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**The Experience of Providing Care for those Dying with Dementia:
Family Carers' Perspectives**

Thesis submitted for the degree of Doctor of Philosophy

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Declaration of Work

This is to certify that this thesis is all my own work and I have not obtained a degree in this University or elsewhere on the basis of this work.

Signed: *Laura Dapsey*

Dedication

This PhD is dedicated in memory of my brother Conor who left this world shortly after I embarked on this PhD journey. I know the strength and courage I received to continue on with this research came from above. Conor you are my shining star to whom I look to each and every night.

“You light the skies up above me. A star so bright you blind me”

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Abstract

Background: It is widely reported that carers who provide care for a family member with dementia endure physical and psychological burdens. Not only do they fulfil an important role for the person with dementia but also for the wider society. This study explored the experiences of carers in Ireland who provide end of life care for a person with late stage dementia at home.

Method: Interpretative Phenomenological Analysis (IPA) was selected as a research design over alternative qualitative approaches as it is consistent with the epistemological position of the research question. The principal aim of IPA research is to ascertain how people make sense of their experiences. The focus of IPA is on the detailed examination of personal lived experience, the meaning of experience to participants and how participants make sense of that experience. Semi-structured interviews were conducted with seventeen current carers and six past carers of a family member with late stage dementia. Data was analysed guided by IPA.

Results: Four super-ordinate themes were identified which described the challenges faced by carers at different stages of their care giving journey: 1) The experience of dementia grief; 2) Parenting the parent; 3) Seeking support; 4) Death, dying and life after death. Dementia grief was experienced by carers as a result of a relationship change and an inability to recognise the person with dementia as their mother, father or spouse. A transition ensued resulting in the carer adopting the role of parent. Carers expressed a desire to provide care for the person with dementia at home until the time of death, however this required support at both individual and community level.

Conclusion: Family carers' required education to assist in recognising the dying phase and ease the shock of death. The findings also suggested that the burden of care leaves family carers' poorly equipped for life adaptations after the death of the person with dementia. Further pre-death support is required to facilitate a better post bereavement adjustment.

List of Publications

- I. **Dempsey, L.**, Dowling, M., Larkin, P., Murphy, K. (2015) The unmet palliative care needs of those dying with dementia. *International Journal of Palliative Nursing*. **21**(3), 126-133.
- II. **Dempsey, L.**, Dowling, M., Larkin, P., Murphy, K. (2016) Sensitive Interviewing in Qualitative Research. *Research in Nursing & Health*. **39**, 480-490.
- III. **Dempsey, L.**, Dowling, M., Larkin, P., Murphy, K. (2018) Providing care for a person with late stage dementia at home: What are carers' experiences? *Dementia: The International Journal of Social Research and Practice* (In press).

Conference Presentations

- I. **Dempsey, L.**, Dowling, M., Larkin, P., Murphy, K. (2015) The Complexities of Conducting Sensitive Interviews using an IPA Approach. Building and Promoting Excellence in Practice. 5th International Nursing & Midwifery Conference. NUI, Galway. February, 2015.
- II. **Dempsey, L.**, Dowling, M., Larkin, P., Murphy, K. (2018) End of life in the persons own home. Growing Excellence in Dementia Care. 10th International Dementia Conference, DCU, Dublin. April, 2018

List of Abbreviations

WHO	World Health Organisation
GDS	Global Deterioration Scale for assessment of primary degenerative dementia
FAST	Functional Assessment STaging Scale
CDR	Clinical Dementia Rating scale
CSO	Central Statistics Office
GDP	Gross Domestic Product
NICE	National Institute for Health and Clinical Excellence
IHF	Irish Hospice Foundation
HSE	Health Services Executive
IOELC	International Observatory on End of Life Care
COPD	Congestive Obstructive Pulmonary Disease
MS	Multiple Sclerosis
GSF	Gold Standards Framework
LCP	Liverpool Care Pathway
GP	General Practitioner
IPA	Interpretative Phenomenological Analysis
PHN	Public Health Nurse

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Preface

I qualified as a general nurse in 1999 and worked on a variety of medical and surgical hospital wards in Galway and Roscommon before traveling to Australia to gain further nursing experience in diverse clinical settings. On my return to Ireland, I embarked on a MSc in Education in 2003 and began my lecturing career in the School of Nursing & Midwifery, National University of Ireland, Galway. I took on the role of course co-ordinator for the Higher Diploma in Nursing (Palliative Care) in 2004 and have directed the programme since then to the present day, developing the course to MSc level.

I became involved in dementia research in 2006 when I was first invited to become a research assistant on a funded dementia study within the School of Nursing & Midwifery and this ignited my interest in this specialist area. Having gained experience in accessing research sites, collecting data using interviews as well as undertaking data analysis, developed my skills in qualitative research. I began to consider potential ideas for my own PhD research which would marry my interest in palliative care with my experience in dementia research. Following discussions with researchers in the School of Nursing and Midwifery and a colleague in University College Dublin, I registered for this PhD.

1. Introduction

An estimated 47 million people are living with dementia worldwide with this number expected to increase to 75 million by 2030 and projected to reach 132 million by 2050 (World Health Organisation, 2017) (WHO). Dementia deaths more than doubled between 2000 and 2015, ranking dementia as the seventh most common cause of death in high income countries in 2015 (WHO, 2017). O'Shea, Cahill & Pierce (2017) estimate there to be 55,266 people living with dementia in Ireland with this number expected to increase at an average rate of 3.6% per annum. This figure is predicted to have doubled by 2036 and have trebled by 2046.

1.1 Dementia: Definitions and Varieties

In medical terms, dementia is a syndrome, characterised by progressive and irreversible decline in mental functioning (WHO, 2017). Loss of cognitive abilities resulting in damage to the neurons in certain areas of the brain is frequently accompanied by a deterioration in emotional control, social behaviour, and motivation. The effects of the damage intensify over time and are disabling and terminal (O'Shea, 2007). 60% - 80% of all cases of dementia are attributed to Alzheimer's disease (Thies & Bleiler, 2013). Other types of dementia include vascular / multi-infarct dementia, Lewy Body dementia, Picks Disease, Huntington's Chorea, Parkinson's, and Creutzfeldt-Jacob Disease. There is no single cause of dementia nor is there any cure for the majority of the dementias. Control and management of a person's circulatory or vascular system in terms of blood pressure management and the use of anti-cholinesterase inhibitors may slow down the decline in these illnesses (Lengel, 2015). In addition, many side effects of Alzheimer's disease such as hallucinations, depression, delirium, or agitation may be controlled or alleviated with proper medication management. However, dementia continues to be a debilitating condition which poses huge physical and emotional strain on patients and their families.

1.2 Symptoms and Staging Dementia

Dementia is mainly a disease of older people, with the rate of progression varying from person to person, however death usually occurs within a decade of the original diagnosis (O'Shea, 2007). All dementia's are characterised by a set of signs and symptoms which tend to progress in stages and vary with different types of dementia. The common

symptoms and behavioural changes are memory loss, confusion, disorientation, agitation, language difficulties, wandering, failure to recognise people and objects, impaired comprehension, reasoning, and judgement, mood swings, night time wakefulness, gradual inability to perform activities of daily living, and hallucinations (Fauth & Gibbons, 2014). Challenging behaviours such as verbal and/or physical aggression, suspicion, repetitive acts, inappropriate sexual behaviour, abusive language, and offensive language may also ensue (Kales, Gitlin & Lyketos, 2015).

The progression of dementia is usually classified into stages, with the affected person exhibiting certain symptoms in each stage, however considerable variation in the symptoms will occur during the course of the illness, thus not everyone with dementia will necessarily progress systematically from one stage to the next (Woods et al, 2003). The disease process in itself is as unique as the person affected with it. Individuals with dementia are likely to experience a combination of symptoms and other potential symptoms in addition to those listed above, making it clear that no one solution exists to the provision of care for these individuals with dementia and their families (Kales, Gitlin & Lyketos, 2015).

Health professionals frequently discuss dementia in "stages," referring to the progression of the disease. Defining a person's disease stage facilitates treatment options and aids communication between health providers and caregivers. Often the stage is simply referred to as mild (S1), moderate (S2), severe (S3) or early stage, middle stage or late-stage dementia (Kovach, 2013). However often a more exact stage is assigned, based on a person's symptoms. One of the most commonly used staging scales is the Global Deterioration Scale (GDS) for Assessment of Primary Degenerative Dementia (Reisberg et al., 1982) which divides the disease process into seven stages based on the amount of cognitive decline. The GDS is most relevant for people who have Alzheimer's disease, since some other types of dementia (i.e. frontotemporal dementia) do not always include memory loss. Another scale used to stage Alzheimer's disease is the Functional Assessment Staging (FAST) scale (Reisberg et al., 1988) which is a seven stage system based on level of functioning and activities of daily living. This scale focuses on the individual's level of functioning and activities of daily living versus cognitive decline. It is noteworthy that a person with Alzheimer's disease may be at a different stage cognitively (GDS stage) and functionally (FAST stage). The Clinical Dementia Rating (CDR) scale (Hughes et al., 1982) is a five stage system used to stage dementia, based on

cognitive abilities and the individual's ability to function. This is the most widely used staging system in dementia research. The individual with dementia is assessed in 6 areas: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care.

1.3 Demography of the Disease, Incidence, and Statistics related to Dementia in Ireland

Prevalence of dementia increases almost exponentially with age, nearly doubling every five years from the age of 65 years onwards. Gould (2011) suggests that prevalence rises from 1% for people aged 60-65 to 13% for people aged 80-85 and 32% for people aged 90-95. Dementia therefore affects around 5% of people over 65 years, increasing to 20% for those aged 80 or more years. With the population living longer, the number of people with dementia in Ireland is steadily increasing. The major increase is expected to occur after the year 2036, with numbers growing to between 115,426 and 157,883 by 2046 (O'Shea, Cahill & Pierce, 2017). On average approximately 4,000 new cases of dementia arise in Ireland each year (Alzheimer's Society of Ireland, 2018).

There is clear regional variation in the prevalence of dementia across the country. The west of Ireland has the highest rate of dementia with counties Roscommon (1.40%) and Leitrim highest of all. Lowest rates of dementia are found in counties on the eastern seaboard (Kildare, Meath, Dublin, Carlow, Louth, Wicklow) (Cahill, O'Shea & Pierce, 2012). The rationale for this inequity across the country reflects the imbalance in age distribution nationwide and a trend of migration to the east of the country for employment purposes for younger people, leaving behind an ageing population in the west. These statistics assist with structuring services accordingly to areas most in need.

1.4 Economic and Social Costs of Dementia

Dementia has significant economic and social costs with respect to direct social costs, medical costs and the cost of informal care. The WHO (2017) recently reported the total worldwide societal cost of dementia to be in the region of US\$818 billion, which equates to 1.1% of global GDP. In an assessment of the economic impact of dementia in Northern Europe, Wimo et al. (2011) revealed that the total cost of dementia disorders was approximately €160 billion, 56% of this attributable to the cost of informal care. The United Kingdom has approximately 820,000 people with dementia, with a cost to services of £23 billion per annum (Luengo-Fernandez et al., 2010).

In the latter half of the 1990s in Ireland, the annual cost per person with dementia was estimated to be £8,261 accumulating to a total cost of IR£248 million (O’Shea & O’Reilly, 2000). Formal care accounted for 50% of the costs while residential care accounting for 33% of the total costs. More recent figures show that the cost of dementia in Ireland, €1.69 billion, equals the combined cost of cancer, cardiovascular and cerebrovascular accidents yet receives minimal funding (Cahill, O’Shea & Pierce, 2012).

The Alzheimer’s Society of Ireland’s *Dementia Manifesto 2007-2009* called for investment of €35 million over three years to improve community services, early diagnosis, intervention awareness, education, and medical and social research. The Irish government gave a commitment in their *Programme for Government 2011-2016* to develop and implement a *Strategy for Dementia for Ireland* with a promise to “...develop a national Alzheimer’s and other dementia strategy by 2013 to increase awareness, ensure early diagnosis and intervention, and development of enhanced community based services. This strategy will be implemented over five years” (Programme for Government, 2011 p.34). In 2014, the Irish government published *The Irish National Dementia Strategy* which aimed to raise awareness of dementia, ensure timely diagnosis and early intervention and the development of enhanced community services for this cohort and their carers’. Combined with philanthropic funding, the Department of Health and the Health Services Executive agreed a joint initiative to implement ‘significant elements’ of the *Dementia Strategy Implementation Programme* between 2014 and 2017.

1.5 Informal Care in the Community

The exact prevalence of dementia in Ireland is difficult to quantify as no Irish epidemiological studies have been conducted in this area. However, based on previous estimates of dementia prevalence for Ireland and applying the EuroCoDe dementia prevalence rates to the most recent Census of Ireland (2016) data, it is possible to estimate the prevalence of dementia in Ireland (O’Shea, Cahill & Pierce, 2017). Estimates derived by applying age-specific dementia rates for those aged 65 and over, to figures from the Census of Population (2016) showed that there was an estimated 55,266 people with dementia aged 65 years and over and of those, 4,311 were aged under 65 years. Of the 55,266 people living with dementia in Ireland, it is estimated that 35,000 of these people live in the community (O’Shea, Cahill & Pierce, 2017).

Pierce, Cahill & O'Shea (2014) content that of those living in the community with dementia, most do not have a formal diagnosis of dementia and many are unaware that they have the disease so are therefore unlikely to access health and social care systems. Community support services are underdeveloped and fragmented. The weakness of community care has affected the wellbeing of people with dementia and their families living at home. Generally, people with dementia do not access health or social services unless a crisis has occurred.

According to the *Developing and Implementing Dementia Policy in Ireland* by O'Shea, Cahill & Pierce (2017), there are approximately 60,000 family carers' in Ireland providing care for someone with dementia. Carers' reported needing greater relief and more support to assist with the ongoing burden of care. It is not clear from the report by O'Shea, Cahill & Pierce (2017) what stages of the dementia disease process these care recipients were at, however it may be assumed that greater care requirements would be necessitated at end of life stage, such as feeding, toileting, washing, dressing, and attending to pressure area care for example, which consequently would increase the already reported stress and strain on these carers' and families. Assuming that individuals living in the community (over 65 years) in Ireland with dementia receive over eight hours of informal care per day, a total of 81 million hours of care is provided by family and friends per year. The weighted average cost of informal care is estimated to be €10 per hour, costing €807 million per year for informal care giving (Cahill, O'Shea & Pierce, 2012). The aforementioned report followed on from *Creating Excellence in Dementia Care: A Research Review of Ireland's National Dementia Strategy* which was a pivotal piece of work used to inform the development of the *Irish National Dementia Strategy* (Department of Health, 2014).

The most commonly used primary and community services for those with dementia include respite care, home help visits, and meals on wheels, with relatively little use of occupational therapists and social workers. The total annual cost of primary and community care for people with dementia was €65 million, 59% of which was accounted for by respite care (Cahill, O'Shea & Pierce, 2012).

1.6 Total Cost of Dementia in Ireland

An estimated average baseline cost of dementia in Ireland in 2012 was over €1.69 billion (Connolly & O'Shea, 2015). Informal care provision by family and friends to people

living in the community with dementia accounts for 48%, while 43% is due to residential long stay care. Formal health and social care provision (primary and community care) comprises only 9% of the total cost of dementia. These figures are comparable to other international studies (Luengo-Fernandez et al., 2010; Wimo et al., 2011).

There is a lack of cost of illness research in Ireland to compare the economic cost of dementia with other diseases or conditions, however from the few studies that are published, it appears that dementia carries a significantly high economic burden. The absence of research also poses problems for obtaining factual data on the number of actual people in Ireland living with dementia, their resources and the associated costs. A national dementia register is required to overcome this problem.

1.7 Rationale for this Study

A plethora of research has been conducted on the experiences of family carers of a person with dementia in long term care facilities (Schulz et al., 2003; Schulz et al., 2004; Clare et al., 2008; Bramble, Moyle & McAllister, 2009; Edvardsson, Fetherstonhaugh & Nay, 2010; Hennings, Froggatt & Keady, 2010; Levine et al., 2010; Denning, Jones & Sampson, 2013; Graneheim, Johansson & Lindgren, 2014; Brooker & Latham, 2015) however less attention has been focused on family carer's experiences of providing care to the person with dementia in the home or on the impact of providing end of life care to a family member with dementia on the carer. Research has been overlooked on this topic in Ireland and knowledge about the reality of providing end of life care to a person with late stage dementia at home is required to develop this field of research. There is also a lack of data on the support services available and accessed by caregivers, the financial burden incurred by the caregiver and the specific end of life caregiving experiences of those who provide care at home. It is important, therefore, to examine these issues in order to understand the needs of carers.

1.8 Aim and Objectives of the Study

Aim: The overall aim of this research was to illuminate family carers' lived experience of providing care for individuals with dementia at end of life.

Objectives: From an Irish perspective, it is anticipated that this study will:

- Provide a meaningful understanding of family carers' experiences of caring for an individual with dementia at the end of life in the home.
- Explore what facilitates or hinders caring for individuals with dementia in the home.
- Explore carers' experiences of supports available or lacking that facilitate or diminish caring for individuals with dementia at home.
- Identify specific end of life care / palliative care needs for individuals with end stage dementia.
- Examine educational and training needs of families and carers.

1.9 Overview of Publications and Thesis Structure

This is an article based PhD comprising of three papers, two of which have been published and the third publication is in press. These three papers are included in appendix 15.

Paper 1: Dempsey, L., Dowling, M., Larkin, P., Murphy, K. (2015) The unmet palliative care needs of those dying with dementia. *International Journal of Palliative Nursing*, **21**(3), 126-133.

Laura Dempsey wrote the paper. Maura Dowling, Philip Larkin, and Kathy Murphy contributed in critiquing and proof reading the paper. Paper one forms part of the literature review in chapter two.

Paper 2: Dempsey, L., Dowling, M., Larkin, P., Murphy, K. (2016) Sensitive Interviewing in Qualitative Research. *Research in Nursing & Health*, **39**, 480-490.

The journal 'Research in Nursing & Health' has an impact factor of 1.693. Laura Dempsey wrote the paper. All authors contributed in critiquing and proof reading this paper. This paper forms part of the methods chapter four.

Paper 3: Dempsey, L., Dowling, M., Larkin, P., Murphy, K. (2018) Providing care for a person with late stage dementia at home: What are carers' experiences? *Dementia: The International Journal of Social Research and Practice* (In press).

The journal 'Dementia: The International Journal of Social Research and Practice' has an impact factor of 1.768. Laura Dempsey conceived and conducted the study. Maura Dowling, Philip Larkin, and Kathy Murphy supervised the study. Laura Dempsey wrote the first drafts of this paper. All authors contributed in critiquing and proof reading this paper. This paper presents most of the study findings from chapters five and six.

In the subsequent chapter (chapter two) a literature review examines and presents the existing evidence base and provides context for the research. This chapter contains some of the literature used to form the first publication examining the unmet palliative care needs of those dying with dementia. Chapter three describes the underpinnings for the research design, presents a rationale for the selection of a research paradigm and discusses how this paradigm fits with the chosen research methodology. Chapter four presents a detail account of the chosen methodology used to conduct this research. This chapter further explains the study methods, the process of data collection and analysis. In addition, content from chapter four was used to construct the second publication from this study which focuses on conducting sensitive interviews in qualitative research. Chapter five presents the research findings from this study while chapter six discusses these findings. The final publications from this research features the findings and discussion while also offering interpretations, opinions and an explanation of the implications of this research. Finally, in chapter six, a conclusion summarises the main findings and implications of this research for this population. The strengths and limitations of the study will be discussed in addition to proposing suggestions for future research and clinical practice which relate to the study's aims and objectives.

2. Literature Review

2.1 Introduction

A review of the current literature which formed the basis for this study was examined in 2013, most of this literature is presented in paper one. This positions this study in the context of the literature currently available.

When formulating a search strategy, a search tool is advocated as an organising framework to list terms by the main concepts in the search question (Methley et al., 2014). The SPICE framework, developed by Booth (2004), is one such framework which facilitates the development of an answerable and evidence based research question (Fig. 2.1).

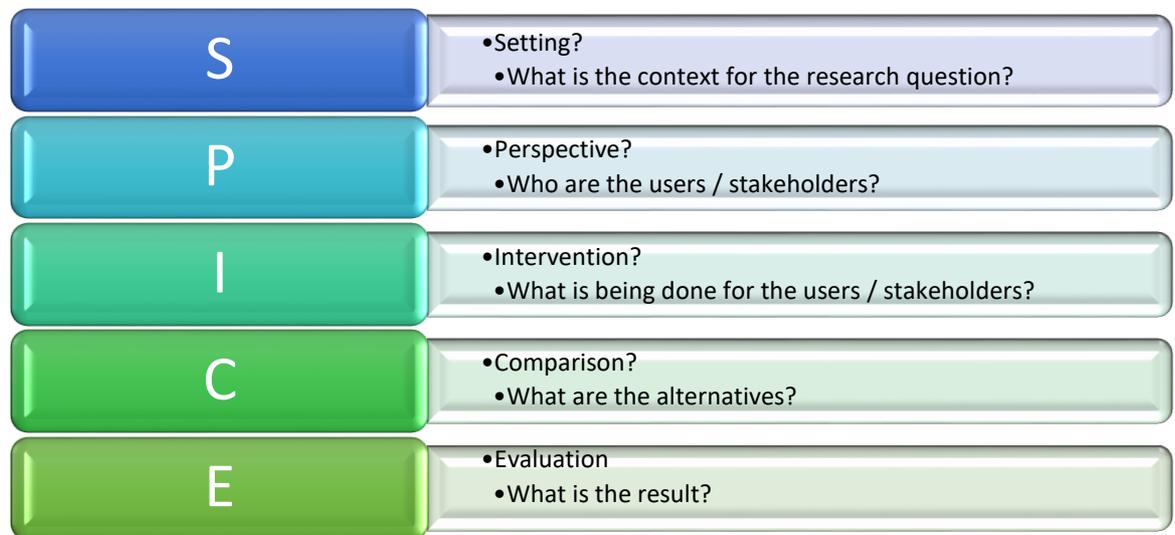


Fig. 2.1 SPICE Framework from Booth (2004)

The importance of a well-defined and focused research question is considered essential as an extensive search of databases is dependent upon it (Booth, 2006). The research question “what are the experiences of family carers who provide care for individuals with dementia at end of life?” was formulated using the SPICE framework. The SPICE mnemonic breaks down the clinical question into searchable keywords (Davies, 2011) and allows the researcher to identify key terms for the search strategy (Table 2.1).

	SPICE	Description	Free Text Search Terms
S	Setting	Home / Community	
P	Population/Perspective	Family Carers Dementia	Carer* OR caregiver* OR care giver* OR family carer* OR family caregiver* Loved one* OR spouse OR children OR patient* OR individual* OR people Dementia OR Alzheimer* Advanced stage OR late stage, OR severe OR end stage OR terminal stage
I	Intervention	Providing End of Life Care	End of life OR end of life care OR palliative care OR terminal care OR care of the dying Death OR dying OR grief OR grief and loss OR loss
C	Comparison	None	Not included in this search
E	Evaluation	What are the experiences of providing end of life care?	

Table 2.1. SPICE framework with search terms

The search of published literature for the review included electronic databases of papers in peer reviewed journals and library sources. Electronic databases such as CINAHL (EBSCOhost), MEDLINE (Ovid), PsycINFO, Cochrane library and EMBASE (Ovid) were searched from the start of electronic records to 2012. These databases were selected as they were relevant to the topic of this review. Depending on which databases were being searched, controlled vocabulary terms were used to search for relevant literature. MeSH terms were used with PubMed, Medline, PsychINFO and the Cochrane library, Emtree terms were used with EMBASE while subject headings were used in CINAHL (EBSCOhost). The use of truncation or wildcards (*) allowed for a greater number of searches to be undertaken. The results were narrowed using the Boolean operators AND / OR. Search terms used were carer*, caregiver*, care giver*, family carer*, family caregiver*, loved one*, spouse, children, patient*, individual*, people, dementia, Alzheimer*, end of life, end of life care, palliative care, terminal care, care of the dying, death, dying, grief, grief and loss, loss, advanced stage, late stage, severe, end stage, terminal stage.

A full sample search strategy for the CINAHL database is shown in Appendix 1. A grey literature search strategy was also conducted to gather unpublished sources of national and international information such as theses, government reports and conference abstracts not appearing in regular channels for scholarly communication. An incremental search of reference lists of relevant studies were also searched to identify additional studies.

A revised literature search was undertaken in 2018 using the same electronic databases and MeSH terms / subject headings to ascertain if any new literature related to this study had been published between 2012 and 2018.

This chapter features content from publication one which examines the literature focusing on ‘the unmet palliative care needs of those dying with dementia’. Before this, an overview of palliative care and end of life care is presented to provide an overview of the development of this specialist care area. Furthermore, subsequent to publication one, the focus of the chapter moves to carers of those with dementia, highlighting the specific experiences faced by these caregivers.

2.2 Palliative Care / End of Life Care: Historical Perspectives

Improvements in end of life care for patients with life limiting illnesses have been a major advance in modern health care. Medical and technical advances made in the 1940s to 1960s were accompanied by a decline in the incidence of dying as a family and community affair. The improvements in end of life care was manifested primarily through the efforts of the hospice movement and through the work of pioneering nurses and physicians (Kemp, 1999). The word hospice is derived from the Latin word *hospes*, the root word for *hospitium*, a place of hospitality. Originally, places of hospitality and welcome for travellers, especially pilgrims, *hospitia*, evolved in the middle ages into hospitals for the sick and hospices for the poor and dying. After the end of the Crusades and Pilgrimages, most hospices disappeared from Europe until the 19th century. In the late 19th and early 20th centuries, several hospices were established specifically to care for the dying, the most noteworthy of these were Our Lady’s Hospice (Dublin) and St. Joseph’s Hospice (Dublin) both operated by the Irish Sisters of Charity (Ling & O’Siorain, 2005).

Dame Cicely Saunders, founder of the modern hospice movement, is renowned for her work for modern hospice care. Dame Saunders began her work with patients at end of

life as a volunteer nurse at St. Luke's Hospital (UK). After completing her medical degree in 1957, Dame Saunders worked at St. Joseph's Hospice and then founded St. Christopher's Hospice (London, UK) in 1967 where modern concepts of hospice and symptom management were realised (Sheehan & Foreman, 1996). The development of hospice care was supported at least philosophically by the work of Elizabeth Kübler-Ross and others. Kübler-Ross, a Swiss psychiatrist working at the University of Chicago, was author of the most influential book, *On Death and Dying*, first published in 1969. This was the first widely read and accessible book on the experience of end of life illness and provided early direction on the provision of quality care for patients and families facing death.

The modern hospice movement is generally considered to have begun when St. Christopher's Hospice (London, UK) opened in 1967 (Ling & O'Siorain, 2005). The movement quickly spread with its ideas and ideals adapted to suit differing health systems and cultural norms. Dame Saunders' modern hospice movement laid the foundation for the concept of hospice care to be recognised as a speciality, namely palliative medicine, by the Royal College of Physicians (London, UK) in 1987.

The term 'palliative care' was adopted in 1975 by French speaking countries, where the term 'hospice' implies custodial care (Lutz, 2011). Until the early 1980s most hospices or palliative care services described the care they provided as 'terminal care', however this was seen as a barrier to health professionals referring patients in time to benefit from care and to patients themselves accepting the care (Milligan & Potts, 2009). Therefore, providing palliative care is a preferable title.

