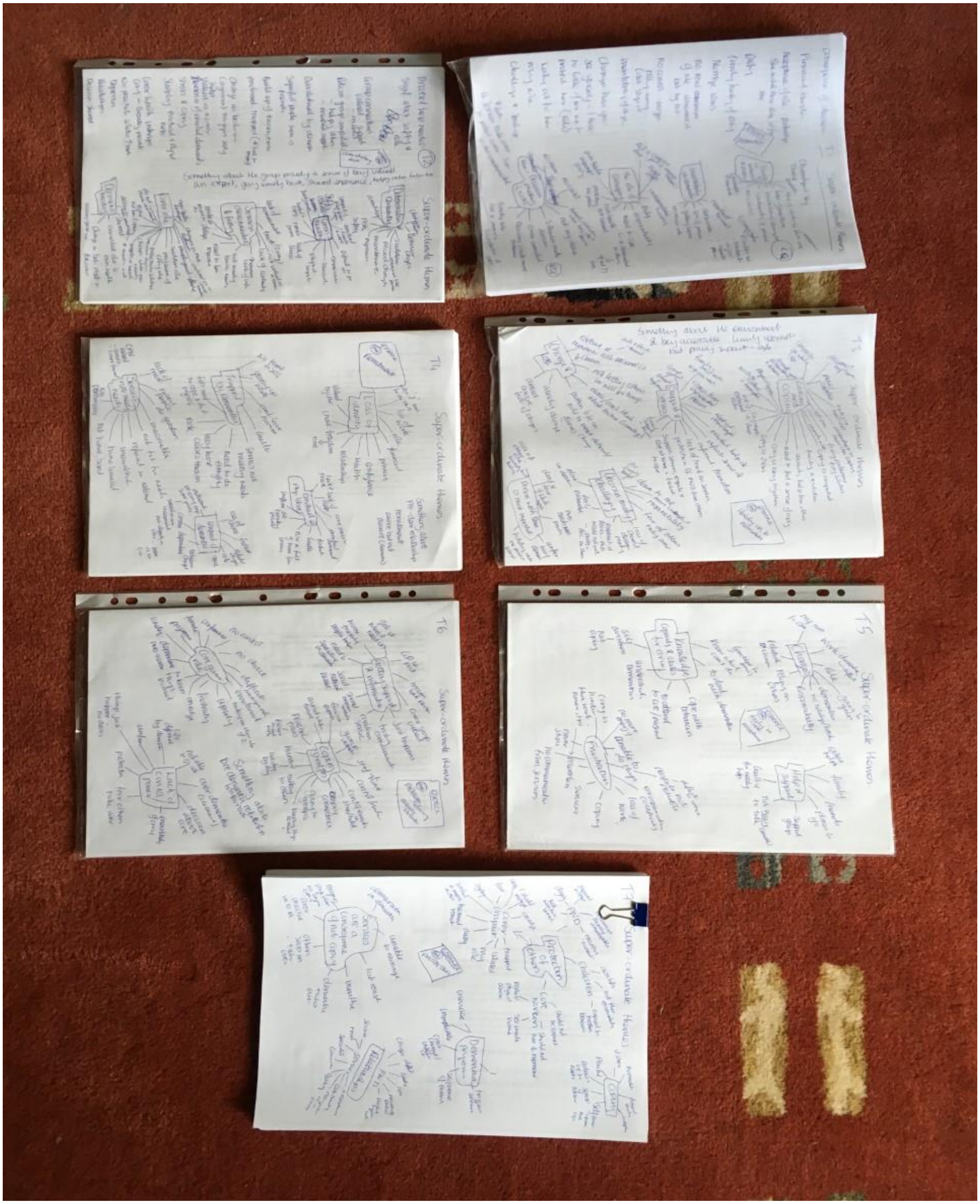
despair

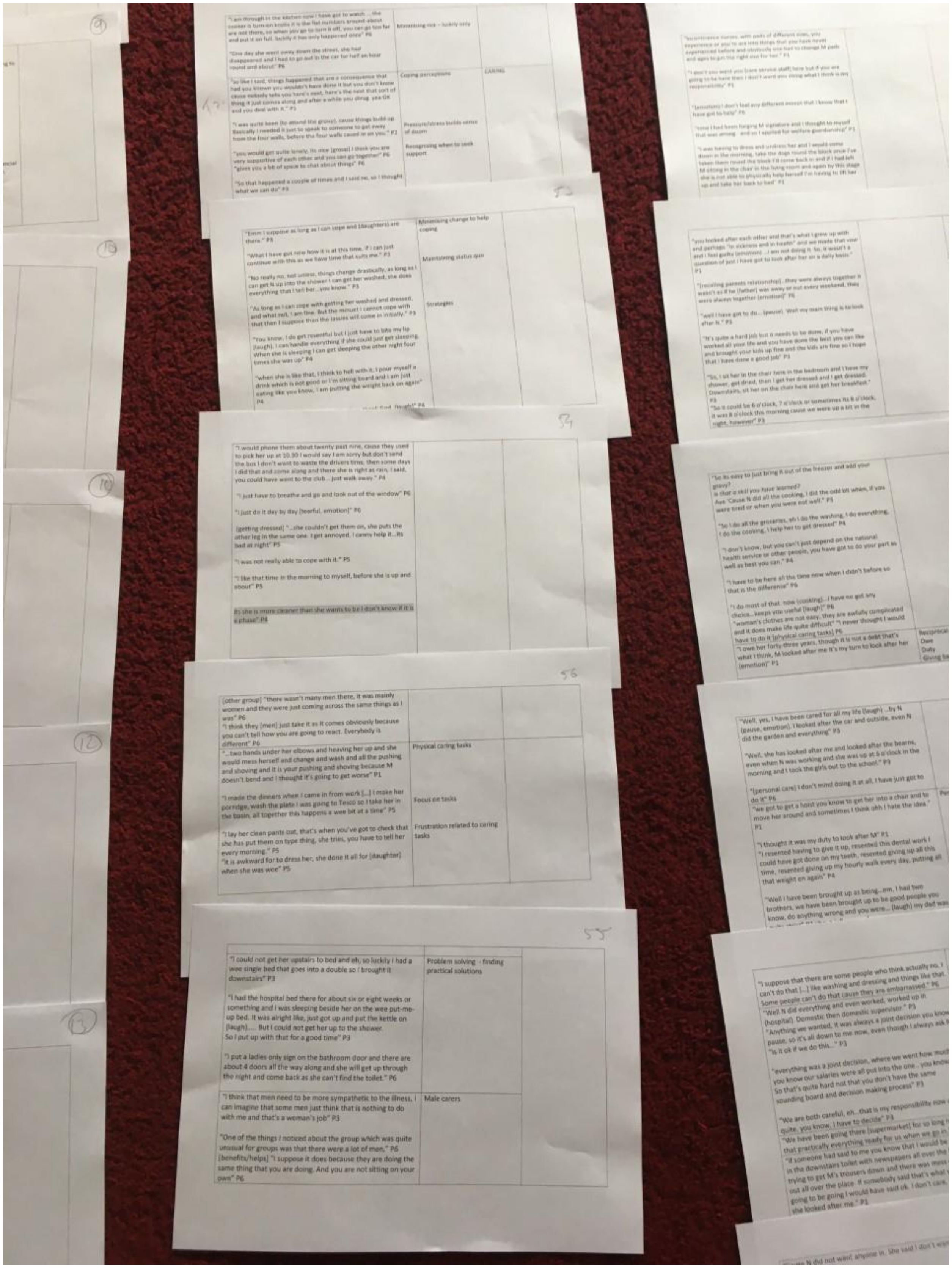
a certain amount of bridge and so a couple…. or one or two evenings a week I should say, I would go and play bridge but I was never even sure if I was even going to get back into the house… she would lock the whole house. Put the deadlocks on or ram a chair under the thing so, you know….anyway in that situation it got completely out of hand and we had an experience when we had to get the police here, you know and they came along and tried to persuade M to open the door. When that wasn't working they got a locksmith who took out the lock at the patio doors at the back of the house so that we could get into the house so it was like that and she would also get involved	Time spent on self personal activities Unsure at the start Worry about consequences of going out Blocked out Shut out of house personal Not able to sort Unmanageable Getting help No choice Police needed to help Unable to talk round Other - they got - not me, others took control. That was what it was like	uncertain ? not always way Quantify certain, couple one or two even - repeat word She - the other Shut down house Whole house - all every part Shut out [illegible] ram Blocked out punished/Shut out loss of grip/hold out of control we? Had to no choice out of my control persuade - talk into access-open Shut out see my side, round back Others not me open She would - Choice exposed. also - as well as	Not able to continue personal activities Changes Punished for doing things for themself Risk Risk Control Uncontrolable control. Others becoming involved Unmanageable Others taking control that was how it was 'out'! acceptance passivity.

T7. Super-ordinate themes



Appendix 10: Example of Analysis (Stage 6)





"I am through in the kitchen now I have got to watch ... the cooker is turn on knobs it is the flat numbers around about are not there, so when you go to turn it off, you can go too far and put it on full. luckily it has only happened once" P6 "One day she went away down the street, she had disappeared and I had to go out in the car for half an hour round and about" P6	Minimising risk – luckily only	
"so like I said, things happened that are a consequence that had you known you wouldn't have done it but you don't know cause nobody tells you here's next, here's the next that sort of thing it just comes along and after a while you shrug, yea OK and you deal with it." P3	Coping perceptions	CARING
"I was quite keen (to attend the group), cause things build up Basically I needed it just to speak to someone to get away from the four walls, before the four walls caved in on you." P3	Pressure/stress builds sense of doom	
"you would get quite lonely, its nice [group] I think you are very supportive of each other and you can go together" P6 "gives you a bit of space to chat about things" P6	Recognising when to seek support	
"So that happened a couple of times and I said no, so I thought what we can do" P3		

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"Emm I suppose as long as I can cope and [daughters] are there." P3	Minimising change to help coping	
"What I have got now how it is at this time, if I can just continue with this as we have time that suits me." P3	Maintaining status quo	
"No really no, not unless, things change drastically, as long as I can get N up into the shower I can get her washed, she does everything that I tell her...you know." P3		
"As long as I can cope with getting her washed and dressed, and what not, I am fine. But the minuet I cannot cope with that then I suppose then the lassies will come in initially." P3	Strategies	
"You know, I do get resentful but I just have to bite my lip (laugh). I can handle everything if she could just get sleeping When she is sleeping I can get sleeping the other night four times she was up" P4		
"when she is like that, I think to hell with it, I pour myself a drink which is not good or I'm sitting board and I am just eating like you know, I am putting the weight back on again" P4		

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"I would phone them about twenty past nine, cause they used to pick her up at 10.30 I would say I am sorry but don't send the bus I don't want to waste the drivers time, then some days I did that and come along and there she is right as rain, I said, you could have went to the club... just walk away." P4 "I just have to breathe and go and look out of the window" P6 "I just do it day by day [tearful, emotion]" P6 [getting dressed] "...she couldn't get them on, she puts the other leg in the same one. I get annoyed, I canny help it...its bad at night" P5 "I was not really able to cope with it." P5 "I like that time in the morning to myself, before she is up and about" P5 Its she is more cleaner than she wants to be I don't know if it is a phase" P4		

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[other group] "there wasn't many men there, it was mainly women and they were just coming across the same things as I was" P6 "I think they [men] just take it as it comes obviously because you can't tell how you are going to react. Everybody is different" P6		
"...two hands under her elbows and heaving her up and she would mess herself and change and wash and all the pushing and shoving and it is your pushing and shoving because M doesn't bend and I thought it's going to get worse" P1	Physical caring tasks	
"I made the dinners when I came in from work [...] I make her porridge, wash the plate I was going to Tesco so I take her in the basin, all together this happens a wee bit at a time" P5	Focus on tasks	
"I lay her clean pants out, that's when you've got to check that she has put them on type thing, she tries, you have to tell her every morning." P5 "It is awkward for to dress her, she done it all for [daughter] when she was wee" P5	Frustration related to caring tasks	

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"I could not get her upstairs to bed and eh, so luckily I had a wee single bed that goes into a double so I brought it downstairs" P3 "I had the hospital bed there for about six or eight weeks or something and I was sleeping beside her on the wee put-me-up bed. It was alright like, just got up and put the kettle on (laugh)..... But I could not get her up to the shower. So I put up with that for a good time" P3 "I put a ladies only sign on the bathroom door and there are about 4 doors all the way along and she will get up through the night and come back as she can't find the toilet." P6	Problem solving - finding practical solutions	
"I think that men need to be more sympathetic to the illness, I can imagine that some men just think that is nothing to do with me and that's a woman's job" P3 "One of the things I noticed about the group which was quite unusual for groups was that there were a lot of men." P6 [benefits/helps] "I suppose it does because they are doing the same thing that you are doing. And you are not sitting on your own" P6	Male carers	

"you looked after each other and that's what I grew up with and perhaps "in sickness and in health" and we made that vow and I feel guilty (emotion) ...I am not doing it. So, it wasn't a question of just I have got to look after her on a daily basis." P1