A growing sense of empowerment among consumers and questions about the human quality of health care for those with a life limiting illness and others also aided the development of hospice or palliative care (Saunders, 2001). Other factors contributing to its development were increased interest in research in grief and bereavement, development and acceptance of the holistic nursing practice model, discussion about the cost of care versus the quality of life and questions about physician assisted suicide and the continuing problem of uncontrolled distressing symptoms experienced at end of life (Kemp, 1999). The hospice movement's emphasis on holistic care of the patient, the family as the focus of care and the importance of multidisciplinary collaboration on a day

to day basis is a philosophy that can be adapted to different settings and cultures both nationally and internationally (Lutz, 2011).

Palliative care is a direct outgrowth of the hospice movement (Ellershaw & Wilkinson, 2011) and like hospice, has as its aim the relief of suffering in all spheres of being. Palliative care is defined in several ways including an approach which enhances the quality of life of patients and their families who experience issues attributed with life threatening illness, through the relief and prevention of suffering by early identification and impeccable assessment and treatment of problems such as pain and other physical, spiritual and psychosocial problems (WHO, 2017).

The goal of palliative care is achievement of the best quality of life for patients and their families. In addition

“palliative care affirms life and regards death as a normal process, neither hastens nor postpones death, provides relief from pain and other symptoms, integrates the psychological and spiritual aspects of primary care, offers a support system to help patients live as actively as possible until death, offers a support system to help family cope during the patient’s illness and in their own bereavement” (WHO, 2017).

Although there is no point at which hospice care begins, there is often an overlap with palliative and curative care. Palliative care may begin before a patient is or is known to be at end of life and takes on increasing importance as the disease progresses.

Lynch, Connor & Clark (2013) mapped palliative care development across the globe depicting changes over time. Building on from a comparative study conducted by the International Observatory on End of Life Care (IOELC) in 2006 which mapped global palliative care development, Lynch, Connor & Clark (2013) reported an increase in the number of countries actively engaging in hospice or palliative care services. In 2006, 115 of the world’s 234 countries had established one or more hospice – palliative care services. In 2011, an increase in 21 countries brought the number of actively engaging countries to 136. On examination of the countries who were actively engaged in either developing a hospice – palliative care service or developing the framework within which

such a service could be delivered revealed a slight increase from 156 countries in 2006 to 159 countries in 2011.

While more people are living with advanced disease, many of these people could benefit from palliative care. Early integration of palliative care has been found to improve the quality of life of both patients with a life limiting illness and their caregivers as well as reducing healthcare costs (El-Jawahri, Greer & Temel, 2011; van der Eerden et al., 2014; Aldridge et al., 2016; Siouta et al., 2016). Early palliative care also results in patients receiving less aggressive care at the end of life but longer survival (Temel et al., 2010). van der Eerden et al. (2014) advocate for the implementation of models using an integrated care approach in palliative care delivery. However, barriers exist to palliative care integration across the globe most notably related to a lack of adequate education and training in palliative or end of life care, challenges in identifying appropriate patients for palliative care referral, cultural issues as well as barriers related to a fragmented healthcare system, inadequate research and funding (Aldridge et al., 2016).

A systematic review undertaken by Siouta et al. (2016) identified empirically-evaluated models of palliative care in cancer and chronic disease in Europe. Fourteen studies were included in the review which evaluated models for chronic disease, cancer, cancer and chronic disease, oncology and end of life pathways. Findings revealed a strong consensus on the advantages of involving a palliative care multidisciplinary team to achieve effective symptom control, reduce caregiver burden, reduce hospital admissions, enhanced continuity of care, cost effective care delivery and compliance with patients' preference for place of death. Based on the results of the systematic review, and in the absence of an accepted model for palliative care delivery and integration, Siouta et al. (2016) developed framework of integrated palliative care which serves as a starting point towards the development of a generic model for malignant and non-malignant disease focusing explicitly on treatment, training and consulting.

2.3 Specialist and Generalist Palliative Care Services in an Irish

Context

Specialist palliative care services are those services with palliative care as their core speciality and which are provided by an inter-disciplinary team, under the direction of a consultant physician in palliative medicine. The Irish Government's commitment to this area of care was first reflected in the *National Health Strategy* in 1994, which recognised

the important role of palliative care services in improving quality of life (Department of Health & Children, 2001). It gave a commitment to the continued development of these services in a structured manner, in order to achieve the highest possible quality of life for patients and their families. The Minister for Health and Children established the National Advisory Committee on Palliative Care who had the responsibility for examining palliative care services in Ireland, results of which are found in the 2001 *Report of the National Advisory Committee on Palliative Care*. Palliative care can be delivered at different levels depending on the needs of the patient / family.

In Ireland, three levels of palliative care specialisation are recognised (Department of Health & Children, 2001). The three levels refer to the expertise of the staff providing the service, rather than the care setting:

1. Palliative Approach: Palliative care principles should be appropriately applied by all health care professionals. This level of palliative care ought to be practiced in all healthcare settings by all disciplines.
2. General Palliative Care: At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals, who although do not engage full time in palliative care, have had some additional training and experience in palliative care.
3. Specialist Palliative Care: These are services whose core activity is limited to the provision of palliative care. Such services are available through in-patient specialist palliative care units (hospices), specialist palliative care homecare teams, day hospices and specialist palliative care teams within acute hospitals.

2.4 Palliative Care for Non-Cancer Patients

It is anticipated that the need for palliative care services will increase in coming years given the increase in the global population of those over 65 years living longer. Traditionally palliative care in Ireland was confined to a limited number of illnesses; namely cancer, Human Immunodeficiency Virus, Acquired Immune Deficiency Syndrome and some neurological illnesses such as Motor Neuron Disease, with 95% of Irish people receiving specialist palliative care having a cancer diagnosis (O’Leary & Tiernan, 2008). The number of people dying from cancer is expected to rise in future years, due to the ageing population. In recent years however, it is acknowledged that patients with other life limiting illnesses (non-malignant conditions) can also benefit from palliative care.

In a systematic review of end of life symptoms, there is evidence of considerable symptom burden across many illnesses at end of life (Solano, Gomes & Higginson, 2006). The Irish Hospice Foundation (IHF) (2008) published a report *Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks* examining the need to expand palliative care to a wider population group, with particular emphasis on those living with chronic obstructive pulmonary disease, heart failure and dementia. The number of patients with multiple sclerosis, motor neuron disease and similar disorders are small, but these diseases have a much longer trajectory of illness towards death than many of the cancers. It has been estimated that the inclusion of non-malignant (non-cancer) patients within the scope of specialist palliative care services at least doubles the need for specialist services, therefore strengthening the case for greater palliative care services both in an acute capacity and in the community.

In determining the need for specialist palliative care services, other population groups with particular needs should also be considered. These include people with intellectual, physical and sensory disabilities, prisoners and intravenous drug abusers to name a few who all possess particular needs in relation to health care (Tuffrey-Wijne et al., 2003; Wagemans et al., 2010; Rowley et al., 2011; Turner, Payne & Barbarachild, 2011; Tuffrey-Wijne et al., 2016). The needs of these groups should be addressed by each Health Service Executive area when planning the future delivery of specialist palliative care services. Ethnic and cultural diversity is now a demographic reality within most western societies and cannot be ignored by specialist palliative care services (McQuillan & Van Doorslaer, 2007; McQuillan, 2011). Palliative care professionals have a duty of care to recognise and facilitate cultural difference.

Nurses working in palliative care play a key role as a member of the multidisciplinary team. Palliative care nurses require a comprehensive understanding of the experience of end of life care for patients and the family unit, and skills to address the psychological, spiritual, social, cultural, physical and developmental needs that may arise. The publication of international and national reports and guidelines on palliative care provision such as the WHO (2008) *The Global Burden of Disease*, National Institute for Health and Clinical Excellence (NICE) guidelines (2006, 2007, 2011, 2014), Department of Health and Children (2001) *Report of the National Advisory Committee on Palliative Care*, the IHF (2008) *Palliative Care for All: Integrating Palliative Care into Disease*

Management Frameworks, the NHS (2010) *National End of Life Care Programme* and the Health Services Executive *National Clinical Programme for Palliative Care* (2010) facilitates providing expert care encompassing all people in society who require specialist palliative care to assist them to die better.

2.5 The Unmet Palliative Care needs of those Dying with Dementia

People with end stage dementia require specialist end of life care to improve comfort and quality of life (Nazarko, 2009). The World Health Organisation (WHO, 2002) defined palliative care as

“an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems”.

WHO Europe (2004) further states that every person with a progressive illness has the right to palliative care. National Institute for Health and Clinical Excellence (NICE) guidelines (2013) recommend that people with dementia receive palliative care from the time of diagnosis to the point of death. The approach to treatment advocated by NICE aims to improve and enhance the individual’s quality of life and allow the person to die with dignity in an appropriate environment. NICE recommends that palliative care is holistic, meeting the physical, psychological, social and spiritual needs of the person with dementia. There is an emphasis on adopting a person-centred approach to care, involving the individual with dementia, their views on treatment options and care provision while the person still has the ability to make decisions and communicate effectively (NICE, 2013).

In Ireland, a report commissioned jointly by The Irish Hospice Foundation and The Health Services Executive (2008) entitled ‘Palliative Care for all – Integrating Palliative Care into Disease Management Frameworks’ assert that it is imperative that an integrated, co-ordinated and person centred model of service provision is provided to those with dementia which is flexible to adapt and respond to the changing needs of the individual. Each person with dementia will have their own complex and unique experience of the disease. This report also highlights the need for education and training for families who provide care and timely palliative care provision. Recognising the need for palliative care

in dementia, the European Association for Palliative Care (EAPC) commissioned a research-based position paper producing the first evidence based consensual definition of palliative care in dementia (van der Steen et al., 2013). In identifying research priority domains important to palliative care in dementia, this white paper presents a framework to provide guidance for clinical practice, policy and research in the provision of palliative care in Europe and elsewhere (van der Steen et al., 2013).

2.5.1 Obstacles to Accessing Palliative Care for those with Dementia

A plethora of literature exists advocating that people with dementia should have access to palliative care and hospice services (Mitchell et al., 2007; Birch & Draper 2008; Shega et al., 2008; Treloar et al., 2009; van der Steen, 2010; deVries & Nowell, 2011). However, it is clear from the literature that many people with end stage dementia do not receive adequate or appropriate end of life care for a number of reasons; end stage dementia is difficult to diagnose and dementia is often viewed as part of the natural ageing process (Phillips et al., 2011; Brown et al., 2013; Illiffe et al., 2013). Furthermore, there is a lack of education of the dementia disease process itself and the ability to identify complications which are encountered at end stage dementia by health care providers, families and carers (Brodaty et al., 2003; Shega et al., 2003; Chang et al., 2005; Birch & Draper, 2008; Barber & Murphy, 2011; Illiffe et al., 2013).

As well as additional complications of bowel and bladder incontinence, pyrexia, infections and decubitus ulcers, terminally ill dementia sufferers have multiple complications with as high as 91% having a co-morbid condition (Moss et al., 2002; Mitchell et al., 2007). Co-morbidities complicate the clinical picture and may create a need for palliative care at any stage of the dementia process, since most people die with dementia rather than from it (Brunnström & Englund, 2009). The evidence base to guide practice with those dying with dementia is less well developed, although is now evolving (Boogaard et al., 2013; Illiffe et al., 2013; van der Steen et al., 2013). Gove et al. (2010) in association with Alzheimer's Europe established practical and consensual recommendations for end-of-life care of people with dementia. The aim of their recommendations is to provide a basis for understanding and action with regard to end-of-life care not only for family caregivers but also for professionals, policy makers and anyone with an interest in palliative care.

Access to hospice and palliative care is also an issue for dementia sufferers. A retrospective case note audit of end of life care for people with dementia in an acute hospital setting conducted by Sampson et al. (2006) found that dementia patients received significantly fewer referrals to specialist palliative care and less palliative medication than cancer patients, despite research indicating that symptom burden in those with advanced dementia and those with cancer was comparable (64% of dementia patients experienced pain and 57% loss of appetite) (McCarthy et al., 1997).

Similarly, Afzal et al. (2010) examined 75 clinical case notes of people aged over 65 years who had died in an Irish hospital within a six-month period revealing that 18 patients were recorded as having dementia, 32 were documented as not having dementia while the remaining 25 patients notes did not specify cognitive status. Findings revealed that dementia patients were less likely to be referred for palliative care, have carer involvement in decision making, or receive palliative medication and suggested that those with dementia may be receiving different end of life care to those who are cognitively intact (Afzal et al., 2010).

A UK study by de Vries & Newell (2011) audited internal case notes of patient admissions to one UK hospice. The hospice admission policy was inclusive of all terminally ill patients including those suffering from non-malignant disease; however of the 288 case notes audited, only 9% of hospice patients had a primary diagnosis of dementia or suffered from dementia as a co-morbidity to another terminal condition. Hospice referrals came from GP's (13), hospitals (12) and community matrons (2). The figure of 9% is much higher than found in earlier studies by McCarthy et al. (1997) and Houttekier et al. (2010) but is more consistent with the US data which is currently around 11% of hospice admissions (Mitchell et al., 2010).

The problem of variable quality of palliative care is particularly, although not exclusively, evident in community settings such as care homes (long term care facilities) and primary care services (Lawrence et al., 2011). A pan-European study found a similar pattern across Europe (Piers et al., 2010). Access to palliative care services and social support are two factors (alongside environmental and material resources) that determine whether older people with dementia can remain living in their own homes at the end of life (Rolls et al., 2011) or necessitate hospital / long stay care admission.

2.5.2 Difficulty Diagnosing Dementia and End of Life Dementia

Early diagnosis of dementia by physicians is imperative for contact with specialist services to be initiated so that timely decisions about treatment and preferences can be made. However, between 28% and 42% of general practitioner's report difficulty disclosing a diagnosis of dementia (Downs et al., 2002; Cahill et al., 2012). As dementia progresses the person's cognitive and communication abilities decline making it more difficult for lay and professional carers to ascertain accurately the wishes and needs of the person with dementia. Koch & Iliffe (2010) identified that dementia is not diagnosed in time and there is a reluctance to diagnose dementia due to diagnostic uncertainty, fear of labelling or stigma within families or the community, lack of support, time and financial constraints. Identifying dementia as a progressive terminal illness allows those with dementia and their carers to consider palliative care approaches more readily and at an earlier stage (Mitchell et al., 2004; Aminoff & Adunsky, 2006; de Vries & Nowell, 2011).

From a qualitative exploratory study conducted by Goodman et al. (2010), it was seen that the transition from living to actively dying for people with dementia can be protracted, and this uncertainty affects how preferences and priorities are discussed, by whom and when, and whose opinions carry the most weight. There can be an imbalance between the individual's perspective, the system of care they are in, for example a nursing home, and wider systems that provide end of life care (Froggatt et al., 2011). The difficulty to identify those at high mortality risk underlines the need to consider the possibility of death with dementia even in the earlier or mild stage of the disease (van der Steen et al., 2013).

A mixed methods research study by Brown et al. (2013) was conducted to develop, deliver and evaluate a training programme in care homes to enhance the quality of care for people with dementia based on the principles of relationship centred care expressed through a senses framework. In order to provide high quality care to people with dementia, including the appropriate level of palliation,

“it is essential to identify and develop validated, reliable, sensitive, and accurate prognostic tools that can be used to identify end-stage dementia and that allow for advance preparation and planning” (Brown et al., 2013, p.390).

Clinical prognostic indicators for end of life care are tools which help provide a guide to estimating when a person with advanced disease is in the last six months or year of life. When interpreted as part of the holistic assessment, it can assist to alert health and social care professionals identify when a patient may require end of life care. CPI's are advocated within the Gold Standards Framework (Thomas, 2000) and are also included within generic standards for palliative care. In addition, they are useful in understanding disease trajectories and can help predict how needs may develop over time.

A US study using data from a Minimum Data Set (June 1, 1994, to December 31, 1997) to identify persons 65 years and older who died within 1 year of admission to any of the 643 New York State nursing homes revealed that only 1% of patients with advanced dementia admitted to a nursing home, were perceived by staff being at end of life with a life expectancy of less than six months, yet 71% died within that six-month period (Mitchell et al., 2004). Tools to improve mortality predictions have been developed for and validated in patients with advanced dementia (Mitchell et al., 2010; van der Steen et al., 2010). Potter et al. (2013) conducted a systematic review of policy, guidelines, publications and position documents aimed to identify evidence based signs and symptoms of end stage dementia. From this review, eight signs and symptoms associated with worsening function and increased mortality were identified and incorporated to develop the REACH toolkit to assist staff to identify people with dementia who were at end of life allowing for a palliative approach to care to be implemented.

Specific prognostic markers for advanced dementia, focusing on a life expectancy of six months have been developed and are based on scales which have attempted to classify the progression of dementia into stages such as the Global Deterioration Scale (Reisberg et al., 1982) or the Functional Assessment Staging Test (FAST) scale (Reisberg, 1988). A recent systematic review by Brown et al. (2013) attempted to identify accurate prognosticators of mortality in elderly advanced dementia patients. Seven studies met their inclusion criteria, five of which were set in the US and two in Israel. Methodology and prognostic outcomes varied greatly between the studies. All but one study found that Reisberg's (1988) Functional Assessment Staging (FAST) scale, widely used to assess hospice admission eligibility in the US, was not a reliable predictor of six-month mortality. The most common prognostic variables identified related to nutrition or eating habits, followed by increased risk on dementia severity scales and co-morbidities. Brown et al. (2013) conclude that although the majority of reviewed studies agreed that the

Functional Assessment Staging (FAST) scale criterion was not a reliable predictor of six-month mortality, a lack of prognosticator concordance across the literature exists.

2.5.3 Care Pathways for those with Dementia

Palliative care for people with dementia is less well systematized (in the sense of having structured care pathways) than that for people with cancer and the evidence base to guide practice in palliative and end of life care for people with dementia is limited (Iliffe et al., 2013).

Integrated care pathways set out steps in the care of patients with specific conditions and describe expected progress of the patient as their condition advances. Care pathways aim to support the integration of clinical guidelines into clinical practice while also promoting better communication with the patient by giving them information about their care which is planned and progressed over time. Integrated care pathways have assisted in the management of chronic conditions but there is a need to recognise palliative care and end of life care as a unique and ultimate period within a person's pathway of care. Palliative care should be integrated within the patient's care pathway so that their care is planned and seamless.

Specific integrated care pathways and programmes were developed and implemented in the UK for patients who are approaching end-of-life such as the Gold Standards Framework (Thomas, 2000) and the Liverpool Care Pathway for the Dying Patient (Marie Curie Palliative Care Institute, 2001). The Gold Standards Framework is a systematic evidence-based approach to optimising the care for patients nearing the end-of life in the community and care homes, so that people are enabled to live and die where they choose. The Liverpool Care Pathway was developed as a mechanism for dying patients, and their relatives and carers, to receive a high standard of care in the last hours and days of life. The Liverpool Care Pathway was originally developed by the Marie Curie Palliative Care Institute in Liverpool for cancer patients in the acute environment, but was adapted for use in all generic care settings irrespective of diagnosis (Ellershaw & Wilkinson, 2011). It encouraged a multi-professional approach to the delivery of care that focused on the physical, psychological and spiritual comfort of patients and their relatives, and had been implemented by both non-specialist and specialist palliative care providers (Ellershaw, 2007). However, in 2012, the Liverpool Care Pathway received serious media criticism, highlighting reports of bad practice and professional concerns, mainly regarding

hydration of dying patients, possible hastening of death, and consent and communication issues (Watts, 2013). An independent review into the use of the Liverpool Care Pathway in the UK recommended that the Liverpool Care Pathway be replaced by a personalised end-of-life care plan backed up by disease-specific good practice guidance (Neuberger et al., 2013).

According to Shipman et al. (2008) there is a need to define good practice, and more needs to be known about the context of provision. A generic model for palliative care in dementia, suitable for use in different health and care systems as a guide to service quality is required, for appropriate outcomes to be identified, so that good care can be characterized in terms of quality indicators and benchmarks and the effects of interventions can be measured (Iliffe et al., 2013). Iliffe et al. (2013) devised one such generic model of palliative care for people with dementia which captures commonalities and differences across Europe (IMPACT project). The model includes features deemed important for the systematisation of palliative care for people with dementia, which are: the division of labour amongst practitioners of different disciplines; the structure and function of care planning; the management of rising risk and increasing complexity; boundaries between disease-modifying treatment and palliative care and between palliative and end-of-life care; and the process of bereavement. The model of palliative care for people with dementia has placed the person needing palliative care within a landscape of services and professional disciplines (Iliffe et al., 2013).

NICE (2014) quality standard for supporting people to live well with dementia guideline outlines a palliative care pathway for people with advanced dementia and emphasises the need for the adoption of a palliative care approach from diagnosis until death to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing. Palliative and end of life care pathways are informed by the regional community facing model which when implemented effectively supports the delivery of quality palliative and end of life care.

2.5.4 The Concept of a 'Good Death' in Dementia Care

At the heart of palliative and terminal care lies the concept of a 'good death'. One of the primary outcomes of end of life care should be the experience of a good death by the patient and the family. Efforts have been made to conceptualise a good death; however, literature suggests that no one definite, clear, shared understanding of what constitutes a

good death exists. It is based on the idea that a good death is not a single event, but a series of social events (Kendall et al., 2007). Closely related concepts such as quality of life at end of life, quality of care at the end of life, and quality of dying cause confusion (Kehl, 2006).

A grounded theory approach to analyse interview data from 32 men and 2 women with advanced AIDS was used by Pierson et al. (2002) and identified a number of major domains defining a good versus bad death. The concept of a good death is highly individual and dynamic, and can be dictated by faith or culture. Some feel that death while sleeping is preferable, while others prefer to be awake and alert at the time of death (Pierson et al., 2002). This example of contrasting opinions of a good death echoes research findings that what one person considers a good death, may be in complete opposition to another. This suggests that clinicians and caregivers should consider the wishes and opinions of the patient and family as to what they consider a good death, and caution must be emphasised to clinicians and caregivers ensuring that their own perceptions of a good death does not bias or overpower the opinions of the patient and family.

A plethora of qualitative research has been conducted in an effort to conceptualise a good death for terminally ill patients (Seale, 1991; Steinhauser et al., 2002; Tong et al., 2003; Beckstrand et al., 2006; Kehl, 2006; Rietjens et al., 2006; Miyashita et al., 2008) however due to the complexity and vulnerability of these participants, experiences of families and caregivers on this topic tend to appear more frequently in the literature (Morita et al., 2002; deWolf Bosek et al., 2003; Teno et al., 2004; Shiozaki et al., 2005; Papastavrou et al., 2007; Sampson, 2011; Lee et al., 2013; van der Steen et al., 2013).

Vig et al. (2002) described good deaths as being pain free, dying in one's sleep, quickly, without suffering, and without knowledge of impending death. Bad deaths were characterised as being in pain, having a prolonged course of dying and being dependent on others. However, numerous studies suggest that a high proportion of patients at end of life die in pain (Steinhauser et al., 2000; Vig et al., 2002). Moreover, an abundance of literature exists to demonstrate that pain is undiagnosed and untreated in patients with dementia (Martin et al., 2005; Herr et al., 2006; Sampson et al., 2006; Horgas, 2007; Husebo et al., 2008; Barber & Murphy, 2011).

An encouraging meta-analysis Dutch study (patient data from three studies; two after death and one partly prospective) by van der Steen et al. (2013) reported possible trends in families' evaluations of the quality of end-of-life care and the quality of dying in dementia. Individual patient data of 372 residents with dementia in 38 nursing homes and 13 residential homes over the period 2005-2010 was analysed. Outcome measures were the End-of-Life in Dementia-Satisfaction With Care scale (EOLD-SWC; range: 10-40) to assess quality of, or satisfaction with, end-of-life care, and the EOLD-Comfort Assessment in Dying scale (EOLD-CAD; range: 14-42) to assess quality of dying (comfort). Findings revealed positive trend of increased satisfaction with end-of-life care. Families of those with dementia at end of life reported a possible increase in residents' end-of-life comfort and the emotional support provided for families and families reported lower levels of emotional distress in residents. van der Steen et al. (2013) suggest that ongoing surveillance of outcomes measuring end-of-life quality is important in view of the increasing healthcare budget constraints, which is a universal issue, which has a knock on effect on care provision.

Several authors have linked a good death to the place of death (Low & Payne, 1996, Payne et al., 1996; McNamara, 2004; Semino et al., 2014). When addressing the needs of the terminally ill, it is important to identify where people die and where people choose to die. McNeil (1998 p.6) presented a very balanced view of whether home deaths should always be held up as the gold standard for a good death, wisely stating that it 'matters less where we die, than how we die'. While the choice of where a person dies is an individual one, ultimately, there has to be resources available to allow that decision to be taken.

This is echoed by Vig et al. (2002) whose descriptive qualitative research findings reported that the location of preferred death was irrelevant, however what was clear was that patients' preferences for end of life care need to be established from the patient themselves from an early stage in order for a good death for the individual to ensue. This is particularly pertinent in the case of people with dementia. Difficulties arise as the disease advances and the person's cognitive and communication abilities decline making it more difficult for informal and professional carers to ascertain accurately the wishes and needs of the person with dementia. Health care professionals need to be more proactive in initiating early discussions around care planning and specifically advanced care planning to ensure that the needs of those with dementia are met (Burns, 2005). Advance care planning allows for improved communication and shared decision making,

reducing unnecessary hospitalisation, the use of burdensome interventions such as tube feeding, and parenteral hydration in advanced dementia (Hertogh, 2006) which also facilitates discussion around place of death with the person with dementia.

In Ireland, The Irish Hospice Foundation (2011) launched their ‘Think Ahead’ programme to encourage people to *think* about important issues; *talk* to others about them (family, GP, etc) and *tell* key people in their lives about their decisions and preferences in relation to these matters. This method of advanced care planning is vital in the case of those with dementia so that their treatment and care preferences are adhered to at end of life. It must be noted however, that Ireland has no legislative provision for advanced care planning at this time.

The increasing requests from patients and families to die at home has put considerable responsibility and pressure on primary care and palliative care teams, as the patient and their family depend on their support and management of the final stages of the patient’s life. With national and international publications such as Palliative Care for all (IHF, 2008), End of Life Care Strategy and NICE quality standards for supporting people to live well with dementia and end of life care for adults (NICE, 2011; 2013) endorsing and supporting this initiative, more and more patients are being afforded the opportunity to die at home. Effective guidelines such as the Gold Standards Framework (GSF) assists to optimise care provision and fulfil the wishes of patients nearing end of life through improved communication and advanced care planning (Tapsfield, 2006). However, Shaw et al. (2010) caution that its use is variable and the direct impact on patients and families of the Gold Standards Framework, especially where dementia is present, is not yet known.

Exley & Allen (2007) reconceptualised data generated from three research projects, each concerned with dying, death and bereavement in the community. In a critique of “home” as the preferred place for end of life care, they observed that “home” is not merely about physical space but the social and emotional relationships that are experienced there. The need for meaningful relationships, purpose and feeling safe for people with dementia in long term care settings at the end of life are known (Birch & Draper, 2008; Hall et al., 2009; Ryan & Nolan, 2009). Goodman et al. (2010) concurs with this with residents in a care home in the UK identifying that relationships made them feel at “home”.