"[recalling parents relationship]...they were always together it wasn't as if he [father] was away or out every weekend, they were always together [emotion]" P6

"well I have got to do... (pause). Well my main thing is to look after N." P3

"It's quite a hard job but it needs to be done, if you have worked all your life and you have done the best you can like and brought your kids up fine and the kids are fine so I hope that I have done a good job" P3

"So, I sit her in the chair here in the bedroom and I have my shower, get dried, then I get her dressed and I get dressed. Downstairs, sit her on the chair here and get her breakfast." P3

"So it could be 6 o'clock, 7 o'clock or sometimes its 8 o'clock, it was 8 o'clock this morning cause we were up a bit in the night, however" P3

"So its easy to just bring it out of the freezer and add your gravy? Is that a skill you have learned? Aye 'Cause N did all the cooking, I did the odd bit when, if you were tired or when you were not well." P3 "So I do all the groceries, eh I do the washing, I do everything, I do the cooking, I help her to get dressed" P4 "I don't know, but you can't just depend on the national health service or other people, you have got to do your part as well as best you can." P4 "I have to be here all the time now when I didn't before so that is the difference" P6 "I do most of that. now (cooking)...I have no got any choice...keeps you useful (laugh)" P6 "woman's clothes are not easy, they are awfully complicated and it does make life quite difficult" "I never thought I would have to do it [physical caring tasks] P6	
"I owe her forty-three years, though it is not a debt that's what I think, M looked after me it's my turn to look after her (emotion)" P1	Reciprocal Owe Duty Giving ba

"Well, yes, I have been cared for all my life (laugh) ...by N (pause, emotion). I looked after the car and outside, even N did the garden and everything" P3

"Well, she has looked after me and looked after the bearns, even when N was working and she was up at 6 o'clock in the morning and I took the girls out to the school." P3

"[personal care] I don't mind doing it at all, I have just got to do it" P6

"we got to get a hoist you know to get her into a chair and to move her around and sometimes I think uhh I hate the idea." P1

"I thought it was my duty to look after M" P1

"I resented having to give it up, resented this dental work I could have got done on my teeth, resented giving up all this time, resented giving up my hourly walk every day, putting all that weight on again" P4

"Well I have been brought up as being...em, I had two brothers, we have been brought up to be good people you know, do anything wrong and you were... (laugh) my dad was

"I suppose that there are some people who think actually no, I can't do that [...] like washing and dressing and things like that. Some people can't do that cause they are embarrassed." P6

"Well N did everything and even worked, worked up in (hospital). Domestic then domestic supervisor." P3

"Anything we wanted, it was always a joint decision you know pause, so it's all down to me now, even though I always ask "is it ok if we do this..." P3

"everything was a joint decision, where we went how much you know our salaries were all put into the one.. you know So that's quite hard not that you don't have the same sounding board and decision making process" P3

"We are both careful, eh...that is my responsibility now quite, you know, I have to decide" P3

"We have been going there [supermarket] for so long that practically everything ready for us when we go in

"If someone had said to me you know that I would be in the downstairs toilet with newspapers all over the trying to get M's trousers down and there was mess out all over the place. If somebody said that's what going to be going I would have said ok. I don't care, she looked after me." P1

N did not want anyone in. She said I don't wa

Appendix 11: Reflexive Diary (Interviews)

Reflection – interviewing

Description: context and roles played

I have selected semi-structured interviews and the method for gathering data for this study. I have used this data gathering method for two previous studies one which explored student nurse perspectives and one which explored family caregivers who contributed to nurse education. Both of these sets of interviews were conducted within a university building.

For this study I was interviewing men who provided care to their partners who had dementia. The offer of where to conduct the interviews was given to the participants to ensure they were in the most suitable environment from their perspective. All of the men who participated in the study selected to be interviewed in their own home.

The interviews for this study were structured to some degree, given the study design I wanted to ensure that the men explored their experience of caregiving in their own way with limited input from me so to avoid leading the interviews to pre-determined topics or concepts.

A set of core questions related to the research questions and aim were drawn up and sent to the participants ahead of the interview to be sure that they were comfortable with the focus of the interview. Some prompt statements were included in my notes just in case there was a need for further detail or alternative language, not designed not designed to direct or influence any particular direction of the narrative.

This reflection will focus on this first interview to help me to process the experience and draw out any new learning or actions that could be taken to enhance the following interviews.

The first interview took place in the kitchen of the home of the man being interviewed. The man was home alone as his wife was in respite care. I was the sole interviewer and used a digital recorder to record the interview. The man had read the information for participants, the outline of interview questions and signed the consent form ahead of me arriving at his home.