Several studies have examined the experience of dying with dementia in a nursing home or residential care setting from the family member or health care professional's perspective. deWolf Bosek et al. (2003) interviewed 57 family member caregivers of a person with Alzheimer's disease whose loved one had died in a US nursing home. Despite the fact that the family member reported their loved one died with dignity, 28% believed that their family member had not experienced a good death. Family members cited a good death as one that conformed to the patient's preferences regarding when and where to die, if the death had occurred with the patient being comfortable, or if the experience by the family member of the dying process was a positive one. deWolf Bosek et al. (2003) highlighted some proactive recommendations to improve the quality and process of the death. These include aggressive pain and symptom management, provision of information for family on the signs and symptoms of the anticipated death, maintaining familiar surroundings, providing accommodation for family presence, and an examination of family and caregiver's attitudes, beliefs, and expectations about death.

More recently Goodman et al. (2010) explored the end of life preferences and priorities of people with dementia residing in a nursing home in the UK. Findings from this integrated review which synthesised qualitative and quantitative evidence on end of life care, revealed that place of death was not a priority for these residents, but the relationships formed with the people around them made them feel at "home". Living and dying with dementia extends beyond any physical care needs and decisions about preferred place of care and according to Moriarty et al. (2012), the challenge is how to develop practice and processes that reflect the fact. Goodman et al. (2010) emphasise the necessity of documenting the end of life priorities of people with dementia at an early stage, as early as on admission, and for this discussion to be ongoing in order to facilitate the wishes and needs of this person with dementia at end of life.

Despite a plethora of literature available highlighting the palliative care needs of people with dementia, it is clear that adequate or appropriate end of life care is not received by this vulnerable group. While great strides have been made to improve dementia palliative care, they still receive fewer referrals to appropriate palliative care services. While excellent end of life care is attainable, greater efforts are required of healthcare staff to firstly recognise dementia as a terminal illness, to initiate the dialogue on end of life care at an early stage of the illness allowing the individual to take the lead on determining their own wishes and preferences of care. A good death with dementia according to Lawrence

et al. (2011) is being pain free and being surrounded by those closest to the person with dementia; these are not unachievable or particularly technical goals but necessitate effective communication, cooperation and coordination by health professionals. With reference to the increasing number of people who will require care as they die with dementia, service models to improve care must be adopted and implemented carefully, taking into account the variety of settings in which people with dementia die, as well as cultural, staff, organisation and budgetary factors, with due consideration to what may work best for whom and in what circumstances (Sampson et al., 2011). Implementing a palliative approach to dementia care facilitates in the appropriate identification of any unmet needs of people with dementia while also promoting a continuum of care focusing on quality of life and values the uniqueness of the person (IHF, 2013).

2.6 End of Life Experiences for Carers of People with Dementia

Sweeting & Gilhooly (1997) pioneered the application of the constructs of ‘anticipatory grief’ and ‘social death’ to the process of caregiving and dementia. According to Blandin & Pepin (2017), pre-death grief experienced by dementia family carers is uniquely termed ‘dementia grief’ which is a specific form of anticipatory grief expressed in response to compounded serial losses of varying significance and evidenced by the ambiguity which characterises the experiences of loss in dementia. Ambiguous loss occurs as a result of a carer’s inability to identify personality characteristics or personal memories which lead to experiences of ambiguity in family members whereby the person with dementia does not appear to be emotionally accessible or the same person (Sanders & Corley, 2003; Large & Slinger, 2015; Blandin & Pepin, 2017). Many carers experience profound pre-death grief similar to post death bereavement as a consequence of experiencing the loss of the person they formally knew (Large & Slinger, 2015). This paradoxical disconnection between the psychological and physical losses, captures the crux of ambiguity in the receding of the known self in dementia grief (Blandin & Pepin, 2017). Pre-death grief occurs as a result of the physical and psychological response to the perceived losses in a loved one with dementia (Lindauer & Harvath, 2014). Significant losses are experienced by carers before physical death experienced as compounded serial losses (Chan et al., 2013; Santulli & Blandin, 2015) which increase in size and number as the disease advances.

Whatever term is used, carers generally consider the person’s death as a relief (McColgan, Valentine & Downs, 2000; Shanley et al., 2011; Chan et al., 2013; Raymond et al., 2014)

in contrast to general literature on bereavement (Bass & Bowman, 1990; Sharpe et al., 2005). In general, carers of people with dementia require greater emotional support and respite care prior to the person's death than afterwards and the greater social support they receive pre-bereavement, the better adjusted they are post bereavement (Mullan, 1992; Almborg, Grafstrom & Winblad, 2000; Schulz et al., 2003). Such families face particular stresses in comparison to other caregiving groups and experience greater detrimental effects in terms of physical and mental health and social isolation. Support groups, training programmes, family based psychosocial interventions and specialist community care interventions have been designed to help each with differing outcomes and levels of efficacy at various stages of the care giving trajectory (Gitlin et al., 2001; Gitlin et al., 2010c; Kajiyama et al., 2013; Kwok et al., 2013; Tremont et al., 2015)

Greater exploration into end of life decision making, adequate preparation for their loved one's death, and measuring quality of life at end of life is required for family carers (Almborg, Grafstrom & Winblad, 2000; Schutz et al., 2003). Shock and devastation among carers after the death of the person with dementia is attributed with a lack of foresight (Collins et al., 1993). Appropriate information and intervention strategies should be provided throughout the care giving trajectory so that the end of life phase is demystified and feared less.

2.6.1 Ethical Issues at the End of Life

The unique aspect of ethical issues in dementia relates to the increasingly and unavoidable need for others to make decisions for the person with dementia. Decisions are based on evidence for the effectiveness of the particular action. However often decisions are complex because they involve clinical and ethical aspects. One such example involves artificial nutrition and hydration in dementia (Druml et al., 2016). The ethical principles of beneficence (an action to benefit others) and non-maleficence (do no harm) explicated by Beauchamp & Childress (1978) must be adhered to and employed in such cases. The decision to provide artificial nutrition and hydration is complex as it depends on the distinction between the person whose condition will lead to death at some stage and the person who is already moribund (Robinson, Clare & Evans, 2005).

In someone with dementia, the decision of how close to death the person is may not always be straightforward or apparent. Difficult decisions are often made in the context of conflicting clinical and ethical issues (Livingston et al., 2010). Family involvement is

paramount in ethical decision making especially at the end of life stage when complex ethical issues such as the administration or withholding of antibiotics or artificial nutrition and hydration may arise (van der Steen et al., 2002; Parsons et al., 2010). The principle of autonomy, which implies the ability and tendency to think for and to make decisions for oneself (Gillan, 2003), must be adhered to and a detailed discussion of how death comes about is required. Being cognisant of the person with dementia and their end of life preferences helps to justify decisions made and should encourage greater willingness to involve families in decisions concerning death and dying (Chan, 2004). This mirrors part of the palliative care approach and the philosophy of palliative care that family carers should be involved in decisions especially in dementia (Hedley & Hughes, 2004).

When it becomes unclear how to ascertain the person's autonomous wishes, carers are required to act in his / her best interests. In some countries certain legislation supports the use of advance directives which have been devised by the person with dementia while they were deemed cognitively able to make decisions about their future care (de Boer et al., 2011; van der Steen et al., 2014; Vandervoort et al., 2014). In addition to this, an enduring power of attorney may be nominated and arranged who would facilitate the person's next of kin or carer to take over power of affairs, and enables discussion for plans for the future (Harris, 2007; Dickson et al., 2013; Mullick et al., 2013). Even in the latter stages of dementia, the person should still be encouraged to make decisions about their care and requirements if cognition allows them to do so. A person's awareness or lack of awareness may be a function of the social environment they find themselves in.

Another issue at end of life which raises ethical questions is the provision or withdrawal of certain treatments such as antibiotic therapy (Parsons et al., 2010). Predictors may suggest in certain cases that antibiotic therapy is warranted and in other cases it may be withheld in people with severe dementia (van der Steen et al., 2002). The distinction between ordinary (usual nursing care) and extraordinary means of treatment (for example administration of artificial nutrition and hydration) needs to be understood in the case of someone with dementia (Parsons et al., 2010). The burden imposed by the particular treatment against the likelihood of benefits accruing to the person concerned has traditionally found to be useful (Hanrahan, Lutchins & Murphy, 2001).

What is noteworthy is that the value of the person concerned should be considered first but attention must be also given to the values of others involved (Robinson, 2004). Virtue

ethics focuses on the character of the moral agent as opposed to the correctness of an action (Gardiner, 2003). Practical wisdom as advocated by Burns (2005) is the sort of virtue or disposition commended by virtue ethicists as a means of dealing with moral dilemmas that arise at end of life. These virtues are acquired throughout experience and practice and requires that weight is put on the value of caring itself as an activity that demonstrates human flourishing. From this point of view, palliative care (with its acceptance of death) seems appropriate for people with severe dementia than the thought that their lives should be ended by either active or passive euthanasia (Post, 2000; Hughes & Dove, 2004). Regardless of the aforementioned, the ubiquity of clinical and ethical decisions at end of life in dementia necessitates specialised knowledge and skill (Robinson, Clare & Evans, 2005).

2.6.2 The Cost of Caring

Caregiving for a person with dementia at home financially saves the healthcare system and government hugely each year, however it comes at the price of high levels of distress among family carers, an increased risk for carers of psychiatric and physical disease and increased mortality (Schulz et al., 2003). Carers of family members with dementia face particularly stressful demands owing to the length of the period of care, the behavioural problems associated with dementia and the extreme impairment of people with end stage dementia.

A systematic review by Chiao, Wu & Hsiao (2015) contends that spouse caregivers and adult children caregivers experience higher levels of burden compared with other informal caregivers of people with dementia. Studies focusing on the issues of dementia care illustrate the burden family members bear, with common findings including risk of mental and physical illness, social isolation, stigmatisation, financial difficulties, stress and difficulty coping (Papastavrou, Kalokerinou, Papacostas, et al., 2007; Orgeta, Lo Sterzo, & Orrell, 2013; Corey & McCurry, 2018; Reily, Evans, & Oyebode, 2018). Despite these significant challenges, however, many carers report a genuine sense of achievement, satisfaction and pride in their role (Roth, 2015; Lloyd et al., 2016).

In a systematic review of the literature, Hennings, Froggatt & Keady (2010) aimed to evaluate current knowledge about family carers' experiences and needs regarding end of life and dying in care homes for people with dementia. Three specific themes emerged from the literature: unfamiliar territory, making decisions, and the grieving carer. This

review by Hennings, Froggatt & Keady (2010) highlighted high levels of unmet needs for family carers. Carers found themselves in situations that they were unfamiliar with and unprepared for, without having adequate experience or knowledge. High levels of stress were reported by family carers in terms of difficult decision making at end of life for their family member with dementia. The personal needs of family carers were not addressed by medical or nursing staff, with family carers seeking effective communication, guidance and companionship from professionals.

Depression is a common condition found in informal caregivers (Dura, Stukenberg & Kiecolt-Glaser, 1991; Coope et al., 1995; Cohen, 2000; Lavertsky et al., 2013; Leggett et al., 2014) however caregivers of individuals with dementia report higher levels of depressive symptoms compared to non-caregivers but also compared to caregivers of physically impaired older adults (Joling et al., 2015; Corey & McCurry, 2018). Recent research also indicates dementia caregivers may be at higher risk of suicidal behaviour. A cross-sectional survey conducted by O'Dwyer et al. (2016) on 566 family carers, found one in six (16%) had considered suicide on more than one occasion in the past year, a rate more than eight times that of the general population (Pirkis, Burgess, & Dunt, 2000; Centres for Disease Control and Prevention, 2011). These rates, while slightly lower than their previous study (O'Dwyer, Moyle, et al., 2013), are still more than four times the annual rate of suicidal ideation in American and Australian adults (CDC, 2011; Pirkis et al., 2000) and exactly four times the rate reported in a population study of non-dementia carers in the UK (Stansfield et al., 2014).

A systematic review conducted by Cuijpers (2005) found that almost half of caregivers suffer from a depressive disorder within one year. In addition, Joling et al. (2010) estimated from their cohort study that spouses of individuals with dementia were four times more likely to suffer from depressive symptoms compared to spouses of people without dementia. There is a need to identify high risk groups in an effort to prevent or minimise the incidence of depression in caregivers to target preventative efforts effectively (Beekman et al., 2010). Failing to achieve this results in a poor quality of life for the caregiver and provision of a lower standard of care to the dementia sufferer.

Joling et al. (2012) set out to identify target groups for the prevention of depression among caregivers of people with dementia in their randomised control trial. Non-depressed caregivers (n=725) were screened and monitored for depressive symptoms

using the Centre for Epidemiologic Studies – Depression Scale (CES-D). Findings reported that targeting people with some signs and symptoms but no disorder is the most effective strategy to prevent the onset or development of full blown disorder and may offer a good starting point for preventive efforts. Cuijpers et al. (2008a) also demonstrated that prevention programmes are a useful method of reducing the incidence of depression in various target populations and settings. Joling et al. (2012) also found poor self-rated health to be a strong predictor of incident depression in caregivers. This risk indicator is well documented in existing depression literature (Beekman et al., 1995; Cole & Dendukuri, 2003). Race or ethnic differences did not yield conclusive or significant findings possibly due to cultural norms regarding family care. Finally, no patient related indicator or indicator relating to specific care giving was discovered relating to the onset of depressive symptoms (Joling et al., 2012).

A systematic review conducted by Allen et al., (2017) examined the psychological burden associated with caring for a person with dementia. Literature pertaining to cognitive and biomarkers of chronic stress in informal dementia caregivers was evaluated in the review, the results of which highlighted an increase in cortisol levels in this cohort, poor performance on attention and executive functioning tests and mixed evidence for memory functioning. While stress reduction interventions were seen to enhance cognitive functioning, it had mixed effects on cortisol.

It is commonly assumed that carer depression, stress and other health related problems resolve spontaneously after the person with dementia dies and the role of caregiver ceases. However, a recent qualitative study revealed that the long term effects of caregiving persist well after the initial post-caregiving period. Former caregivers of people with dementia experienced ongoing sleep disturbances, adverse alterations in health status and the challenges of learning to adapt to life pre-caregiving (Corey & McCurry, 2018).

2.7 The Needs of Carers of those with Dementia

Empirical studies have demonstrated that little information is provided by healthcare professionals to carers at the time of diagnosis (Carpenter & Dave, 2004; Robinson, Clare & Evans, 2005). The NICE (2007) guideline on supporting people with dementia and their carers' in health and social care, recommend that the educational needs of carers should be addressed using a variety of interventions including peer-support groups with

other carers, individual or group psycho-education, specifically focusing on the needs of individual carers depending on the stage of dementia of the person receiving the care. Additional recommendations include education about dementia, benefits and services, and communication and problem solving while caring for a person with dementia.

There is a need for individualised educational and support programmes for carers to learn positive coping strategies and manage the care of the person with dementia at the time of diagnosis (Beinart et al., 2012). A systematic review of randomised control trials (Olazaran et al., 2010) suggests that individually tailored interventions effectively reduce caregiver burden. Caregivers without adequate preparation for the role experience low self-confidence and feelings of guilt if not providing the required care to the person with dementia, which increases caregiver stress (Given & Reinhard, 2017).

Carers vary considerably how they interpret and respond to information about dementia. Cognisance should be given on carers' preferences for information and how this information is delivered. Demiris, Parker & Wittenberg-Lyles (2011) suggest that 'patient portals' are a method of supporting care and disseminating information to caregivers. Using online support groups and communication with healthcare professionals provides a virtual support network to carers in their own home. Developing online educational packages for carers is another strategy to assist carers receive vital information without having to leave their home (Beinart et al., 2012; Gallagher-Thompson et al., 2012; Given & Reinhard, 2017).

In an effort to reduce care-giver burden, effective communication between the primary carer, family members and healthcare professionals is required to facilitate shared decision making and advanced care planning (Given & Reinhard, 2017). These discussions should occur in the early stages of the disease, which will allow the person with dementia be part of the discussions and decisions made and agreed upon before unexpected changes occur. While it is important to identify who will be the primary caregiver, all family members should be involved in care giving, offering practical support and respite when required. Receiving emotional support from family members enhances caregiver well-being, self-efficacy, and life satisfaction as well as reducing symptoms of depression (Gallagher-Thompson et al., 2012). It is noteworthy that not all carers seek support from family members as often their unwelcomed support may be more stress inducing than helpful (Brodaty & Donkin, 2009).

Carers acknowledge the need for self-care, however without financial assistance and support to take over the care giving role, carers are forced to restrict time with family and friends and sacrifice hobbies and leisure pursuits, all of which contribute to feelings of social isolation (Brodaty & Donkin, 2009). Healthcare professionals need to address not only the needs of the person with dementia, but also the self-care needs of caregivers (Nielsen et al., 2016; Kramer & Boelk, 2015). This can be achieved by offering supportive care and making referrals to appropriate community services (Given & Reinhard, 2017).

2.8 Methodological Issues

This literature review revealed that the majority of reported studies had adopted a quantitative research design. The most common data collection methods included case note audits, systematic reviews and randomised control trials. Some qualitative research was reported which mainly consisted of descriptive research designs utilising interviews and focus groups to collect data. Also noted were a small number of studies adopting mixed method designs.

Most of the research focusing on caregiving was conducted with former carers who had previously cared for a family member at home but no longer did so due to the person with dementia now being cared for in a long stay care facility. There was a notable absence of Irish research pertaining to the topic under investigation.

The apparent dearth of qualitative Irish studies particularly employing a phenomenological approach was evident which led to the selection of interpretative phenomenological analysis (IPA) as the methodology of choice for this research. Adopting a phenomenological approach would result in a deeper understanding carers' experience of providing care to a person with dementia in the home.

2.9 Conclusion

This chapter described a range of areas related to end of life care for people with late stage dementia. The prevalence of dementia internationally and nationally, the cost of care in Ireland and informal caregiving in the community have been discussed. The chapter also presented an overview of palliative care and how this service provision has evolved to meet the needs of malignant and non-malignant patients, as well as

highlighting the difficulties associated with caregiving for this cohort of patients. The unmet palliative care needs of those dying with dementia were identified. The chapter concluded with a presentation of international literature related to specific issues carers face when providing care to people with dementia and their distinctive needs required to carry out this role. However, an absence of research examining the experience of providing care in the home and an absence of research from an Irish context, presents a rationale for this study to be undertaken.

3. Philosophical Underpinnings for Methodological Decisions

3.1 Introduction

According to Creswell & Creswell (2017) there are three essential elements which a researcher must include within a research framework; the paradigm, the research strategy and the research methods. This chapter examines a number of research paradigms in detail. A rationale for the selection of interpretivism will be presented describing how the paradigm fits with the chosen research method. The subsequent chapter examines the research strategy, data collection methods and analysis which provides a justification for the overall research framework.

3.2 Research Paradigms

Academic research stems from a philosophical tradition of systematic knowledge development, the underlying premise of which is that any knowledge claim is only defensible within a wider set of assumptions about the nature of reality (Denzin & Lincoln, 2008). Bordage (2009) contends that the conceptual framework within a study dictates, whether you are aware of it or not, what you choose to do and how you interpret your outcomes and results. According to Reeves et al. (2008) this is also true for the research paradigm, which is itself a grand theory. The term paradigm was first conceived in 1970 by Kuhn to describe a “heuristic framework for examining the natural sciences and disciplinary matrix for social sciences” (Weaver & Olson, 2006 p.460). Weaver & Olson (2006) highlight the confusion surrounding the clarification of paradigms for nursing research due to the lack of clarity between terms such as ‘paradigm’, ‘worldview’, ‘research tradition’ and ‘disciplinary matrix’.

Paradigms can simply be described as schools of thought (Parahoo, 2014) or a basic set of beliefs that guide action (Denzin & Lincoln, 2008). Paradigms influence the type of phenomena that should be researched, the methods by which they can be studied and the techniques by which data can be analysed and interpreted, which contributes to knowledge available for implementation in practice (Parahoo, 2014; Weaver & Olsen, 2006). In addition, paradigms assist to bridge the gap between the aims of a study and the methods by which to achieve those aims (Houghton, Hunter, & Meskell, 2012).

Paradigms are characterised by ontological, epistemological and methodological difference in their approaches to research and contribution towards disciplinary knowledge (Weaver & Olson, 2006; Welford, Murphy, & Casey, 2011). Ontology refers to beliefs about the nature of reality, epistemology focuses on the relationship between the researcher and what can be known or the nature of knowledge, and methodology refers to the nature of the approach to research or simply conducting research relative to the research question and context (Weaver & Olson, 2006; Denzin & Lincoln, 2011; Houghton, Hunter, & Meskell, 2012). It is noteworthy that the use of paradigms are essential for ensuring philosophical and ontological congruity of the research, however, the aims, paradigms and method of the research must also ensure epistemological and ontological integration. Many paradigms are recognised in nursing research, however Denzin & Lincoln (2011) describe six major paradigms: positivism, post-positivism, interpretivism, critical social theory, constructivism, and participatory action frameworks. Paradigms mainly used for nursing research are positivist, post-positivist, pragmatism, interpretive and critical social theory (Weaver & Olson, 2006).

3.2.1 Positivism and Post-Positivism

Positivism has influenced much health and social science research and began from a philosophy known as logical positivism based on the rigid rules of logic and measurement, truth, absolute principles and prediction (Parahoo, 2014). Positivists use reductionism to allow the researcher to reduce down complex phenomena into simple laws. These laws have the ability to precisely predict the probability of an event or phenomena occurring and test hypotheses (Young, 2008). Methodologically, positivists use scientific methods in their enquiry such as questionnaires and experiments to develop abstract theories which describe relationships in the physical world (Suppe & Jacox, 1985).

The goal of positivist research is therefore control and prediction (Weaver & Olson, 2006). Epistemologically, positivists believe that such laws can be uncovered for social phenomena (Parahoo, 2014), due to their ‘realist’ views of social phenomena. By taking an objective stance, positivists or realists have the ability to separate researchers from their object of inquiry, in other words, a separation exists between those who study reality and those who experience it (Welford, Murphy & Casey, 2011).

Post-positivism emerged after positivism in response to the realisation that reality can never be completely known and that attempts to measure it are limited to human comprehension (Weaver & Olson, 2006). Instead post-positivists believe that it is possible to get as close as possible to the truth, a position is known as ‘critical realism’, (Parahoo, 2014) but take the view that truth cannot be found with the means available to them. So while post-positivists agree with the positivist view that objective truth exists, they challenge the notion that there is absolute truth of knowledge (Phillips & Burbules, 2000).

Epistemologically, post-positivism is objective and knowledge is gained through replication, the goal of this type of research being control and prediction with theory being established deductively (Weaver & Olson, 2006). Unlike positivists, post-positivists realise that it is impossible to predict a social event with the same degree of certainty that natural scientists can with physical events. Post-positivists are more realistic and acknowledge the probable nature of predictions in social science. Research is focused on establishing correlations or relationships between variables instead of searching for cause and effect in the study of human and social behaviour (Parahoo, 2014).

Methodologically, post-positivists use controlled research methods, precise instrumentation and empirical testing and do not place strong emphasis on early design of strategies and methods. Researchers still aim to produce generalisable findings, however they take greater care as to how this is accomplished. Post-positivism acknowledges the fallibility of all measurement and emphasises the importance of multiple measures and observation (Houghton, Hunter & Meskell, 2012). Research questions are decided in advance, key terms are defined, data collection methods are selected before data collection takes place and data analysis is primarily quantitative in nature however some qualitative methods can also be utilised. A mixed methods approach to research would be congruent with the ontological and epistemological stance of this paradigm. It has been argued by Crossan (2003) that post-positivist research neglect the person as a whole and concerns itself with studying the parts instead however this is refuted by Schumacher & Gortner (1992) arguing that post-positive research does in fact attempt to address holism.

3.2.2 Pragmatism

Ontologically and epistemologically, pragmatism reflects a pluralistic emphasis on understanding the world and how research questions can be answered (Morgan, 2007; Tashakkori & Teddie, 2010). Pragmatism developed from a movement which advocated for the use of research approaches which include a combination of qualitative and quantitative methods. However instead of ‘mixing methods’, Kelly et al. (2016) caution that a ‘mixed methods’ approach should use common research designs which compliment research, thus creating a relationship based on a reciprocal partnership. In doing so, it acknowledges the separateness of conflicting opinions while also appreciating the beliefs, attributes and characteristics of both qualitative and quantitative methods (Armitage & Keeble, 2007). More importantly, by adopting this approach, pragmatism recognises the strengths of both approaches and reduces their respective weaknesses (Patton, 2015).

Pragmatists place importance on methodological openness (Patton, 2015) to address the intricacy of research reflecting innumerable real life challenges (Crewell, 2014). Thus pragmatists place emphasis on the various approaches, designs and methods they can select to satisfactorily answer their research question (Kelly et al., 2016).

3.2.3 Critical Social Theory

Critical social theory emerged as a result of the writings of Marx, Habermas and Freire and includes feminism, grassroots and emancipatory movements (Weaver & Olsen, 2006). It concerns itself with the study of social institutions, countering oppression, issues of power and alienation, redistribution of power, and envisioning new opportunities and resources (Gilles & Jackson, 2002; Weaver & Olson, 2006). Research becomes a means for taking action and a theory for explaining how things could be. Emphasis is placed on the process and not the product, with the desired focus being praxis or the combination of reflection and action which will effect transformation (Mill et al., 2016).

Prior to the early 1980s, critical social theory was rarely utilised as a philosophical orientation used to inform nursing science, nursing practice or the development of nursing theory (Boutain, 1999b). However, as interest grew in critical theory, the validity of empiricism as a historical foundation in nursing was questioned by nursing scholars (Browne, 2000). In addition, the limitations of interpretivism in developing nursing knowledge also came into question. Critical social theory was viewed as a preferable framework to expand the focus of nursing science on oppression, domination, political

conditions and power relations (Browne, 2000). This helped develop an emancipatory drive to nursing science, praxis and social action. The connection between emancipatory theory and action rooted in critical social theory were also viewed as a method of decreasing the theory practice gap in nursing (Heslop, 1997). An example of methods used in critical social theory nursing research include participatory action research.

3.2.4 Interpretivism

Interpretivism originated from the traditions of hermeneutics and phenomenology (Ryan, 2018) and emphasises understanding the meaning individuals ascribe to their actions and others' reactions (Weaver & Olsen, 2006). Mutual recognition between the researcher and participant is encouraged and valued (Ormston et al., 2014). Instead of truth finding, interpretivism concerns itself with the opening up of possibilities, and understanding is embedded in social interaction and the researcher's interpretation of the world (Todres & Holloway, 2006; Houghton, Hunter & Meskell, 2012). To advance beyond the data, meaning and interpretation are essential (Graneheim & Lundman, 2004; Rapport & Wainwright, 2006).

Interpretivism is concerned with truth being viewed from multiple perspectives and multiple realities that are holistic, local and specific (Welford, Murphy & Casey, 2011). Interpretivism finds itself in a relativist ontology as more than one truth exists and reality is socially and experientially based (Denzin & Lincoln, 2008). As a consequence, reality is unique and differs for each person. Epistemologically, it requires researchers to be subjective, reflexive and self-aware of the impact their personal perceptions may have an impact on the research. A paradox exists of how to develop an objective science from subjective experience (Denzin & Lincoln, 2011). This paradox can be overcome by denying the opposition of objectivity and subjectivity (Rabinow & Sullivan, 1987) as both subjectivity and objectivity can coexist. Theory emerges inductively with understanding and meaning found in the experience from multiple perspectives (Welford, Murphy & Casey, 2011).

Methodologically, interpretivism aims to capture participants' subjective experiences and interpreting data demands a deeper understanding of phenomena, therefore lending itself to qualitative methodologies (Shah & Corley, 2006), examples of which include phenomenology and hermeneutics.

3.3 Choice of Research Paradigm

After reviewing and considering the different paradigms in relation to their ontologies, epistemologies and methodologies, interpretivism was deemed the most suitable for the proposed research study. Positivism was discounted due to its methodological focus on rigid scientific enquiry using quantitative data collection and analysis methods. In addition, it was not the researcher's intention to test hypotheses or adopt a reductionist or determinist approach (Welford et al., 2011). While post-positivism attempts to respond to the criticisms of positivist research, it does so in a limited manner. Post-positivism was deemed unsuitable to use due to its use of controlled research methods, empirical testing and precise instrumentation (Denzin & Lincoln, 2008). It fails to recognise the 'whole' person by examining parts and neglects to explicitly demonstrate how the beliefs of participants are incorporated into the research process (Wahyuni, 2012). Both paradigms have shortcomings related to examining human experiences which makes these paradigms insensitive to a social phenomenon intrinsic in this study. Critical theory was also considered an unsuitable option for this study as it does not have an explicitly emancipatory or feminist aim.

While interpretivism was deemed the most suitable paradigm for this research, it must be acknowledged that the researcher was also influenced by a pragmatic philosophy. As previously discussed, pragmatism employs a mixed methods of research designs but also asserts that qualitative researchers need to use what they can at the time (Kelly et al., 2016). For example, it was the researcher's intention to conduct repeat interviews with carers who were actively providing end of life care to a family member with dementia at home and then to conduct a repeat interview six months after the person with dementia had died. However, for a number of reasons outlined in section 4.5.5 (Research Participants), repeat interviews were not feasible and did not take place. In addition, it was the researcher's intention to conduct only individual interviews with participants, however on two occasions, a couple dyad interview was conducted because the spouse of the caregiver also wanted to participate in the interview (see section 4.5.5 Research Participants). The qualitative researcher becomes a *bricoleur* who learns to borrow from many different disciplines or philosophies. The term *bricoleur* (Jill/Jack of all trades) was proposed by Denzin and Lincoln (1994) to reflect the characteristics of the qualitative researcher who had to be flexible, responsive and reflexive. The product of the *bricoleur's* labour is a bricolage, a complex, dense, reflexive, collage-like creation that represents the researcher's images, understandings, and interpretations of the world

or phenomenon under analysis. “This bricolage will connect the parts to the whole, stressing the meaningful relationships that operate in the situations and social worlds studied” (Denzin & Lincoln 1994, p.3).

Interpretivism enables the researcher to anticipate and reveal multiple, diverse interpretations of the reality of caring for a person with dementia as opposed to seeking to reveal an overarching ‘truth’. Interpretivism is associated with an interpretive effort to gather a range of in-depth accounts with the aim of building a detailed picture of how the phenomenon of caring is understood by the carers who have personal experience of it (Ormston et al., 2014). The phenomenon can be clarified and understood through interpretivism and an examination of how carers function in the real world can be illustrated.

A plethora of evidence exists, advocating a range of qualitative approaches to be used within interpretivism (Fish & Purr, 1991; Miller et al., 1994; Walker & Dewarb, 2000; Stahl, 2005; King & Horrocks, 2010; Ormston et al., 2014). As well as essentially valuing the diverse opinions and belief systems of individuals, it also emphasises the importance of context in gaining an understanding of the phenomenon under investigation. This means that a central part of the investigative process involves the researcher actively seeking to uncover the social, institutional, political and cultural context of end of life care for people with dementia in all its complexities (Parlett, 1981).

Within the interpretive paradigm, it is acknowledged that there are multiple realities which are always constructed within a context, and these realities are not fixed (Munhall, 2012). An interpretivist perspective therefore recognises that the ultimate truth or falsity cannot ever be established (Polit & Beck, 2008). According to the philosophy of interpretivist research, the role of the researcher is to interpret the world being investigated, and the objectivity and reliability of those interpretations reside in the distance maintained between the researcher and the focus of the investigation (Walker & Dewarb, 2000). There are, however, some reservations to make against such views. Myers & Avison (2002) caution that the word ‘qualitative’ is not synonym for ‘interpretive’ and that qualitative research may or may not be interpretive, depending on the underlying philosophical assumptions of the researcher.

3.3.1 Interpretivism in Qualitative Research

The aim of understanding an individual's subjective meaning is key in the interpretive paradigm. This was a dominant claim in the Verstehen sociology of Max Weber (1978): the postulate of subjective interpretation. Inspiration from phenomenology allowed Alfred Schutz (1970) to bring the Verstehen sociology further. He claimed that scientific knowledge (regarding social life) was of second-order character, which should have its basis on the knowledge and meanings of the research participants. Silverman (1971) explains the variation between social scientists and natural scientists being that they work with diverse realms. The natural world of matter is meaningless until the scientist imposes meaning-constructs upon it. Conversely, the social world of people is full of meaning, assembled on shared and subjective meanings. Silverman (1971 p.127) synopsis the differences stating that "social life, therefore, has an internal logic which must be understood by the sociologist; the natural scientist imposes an external logic on his data". The central concept of interpretivism is to work with these already existing subjective meanings within the social world; that is to recognise their presence, to reconstruct them, to comprehend them, to refrain from altering them, and to use them as foundation stones in theorising.

3.3.2 Constructivist Ontology

Interpretivism is reliant on constructivist ontology. Ontologically, interpretive research supposes that the social world (which encompass organisations, division of labours, social relationships) are not "given". Instead the world is created and reinforced by people through action and interaction. Interpretive research aims to understand how the participants of a social group, through their involvement in social activities, perform their particular realities and give them meaning, and to show how these meanings, beliefs and intentions of the members help to constitute their actions. In this ontological depiction cognitive components (intentions, beliefs and meanings) appear to be essential.

3.3.3 Understanding through Interpretation

Epistemology and ontology are interconnected in interpretivism because knowledge is essential in the ontological suppositions of the composition of the world. A set of principles for interpretive studies have been recommended by Klein & Myers (1999). These principles have stemmed from hermeneutics, phenomenology and anthropology and aim to support the formation of a hermeneutically based understanding. Hermeneutics is the theory of interpretation (Smith et al., 2009) and will be discussed in

detail in chapter four. The main determinant is the fundamental principle of the hermeneutic circle. Their interpretation of this principle is the back-and forth movement between the whole and its parts. This is in contrast to positivistic studies, which appear to work with a fixed set of variables.

It is important to create a holistic understanding of the studied area in interpretive research. The understanding should develop as a result of the dialectical movements between the holistic understanding and the understandings of singular parts. According to Klein & Myers (1999) this principle is the basis for all interpretive work and in addition is the basis for the other six principles. An additional principle is the principle of contextualization. A reconstructive understanding of the historical and social context of the research area is required. Klein & Myers (1999) assert that it is paramount that the proposed audience can envision how the current situation under investigation emerged. This importance of historic emergence can be traced to hermeneutics. Their contextualistic orientation towards historic background and emergence must also be noted. This can somewhat be contrasted to Madill, Jordan & Shirley (2000) who identify contextualism as the position that all knowledge is temporary, local and situation dependant.

3.3.4 The Researcher's Relationship to the Study and Participants

One of the interpretive principles is the principle of interaction between participants and researchers, mainly during the generation of data (Klein & Myers, 1999). It is highlighted that participants are co-producers and interpreters of meaningful data. This suggests that empirical data generation is viewed as a method of socially constructed meanings; that is socially constructed by both participant and researcher (Bunniss & Kelly, 2010). As previously stated, this principle concerns the interaction between the participant and the researcher during data generation. Klein & Myers (1999) fail to identify anything pertaining to interaction (knowledge transfer and use) in circumstances external to the empirical study. They also neglect to comment on the value of the created knowledge. It is asserted that "interpretive researchers are interested in using theory more as a sensitising device to view the world in a certain way" (Klein & Myers, 1999, p. 75). This is also consistent with Walsham (1993, p.6) who posits on truth in relation to scientific knowledge: "In the interpretive tradition, there are no correct and incorrect theories but there are interesting and less interesting ways to view the world". However, from a

pragmatic perspective, the key focus is on useful ways to view the world, rather than just interesting ways.

Interpretive research considers knowledge as understanding and one dominant purpose is that it should be appealing to audiences. Interpretive researchers work close to the study area, and engage in the studied practices. As a consequence, Schwartz-Shea & Yanow (2013) assert that the researcher can never assume a value-neutral stance. This can be contrasted with what Schutz (1970) suggests about the researcher-role in relation to the empirical practices. Schutz, one of the key figures in interpretive sociology, distinguished between practical versus cognitive interests in the world. He posited that the researcher 'is not involved in the observed situation, which is to him not of practical but merely of cognitive interest'. He continues to say that the researcher 'looks at the observed situation with the same detached equanimity with which the natural scientist looks at the occurrences in his laboratory'. He surmises that the attitude of the researcher is characterised as 'a mere disinterested observer of the social world'.

It can be assumed that some contemporary interpretive researchers, for example IPA researchers, do not conceive themselves as detached and disinterested observers and this suggests how interpretivism has evolved since the earlier work of Schutz. This is one example of the diversity of views within interpretivism.

3.4 Conclusion

This chapter examined the philosophical underpinnings for methodological decisions made by the researcher. After reviewing and considering the various paradigms in relation to their ontologies, epistemologies and methodologies, interpretivism was deemed the most suitable for this research study. This chapter provided a clear rationale for the selection of interpretivism and how the paradigm fits with the chosen research method. As well as being suited to intensive small scale studies, interpretivism values the diverse belief systems and opinions of research participants, and emphasises the importance of context in gaining an understanding of the phenomenon under investigation. The succeeding chapter will examine the research strategy, data collection methods and data analysis procedure undertaken, providing a justification for the overall research framework.

4. Methodology and Methods

4.1 Qualitative Approaches to Research

Qualitative research methodologies have a close affinity with the naturalistic paradigm which seek to understand phenomena in context specific settings such as “real world settings whereby the researchers aim is not to manipulate the phenomenon of interest” (Patton, 2001, p.39). These methodologies have been described as a form of social enquiry featuring an interpretive approach to understanding and describing phenomena as perceived by a specific population (Holloway & Wheeler, 2010). In comparison to quantitative methods, qualitative methods focus on understanding the emic perspectives of their study participants (Holloway & Wheeler, 2010). Qualitative methods generate data which is rich in thick, in-depth description which contributes to knowledge in numerous ways, namely the generation of theories, understanding phenomena and discovery of true feelings. Exploration is not limited to scientific enquiry, instead a dynamic and holistic approach is utilised to understand all aspects of the human experience (Polit & Beck, 2004).

Researchers have long debated the relative value of qualitative and quantitative inquiry (Patton, 2015). Nurses’ interest in qualitative research began in the 1970’s and has proved useful in describing and comprehending human experiences such as pain and comfort, also focusing on understanding the whole, which is consistent with the holistic philosophy of nursing (Baer, 1979; Leininger, 1985; Munhall & Oiler, 1986; Ford-Gilboe, Campbell & Berman, 1995). Qualitative research allows a broader understanding and deeper insight into complex human behaviours in comparison to what might be obtained from surveys or other linear measures of perceptions (Denzin & Lincoln, 2008). Benefits associated with qualitative approaches also include the generation of rich and deep meaningful insights as it seeks to interpret the participant’s experiences and to develop understanding inductively from the data (Polit, Beck & Hungler, 2001).

A qualitative approach to research strives to study people in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them (Denzin & Lincoln, 2008) or in simpler terms, it examines life experiences in an effort to understand and give them meaning (Byrne, 2001). There are however limitations to qualitative research. Mays & Pope (1995) summarise the main criticisms

as strongly subject to research bias, lack of reproducibility and generalisability. Parahoo (2014) views the researcher's role in accepting or rejecting data as a subjective exercise to be a main weakness.

For the purpose of this research study, a qualitative approach is in keeping with the researcher's chosen subject of interest and the research question. It was the researcher's opinion that a quantitative approach to research would be inappropriate to utilise, as it would fail to describe or interpret the experiences of the select cohort of people who provide care to people with dementia. After conducting a literature review, it was apparent that the dominant research approach undertaken was quantitative. There was a notable absence of Irish qualitative research examining the caregiving experience. Consequently, this led the researcher to select a qualitative phenomenological approach which was deemed best suited to answer the research question.

There are various methods and designs employed by researchers to carry out qualitative research. The common approaches to qualitative research are ethnography, grounded theory, case study, discourse analysis and phenomenology (Parahoo, 2006). A description of phenomenology will be presented below illuminating how the chosen research design, Interpretative Phenomenological Analysis (IPA) evolved from this philosophy.

4.1.1 Grounded Theory

Grounded theory was one of the first formally-identified methods for qualitative researchers (Smith, Flowers & Larkin, 2009). At its inception, grounded theory (Glaser & Strauss, 1967) was developed in order to offer social researchers a clear, systematic and sequential guide to qualitative fieldwork and analysis. Stern (1980) reports that grounded theory is a research method used to search out factors or to relate factors that pertain to the research problem at hand. The research data is grounded in fact and generates a theory from the data (Burns & Grove, 2011). This data is collected utilising field techniques consisting of interviews and observational methods and is analysed by a system of constant comparisons until the investigation generates a number of hypotheses (Strauss, 1987). The researcher then consults the literature to relate the emerging hypotheses to already developed theories (Stern, 1980). McCann & Clark (2003) posit that grounded theory focuses on the process of building inductive theory based on broad experiences, as opposed to the more specific focus on a particular "lived experience" which this study concerns itself with. There are various versions of this approach (some

have an idealist focus and some have a realist one), however constructivist grounded theory appears to offer greater flexibility of process and a clearer epistemological position (Charmaz, 2014).

Grounded theory was deemed inappropriate for the requirements of this study for a number of reasons; Firstly, this study did not aim to develop a theory (Charmaz, 2011), secondly, the researcher has some knowledge of the phenomenon under investigation, it would be difficult to suspend concepts drawn from clinical practice and knowledge of previous research and theory (Life, 1994), and finally, grounded theory affords more significance to processes and social structures than individualised 'insider perspective' accounts (Eatough, Smith & Shaw, 2008) which was the aim of this research.

4.1.2 Ethnography

Closely associated with anthropology, ethnography is utilised to seek understanding of cultural behaviour and social structures of a group of people in society (Polit & Beck, 2004). Ethnographers immerse themselves in the culture for investigation where they may assume participant or observer roles to collect data and complete lengthy and intensive fieldwork (Polit & Beck, 2004). Researchers utilise literature reviews as the basis for their interviews or observations, while data is analysed by using content analysis and pattern identification as they explore the meanings of words, behaviours, events and objects. The main advantage of this methodology according to Robson (2011) is its production of descriptive data free from imposed external concepts and ideas. A criticism of this methodological approach is that there is a concern for researchers becoming over-involved with the participants under investigation, disturbing and changing their natural surroundings, therefore compromising the quality of the research (Robson, 2011). However, ethnographers defend this methodology stating that "in order to truly grasp the lived experience of people from their point of view, one has to enter into relationships with them, and hence disturb the natural setting" (Davidson & Layder, 1994 p.165).

The ethnographic approach was rejected for this study due to its methodological limitations. Ethnography relies on the researcher's ability to collect data in the natural environment of the participant by immersing themselves in the culture and habits of the participant (Parahoo, 2006). However, it would be unsuitable for the researcher to disturb the research participants in their own homes for a protracted period of time. Thus, the research aims could not be achieved using this approach.

4.1.3 Case Study

Case study is a strategy for conducting research involving an empirical investigation of an individual, group, organisation or phenomenon, characterised by the use of multiple methods for data collection (Stake, 1995; Robson, 2011). As a research method, a case study can be utilised to add to knowledge about various situations including organisational or group behaviour, or political or social situations. As a methodology it aims to understand a contemporary phenomenon and its context where the boundaries between both are not distinct (Yin, 2009). The central defining characteristic is concentration on a particular case examined in its own right, however its context must be considered (Robson, 2011). This case is bound by activity and time and utilises a variety of data collection process over a certain timeframe (Creswell & Creswell, 2017). A case study functions within a social, political, historical, or cultural context (Stake, 1995) and the methodology can be utilised to examine real life events within a present day context but where behaviour cannot be controlled, as for example, in an experiment (Yin, 2009).

Platt (1998) in Smith, Flowers & Larkin (2009 p.30) contends that a case study is justifiable when it “describes something intrinsically interesting”. This methodology could have been utilised for its flexible design and for the potential of its practical application (Baxter & Jack, 2008). It has been positively endorsed as a method of choice for nurses owing to it placing the patient in the centre of the research process (Zucker, 2001; Anthony & Jack, 2009; Munhall, 2012). However, this study is not clinically based and only seeks to ascertain the carer’s experiences of providing care and not the person with dementia’s perspective or others’ perspectives. Consequently, this research strategy was not adopted.

4.1.4 Phenomenology

Finlay (2009) suggests that the essence of phenomenology is to capture the lived experience in all its ambiguity, urgency, and immediacy and capture insider meanings of that lived experience. Phenomenology explicates the structure or essence of a phenomenon in search for the unity of meaning, and its accurate description through the everyday lived experience (Byrne, 2001).

According to Cohen & Omery (1994) three distinct school of phenomenology exist; eidetic or descriptive phenomenology based on the teachings of Husserl (1970), hermeneutics (existential / interpretive) guided by philosophers such as Heidegger (1962)

and Gadamer (1976), and the Dutch (Utrecht) school of phenomenology which has its foundations in descriptive and interpretive phenomenology and draws on the work of van Manen amongst others. More recently, other phenomenological research approaches particularly from the past two decades, can be located in these schools (Thomason et al., 2011). These include Lifeworld phenomenology (Dahlberg, Drew, & Nyström, 2001) and interpretative phenomenological analysis (IPA) (Smith, 1996). The three schools of phenomenology offer varied perspectives on the “multifaceted nature of phenomenology, but all approaches having a common concern with the lived experience” (Dowling & Cooney, 2012 p.22). Husserl and Heidegger are the two most noteworthy and significant philosophers in terms of phenomenology. Phenomenology, as a philosophical research tradition, was developed at the start of the 20th century, as an alternative to the empirically based positivist paradigm (Spiegelberg, 1982).

Edmund Husserl is credited with developing transcendental phenomenology and introducing the study of ‘lived experience’ or experiences within the ‘life-world’ (Lebenswelt) (McConnell-Henry, Chapman & Francis, 2009). Husserl’s method aimed to investigate consciousness as experienced by the individual. Husserlian phenomenology focused on individual interpretation of their experiences and the ways in which these experiences were expressed. One of the central features of Husserlian phenomenology is the idea of bracketing (epoché) whereby the researcher suspends their personal preconceptions, prejudices and beliefs in an attempt not to interfere with or influence the participant’s description of their experience.

Martin Heidegger, a student of Husserl, further developed Husserl’s eidetic or descriptive phenomenology into existential philosophy and hermeneutics (Pietkiewicz & Smith, 2014). Heidegger was concerned with the ontological question of existence itself and believed that transcendental phenomenology was not possible as human beings will always interpret phenomena from within their world. Heidegger rejected the notion of bracketing as it is thought that a researcher cannot separate description from one’s own interpretation (Koch, 1995). Both the researcher and the participant have their own preconceptions and prejudices. Heidegger’s hermeneutic phenomenology regards preconceptions or ‘fore-structure’ as essential to understand how people experience phenomena differently. Bracketing will be discussed further section 4.6.3.

Heidegger's main concept was 'Dasein' which is concerned with human beings, whereby the researcher is a legitimate part of the research, as 'being in the world' of the participant. Heideggerian phenomenology seeks to find out how individuals' personal history, past life events and their psychological makeup influences the way in which they experience phenomena (Parahoo, 2014). According to Smith, Flowers & Larkin (2009), Heidegger believed that human beings can be conceived of as 'thrown into' a world of relationships, objects, language, culture, projects and concerns. Heidegger, along with other phenomenological philosophers such as Sartre (1956) and Merleau-Ponty (1962) move away from Husserl's descriptive commitments and transcendental interests towards an interpretative and worldly position which focuses on "understanding the perspectival directedness of our involvement in the lived world" (Smith, Flowers & Larkin, 2009 p.21). In an effort to understanding 'experience' a lived process is required, which uncovers meanings and perspectives. These perspectives are unique to the individual's situated and embodied relationship to the world. Because of this concern with the lived experience, a phenomenological approach was identified as a suitable research design for the current research study. The next methodological decision made was which form of phenomenological approach would be most suitable to answer the research question and fulfil this research study's aims and objectives.

4.1.4.1 Descriptive Phenomenology

Giorgi (1985) led the emergence of descriptive phenomenological research in the 1970s where he set out to develop a rigorous empirical phenomenological psychology motivated by Husserlian concepts. This type of phenomenology aims to analyse essences as they appear in consciousness (Giorgi, 1985), with consciousness being the medium between people and the world. Husserl advocated for researchers to be devoid of contamination by pre-determined theoretical ideas or preconceptions and instead to describe the immediate experience (a phenomenon's general characteristics) provided (Finlay, 2009). Giorgi's (1997) method of descriptive phenomenology involves three interconnected stages: Bracketing which is frequently referred to as phenomenological reduction, description, and the search for essence of the phenomenon. Descriptive phenomenology advocates for there to be maximum variation sampling where participants vary as much as possible from each other, thus increasing variation. During data analysis, the researcher identifies elements of the experience which do not vary across participants, therefore supporting the experience under investigation (Langdrige, 2007). Unlike the constant comparative method of analysis used in grounded theory, descriptive phenomenology

seeks to describe the essence of the phenomenon as it is revealed across participants' lived experiences.

This phenomenological approach was rejected for a number of reasons. Firstly, because of its emphasis on maximum variation sampling, the researcher was unsure she could maximise participant's demographic characteristics enough to adhere to the requirements of this methodology. Secondly, as the researcher had prior knowledge and experience in the area of dementia research and having conducted an extensive literature review on the topic under investigation, it proved difficult to bracket or set aside existing knowledge. Finally, it was the researcher's intention to not only describe the experience of participants but instead focus on meaning and interpretation of that experience, therefore an alternative phenomenological approach was sought to allow the researcher to achieve this aim.

4.1.4.2 Interpretive Phenomenology

Interpretive phenomenology, also known as hermeneutics, aims to understand, describe and interpret the experience of participants. Its focus is to explore the lived experience and how the world in which people live influences their reality. Moreover, people's experiences are linked to cultural, social and political contexts (Tuohy et al., 2013). 'Being in the world' (Dasein), 'life world existential themes', 'fore-structures' and the 'hermeneutic circle' are concepts in interpretive phenomenology which will be discussed later in the chapter. The concept of bracketing out, reduction or epoché is advocated for objectivity to be achieved. However, McConnell-Henry, Chapman & Francis (2009) refutes the notion of bracketing suggesting that it has no place in interpretative phenomenology owing to the fact that the researcher is an integral part of the research who enters into the life of the participant and it is the past experiences and knowledge of the researcher which enhances interpretation. According to Finlay (2008) and Flood (2010), researchers need to be aware that people's realities are influenced by the world they live in. Researchers have a duty to be aware that experiences are linked to social, political and cultural contexts and realise how these factors influence how an experience is interpreted (Flood, 2010). Rather than becoming overtly focused on bracketing, researchers are encouraged to be reflexive about how their past knowledge, experience and assumptions may impact on the research (Finlay, 2009). One commonly used hermeneutic approach in practice is Interpretative Phenomenological Analysis (IPA) which was adopted by the researcher for this study and will be discussed in the proceeding section.

4.1.4.3 Interpretative Phenomenological Analysis

As a qualitative research approach, the principal aim of IPA research is to ascertain how people make sense of their experiences. The focus of IPA is on ‘the detailed examination of personal lived experience, the meaning of experience to participants and how participants make sense of that experience’ (Smith, 2011a, p.9).

This methodology was developed by Jonathan Smith, a British psychologist, in the mid 1990’s. While phenomenology was utilised in psychology, Smith argued for an approach to psychology which was able to capture the experiential and qualitative, and which could still dialogue with mainstream psychology. Smith wanted to stake a claim for a qualitative approach centred in psychology, rather than importing one from different disciplines. However, IPA clearly draws on concepts and ideas with much longer histories and on the fundamental principles of phenomenology, hermeneutics and idiography, which comprise the theoretical foundations for this research methodology.

Phenomenology, the first main theoretical underpinning for IPA, is concerned with the individual’s personal perception or account of an event or object as distinct from an attempt to produce an objective statement of the event or object itself (Smith, Jarman & Osborn, 1999). A good interpretative phenomenological analysis is one which balances phenomenological description with insightful interpretation, and which anchors these interpretations in the participants’ accounts. Methodologically, an IPA study involves a highly intensive and detailed analysis of the verbatim accounts produced by a relatively small number of homogenous participants. This is in direct opposition to descriptive phenomenology which employs the sampling method of maximum variation sampling. IPA researchers aim to understand participants’ relationship to the world which are interpretative and capture their attempts to make sense or meanings out of what is happening to them (Larkin, Watts & Clifton, 2006). The second aim is to develop a more overtly interpretative analysis. By achieving this, it will provide a critical and conceptual commentary on the participant’s personal sense making activities (Smith & Osborn, 2003).

4.1.4.4 Hermeneutics

The second major theoretical underpinning of IPA is hermeneutics. Hermeneutics is regarded as the theory of interpretation (Eatough & Smith, 2008) and adopts a process which clarifies the phenomenon of interest in its context (Hein & Austin, 2001). Heidegger advocated the use of hermeneutic phenomenology as a research method to explore the lived experience (Dowling, 2007). According to Heidegger, being in the world is hermeneutic and understanding is a reciprocal, cyclical process (Dowling, 2007). The role of the researcher is to interpret the accounts of experience that are given by the participants. Finlay (2009) purports that meanings can never be fixed for hermeneutic phenomenologists; they are always emergent, contextual and historical. These meanings shape our understandings and need to be acknowledged. Researchers are encouraged to reflect on how their past experiences, assumptions and knowledge may impact on the research (Finlay, 2009), thus rejecting the notion of bracketing.

Schleiermacher (1998) was one of the first to write systematically about hermeneutics in its generic form at the turn of the nineteenth century. For him, interpretation involved grammatical and psychological interpretation (Smith, Flowers & Larkin, 2009). Grammatical interpretation refers to exact and objective textual meaning while psychological interpretation is concerned with the individuality of the writer. Schleiermacher posited that interpretation is an art involving a variety of skills including intuition and that the process of interpretation is to understand the text as well as the writer. Thus, if a researcher has conducted a comprehensive, detailed and holistic analysis, the result will be “an understanding of the utterer better than he understands himself” (Schleiermacher, 1998 p.226). It is the intention of an interpretative IPA analyst to offer a detailed and systematic analysis of text, offering meaningful insights which exceed and subsume participants’ explicit claims.