At the point of sitting down at the kitchen table after introducing myself and outlining the aim of the study the man started to talk about his experience of caring for his wife. I had started the recording although had not asked any questions.

The man spoke for 42 mins without any questions from me or the use of any prompts. There were two interruptions in his narrative, one to answer a telephone call and one to move his dog into the living room as he had started to bark.

Feelings: what was I thinking and feeling at the time? How have these changed?

I recall parking the car in his street and making sure I had all the information and items I needed for the interview. I had some feelings of anxiety and some trepidation that I took to be related to this being my first interview and I had not carried out one as a researcher where the focus has been on experience of caregiving.

Once in the man's house I was more relaxed and felt ease at drawing from my experience as a community nurse. I had a spike in my anxiety when I first prepared the recorder even though I had checked it and had spare batteries and this remained for a while as the interview started.

As the man began to talk I tried to concentrate on his spoken word taking note of this non-verbal communication and his general manner and presentation. As this continued and there were no breaks in his narration I started to become more uncomfortable, realising I was contributing nothing. However, there was some reassurance as he had a copy of the interview questions in front of him and he was following them as he spoke. This reassured me to some extent but I was very aware of my anxieties showing and if I interrupted him I would be changing his direction and flow.

I was concerned that I was missing key details and fine variations in his tone and non-verbal communication as he spoke very fast and did not break other than to attend to the telephone call and the dog. This gave me time to look at my questions and make some notes without looking distracted.

There were a number of moments and at times with increasing intensity, where it was clear that the man was struggling with the depth of emotion attached to his account of the experience he had caring for his wife. The level of distress and emotion displayed made me feel uncomfortable and guilty at instigating this level of emotion by asking him about this very personal experience.

I had some sense of relief when the interview was over and when the recording had been successful although I was left with the uncomfortable feelings and sense of guilt as I left the house and drove away.

Evaluation: what was good and bad about the experience – make a judgement

The interview was successful in that there was an excellent account of this man’s experience and rich data on which to start the analysis for my research. There was a good indication that the way that I had structured my questions and prompts elicited the discussion and detail needed to address the research questions I had.

The aspects of the interview that were more difficult was may lack of control and my level of distraction due to trying to maintain an eye on the questions to be asked and make notes without disconnecting with him while he spoke. The other aspect that I found both challenging and unanticipated was the level of expressed emotion and my reaction to this.

Analysis: What sense can you make of the situation?

The sense I can make of this experience is twofold, first there are the practical and technical elements of the interview. I was attempting to gain some sense of control when really I should be focusing on the depth of detail the man offered. I think that this was likely to be related to my lack of confidence in conducting the interview and my surprise when he held the interview questions and took control of answering each one in turn. I anticipated more involvement in the interview and was take off guard when that role was taken away from me.

My anticipation of the role of the researcher and way in which this role differs from the roles I have had in the past was of particular importance for me when reflecting on this experience. Formally as a nurse I would work with family caregivers to identify their support needs, access and provide required information, refer for services and provide emotional support. I would be there for the person, to meet their needs and to work collaboratively to improve their experience. As a researcher however, I was not there for the person, I was there with my own agenda and to meet the needs of the research study. This was a real issue for me both emotionally and professionally.

The emotional impact of realising that I was asking the men in the study to explore and discuss the emotive and challenging experience of caring for their partners without any offer of intervention or support for them made me feel uncomfortable and ill at ease. I had an increased sense of guilt coupled with a disconnect with the professional identity I had as a nurse and now a researcher.

I struggled with how to end the interaction due to this change in role, I would not be in contact with the man again following this, I can offer no interventions or ongoing support and was left with leaving contact information for support networks he could access following the interview.

Conclusion: what have you learned, what else could you have done?

I have learned so much from this experience about myself and how I identify with my role as a researcher. I had not anticipated this reaction and the strong emotions that came to the fore. I would have benefited from reading around the experiences of researchers and undertaking interviews in more detail rather than assuming that this was a skill I had due to my previous role as a mental health nurse.

I could have also gave more consideration to the emotional aspects of the caregivers experience to better prepare me for hearing this.

Action plan:

The learning from this reflection and the experience itself has allowed me to think more about the use of my supervisory team and the use of the connections I have with fellow PhD students. I underused this support network in the early stages of my studies and it would have given me some space to explore and work through my emotional reactions to the experience as well as identify strategies to support me in the following interviews.