As previously seen, Heidegger advocated for the utilisation of hermeneutic phenomenology. It is through interpretation that access to lived time and engagement with the world is achieved. In his major work, *Being and Time*, Heidegger (1962) micro-examined the definition of phenomenology, and specifically the two parts ‘phenomenon’ which means to appear and ‘logos’ which he translated as discourse, reason and judgement. From his investigations he concluded that phenomenology examines something which may be disguised as it emerges into the light. So the phenomenon appears, but the phenomenological researcher can assist this to help make sense of that

which is appearing or emerging (Smith, Flowers & Larkin, 2009). Heidegger discussed interpretation explicitly in his work *Being and Time* and his formulation of phenomenology as an explicitly interpretative activity and his connections with hermeneutics sit well with an IPA approach.

Heidegger is widely known for his beliefs on presuppositions or fore-conceptions which is in direct opposition to Husserl. Heidegger posited that when something is interpreted, the interpretation will be based on a fore-conception. Simply put, the researcher will have their own thoughts, views, and opinions and cannot help let their past experiences affect a new experience. However, Heidegger contends that

“while the existence of fore-structures may be inherent and may precede our encounters with new things, understanding may actually work the other way, from the thing to the fore-structure”, making it a cyclical process (Smith, Flowers & Larkin, 2009 p.25).

While as a student of philosophy in Freiburg, Germany in the 1920s, Hans-George Gadamer (1976) was influenced by Heidegger’s work and moved to extend Heideggerian phenomenology into practical application. Gadamer acknowledges Heidegger’s relationship between fore-structure and the new object and the complex relationship between the interpreter and the interpreted. Gadamer contends that one may only really learn what the individual’s fore-conceptions are on commencement of interpretation so for this reason advises to withhold from putting one’s fore-conceptions up front prior to doing interpretation. In doing this, it allows a new stimulus to speak in its own voice, the danger being that one’s fore-conceptions could prevent this occurring. Gadamer acknowledges that our fore-conceptions are inevitability present. On occasion, we can identify these fore-conceptions in advance and other times, they will emerge during the process of engagement with the new stimulus, however a sense of openness is required. Gadamer disagrees with Schleiermacher’s (1998) belief that the interpreter can know the utterer better than he/she knows themselves. He makes the distinction between understanding the meaning of the text and understanding the person, and states that the former is the priority. Interpretation according to Gadamer, focuses on the meaning of the text which is strongly influenced by the moment at which the interpretation is conducted (Smith, Flowers & Larkin, 2009).

The researcher adopted Heidegger's engagement with fore-knowledge prior to data collection and analysis. Individuals are influenced by the world in which they live and work in, and the experiences they encounter. It is how the researcher's prior knowledge and experiences interact with new experiential encounters that is of significance to IPA (Peat et al., 2018). Rather than bracketing the researcher's prior conceptions before engaging with participants and the data, it was preferable to acknowledge how they reveal themselves throughout the research process (Smith, Flowers & Larkin, 2009). Therefore, the researcher needed to be aware of her own opinions, experiences and beliefs so that interpretations can be enriched as opposed to being an obstacle to making sense of the participant's experiences (Goldstein, 2017). This was achieved by engaging in reflexivity (see section 4.8.4)

Several hermeneutic approaches utilise hermeneutic phenomenology and include IPA (Smith, 2007), the lived experience approach of van Manen (1990), Dahlberg, Drew & Nyström (2001) open lifeworld approach, and Halling, Leifer & Rowe's (2006) dialogue approach. IPA follows the interpretative tradition of Heidegger rather than the descriptive tradition of Husserl (Chamberlain, 2011). Smith (2004) describes IPA as strongly connected to the interpretative or hermeneutic tradition, stating that "understanding experience requires a process of hermeneutic perspective" (Smith, 2004 p.3). Reid, Flowers & Larkin (2005, p.20) content that participants are "experts on their own experiences and can offer researchers an understanding of their thoughts, commitments and feelings through telling their own stories". In order for a researcher to deliver a richly interpretative and meaningful analysis of the expert's experiences, interpretations are bounded by participants' abilities to articulate their thoughts and experiences adequately and by the researcher's ability to reflect and analyse (Brocki & Wearden, 2006).

4.1.4.4.1 The Hermeneutic Circle

According to Smith, Flowers and Larkin (2009) the hermeneutic circle is perhaps the most resonate idea in hermeneutic theory and is concerned with the dynamic relationship between the part and the whole and is associated with many hermeneutic writers. In order to understand any given part, you must look at the whole, and vice versa, thus making it a cyclical process. The hermeneutic circle operates at a number of levels. The meaning of a word only becomes clear when seen in context of the whole sentence. At the same time, the meaning of the sentence depends on the cumulative meanings of the single word.

The part and the whole can be understood to describe a number of relationships (Table 4.1).

The Part	The Whole
The single word	The sentence in which the word is embedded
The single extract	The complete text
The particular text	The complete oeuvre
The interview	The research project
The single episode	The complete life

Table 4.1 Relationships between the part and the whole. From Smith, Flowers & Larkin (2009 p.28)

In IPA research, the process of analysis is iterative whereby the researcher moves back and forth through a range of different methods of thinking about the data, as opposed to completing each step one after the other as would be the case with other approaches to qualitative data analysis (Fig 4.1). As the researcher moves back and forth through the process, it is advised to also think of one's relationship to the data according to the hermeneutic circle (Smith, Flowers & Larkin, 2009). The aim is that the meaning of a text can be made at various levels, all of which relate to one another and many which will offer different perspectives on the part-whole coherence of the text.

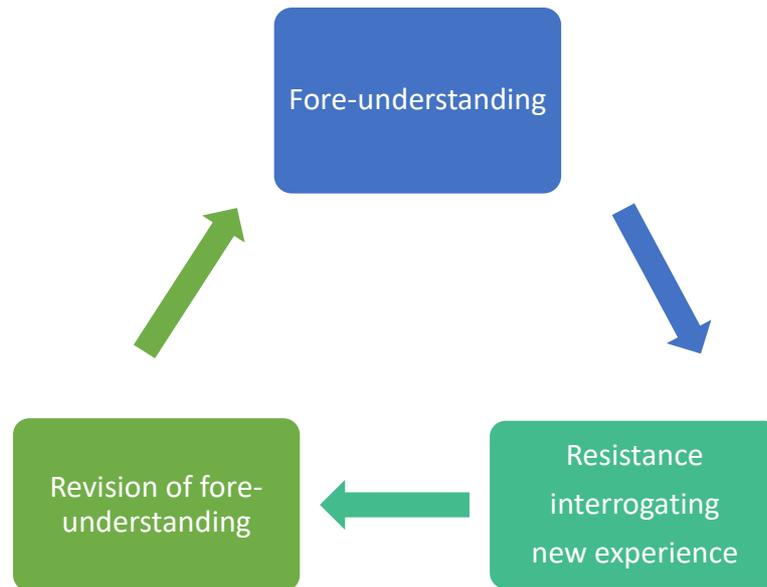


Figure 4.1. The hermeneutic circle: A dynamic relationship between the part and the whole

Furthermore, IPA recognises the role of the researcher in making sense and understanding participants' personal experiences (Smith, 2004). This requires the researcher to make sense of the participant making sense of their experience, known as a double hermeneutic (Smith & Osborn, 2003) (Fig 4.2). Here, the researcher is attempting to understand both in the sense of 'trying to see what it is like for someone' and in the sense of 'analysing, illuminating and making sense of something' (Smith, Flowers & Larkin, 2009). The value of this double hermeneutic, intrinsic to IPA, is in the understanding that both the researcher and participants have of the same phenomenon, that being the experience of the participant, from different viewpoints (Wagstaff et al., 2014). Smith et al. (2009) suggest that since the researcher's theoretical knowledge facilitates him/her to see what the participant does not, it is occasionally necessary to 'disagree' with the surface meaning of the participant's account to 'agree' with the deeper meaning.

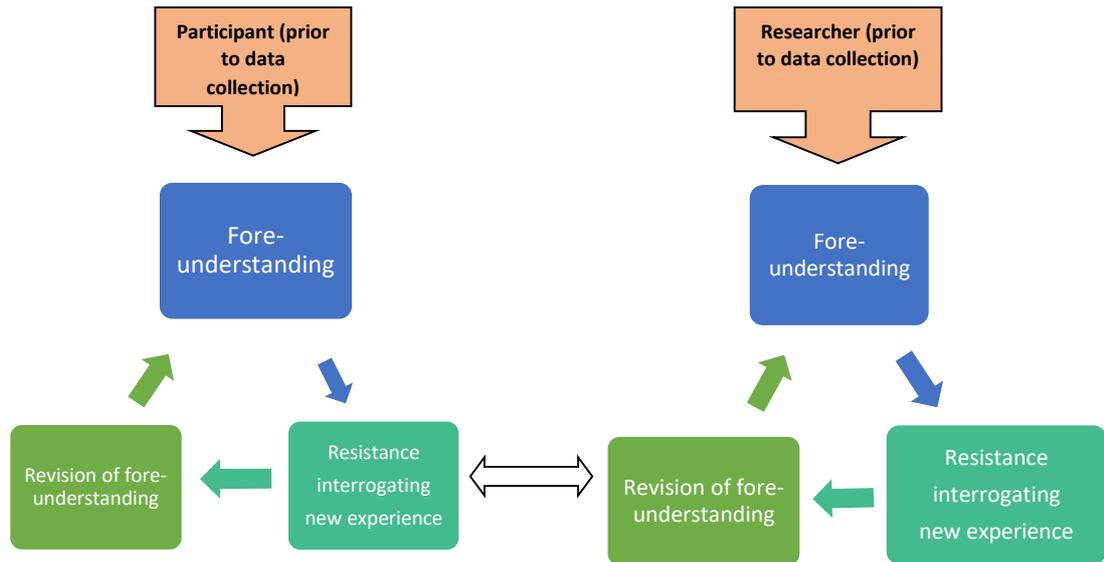


Figure 4.2 Double Hermeneutic

In summary, IPA involves a combination of phenomenological and hermeneutic insights. The phenomenological researcher attempts to get as close as possible to the participant’s personal experience, however it also acknowledges that this is an interpretative endeavour for the researcher and participant. “Without the phenomenology, there would be nothing to interpret; without the hermeneutics, the phenomenon would not be seen” (Smith, Flowers & Larkin, 2009 p.37).

4.1.4.5 Idiography

According to Eatough & Smith (2008, p.183) idiographic methods claim to

“address the subjective and interpersonal involvedness of human emotion, thought and action, and the messy and chaotic aspects of human life, in the hope of getting a better understanding of the phenomena under investigation”.

In simpler terms idiography, which is the third theoretical underpinning of IPA, is concerned with the particular and IPA shares this focus. Typically, IPA uses small, homogenous sample sizes and has an emphasis on exploring participants’ personal experience in their particular contexts (Smith, Flowers & Larkin, 2009). Purposeful sampling allows for the identification and selection of information-rich participants who possess specific knowledge about the phenomenon under investigation (Creswell & Plano Clark, 2011). It is also worth noting that this method of sampling should consider the

willingness and availability of participants to involve themselves in the research and their ability to articulate and reflect on experiences and opinions (Palinkas et al., 2016). Utilising small, purposively selected and carefully situated samples affords the IPA researcher to make effective use of single case analyses or to a process which moves from the analysis of the single case to more general claims looking across all cases (Eatough & Smith, 2008).

As a result, idiography locates generalisations in the particular and allows for more considered development of them. IPA adopts analytic procedures for moving from single cases but then cautiously moves to an examination of similarities, differences and more general statements across the cases. According to Smith, Flowers & Larkin, (2009), this process allows the researcher to produce detailed accounts of patterns of meaning for a participant's reflection on a shared experience but which still allows one to retrieve particular claims for any of the individuals involved.

4.2 Rationale for choosing IPA

The principal reason for selecting IPA over alternative qualitative approaches should be because it is consistent with the epistemological position of the research question (Smith, Flowers & Larkin, 2009). Methodologically, IPA concerns itself with examining the lived experience and how individuals make sense of their experience. This research study aimed to understand carers' experiences of providing end of life care for those with dementia. This is consistent with the aims of IPA research which tends to focus on individuals' experiences and / or understandings of a particular phenomenon (Smith, Flowers & Larkin, 2009). IPA is ideally suited to examine how these carers make sense of their situation and allows the researcher to interpret their accounts of this life experience. IPA allows a naturalistic approach to interviewing and a flexibility that enables lived experience to be highlighted and interpreted based on a close exploration of each participant's words. This methodology is considered to be respectful to participants who are very much in charge of the interview process. Qualitative interviewing advocates for data collection to take place at a time and location suited to the research participant (Gill et al., 2008) and this strategy is also adopted by IPA researchers. Participants in this study were invited to take part in the interview process at a time and location selected by them.

The focus on idiography in IPA attracted the researcher. Given the sensitive nature of the research, and the potential difficulty to recruit family carers' who would be willing and able to participate, the small homogenous sample size typically used in IPA was appealing.

The practical guide to research which IPA offers in conjunction with the series of structured steps to data analysis also appealed to the researcher. Smith (2004) cautions that the guide is not intended to be followed as a cookbook but offers suggestions to be adapted and developed by researchers. The set of steps utilised for analysis purposes facilitate a sense of manageability and order in the analytic process (Smith, Flowers & Larkin, 2009). Producing a detailed and high quality analysis of the data is dependent on the researcher's personal analytic work conducted at each stage of the procedure.

4.3 Strengths and Limitations of IPA

There is a common misconception that IPA is simply a descriptive methodology (Larkin, Watts & Clifton, 2006). Researchers are often drawn to IPA for its applicability, accessibility and flexibility, however it is this flexibility which is often mistaken for lack of rigour. As with some other qualitative methodologies, "IPA can be easy to do badly and difficult to do well" (Larkin, Watts & Clifton, 2006 p.103). However, while Larkin, Watts & Clifton (2006) firmly contend that IPA is not an easy option, it does attempt to differentiate itself from other qualitative methodologies and when carried out with the required commitment and care, IPA research can be very powerful. IPA goes beyond describing an experience; it focuses on sense making activities and our 'involvement in the world' (Larkin, Watts & Clifton, 2006). Taking the insider perspective is just one aspect of the analytic process. The analyst additionally offers an interpretative account of what it 'means' for the participant to have concerns within their particular context. This is generated by having carefully formulated research questions, a willingness on the part of the researcher to reflect on the process of data collection and data analysis, which ultimately produces a rich, contextualized account (Larkin, Watts & Clifton, 2006).

Much has been written about assessing the rigour and validity of qualitative studies (Sandelowski, 1993; Pringle et al., 2011; Barbour, 2013). Smith, Flowers & Larkin (2009) contends that being open to external audit can enhance rigour. In IPA, the analysed data is by its very nature, the interpretation of one researcher. This may question the significance of data findings. However, Smith, Flowers & Larkin (2009) posit that audit

ensures that the account produced is a credible one, not the only one. In addition, IPA encourages researchers to employ a variety of data collection tools such as in-depth interviews, diaries and reflective notes which enhance findings and improve the completeness of data. IPA studies should go beyond an analysis that is just ‘good enough’, providing explicit detail about the commitment and rigour with which the study was conducted (Pringle et al., 2011).

A strength of IPA is reported to be its individual or idiographic nature. Idiography allows for a complete and in-depth insight into a participant’s experience and the phenomenon under investigation (Pringle et al., 2011). However, Malim, Birch & Wadeley (1992) highlights that generalisations are mostly unfeasible and idiographic studies can be subjective, impressionistic and intuitive. This causes difficulty to identify which variables are essential, particularly given the small sample sizes advocated for an IPA study. With that said, although broad generalisations may not be possible, commonalities across accounts and analytic commentary can lead to useful insights which have wider implications (Reid, Flowers & Larkin, 2005). The purpose of an IPA study is not to generate theory, merely to influence or contribute to it in a broader sense. According to Caldwell (2008), theoretical dialogue, generalised from an IPA study, can contextualise the contribution the research makes to the wider literature, thereby validating its contribution to ‘theory’. As a result, by gaining insight into the individual, insight into the whole is also achieved. In this respect, thinking is encouraged in terms of theoretical transferability rather than empirical generalizability (Smith, Flowers & Larkin, 2009).

The use of small sample size in IPA studies may be considered a limitation by some researchers. Indeed, qualitative researchers have frequently been disparaged by their quantitative counterparts for not utilising a representative sample, to produce objective findings, to yield reliable measures or to generate replicable results (Yardley, 2000). Small sample sizes allow for a richer depth of analysis which could be inhibited by a sample size sufficiently large to be statistically representative, and to do so would produce large quantities of data which would become too complex and hopelessly over specified in statistical terms (Smith, Flowers & Larkin, 2009). IPA encourages researchers to go beyond immediate apparent content to facilitate the production of a deeper and more interpretative analysis. Yardley (2000) encourages researchers to consider the ‘quality’ in their ‘qualitative’ research and proposes four principles as a guide to assessing the validity of a qualitative analysis which are sensitivity to context, commitment to rigour,

transparency and coherence and impact and importance. A discussion on ensuring quality will follow in section 4.8.

IPA, by its very nature is a non-prescriptive, adaptable approach to research (Smith, Flowers & Larkin, 2009). Despite presenting IPA as a series of steps and offering a guidebook on how to conduct research using this approach, Smith, Flowers & Larkin (2009) continually acknowledge that such are guidelines which are open to adaptation in the given research situation. Those researchers accustomed to conducting research in the “more rigid world of scientific experimentation and randomized controlled trials” may find the complexity of such openness baffling (Pringle et al., 2011 p.22).

4.4 Ethical Considerations

To complete research on a chosen topic, achieving ethical approval prior to commencing the research is essential. Ethical approval was sought and granted by the Research Ethics Committee of the National University of Ireland, Galway (University Ethics Reference Number: 12/Mar/12). Safeguarding the welfare of research participants is a research imperative. Historical unethical practices resulted in the formulation and implementation of a number of ethical codes to guide researchers before, during and after the completion of a research study. Ethical codes such as Declaration of Helsinki (2013), which is widely regarded as the cornerstone document on human research ethics, emphasises the significance of freedom from oppression, informed consent, and the inclusion of a risk-benefit assessment before commencing a research study.

Topics appropriate to using IPA as a research methodology include those central to the unique life experiences of individuals and may be classified as sensitive areas of investigation due to the potential for intrusion into people’s private lives. This in turn highlights issues of ethical significance that may be encountered throughout the research process (Walker, 2007). While it is paramount to achieve ethical approval from institutional ethics committees, qualitative research also requires sustained reflection and review (Smith, Flowers & Larkin, 2009). Parahoo (2014) highlights that there are ethical implications throughout all stages of the research process, from the choice of research topic, choosing an appropriate research design and the publication of research findings. Researchers need to know the implications of research in order to safeguard participants. The International Council of Nurses (2003) offer six ethical principles for nursing and healthcare professionals to utilise to ensure safety for participants. Beneficence refers to

the benefit research participants can receive from participating in a research study. Non-maleficence translates into avoiding harm to research participants. While the potential for physical harm to participants may be obvious to researchers, the effects of psychological harm may be less obvious. The principle of veracity refers to truth telling, being sincere and honest (Hekk, Judd & Moule, 2004) while the principle of fidelity involves building a trusting relationship between the researcher and participant. If a researcher suspects any potential risk to the safety of the participant, measures must be taken to avoid this situation arising. Justice and fairness to all participants should be ensured with the participants' needs superseding the aims of the study. Justice is also concerned with ensuring the research is conducted in a non-hierarchical fashion with an equal distribution of power afforded to the participant as well as the researcher. The final principle, confidentiality, pertains to how the information retrieved from participants is safeguarded. All information pertaining to participants must be anonymised so that the identity of the participant is not revealed (International Council of Nurses, 2003).

Topics studied using IPA or other qualitative approaches include those central to the unique life experiences of individuals and may be classified as sensitive areas of investigation, due to the potential for intrusion into people's private lives. Even talking about sensitive issues with participants may constitute harm for them.

In an effort to protect a participant's identity, transcripts of interviews should only be viewed by the research team, and data for wider use such as for publication should be carefully edited for anonymity. Smith, Flowers & Larkin (2009) contended that anonymity is all that qualitative researchers can offer; by saying that something is confidential is to say that no other individual will see it, which is not the case. Researchers can represent participants and make their voices heard within an academic or professional forum, but this should not be achieved at the cost of anonymity. Because total anonymity is impossible in a face- to-face interview, data must be stored and reported in a way that the source is unidentifiable. This is ensured through coding personal data to protect participants' identity and storing data securely.

Risk assessment is important when conducting research on sensitive topics. Despite efforts to predict risks at the outset of a study, researchers cannot know what an interview will uncover. A risk assessment should be completed and a distress protocol developed prior to data collection in sensitive contexts (Sammut Scerri et al., 2012) to ensure that

researchers consider any potential distress participants may experience during the course of the study and develop strategies to deal with upset if it occurs. Researchers should ask themselves questions such as, is this study likely to cause any discomfort or distress, either physically or emotionally? If the answer is yes, then the researcher should estimate the degree and likelihood of discomfort or distress and the precautions needed to minimize them. Participants should be provided with access to appropriate supports in the event of becoming upset during an interview. An ethical protocol for dealing with distress was developed for this research study because the topic had the potential to cause distress when discussing end of life issues with participants who were a vulnerable group (Appendix 2).

Researchers may have feelings of guilt related to the interview process, the effects of the research on the participants, or the data collected (Dickson-Swift et al., 2007). Researchers do not set out to exploit or use participants (Edwards, 2009), but researchers may feel simultaneously excited and guilty about the data (Dickson-Swift, 2007; Sammut Scerri et al., 2012), referred to as an ethical hangover (Lofland & Lofland, 1995). Qualitative researchers must acknowledge the power granted to them when participants trust them to report and disseminate their personal narratives with the wider public (Shamai, 2003). Research supervisors or team members can be of great help in dealing with feelings of guilt, upset, or vulnerability. Supervision and self-care are important to deal with the stress and strain of sensitive interviews (Mitchell, 2011).

4.5 Sampling

4.5.1 Determining the Sample

Participants consisted of family carers of a person with late stage dementia who provided direct care and resided within the geographical region of the West and North-West of Ireland. It was anticipated that participants would offer authentic perspectives on a shared experience, that of caring for a person with dementia at the end of their life. IPA researchers seek out a homogenous sample for whom the research question will be meaningful (Smith, Flowers & Larkin, 2009).

4.5.2 Sample Size

According to Smith, Flowers & Larkin (2009), participants are selected for a research study on the premise that they can grant access to a specific phenomenon under investigation. Because IPA is an idiographic approach, concerned with understanding

specific phenomena in particular contexts, sample sizes are usually small; a reasonable sample size suggested to be between three and six participants (Smith, Flowers & Larkin, 2009). Given that the primary concern of IPA is producing a detailed account of an experience or phenomenon, a smaller sample size allows the researcher develop meaningful points of similarity and differences across participants and avoids a situation where the researcher becomes overwhelmed with a large amount of data generation.

Purposeful homogenous sampling was used to select this specific cohort of research participants. The use of purposeful sampling allows control over the composition of the sample and its power lies in selecting knowledgeable individuals for in depth study (Parahoo, 2014). According to Smith, Larkin & Flowers (2009) purposive homogenous sampling allows for consistency within a group of individuals according to apparent social influences or other theoretical aspects pertaining to the study. This facilitates the researcher to conduct a thorough inspection of psychological variability within the group by analysing the pattern of convergence and divergence which occurs.

Gatekeepers were utilised to access the study sample owing to participants' vulnerability and study's sensitive aim. Literature suggests that gatekeepers can bias a sample by 'cherry picking' the best participants to take part in research (Oppong, 2013). In addition, they can potentially be "paternalistic and tokenistic, preventing potential participants from speaking for themselves or exercising agency in their own right" (Walker & Read, 2011, p.18). This raises questions about the philosophical nature of gatekeeping (Miller & Bell, 2002). Gatekeeping will be discussed further in section 4.6.2.3 (Accessing Vulnerable Groups).

In the case of this study, relations with the various gatekeepers were mostly beneficial and facilitated access to the homogenous sample. Cherry picking participants was not an issue in this research as gatekeepers posted participant invitation and information letters to all family carers (of someone with late stage dementia) registered with them, allowing all family carers the opportunity to self-select to partake in the research. The sample who self-selected to take part identified that they met the inclusion criteria to share their experiences with the researcher. They also possessed the confidence to take part in an interview which may be a daunting prospect for other carers. Finally, self-selecting participants felt they possessed the required communication skills to describe their caregiving experience with the researcher and had a desire to tell their story.

All participants were Irish, all were carers with a minimum of six months' experience caring for a family member with advanced dementia. Two homogenous groups were selected purposively because they could offer insight into the particular experience under investigation. Twenty-five participants were sampled in total consisting of two groups; a sample of current carers and a sample of past carers. These two samples were to be studied separately and then in conjunction with each other.

4.5.3 Inclusion Criteria:

- Participant is the main carer for someone with late stage dementia (Person with dementia may die in the next 9-12 months)
- Provides main care for the person with dementia at home
- Are cognitively and physically able to participate
- Are willing to participate at two time points
- Are willing to undertake a digitally-recorded interview
- Are aware of the diagnosis of the person with dementia
- Able to converse in English

4.5.4 Exclusion Criteria:

- Have cared for someone with dementia for less than six months (these carers may not have had sufficient experience and/or sufficient time to reflect on the experience of caregiving)
- Is not the main care provider
- Does not have the ability to converse in English
- Is cognitively/physically unable to participate in the interview

4.5.5 Research Participants

It was envisaged at the outset of this study that 25 participants would be interviewed on two different occasions. Stage one interview would occur when participants were providing care for the person with dementia at end of life stage and stage two interview would consist of a repeat interview occurring six months after the person with dementia had died. Repeat interviewing offers an alternative to single interviews and involves talking to participants who share an experience, perhaps several times over a certain time period. It affords the participant the opportunity to relay their story several times providing the researcher with multiple and often altering accounts (Alaszewski, 2018).

However, it remains a guided conversation, structured and designed by the researcher. Employing this method of re-interviewing participants, allows the researcher to verify data already received on the initial interview which would add to the richness of the overall interview data collected. Re-interviewing also allows a comparison of the experience to be made from the time of providing direct care with experiences after the person with dementia had died, attempting to reveal different perspectives of caregiving at two distinct points in time (pre-death and post death). Revisiting carers six months after the death of the person with dementia was deemed an appropriate time scale as leaving a protracted amount of time after the person with dementia had died could affect the participant's recall of the caregiving experience.

However, the recruitment and interview strategies had to be revised and modified to include an alternative sampling strategy as it was quickly seen after completing three interviews that given the relatively short time frame available to the researcher, and the protracted nature of the dementia disease process, those participants interviewed at stage one while they were providing care may still be providing end of life care for a prolonged period of time. Despite the person with dementia being in the late stages of the disease, and drawing from the researcher's past nursing experience, it was felt that the person with dementia could still be alive in 12 months, mostly owing to the quality of care they were receiving from the caregiver.

In addition, gatekeepers identified recently bereaved carers who wished to take part in the research who were not interviewed previously by the researcher while they were providing end of life care. Therefore, the sample was amended to include carers who were the primary caregiver to a person with end stage dementia 'or' who had previously been a carer for a person with dementia who had died at home in the previous six months.

A final revision to the research sample occurred when the researcher arrived to two locations with the intention of interviewing a participant, however the participant's spouse was also present and wished to participate in the interview. It was not the researcher's intention to interview couples however it would have been ill mannered to refuse the spouse's request to be part of the research and during the course of the interview it became apparent that both individuals shared the care giving workload and supported each other in this role, therefore it was very appropriate that both individuals should be interviewed at that time. This dyad added a further dimension to the research.

4.5.6 Research Participants Profile

Participants included seventeen current carers and six former carers for a family member with dementia residing in the West and North-West of Ireland (Table 4.2). Twenty-one interviews were conducted in total, two of which were with couples while the other nineteen interviews were one-to-one interviews (n=23). A brief demographic form was utilised to collect information pertaining to the participant's age, gender, number of years caring, and support services used by the person with dementia. Almost three quarters of participants were female (n=16), the average age of a carer was between 50-59 years, the average length of time caring was between 5-9 years and the majority of participants cared for their mother (n=17). All current carers resided with the person with dementia. Former carers also resided with the person with dementia prior to their death.

Table 4.2. Demographic Profile of Participants

Carer's Pseudonym	Caregiving Status	Age Range	Gender	Years of Caring	Relationship to Person with Dementia	Highest Level of Education Achieved	Supports available
Mary	Current	40-49	Female	5-9 Years	Mother	Third level - non degree	Respite: 3 weeks/year, Professional Carers: 10 hours/week, Family Carers: Sisters on Saturday & Sunday
Lisa	Current	50-59	Female	0-4 Years	Mother	Third level - non degree	Respite: 8 weeks/year, Day Care: 2 days/week, Professional Carers: 11 hours/week, Family Carers: Son
Kate	Current	70-79	Female	15-19 Years	Husband	Third level - non degree	Professional Carers: 61.5 hours/week
Maureen	Current	60-69	Female	5-9 Years	Husband	Third level - Degree or above	Respite: 2 weeks/year, Professional Carers: 1 half day/week
Fiona	Current	60-69	Female	10-14 Years	Mother	Secondary School	Professional Carers: 9 hours/week
Ava	Current	30-39	Female	0-4 Years	Mother	Third level - non degree	Respite: 2 weeks/year, Day Care: 3 days/week, Professional Carers: 45 mins x 5 days/week
Donna (Couple dyad 1)	Current	50-59	Female	10-14 Years	Mother	Third level - non degree	Respite: 2 x 2 weeks/year, Professional Carers: 13 hours/week plus 100 hours homecare package, Family Carers: Husband & Brother in Law
Michael (Couple dyad 1)	Current	50-59	Male	10-14 Years	Mother in law	Secondary School	Respite: 2 x 2 weeks/year, Professional Carers: 13 hours/week plus 100 hours homecare package, Family Carers: Wife & Brother
Derek	Current	50-59	Male	10-14 Years	Mother	Secondary School	Respite: 2 x 2 weeks/year, Professional Carers: 13 hours/week plus 100 hours homecare package, Family Carers: Brother & Sister in Law
Alec (Couple dyad 2)	Former	50-59	Male	0-4 Years	Mother	Secondary School	Respite: 1 week/year, Family Carers: Wife
Isobel (Couple dyad 2)	Former	50-59	Female	0-4 Years	Mother in law	Third level - Degree or above	Respite: 1 week/year, Family Carers: Husband
Caroline	Former	50-59	Female	0-4 Years	Mother	Third level - Degree or above	Respite: 3 times/year, Professional Carers: 21 hours/week
Cillian	Former	50-59	Male	5-9 Years	Mother	Third level - Degree or above	Day Care: 1 day/week, Professional Carers: 12 hours/week
Ben	Current	30-39	Male	15-19 Years	Mother	Secondary School	Professional Carers: 24 hours/week
Grace	Former	60-69	Female	5-9 Years	Mother	Secondary School	Professional Carers: 7 hours 30 mins per week
Jack	Former	60-69	Male	10-14 Years	Mother	Secondary School	Professional Carers: 24 hours/week
Aaron	Current	40-49	Male	5-9 Years	Father	Third level - non degree	Respite: 4 weeks/year, Professional Carers: 7 hours/week, Family Carers: Few hours on a Sat
Emma	Current	50-59	Female	0-4 Years	Mother	Third level - Degree or above	Professional Carers: 10 hours/week
Hannah	Current	50-59	Female	5-9 Years	Mother	Third level - Degree or above	Professional Carers: 14.15 hours/week, Family Carers: Husband
Helen	Current	50-59	Female	0-4 Years	Mother	Secondary School	Professional Carers: 2 hours/week, Family carers: Husband
Natalie	Current	30-39	Female	0-4 Years	Mother	Third level - Degree or above	Respite: 3 weeks/year, Day Care: 1 day/week, Professional Carers: Home-help 4 hours/week, Privately funded Professional Carers: 5 hours/week
Ellie	Current	70-79	Female	5-9 Years	Husband	Secondary School	Day Care: 2 days/week, 6 adult children living locally
Irene	Former	50-59	Female	5-9 Years	Mother	Third level - non degree	Respite: 3 times/year, Professional Carers: 3-5 hrs/week, Family carers: Brothers & neighbours

4.6 Data Collection Method: Interviews

Research information may be collected in various ways. The choice of data collection instrument is influenced by the research approach and the research question to be addressed (Lewis, 2015). Qualitative data collection requires a degree of probing in the form of questions, into participants' private thoughts (Price, 2002; Bourgeault, Dingwall & de Vries, 2013). In qualitative nursing research, the major mode of data collection is interviewing with semi-structured interviews figuring to be the most common data gathering technique (Holloway & Galvin, 2016).

In western culture, the interview is a recognised form of social interaction in which one person is authorised to control what is discussed through a series of questions (Seidman, 2013). The manner in which the interviewer evokes a participant's recall, information, expression, and feelings has a direct impact on the quality of the data collected (Edwards & Holland, 2013). Collecting research data is not an easy task, and the dialogue used for inquisitive purposes must be considered as well as legitimising the research questions, aiding participants to evaluate the place of the research and their part in it (Wimpenny & Gass, 2000). The aim of interviews are

“to produce a detailed and systematic recording of the themes and issues addressed in the interviews, to link the themes and interviews together under a reasonably exhaustive category system” (Burnard, 1991 p.416).

Semi-structured interviews as a means of data collection allows participants to describe their experiences in their own words (Holloway & Galvin, 2016), and enable the interviewer to clarify misunderstood questions, or probe deeper for additional information from the interviewee (Polit, Beck & Hungler, 2001).

4.6.2 Sensitive Interviewing in Qualitative Research

Much of nursing and health research focuses on aspects of living that may be considered sensitive (Enosh & Buchbinder, 2005). While all research topics have the potential to be sensitive (Corbin & Morse, 2003), some studies elicit more distress than others, often causing the risk of harm to participants and evoking emotional responses such as sadness, anger, anxiety and fear (Elmir, Schmied, Jackson & Wilkes, 2011). Furthermore, when sensitive research is being undertaken, reasonable and appropriate safety measures must

be taken to reduce the risk associated with breaches of confidentiality and invasion of privacy (Mealer & Jones, 2014).

For sensitive topics, many researchers choose a qualitative design using in-depth face-to-face interviews (Liamputtong, 2007; Elmir et al., 2011; Taylor et al., 2011). Interviewing requires the skill of conducting an incisive interview that yields rich and meaningful data, while at the same time allowing participants to feel safe and at ease discussing difficult or sensitive experiences with a stranger (Knox & Burkard, 2009).

Sensitive research is difficult to define but has been associated with taboo topics or those “laden with emotion or which inspire feelings of awe or dread” (Lee, 1993, p.6). Renzetti & Lee (1993) defined sensitive research topics as those which intimidate, discredit, or incriminate the participant. Health researchers conduct research on a wide variety of topics that could fall into these categories, such as research focused on rape, post-traumatic stress disorder, drug use, death, grief, or birth (Lowe, Chan & Rhodes, 2011; Mealer & Jones, 2014; Taylor et al., 2011). Dickson-Swift, James, Kippen, & Liamputtong (2008, p.2) favored the definition, “research which potentially poses a substantial threat to those who are or have been involved in it,” acknowledging that all who participate may be affected. The topic itself may be perceived as sensitive, or the research may evoke emotions from those participating in it. Researchers also may be affected and should prepare to disengage both physically and psychologically on completion of the research. Studies of this nature require careful planning and consideration on the selection of an appropriate research design and data collection method (Dickson-Swift et al., 2008; Ashton, 2014).

Although sensitive topics do pose an element of risk to participants, avoiding this research may be seen as evasion of responsibility and disempowering to the individuals involved (Dickson-Swift et al., 2008; Sammut Scerri, Abela & Vetere, 2012). Often, researchers cannot predict how participants may be affected because some issues are not always apparent at the outset (Corbin & Morse, 2003). Dickson-Swift et al. (2008) contend that the experience of participating in such research may bring about a change in participants, which may be positive or negative.

The benefits of undertaking sensitive research must outweigh the risks. Ethical guidelines provide useful advice when planning research on sensitive topics (Ashton, 2014). Corbin

& Morse (2003) recommended following a code of ethics to guide the research process, from framing the research question, to selecting participants, through to writing up and disseminating findings. The moral complexities of the research relationship need to be addressed and sensitivity shown for participants' needs throughout the research process (Hewitt, 2007).

The term "vulnerable" when referring to target populations for research is often used interchangeably with other terms, such as hard-to-reach, sensitive, or hidden populations (Liamputtong, 2007). Vulnerable groups may hold a social status that diminishes their autonomy and marginalizes their lives. Participants in this study were vulnerable as members of a population known to experience mental and physical illness, social isolation, financial difficulties, stress, and difficulty coping (Flynn & Mulcahy, 2013; Jones, Tudoe Edwards & Hounsome, 2014). The population also is emotionally vulnerable due to their involvement in end-of-life care.

4.6.2.1 A Framework for Sensitive Interviews with Vulnerable Groups

Qualitative researchers must attend to special considerations when planning and conducting interviews on sensitive topics to ensure a good outcome for both the interviewer and interviewee. After revisiting reflective field notes on the challenges presented when conducting such interviews, a framework for sensitive interviews with vulnerable groups (Table 4.3) was developed by the researcher to assist and encourage novice qualitative researchers to plan for a variety of considerations before embarking on data collection. This framework aims to improve the effectiveness of sensitive interviewing with vulnerable groups and to avoid omission of critical information.

Access to vulnerable groups and participant satisfaction may be enhanced with a standardised framework for sensitive interviewing. In addition, strengthened interpersonal relationships between the researcher and gatekeepers may result from an approach that places the participants' needs at the forefront. The framework offers points for consideration prior to starting the research, aiming to guide interviewers through the swampy lowlands of data collection and avoiding common pitfalls along the way.

Table 4.3. Essential Elements in Qualitative Interviewing Framework

Elements	Considerations	Action
Preparation, Planning & Implementing an Interview Schedule	Preparation is vital. Select the correct research methodology and data collection tool/s to acquire data from participants.	Liaise with research supervisor or research team to decide which research methodology best addresses the study's research question, aims and objectives.
	Develop an interview guide and have a thorough knowledge of this interview guide.	Develop an interview guide with predetermined questions focusing on the study's research question and aims.
	Use the interview guide flexibly as a guide to facilitate meaningful discussion between the researcher and participant.	Conduct pilot interviews to troubleshoot issues with interview schedule questions. Pilot interviews will aid skilful and effective questioning.
Accessing Vulnerable Groups	Consider issues with accessing gatekeepers of vulnerable groups and negotiating access to participants.	Meet gatekeepers in person to facilitate relationship building, develop trust, allow questions to be asked and clarification to be sought. Explain to gatekeepers the perceived benefits of taking part in research.
	Participants require sufficient information to make an informed decision to participate.	Provide detailed study information to potential participants and contact names and numbers if they wish to partake in the research.
	Consider how participants may contact researchers to self-select to participate in a research study (text message, telephone call, or return postal consent form).	Consider utilising social media to recruit participants.
Time & Location of Interviews	Flexibility on the part of the researcher.	Conduct interviews at a time and location which is suitable for the participant.
Rapport & Relationship Building	Consider how to deal with distress and emotions.	Effective listening is required.
	Care is required for the participant and researcher.	Support structures may be required to deal with distress.
	Interviews may be cathartic for participants. Relationship development which is mutually trusting and positive facilitates discussing sensitive topics.	Rapport development and a trusting relationship are key to facilitating discussion of sensitive topics.
Cathartic Interviewing	Know your interview questions so that your schedule is a guide, allowing free flow of conversation.	Thorough knowledge of interview questions is required for free flowing conversation between researcher and participant.
	Develop skills in empathic listening and being comfortable with interview silences.	Avail of qualitative interviewing training.
	Consider how you will deal with distressed participants.	Develop a distress protocol (Appendix 2).
	Location of the interview is key to allow for free flowing discussion.	Source a quiet, private interview location free from interruptions.
	Consider the need for refreshments and tissues during interviews.	Provide water and tissues to participants to promote comfort.
Concluding Interviews	Closing of relationship after data has been collected.	Debriefing with participant after interview has ended.
	Ensure positive closures for the participant and the researcher.	Provide contact numbers of support services as required.
	Reflexivity is required to consider values, beliefs, perceptions which may influence the research process.	Meet with supervisor or research team to discuss the interview process. Bracket interviews: meet with a critical friend/supervisor/research team to challenge self-deceptions, keep a reflective diary.
Ethical Considerations	Trust. Informed Consent. Anonymity and Confidentiality.	Devise a risk assessment and distress protocol. Adhere to ethical research principles.

4.6.2.2 Preparation, Planning and Implementing an Interview Guide

Using an interview guide when conducting semi-structured interviews is advised especially for novice researchers. However, it should be used in a flexible manner and acts as a guide, incorporating ideas of how best to phrase questions and how to move from broader issues related to the subject matter to more specific and sensitive topics pertaining to the participant's perspective (Doody & Noonan, 2013). It is noteworthy that the role of researcher is to ask skillful questions but also to assume the role of active listener, so setting aside an interview guide to listen to the participant's narrative is preferable. The onus is on the researcher to be sufficiently familiar with the interview questions in advance of the interview and not be reliant on the guide during an interview. Two interview guides were developed and utilised for this study; one for current carers (Appendix 3) and the other for former carers (Appendix 4).

Naturally, an interview does not have to follow the sequence of the guide and in some instances, the participant may move completely away from the guide and follow an alternative course. Because semi-structured interviewing has its basis in human conversation, it allows the interviewer to skilfully modify the style, pace and ordering of questions to evoke the fullest responses from the interviewee (Qu & Dumay, 2011). Including one broad opening question, asking the participant to describe the experience or phenomenon under investigation, may result in the participant answering some of the pre-determined interview questions, thus altering the sequence of questioning. It is important to probe the participant to find out more on certain interesting topics which they may have discussed (Doody & Noonan, 2013). This requires intent listening on the part of the researcher to the conversation and probing spontaneously at certain points (Smith, Flowers & Larkin, 2009).

An interview guide was developed containing a series of questions which would address the aims and objectives of the study. The researcher attended several IPA workshops in the UK and Ireland facilitated by experts in IPA to develop her skills in the design of interview guides, conducting semi-structured interviews and data analysis. It was advised that all interview questions should be open-ended allowing the participant sufficient scope to answer the question. Flowers (2016) reminds novice researchers that the first 'real' question posed is the most important and perhaps the only one the researcher systematically asks. Once the interview guide was devised, approval was sought and received from the researcher's supervisor.

Four pilot interviews were undertaken for the purpose of interview practice which afforded the researcher the opportunity to amend and improve questions on the interview guide, thereby ensuring questions were clear and unambiguous. These pilot interviews were not included in the analysis owing to the fact that participants did not meet the inclusion criteria. For example, participants did not reside with the person with dementia, were not the primary care giver and / or the person with dementia was in the early stage of the disease.

From four pilot interviews conducted with current carers, it was found having a predetermined schedule of questions positioned within the researcher's line of vision was off-putting to participants and created a formality to the interviews that was less conducive to open and free flowing discussion. Interview guides are to be used as a guide but according to Smith, Flowers & Larkin (2009) the researcher's role is that of active listener and in the case of vulnerable participants, it is often preferable to set aside the structure and to fully concentrate on the participant's needs instead. It was the researcher's intention to make participants feel at ease in the familiar surroundings of their own homes and facilitate a conversation between two people as opposed to a question and answers type session between strangers. Therefore, having a thorough knowledge of the interview questions and topics prior to data collection is crucial for a successful interview between participant and researcher.

The researcher asked participants at the start of each interview to "*describe your experience of providing care for your family member who has dementia*". This broad and open question allowed scope and flexibility for the participant to tell their personal story. When participants discussed topics which were of particular interest to the research and formed part of the interview guide, the researcher probed the participant by asking "*can you tell me a little more about that*" or "*you mentioned how difficult this has been for you, can you explain what these difficulties are*". Knowing when to probe and how to choose the appropriate probe requires skill and an understanding of the purpose of each question (Polit & Beck, 2012). Nondirective probes facilitate the discussion to return back to the topic under investigation in a natural way eliciting more detailed information from the participant.

A limitation of utilising interviews as a data collection method is the way the researcher deciphers what the participant is trying to convey (Sjostrom & Dahlgren, 2002). There is

a need on the part of the interviewer to interpret immediately what the participant is saying in order to decide about further questioning or probing. Any misunderstanding in this respect may jeopardise the quality of the interview data. The researcher must be aware that interviews may pose additional challenges such as coping with unanticipated problems from the participant, recording the interview and managing a large volume of data. However, King & Horrocks (2010) suggests that a skilful facilitator can overcome much of the criticisms outlined.

Qualitative researchers aim to understand people's lives as they are lived generating deeply contextual accounts of participants' experiences and their interpretation of them (Schultze & Avital, 2011). The participant has experiential expertise and should be the sole focus of the researcher's attention (Smith et al., 2009). By listening intently to the participant's story, the researcher conveys interest in what the participant is saying and facilitates the conversation to flow freely.

4.6.2.3 Accessing Vulnerable Groups

Accessing participants for research purposes is often problematic if the sample is seen as vulnerable or the research topic under investigation is sensitive in nature. Gatekeeping is the process by which researchers are permitted access to a research setting under investigation and/or to the participants in that setting (Kawulich, 2011). Obtaining the support of gatekeepers when conducting research with minority groups or vulnerable groups is vital (Berg, 1999). Gatekeeping means more than meeting the right people to open doors; involving gatekeepers can have great benefits in that they may have local influence and power to add credibility and validity to research by their acceptance of it (Seidman, 2013). In addition, they can play an important part in disseminating research findings. All gatekeepers in this study were sent three publications as acknowledgement for their assistance in recruiting participants but also as a means of distributing the findings to their colleagues and other relevant personnel.

Sixsmith, Boneham & Goldring (2003) contend that gatekeepers can also block research and prevent access to participants. Two problems have been identified in relation to gatekeepers and the consent of study participants. The first concerns the over-protectiveness of gatekeepers, which may result in people being denied the opportunity to participate in research (Heath, Charles, Crow & Wiles, 2007). The second concerns a failure of gatekeepers to provide opportunities for potential participants to exercise choice

in participating in research (Miller & Bell, 2002), which may occur in schools or institutional settings. Seidman (2013) classified gatekeepers into two groups: absolutely legitimate (to be respected) and self-declared (to be avoided), cautioning that self-declared gatekeepers may be working to their own agenda, attempting to influence the research process by selecting participants approved of by themselves.

While gatekeepers correctly serve to protect individuals in their care, Alderson & Morrow (2004) highlighted that this may also exclude and silence potential participants without consulting with them in person and may result in a biased sample. Access to participants may be denied by gatekeepers due to pressures of time and inconvenience, reluctance to expose organisations or institutions to public scrutiny, or inappropriateness of the research topic and/or its methods (Heath et al., 2007). The latter reason must be respected, as it is acknowledged that the role of gatekeeper is to prevent harm and protect those in their care. Researchers have little choice but to respect gatekeepers' judgments but may on occasion seek to contest them (Heath et al., 2007).

The first strategy is to secure access to the organisation from which participants will be recruited. Researchers often must negotiate access to a research site with influential gatekeepers at multiple points or with multiple gatekeepers in different sites. When the researcher or others from the researcher's organisation have conducted research in the institution, positive relationships may have been formed before recruitment begins, but novice researchers should consider strategies to gain access to organisations and participants in advance of data collection.

Negotiating access is based on building relationships with gatekeepers, which is an "ill-defined, unpredictable and an uncontrollable process" (Wanat, 2008, p.192). Having knowledge of the organisation and the appropriate gatekeeper to contact will assist in negotiation, keeping in mind that lower-level gatekeepers may not appreciate feeling ordered to co-operate by their superiors. Le Compte and Preissle (1993) advised meeting gatekeepers in person, which is integral to acquiring cultural or organisational knowledge. Developing a rapport is vital to fostering research relationships that are honest and respectful to both parties (Kawulich, 2011). In a face-to-face meeting, information about the research can be shared in an open and transparent way. Any questions pertaining to the research can be answered and clarification provided. This meeting allows the gatekeeper to evaluate the researcher's professional suitability and

allows the researcher to emphasise the value of his or her personal contributions (Shenton & Hayter, 2004).

Researchers should detail the level of involvement required of gatekeepers. Gatekeepers may decline to be involved in research if it will add burden to their workload. Co-operation is often influenced by what gatekeepers perceive as a benefit or a threat to participation (Kawulich, 2011). If gatekeepers recognise the benefit of the research to themselves or participants, they may be more likely to co-operate. However, they may be less likely to take part if they feel a threat to themselves personally or to their role. Furthermore, gatekeepers can avoid cooperation, shift responsibility to other organisations, control communication, request additional information, or forget to follow through on promises of assistance.

Shenton and Hayter (2004) posited that entry is best ensured if the researcher is in a position to offer something back to the organisation and participants. This reciprocity may take the form of incentives to gatekeepers or participants or sharing study findings with the collaborating organisations. In this study, the researcher endeavored to provide a sense of reciprocity by offering gatekeepers copies of published papers from the research data and bringing a cake and flowers to each participant's home. Giving back to the participants who share their experiences is customary because without their stories, the research would not exist (Kawulich, 2011). Each research setting is unique, and it is noteworthy that gaining permission from an authority does not mean that entry has been achieved (Kawulich). However, these strategies may result in greater cooperation (Wanat, 2008).

The recruitment process for the present study relied on gatekeepers who selected individuals deemed suitable. Initial contact by telephone was made with gatekeepers (managers of carer support groups, home help services, or nurse managers working with people with dementia) to describe the study in detail and its potential benefits to participants. Without doubt, speaking to gatekeepers and allowing an opportunity for them to ask questions and seek clarification on aspects of the study facilitated access. Once the gatekeepers understood what was involved and had information about the first author's background and experience in this area, they were extremely encouraging of the research and willing to provide access to suitable participants. Gatekeepers then

distributed research information letters to potential participants, which allowed them to self-select to take part in the research by contacting a named researcher.

One gatekeeper denied access to potential participants, deeming those who satisfied the entry criteria to be “too vulnerable.” While this was frustrating and disappointing, the gatekeeper had a good knowledge of the individuals and of their situations, and the decision was respected, despite awareness that potential participants were not afforded the opportunity to make an informed decision.

4.6.2.4 Timing and Location of Interviews

Successful interviewing requires meticulous planning, and the location of interviews needs careful consideration. It is important for participants to feel safe, comfortable, and at ease during interviews (Elmir et al., 2011). The environment should be private and free from interruptions, particularly when discussing sensitive issues. Interviews should always be conducted at a place and time selected by the participant (Doody & Noonan, 2013). Interviews in participants’ homes give researchers entry into a private part of participants’ lives (Dickson-Swift et al., 2007) but also place the participant in a position of some control (Doody & Noonan, 2013).

Time dependence burden of caregiving is significant and influenced by the degree of impairment and caregiving involvement (Hoskins, Coleman & McNeely, 2005). This was true for carers for persons with end-stage dementia. A plethora of evidence exists on caregiver burden (Van Vliet et al., 2010; Flynn & Mulcahy, 2013; Hawkins et al., 2013) and its impact on family carers. Etters, Goodall, & Harrison (2008) attributed depression, ill health, and decreased quality of life to caregiving, and lack of social support and isolation are among risk factors of this role (Flynn & Mulcahy, 2013).

Participants were offered the opportunity to be interviewed at any location suited to them, and all participants opted to be interviewed at home. Reasons were varied; most participants were current carers who did not have an abundance of free time and were not in a position to leave the home or their caring duties. Some did not have other family members or supports to facilitate social outings. Former carers also selected to be interviewed at home.

When carers made contact with the researcher by text message or telephone to consent to be interviewed, they typically requested that the interview take place the following day or within a few days of this first contact. A great degree of flexibility was required to organise interviews with participants who were current carers. By virtue of their ongoing and intense caring role, these participants often were not in a position to plan very far in advance. Therefore, interviews had to occur within a day or two of the first contact. Initially, this required a great deal of reorganisation of the researcher's work schedule to facilitate these requests. The researcher had to prioritise interviews over other work and block off periods of free time over a number of days, to ensure that participants had a choice of days and times for the interview.

The safety of the researcher must also be considered prior to and during data collection. Researcher safety is seldom discussed in the methodological literature (Sturges & Hanrahan, 2004; Oltmann, 2016) and many research settings pose some element of risk to researchers (Hamm & Ferrell, 1998). Such risks may include impropriety or sexual harassment (Wilson, Roe & Write, 1998). Given that the researcher was female and travelling alone to unknown locations, it was of paramount importance that safety issues were considered. Prior to each interview, the researcher informed her supervisor of her intended destination and provided her mobile phone number. A brief phone call was made by the researcher on completion of each interview to confirm that no issues regarding her safety arose. At no time did the researcher feel unsafe or uncomfortable in participants' homes.

4.6.2.5 Rapport & Relationship-Building

Researchers enter other people's lives, often at a time of crisis and stress, and ask them to discuss their experiences (Liamputtong, 2007). This can be for an extended period of time, such as with repeat interviewing or as a one-off event. The process of conducting qualitative research may be complex, personal, and intense. Interviewing people considered vulnerable about sensitive topics makes the establishment of a trusting relationship with the researcher especially important (Murray, 2003). Investigation of a sensitive topic may precipitate participants' intense emotions. Researchers must consider the vulnerability of their participants and devise a plan to provide appropriate support when required. Ensuring researchers have a good understanding of the appropriate boundaries of the researcher-participant relationship and the ethical issues that may arise will lead to a mutually beneficial experience to both parties (Murray, 2003).

Paramount to building an effective research relationship is initiating a rapport-building process from the outset, which will facilitate access to a participant's narrative (Dickson-Swift et al., 2007) by helping participants feel at ease to disclose intimate and sensitive information. A strategy to ensure that the researcher – participant relationship is non-hierarchical is reciprocal sharing of personal stories by both participant and researcher (Liamputtong, 2007). Prior to the commencement of the interview, the researcher detailed her clinical experience of caring for patients with dementia and for those at end of life. While it was emphasised that the researcher had not been a family carer and did not possess the same experiential knowledge that the participant had, sharing her experiences with the participants demonstrated some limited knowledge and insight into their caregiving journey. This creation of a level playing field enhances rapport as well as showing respect for participants and validating their stories. In research on sensitive topics, the frequency and intensity of researcher disclosure may differ (Lee, 1993; Renzetti & Lee, 1993) and has the potential to make researchers feel vulnerable (Fontana & Frey, 2005).

When questions are posed to researchers with a healthcare background, a role conflict arises (Ashton, 2014). Although the researcher is there as data collector, it is difficult to shed nursing knowledge and experience and enter the field with a blank curriculum vitae (Johnson & Macleod Clarke, 2003). In such cases, sustaining an impartial role is challenging, and nurses with experience and training will draw on experiential knowledge and answer clinical questions, discuss concerns with participants, and refer on if required. While according to Jack (2008), information provided by nurse-researchers has the potential to influence participants' responses or discourage the participant from openly sharing more information, refusing to answer health-related questions also may adversely affect the interview. Britten (1995) advocated deferring requests for answers or information until the end of the interview, and, if a need for further intervention is identified, referring the participant to another health care professional.

While researchers must be empathic to the participants' needs, they should remember that they are researchers and not counselors (Hennink, Hutter & Bailey, 2010). Murray (2003) advocated retaining clear boundaries with participants, to prevent nurse researchers from becoming nurse therapists. Empathic distance is required to engage with participants without becoming too involved (Valentine, 2007). Nonetheless, nurse researchers can draw on experience to spot signs of distress (Ashton, 2014). Dowling (2006) highlighted

the difficulties in separating the nurse from the researcher and contended that participants may consent to partake in research studies as a result of being a healthcare user, or in this case, the carer for a healthcare user. Dowling (2006) found it unjustifiable to use the role of the nurse to recruit participants and then abandon this identity once the study commences.

Carers asked the researcher about her feelings on end-of-life care and about the dementia disease trajectory. They were aware that the researcher was a registered nurse, based on information provided in the information letter. On occasion, the researcher was asked medical questions with the belief that, *“well you are a nurse so you understand.”* One participant discussed a dilemma of whether or not to allow administration of antibiotic therapy to her mother with end-stage dementia. The participant asked the researcher, *“What would you do if you were in my situation?”* The researcher responded by saying, *“That is a very difficult situation to be in, and one that I would find hard making a decision. Perhaps we can discuss this further when the interview has finished?”* This response acknowledged the difficulty faced by the participant and showed empathy. However, the researcher was aware that engaging in a discussion about this topic could change the interview’s focus.

4.6.2.6 Cathartic Interviewing

Any interview is sensitive because disclosing information about the self renders the respondent vulnerable to emotional turmoil (Drury, Francis & Chapman, 2007). Qualitative researchers encourage participants to provide rich data by eliciting underlying emotions and listening intently to participants’ utterances. Despite the potential for participants’ upset or distress, cathartic disclosure can be a revelation or prompt a new understanding of past or recent events (Birch & Miller, 2000). The researcher should create a space in which a participant can relive difficult emotions, providing relief and reinforcement of participants’ experiences (Ashton, 2014).

Holloway and Wheeler (2010) suggested that research interviews can be cathartic. Birch and Miller (2000) used the term ‘therapeutic’ to represent a process (which is sometimes emotional) by which an individual reflects on and comes to understand previous experiences in different ways, promoting a changed sense of self with new understandings. Qualitative interviews involve disclosing aspects of the self, revealing intimate personal experiences in the presence of an effective listener. Allowing

participants the space to reflect on, re-order, and give new meanings to past experiences is the essence of an effective qualitative interview (Sammut Scerri et al., 2012). Moreover, social theorists have highlighted the merits of expressive culture, appreciating the value of expressing feelings and not keeping them bottled up (McLeod, 1997).

Cathartic change, according to Rose (1991), requires the resolution and release of repressed emotions. In this study, having developed an interview guide prior to data collection allowed the researcher to anticipate the likelihood of emotional responses and to adequately prepare for them. This gave rise to the creation of an ethical protocol for dealing with distress (Appendix 2), which could be implemented to protect participants in the event that upset did occur. Indeed, some participants did become upset, but all agreed to continue and found being able to express emotion and discuss their role as carer as cathartic. One participant spoke about agreeing to participate in the research, as it was a chance for her to talk about herself: *“This is the first time anybody has ever actually asked me about me, because any time anybody comes in the door it’s ‘how is your Mum,’ but nobody has ever said ‘how are you, Elizabeth?’”*

How researchers deal with distress and emotional situations is based on personal style. Much has been written on how researchers should deal with such events (Ashton, 2014; Hewitt, 2007; Walls et al., 2010). Roulston, deMarrais, and Lewis (2003) advised that if researchers become uncomfortable dealing with participant emotions, changing topic can be a useful tactic, but they cautioned that this may be a lost opportunity for knowledge to be gained. In one case, the first author acknowledged a participant’s upset by saying, *“I see that you are upset, would you like to take a break from the interview for a while?”* Mitchell (2011), however, encouraged acknowledging the participant’s upset by maintaining eye contact, and attempting to talk through the issue. Emotions expressed during an interview enhance our understanding of the participant’s experience and are as epistemologically beneficial as other data, allowing the researcher to enter into the life-world of that person. Hofmann (2007) advocated for a greater emphasis on reporting, expressing and understanding of emotions during interviews, to increase sensitivity to such situations and yield more meaningful interpretations of data.

4.6.2.7 Concluding the Interview

After an interview, Ashton (2014) advised allowing participants time to regain composure and to allow for feedback and discussion. Emotional interviews also can affect the

researchers' physical and emotional health (Dunn, 1991) and leave them emotionally drained and burned out (Geerish, 2011). Hammersley and Atkinson (1995) noted that researchers conducting sensitive interviews rarely leave the field unscathed. Preparation and planning for such events is imperative. Researchers should plan for self-care and informal support networks (Hallowell, Lawton & Gregory, 2004).

Disengaging from the research field may be more of a process than a single event, particularly if the study involves repeat interviews with participants. Participants' involvement in research may have lasting effects on them, particularly after discussing sensitive topics. In addition, participants and researchers may become close through the passage of time. Researchers attempt to construct a social relationship of reciprocity, friendship, and shared understandings, in an effort to uncover a deep meaning of the topic under investigation (Birch & Miller, 2000). A blurring of boundaries may occur, whereby participants may see the researcher as a friend, which may be a reason for concern. Burns (2000) suggested withdrawing gradually, returning to participants during the write-up and analysis stages to recheck and clarify points before finally concluding the research relationship.

Corbin and Morse (2003) reported that no evidence had emerged that participants have suffered negative long-term effects or have been referred for counseling as a result of being interviewed, and that anecdotal evidence suggests that interviews are more beneficial than harmful. That being said, participants should be afforded the opportunity for feedback and discussion of their feelings on completion of an interview (Murray, 2003), spending time discussing the interview experience and the impact it may have had on them. Sammut Scerri et al. (2012, p.107) also advocated debriefing with participants on completion of sensitive interviews, to "help the participant back to a normal state of arousal from the intensity of the interview." The researcher is responsible to identify additional support needs and provide contact details on sources of support as required.

One of the final questions asked by the researcher during interviews was, "*What is good about being a carer for someone dying with dementia?*" Interviews conducted on this topic have the potential to focus only on the negative aspects of being a carer, and refocusing on the positive aspects of their caring role allowed for a positive ending to the interview. Not all participants identified many/any positives, but the majority did identify good points, such as feeling good about being able to fulfill a promise to care for their

loved one at home, having the opportunity to get to know their family member better, and doing what felt right by them and for them in their time of need.

4.6.3 Bracketing

A fundamental challenge for any qualitative researcher is to explore how their experiences and assumptions influence the development of knowledge. Bracketing (epoché), which originates from Husserl's descriptive phenomenology, prompts researchers to set aside their own understandings and assumptions in an effort to allow the phenomenon under investigation to speak (Crotty, 1996). Bracketing interviews are often employed to explore the impact of the researcher's personal and professional experiences during data collection and analysis. Husserl's bracketing proceeds through a series of reductions with each reduction intended to lead the researcher away from their own preconceptions or assumptions and ultimately leads back to the essence of the experience of the phenomenon (Smith, Flowers & Larkin, 2009). As previously discussed in section 4.1.4, Heidegger rejected the notion of bracketing claiming that one cannot separate description from one's own interpretation and believed that preconceptions or 'fore-structure' is essential to understanding how individuals experience a phenomenon differently.

Smith, Flowers & Larkin (2009) advocate the use of bracketing in IPA research. By bracketing, the researcher temporarily suspends prior knowledge and actively listens to the participant describing their individual reality (Hamill & Sinclair, 2010). A great degree of reflexivity and bracketing of assumptions was required of the researcher by virtue of being a registered general nurse, with knowledge of the dementia disease trajectory and of palliative care. During the interview process, Smith, Flowers & Larkin (2009) encourage the researcher to leave his/her research world and come around the hermeneutic circle into the world of the participant. Bracketing can be achieved by listening intently to the participant's words, and thereby suspending the researcher's own pre-existing concerns, beliefs or opinions. An opportunity exists to reintroduce the researcher's personal interpretations and opinions as s/he passes back around the hermeneutic circle once the interview is concluded and the researcher leaves the interview setting (Smith, Flowers & Larkin, 2009). The implications for this research was that data was collected and analysed in ways that did not prejudice the subject matter (Crotty, 1996), which assisted the researcher to objectively explore any hidden or blind assumptions she may have had. According to Myerhoff & Ruby (1992) bracketing also

requires an ability to reflect on oneself, the supportive environment and reflective skills, however Ahern (1999) suggests the use of reflective diaries and journals to aid this process. Memos and reflections were detailed immediately after each interview, with the intention to document initial thoughts and feelings for discussion with the supervision team.

4.7 Data Analysis

Qualitative data analysis is an intricate process, primarily research led with no rigid rules for analysing and presenting data, but rather a proposed direction (Frogatt, 2001; Polit & Beck, 2004). A variety of approaches exist dedicated to analysing qualitative data, and is dependent on the philosophical underpinnings of the approach adopted (Jacelon & O'Dell, 2005). The purpose of data analysis within research is to provide structure, systematise, and extract meaning from a great deal of raw information (Polit & Beck, 2004).

For many novice researchers, the most complicated step in the research process is that of analysis (Leech & Onwuegbuzie, 2011). Knowing which analysis to use with different types of research questions and various types of data can be very confusing. An overview of the theoretical assumptions underlying some of the more common approaches can be helpful in understanding what a researcher is trying to say about how data were sorted, organised, conceptualised, refined and interpreted.

Constant comparative analysis, originally developed by Glaser & Strauss (1967) for use in grounded theory, involves taking a component of data and comparing it with others which may be alike or differing in an effort to create conceptualisations of the possible relations between various pieces of data (Thorne, 2000). In many qualitative studies whose purpose it is to generate knowledge about common patterns and themes within human experience, this process continues with the comparison of each new interview or account until all have been compared with each other. Constant comparison analysis is ideally suited to grounded theory owing to its design which is specifically utilised to investigate those human phenomena for which the researcher adopts social processes to explain an aspect of human experience and behaviour. Thematic analysis, naturalistic inquiry, and interpretive description are methods which rely on constant comparative analysis processes to foster methods of understanding human phenomena within the context in which they are experienced.

Narrative analysis is an approach which recognises the impact and insight people's stories offer about their lived experiences. Analytic processes facilitates individuals' understanding and sense making about their lives by detecting the main narrative themes within the relayed participants' accounts about their lives. Verbalising experience with words, transforms the actual experience into a communicable representation of it. Therefore, the experiences themselves are not what the participants say, but are a culturally and socially constructed device for constructing shared understandings about them (Thorne, 2000).

Contrastingly, discourse analysis identifies speech not as a direct representation of human experience, but as an explicit linguistic tool constructed and shaped by numerous social or ideological influences. Discourse analysis strategies rely on theories developed from cognitive psychology and sociolinguistics in an effort to understand what is signified by the many ways in which individuals communicate beliefs. Critical inquiry is conducted into the language used and the manner in which it is used to uncover the societal influences underpinning thoughts and behaviours (Thorne, 2000). Therefore, although narrative analysis and discourse analysis both rely heavily on speech as the most pertinent form of data, their motives for analysing speech vary.

Not all qualitative methods are oriented toward uncovering commonalities and patterns within human experience, but instead search to reveal some of the core structure or essence of that experience through the intensive study of individual cases such as phenomenological approaches (Thorne, 2000). Cross comparisons are explicitly avoided in studies utilising these analytic methods and instead position the researcher toward the detail and depth which can be appreciated through a thorough, systematic, and reflective analysis of experiences as they are lived. The researcher is challenged to set aside or "bracket" any preconceptions in an effort to work inductively with the data to produce new conceptualisations and descriptions. For instance, Giorgi's work on descriptive phenomenology (from the Deschene School) has resulted in a phenomenological approach that provides a set of manageable stages and processes for analysing data and are a frequently occurring reference sources among phenomenological nurse researchers. Ethnographic analysis adopts an iterative process in which cultural ideas arising during active involvement "in the field" are transformed, translated, or represented in a written text. Sifting and sorting through elements of data to identify and interpret thematic

categorisations is required as well as searching for contradictions and inconsistencies to finally generate conclusions about what is occurring and why (Thorme, 2000).

4.7.1 Analysing Data using IPA

Smith, Flowers & Larkin (2009) contend that the core of IPA rests in its analytic focus; that focus directs analytic attention to research participants' efforts to make sense of their experiences. The analysis moves from "the particular to the shared, and from the descriptive to the interpretative" (Smith, Flowers & Larkin, 2009, p.79). A sequential series of steps to analysis was developed by Smith, Flowers & Larkin (2009), however they caution researchers that while the stages are intended as a framework for analysis, they should be used flexibly and innovatively. Analysis using IPA shares similar attributes to those in other phenomenological approaches (such as Giorgi's descriptive phenomenological approach) whereby the researcher strives to produce a highly detailed, thorough and reflective analysis of a particular lived experience. However, data analysis in IPA also involves a process of engagement and rich interpretation involving both the researcher and the participant. This engagement, known as the double hermeneutic approach to analysis, requires the researcher to interpret and make sense of the participant(s) making sense of their world(s). To facilitate this process of meaning-making, IPA encourages researchers to engage with the hermeneutic circle, which is an iterative process involving moving between smaller parts of meaning to larger parts or the whole of the investigated phenomena or lived experience (Peat, Rodriguez & Smit, 2018).

Data analysis begins as soon as the first data is collected during the interview process and involves actively listening to, reflecting on what was said and clarifying meaning. All interviews were digitally recorded and initial data analysis commenced when the researcher returned to her car on conclusion of each interview. Notes pertaining to the interviews were made by the researcher which described the carer, where they lived, initial reflections on how the interview unfolded and any feelings generated from the interview (Fig 4.4). Memos were also recorded using the data management tool known as NVivo (QSR International Pty Ltd. Version 10, 2014) during interview transcription. Keeping reflective notes and memos assisted in reflexivity and also provided evidence from which the decision trail could be audited. Koch (1995) asserts that the trustworthiness of a study is established if the reader is able to audit events, influences and actions of the researcher from the beginning to the end of the research.

NVivo qualitative data analysis software was employed by the researcher as a tool for efficiency and support and not to surrender the hermeneutic task of data analysis to the logic of a computer. Notably, software such as NVivo also serves as a tool for transparency. This is achieved through NVivo's recording of data movements, coding of patterns, charting of conceptual groupings and thought progression making the stages of IPA analysis transparent and visible. This in turn allows for the production of an explicit, thorough and plausible audit trail in addition to the manual analysis undertaken.

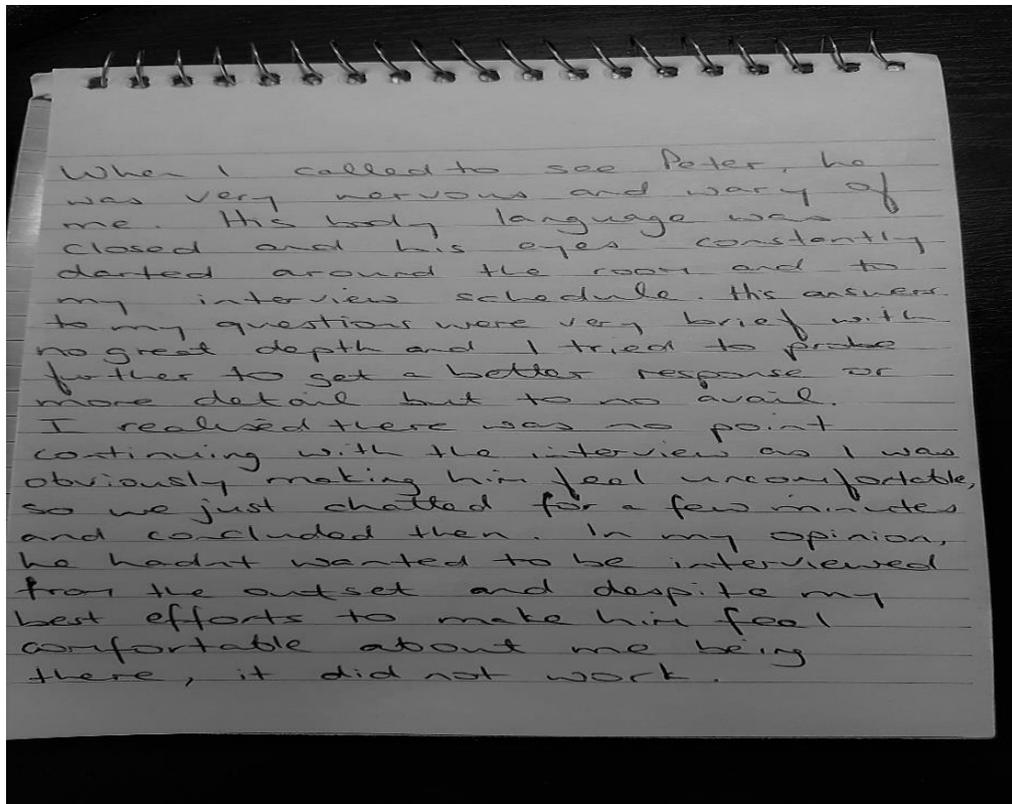


Figure 4.3. Handwritten memo following an interview

4.7.1.1 Step 1: Reading and Re-reading

The first stage of interpretative phenomenological data analysis advocates that the researcher immerse themselves in some of the original data and enter a phase of active engagement with the interview transcripts. After all interviews were transcribed, interviews were listened to a number of times while reading down through the typed text. This allowed the researcher to become very familiar with the data and to be transported back to the participants' kitchens and living rooms where the interviews took place. Transcripts were imported into NVivo data management tool. Additional reflective memos were recorded about the interview which may not have been captured from initial

notes made at an earlier stage (Fig 4.4). Making notes allows the researcher bracket off ideas or possible connections allowing the focus to remain on the participant and the data (Smith, Flowers & Larkin, 2009).

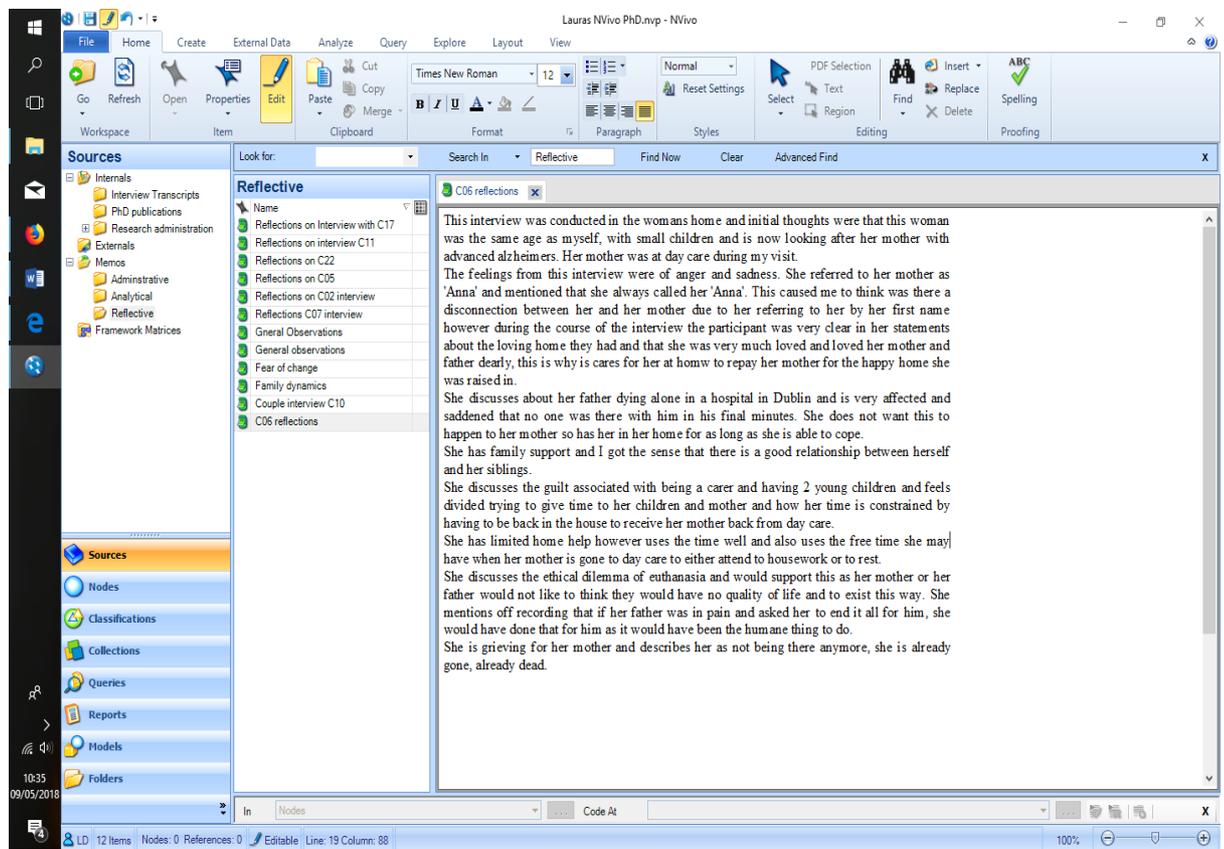


Figure 4.4. Example of a reflective memo from NVivo

4.7.1.2 Step 2: Initial Noting

Stage two of data analysis involves examining the language and semantic content on an exploratory level, whereby the researcher records areas of interest in the transcribed data. Initial handwritten notes are made on the transcript and the activity of re-reading the transcript several times allowed the researcher to remain close to the data adding further exploratory comments on subsequent readings. Three discrete types of comments were identified from the text: Descriptive comments, linguistic comments and conceptual comments. Descriptive comments have a clear phenomenological focus and remain close to the participant's exact meaning, which is, examining what the participant actually said. Key words, events, explanations and phrases used by the participant were noted as these structure the participant's thoughts and experiences. Linguistic comments examine participants' language and facilitates the analysis to consider the context of their concerns and identify more abstract concepts. Analysis at this stage involved noting emphasis

placed on certain words, repetition of words or phrases, pauses, laughter, specific terms used and tone of voice. Conceptual comments focused on engaging with the data at a more interrogative and conceptual level. This stage was more time consuming causing the researcher to reflect and refine ideas. In addition, this stage often prompted further questions where data had to be revisited, re-analysed or an attempt was made to make meaning from codes already identified in an effort to achieve answers to questions.

4.7.1.3 Step 3: Developing Emerging Themes

Developing emerging themes from the analysed data became the priority for the researcher during this stage of the data analysis process. The initial notes and comments became the focus rather than the transcript so that patterns, connections and interrelationships between exploratory notes could be mapped. The analysis moved away from examining the interview transcript as a whole, and instead concentrated on a set of parts to conduct the analysis. In order for themes to emerge, the researchers own interpretation of the participant's original words and thoughts were captured.

NVivo was utilised to create codes from the interview transcript. Codes aim to reduce the original data to descriptive phrases and notes (Table 4.4). This iterative process involved going through each transcript again several times to review the descriptive, linguistic and conceptual comments already written on the transcript, and then allocating a code name which would capture the 'units of meaning' and overall description of the content. Rich descriptive comments were attributed to each code providing coding transparency. Finally, reflexive and conceptual memos were added arising from the interview. 40 emerging themes were recorded from the interview transcript and in NVivo.

Phase 1 - Initial Noting & Coding 40 initial codes developed	Number of interviews in which code was present	Units of Meaning Coded
Support	21	786
Challenges	21	621
Burden of care	21	614
Coping strategies	21	553
Information	21	518
Struggle	22	505
Knowledge	21	459
Challenging behaviours	21	426
Frustration	21	306
Family impact	21	298
Control	21	222
Preparedness for the role	21	208
Grief & loss	21	200
Disconnect	21	191
Change in body function	21	189
Care for the carer	20	183
Role change	21	173
Dualism	21	149
Anger	17	138
Disembodiment	21	133
Examples of poor professional care	16	133
Financial legal affairs	20	131
Death & dying	19	127
End of life care	18	123
Contradiction	18	121
Time	18	119
Temporality	21	105
Benefits of caring	19	82
Personhood	18	58
Regret	15	58
Humour	18	41
Religion	15	41
Guilt	14	40
Fear	17	38
Benefits of good care received	11	36
Signs & symptoms	10	36
Stigma	12	35
Self-image	12	26
Therapeutic Interviewing	4	13
Risk taking	3	9

Table 4.4. Emerging themes from NVivo

4.7.1.4 Step 4: Identifying Connections across Emergent Themes

All 40 emerging themes were reviewed during this stage of the data analysis process and considered how they fit together to form subordinate themes. A mapping exercise was undertaken using post-it notes, whereby the researcher wrote the name of each emerging theme on a post-it and placed it on the floor. How themes related to each other were considered and physically moved around. Some emergent themes were discarded at this stage as they did not fit with the research question or any identified sub-ordinate theme.

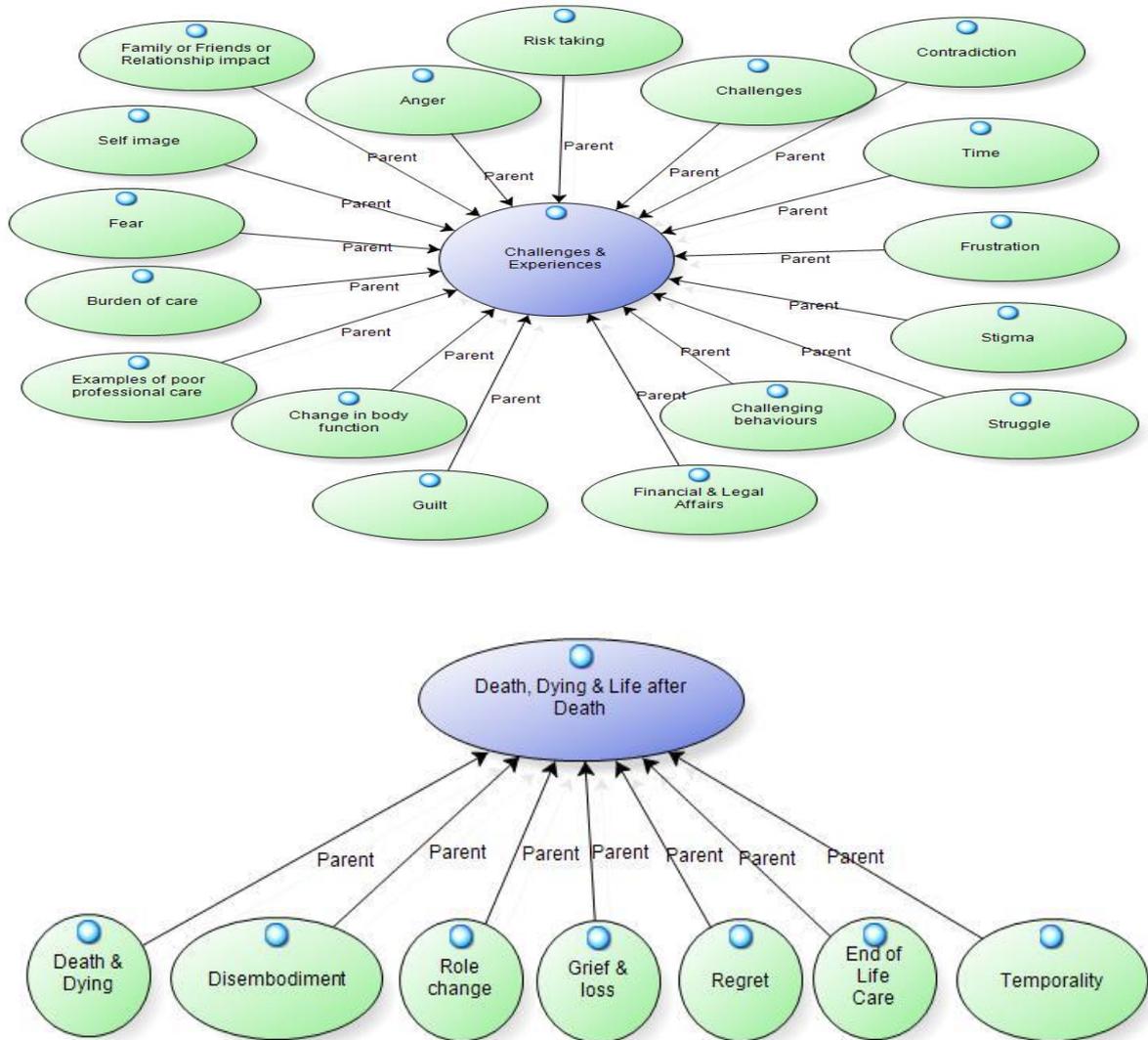
Smith, Flowers & Larkin (2009) advocate using a series of approaches to search for patterns and connections between emergent themes such as abstraction, subsumption, polarisation, numeration, contextualisation and function. Several of these processes were employed to search for connections between emergent themes. Abstraction allowed the researcher to identify sub-ordinate themes by clustering together similar themes and renaming this cluster. Subsumption operated when an emerging theme became a sub-ordinate theme by grouping together other related themes. Polarisation involved considering opposite themes while the frequency of a theme was supported and also noted by numeration. It is noteworthy however that despite a theme appearing numerous times throughout the transcript, this did not indicate its overall importance as other themes were found to be of greater importance on occasion despite being only in evidence once.

NVivo afforded the researcher the opportunity to reorganise codes (themes) by grouping the related codes (themes) under eight categories (sub-ordinate themes) and order them into a framework to further the analysis of the data set and address the research question (Table 4.5, Fig 4.5a & 4.5b).

Phase 2 -Developing Subordinate Themes - initial codes mapped and collapsed to 8 subordinate themes	Number of interviews in which code was present	Units of Meaning Coded
The Experience of Caring	24	1708
Anger	15	72
Burden of care	20	146
Challenges	17	102
Challenging behaviours	12	35
Change in body function	20	151
Contradiction	15	96
Examples of poor professional care	16	117
Family or friends or relationship impact	21	275
Fear	17	42
Financial & legal affairs	20	170
Frustration	20	137
Guilt	14	42
Risk taking	7	17
Self-image	11	25
Social isolation	10	28
Stigma	15	45
Struggle	18	90
Time	19	117
Information	20	887
Information	19	364
Knowledge	17	329
Preparedness for the role	18	144
Signs & symptoms	11	36
What was known about dementia	9	13
Parenting the Parent	24	875
Care for the Carer	17	75
Control	20	160
Coping Strategies	23	568
Personhood	17	63
Death, Dying & life after Death	24	697
Death & dying	18	112
Disembodiment	20	101
End of life care	18	111
Grief & loss	19	127
Regret	14	37
Role change	20	135
Temporality	19	73
Support	24	632
Family support	22	119
Financial support	6	18
Professional support	23	410
Other support	17	58
Support groups	10	26
Dualism	22	181
Disconnect	20	96
Dualism	16	84
Positives	21	145
Benefits of caring	19	80

Benefits of good care received	12	30
Humour	13	27
Therapeutic interviewing	3	6
Religious influence	15	42
Religion	15	41

Table 4.5. A tabular representation of the structure of the emerging themes and sub-ordinate themes



Figures 4.5a and 4.5b Example models of emerging sub-ordinate themes in NVivo

4.7.1.5 Step 5: Moving to the next Case

In previous stages, each participant's transcript (also referred to as a 'case') was analysed individually, treating it as distinct from the one that went before. The next step of data analysis involved moving to the next participant's transcript and repeating the process. Tensions arise for researchers between bracketing preconceptions against using them as insight (Finlay, 2008). Smith, Flowers & Larkin (2009) identify the difficulty in bracketing the ideas that came from previous cases while analysing the next, however bracketing is in keeping with the methodological idiographic element, therefore every effort was made to keep this commitment. By engaging in reflexivity, the researcher was able to identify any preconceptions by bringing them to the fore and then attempted to set them aside by documenting them in reflective memos. These were then revisited throughout the data collection and analysis process. Systematically following the steps of data analysis ensures rigour and allow new themes to emerge from subsequent cases (Smith, Flowers & Larkin, 2009). Themes which emerged from other cases were then added to the existing codes in NVivo.

4.7.1.6 Step 6: Looking for Patterns across Cases

The final stage of the analytical process involved reviewing all 40 emergent themes, looking for connections across all cases, identifying prominent and frequently occurring themes and grouping similar themes together (Fig 4.6). Some theme names were revised as a result of reconfiguring certain themes. This process of further consolidation and merging of codes reduced the number of initial codes from 40 down to eight sub-ordinate themes (Fig 4.6).

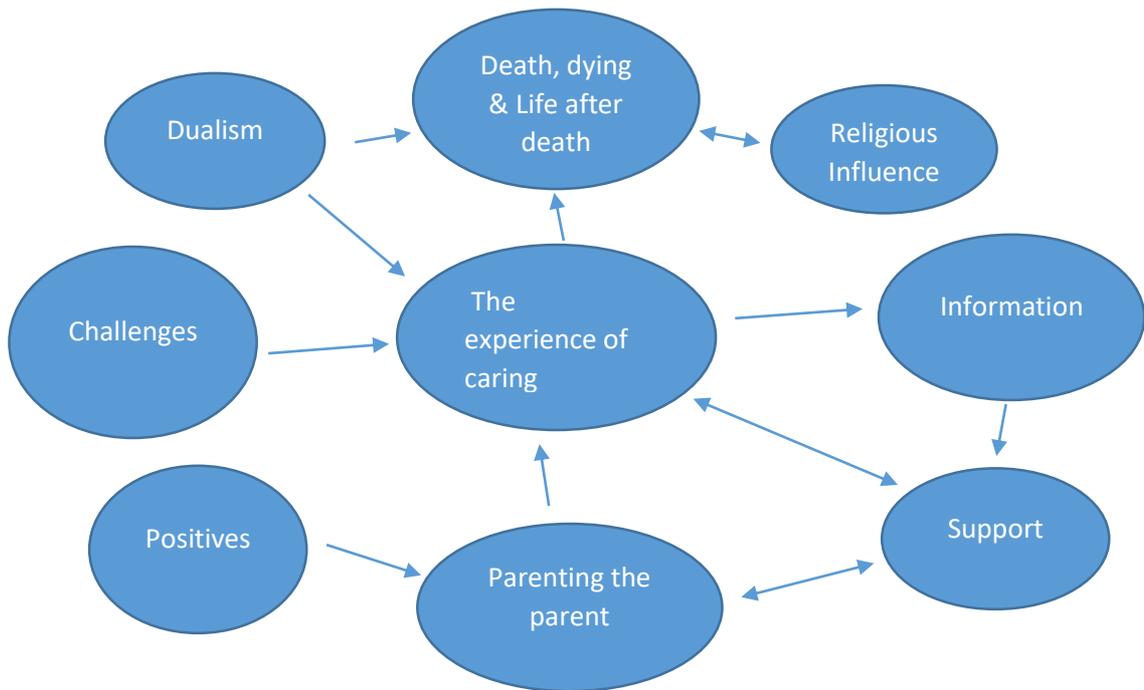


Figure 4.6 Mapping 8 emerging sub-ordinate themes and how they relate to each other

One final review of patterns, connections, and frequently occurring themes facilitated a theoretical level of analysis whereby instead of looking at the analysis from the part to the whole, this is now reversed and the whole is reviewed in terms of each part. The recurrence of themes was also considered. Smith, Flowers & Larkin (2009) contend that for a super-ordinate theme to be classed as recurrent, it has to be present in more than half of the cases and ideally across all cases. Four final super-ordinate themes were identified (Fig 4.7, Table 4.6).

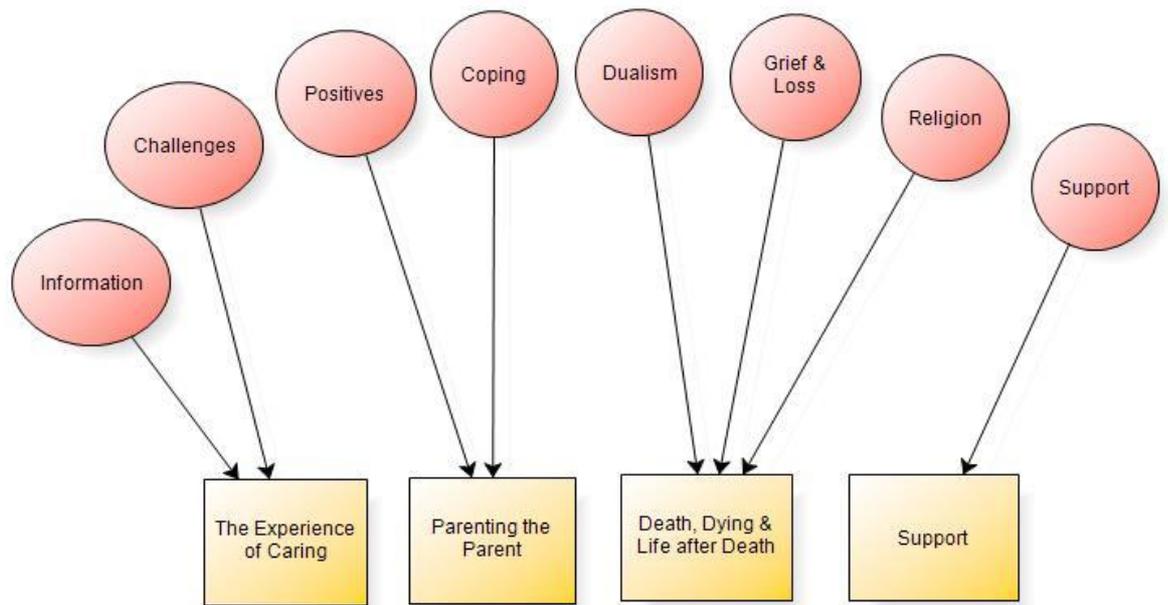


Figure 4.7 Eight sub-ordinate themes and four super-ordinate themes

Phase 3 - following in case & cross case analysis - 8 sub-ordinate themes were consolidated to 4 super-ordinate themes	Number of interviews in which code was present	Units of Meaning Coded
The Experience of Caring	21	1708
Parenting the Parent	21	875
Death, Dying & Life after Death	21	697
Seeking Support	21	632

Table 4.6. Final four super-ordinate themes showing interviews coded and units of meaning coded

Data analysis involving a large sample size was not without its challenges. As well as the time required to analyse each single case, the researcher was committed to produce not only a ‘good enough’ analysis of each participant’s experience but also a detailed analysis. Emergent themes were identified for each case and then patterns and connections were examined for all cases. NVivo allowed in case and cross case analysis of themes across all cases. This facilitated measuring recurrence of themes across cases and evidenced when super-ordinate themes were present for each participant.

4.8 Ensuring Quality

Qualitative research should be assessed in relation to criteria applicable to it instead of criteria used for reliability and validity as applied to quantitative research. Smith et al. (2009) focus on the criteria proposed by Yardley (2000), who presents four principles to ensure quality in qualitative research.

4.8.1 Sensitivity to Context

A thorough literature search and subsequent review of the literature was undertaken in order to describe and critique the relevant literature and previously conducted empirical work in the areas of dementia, end of life care and caregiving. From this initial phase of the research study, a literature review was published which formed publication 1 in this thesis.

A central objective is to question and highlight concepts and assumptions which mould our uninformed explanations and observations (Harding & Gantley, 1998). Thus, qualitative researchers should possess a well-developed grounding in the philosophy of the approach adopted. In order to accomplish this, the researcher attended workshops, and received training and education on various aspects of methodological relevance to provide the scholastic tools to undertake analysis. The researcher attended workshops on IPA facilitated by experts in the field, and on developing interview guides for IPA data collection. In addition, training was received on interviewing and on using NVivo to manage interview data.

The socio-cultural context of the interaction between the researcher and participant is vital to ensuring quality is maintained in a research study. Yardley (2000) contends that sensitivity to the linguistic and dialogue contexts of the participant's words is key to interpreting its function and meaning. The researcher adopted the role of active listener during the interview process paying close attention to each utterance and interpreting what the participant was saying from the start of the interview. Consistency in this study was maintained by being mindful of the research question. All interviews commenced with the same open-ended questions in an attempt to ensure consistency in the process of the data collection (Polit, Beck & Hungler, 2001).

During the pilot interviews, the researcher was afforded the opportunity to rephrase questions which may have appeared unclear or ambiguous, thus reducing the potential risk of misinterpreting what was said by participants. In an effort to maintain rigour, Yardley (2000) advises interviewers to keep a cautious balance between closeness and separateness and to be consistent when probing, paying attention to key cues from participants and delving deeper. Recording all interviews and writing notes immediately after each interview also ensured that the participants' exact words were retained which increases reliability when conducting the analysis phase of this research. Notes and memos were utilised for the purpose of the researcher making mental notes to herself, highlighting areas of key significance in the interview, which also proved beneficial during the analytical phase of the research process.

A detailed and interpretative analysis depends on the conduct and qualities of the researcher and how these effect the balance of power during the interview process (Yardley, 2000). Building an effective research relationship is initiating a rapport-building process from the outset, which will facilitate access to a participant's narrative (Dickson-Swift et al., 2007) by helping participants feel at ease to disclose sensitive information. A strategy to ensure that the researcher – participant relationship is non-hierarchical is helped through reciprocal sharing of personal stories by both participant and researcher (Liamputtong, 2007). This creation of a level playing field enhances rapport as well as showing respect for participants and validating their stories.

4.8.2 Commitment and Rigour

Commitment embodies the researcher's continued engagement with the research topic and the acquisition and advancement of skills and competency in the methods used. At the outset of this research study, knowledge deficits were identified in relation to methodological content, data collection techniques and analysis skills. The researcher then and sought the expertise of specialists and experts in the areas to achieve the required level of competence required.

Rigour within a research piece is concerned with demonstrating a precise portrayal of the participant's descriptions (Thomas & Magilvy, 2011) and is the terminology of choice in the context of representing integrity in qualitative research. To establish rigour the researcher needs to demonstrate the appropriateness of the selected sample, the quality of the interview and the completeness of the analysis undertaken (Yardley, 2000), thus

ensuring accuracy and confidence in the findings. Data analysis was conducted thoroughly and systematically with sufficient idiographic engagement. The researcher conducted a manual analysis of the data and then a further analysis using NVivo software to ensure codes identified were accurate. This duplication of data analysis was time consuming however it allowed the researcher to become thoroughly familiar with each participant's transcript, have a clear understanding of the process of reorganisation and reduction of themes / codes and present a clear interpretation of what the analysis meant.

Remaining true to IPA, reliability was maintained by following an iterative process whereby transcripts analysed at the outset were revisited and checked with transcripts analysed during the latter stage of the data analysis process. This ensures that coded themes are consistent throughout. de Visser et al. (2015) advises that all interpretation should be evidenced in the raw data therefore a large number of direct quotations from the study participants and the researcher's interpretations of these quotations are presented in the findings chapter.

4.8.3 Transparency and Coherence

Patton (2015) maintains that external checks are essential in maintaining the credibility and dependability of a study. The involvement of a research supervisor who provides advice throughout the research study's trajectory further amplifies dependability (Tobin & Begley, 2004). The researcher engaged the support of her primary supervisor throughout all phases of the research process and met annually with her graduate research committee to discuss progress, set aims for the following year and allow the graduate research committee to provide expert opinion on any issues raised by the researcher.

To assist with transparency, the researcher endeavoured to describe each stage of the research process clearly in her final report of the study, detailing her sampling strategy, illustrating her interview schedule, and the process used during interviewing. Screen shots and tables were additionally included to demonstrate the steps used during data analysis.

4.8.4 Reflexivity

Reflexivity involves openly reflecting on how our experience of the world is profoundly influenced by our assumptions, intentions and actions. Yardley (2000) advocates for researchers to consider how the aforementioned factors may have impacted on the process and product of research. The researcher is a registered nurse with previous clinical experience caring for people with dementia and is also a third level lecturer who facilitates student learning on end of life care, resulting from which, arose the motivation to undertake research in the area of end of life care for those with dementia.

The purpose of conducting interviews with participants was to collect data of a personal and somewhat sensitive nature, therefore, the researcher felt it was important to disclose some information about herself at the outset of the data collection process. The researcher's name, contact details, professional qualifications and current role in education was included in the participant invitation and information letters so that participants had some knowledge of who the researcher was before they made a decision to participate in the research or not. The researcher was aware that including these professional details may have positively influenced participants to take part in the study. Dowling (2006) highlighted the difficulties in separating the nurse from the researcher and contends that participants may consent to partake in research studies as a result of being a healthcare user, or in this case, the carer for a healthcare user.

Another reason for detailing information about the researcher's professional background on participant information and invitation letters was that it felt appropriate for participants to know who they were inviting into their homes. This target population was deemed a vulnerable group in society due to the sensitive nature of the enquiry (Liamputtong, 2007) therefore, it was important they had some knowledge of who the researcher was prior to consenting to participate in the research.

During interviewing, the role of the researcher is that of data collector, however given the researchers prior nursing and educational knowledge, it was difficult to shed this information and enter the field with a blank curriculum vitae (Johnson & Macleod Clarke, 2003). As previously discussed earlier in section 4.6.2.5, sustaining an impartial data gatherer role is difficult, and nurses with experience and training will draw on experiential knowledge and answer clinical questions, discuss concerns with participants, and refer on if required. Equally, nurse researchers can draw on experience to spot signs of distress

(Ashton, 2014). During two interviews conducted, participants experienced some upset and began to cry. The researcher referred to her distress protocol (Appendix 2) and offered the participants the opportunity to pause or discontinue the interview, however on both occasions, the participants requested to continue on. In the clinical setting, nurses frequently encounter patients or family members who are upset and use their nursing and experiential knowledge to manage these situations effectively by empathising with the person and offering reassurance and comfort as required. In the case of the research participants who became upset during the interview, the researcher was able to utilise her prior nursing knowledge and experience and offer this same support and reassurance by acknowledging the participants upset and allowing them time to cry and voice their feelings on the topic being discussed at that time. The researcher felt comfortable with the situation which facilitated free flowing conversation despite the upset experienced by the participant.

Etherington (2004) affirmed that researchers are intimately involved in both the process and the product of research, but to maintain credibility and objectivity, the researcher is required to be reflexive and aware of influences on the researcher's internal and external responses as well as the relationship to participants and the research topic. The researcher is obliged to self-reflect (Carolan, 2003) or to self-critique, explaining how his/her own experiences, values, beliefs, and perceptions have or have not influenced the research process (Koch & Harrington, 1998). Reflexive notes and memos were recorded by the researcher throughout the research process detailing thoughts, assumptions and opinions experienced prior to, immediately after data collection and throughout the data analysis phase. The researcher's supervisor was also a valuable asset to the researcher to discuss issues which arose and to also ensure the research was not influenced by the researcher's pre-suppositions.

Further issues pertaining to reflexivity are discussed at the end of the findings chapter in section 4.2 Reflection on Research Findings.

4.8.5 Impact and Importance

The impact and utility of any piece of research is the decisive measure on which it is evaluated. The worth of a piece research can only be judged according to the objectives of the analysis, its intended purposes and the population for whom the results were considered pertinent (Yardley, 2000). Despite this study involving a small homogenous

sample from the West and North West of Ireland, it is unique to the Irish context, and the papers already published from this study may have a wider impact not just in terms of its findings but also in terms of methodological guidance on sensitive interviewing. Most notably, this study opens up new ways of understanding the topic of caregiving in the home to those with end stage dementia. Finally, this qualitative study which employs the methodology of IPA can complement the existing body of empirical research in this area.

4.9 Summary

This chapter provided a brief overview of qualitative approaches to research before presenting a detailed description of the selected methodology, IPA, and how this methodology relates to phenomenological hermeneutics. A discussion on sampling followed with the specific issues encountered accessing the sample illuminated. Detail was offered on using interviews as a data collection tool and specific focus was given to the steps of data analysis which is unique to IPA. Finally, the importance of adhering to research ethics with a potentially vulnerable population and maintaining rigour was discussed. The proceeding chapter presents the findings of this research study which forms publication 3, followed by a discussion of these findings.

5. Results

This chapter presents the findings of the study. The findings are presented in chronological order, depicting how the story was told by the research participants, who described their caregiving journey from the initial stage of assuming the role of main carer, through to the final stage of care provision. Verbatim comments are presented to evidence the double hermeneutic of the experience of caregiving. During transcription, the use of [] indicates that part of the participants' transcribed conversation that has been omitted. This was non-relevant narrative and omitted to aid coherence. The experience of providing care to a person with late stage dementia can be a protracted and difficult journey. The challenges of providing care to a person with late stage dementia at home was the overarching theme to emerge from the analysed data. However, the challenges were abundant and varied depending on where the carer was situated within the caregiving trajectory.

Table 5.1. Four Super-Ordinate Themes and their Corresponding Sub-Ordinate Themes

Super-ordinate Theme 1	<p>1. The Experience of Dementia Grief</p> <p>1a. Questioning the self and their own sanity</p> <p>1b. The struggle to care</p> <p>1c. Burden of Care</p>
Super-ordinate Theme 2	<p>2. Parenting the Parent</p> <p>2a. Conflicted parenting</p> <p>2b. Quality of care</p> <p>2c. Parental guilt</p>
Super-ordinate Theme 3	<p>3. Seeking Support</p> <p>3a. Support in the form of information</p> <p>3b. Accessing formal support and services</p> <p>3c. Informal support: A help or a hindrance</p> <p>3d. The need for social support</p>
Super-ordinate Theme 4	<p>4. Death, Dying and Life after Death</p> <p>4a. Regret at not discussing death and dying</p> <p>4b. Striving for a good death</p> <p>4c. Life after death</p> <p>4d. Already grieving</p>

Super-Ordinate Theme 1: The Experience of Dementia Grief

The experience of dementia grief	Caregiving status = Current carer	Caregiving status = Former carer
Challenges	442	203
Anger	27	27
Burden of care	89	22
Difficulty attending medical appointments	4	0
Fight for your rights	10	0
Going crazy	4	2
Medication administration	1	11
Your house is not your own	5	3
Challenging behaviours	23	2
Anxiety / agitation	8	10
Dressing and washing	16	1
Eating & drinking	19	7
Emotional	18	10
Hallucinations & delusions	16	3
Mobility	22	9
Money concerns	7	0
Pain	0	6
Physical impact of caregiving	13	2
Remembering the past	16	2
Repetition	13	0
Safety of the person with dementia	27	12
Sleep	19	7
Toileting	12	3
Verbal	25	11
Wandering	10	12
Change in body function	75	40
Contradiction	40	39
Examples of poor professional care	45	29
Family or friends or relationship impact	141	61
Fear	22	8
Financial & legal affairs	49	48
Frustration	51	28
Guilt	17	11
Risk taking	12	3
Self image	6	10
Social isolation	13	4
Stigma	27	10
Struggle	34	25
Time	48	31

Table 5.2. The experience of dementia grief codes and caregiver status

Table 5.2 highlights the many challenges carers experience while delivering care to a person with dementia in the home. These challenges mainly pertained to coping with behaviours that challenge, the burden of care and the impact the role of caregiver had on relationships with family and friends. Current carers, who were actively providing care experienced greater challenges than former carers.

1a. Questioning the Self and their own Sanity

Carers identified unusual behaviours, changes in personality and signs of dementia often years before a formal diagnosis was made. Despite carers reporting these concerns to other family members and medical professionals, they felt unheard, disbelieved and frustrated. Many carers expressed their discontent with medical professionals throughout the dementia disease trajectory, especially in the initial phase related to receiving support and a diagnosis of dementia.

Fiona: "I must be two years telling them but they didn't believe me. You know because you see things, you know your mother. [] Then I remember being at the doctor and I said 'I don't know, there is something not right' and he said 'you know now when she is in pain' but it wasn't, do you know, it was little things. But he put it down to old age [], then I went in to him, I had enough, [] and I told him that, that there was something not right. But eventually he had to, so he brought her in and it was vascular dementia".

Carers reported instinctively knowing there was something amiss with their loved one but found it difficult to articulate exactly what it was. Frustration was evident when other family members dismissed the carer's concerns. Ben describes how feeling under pressure to almost set a trap to catch his mother out in an effort to prove to his family that his concerns were justified

Ben: "They would deny it and it felt like I was putting her under pressure to find something wrong with her, when I knew there was something wrong with her but I couldn't find it and like everybody else was in denial about it but I could see her".

The physical signs of illness are often apparent however psychological signs are less obvious to those who do not know the person with suspected dementia as intimately as a carer. Emma described her mother's dementia as 'the elephant in the room', highly apparent to her but a reluctance of others to discuss or diagnose it

Emma: "I mean there were times when I felt like walking out that door and never coming back. I knew there was something wrong, but I just didn't know what it was. She was physically deteriorating. But looking back now and knowing what I know now, it was like the elephant in the room, it was so obvious".

Due to repeated disbelief by others and the enormity of their care giving role, carers felt overwhelmed and stressed, which adversely affected their mental health.

Emma: "They thought, they thought it was me. They thought I had Alzheimer's [] I couldn't go to the toilet on my own, I wasn't sleeping on my own, she was with me twenty-four hours a day, with no break, and deteriorating in front of my eyes, physically and mentally. And they were all looking at me as if I was exaggerating, as if I was going mad [] I really, I really found it very, very, very, very, difficult".

Ben: "It was unbelievable, at the beginning I don't know how I did it, I just don't know how I didn't crack".

Caroline emphasises her fear of 'going mad'

Caroline: "Okay, there were times when she was difficult, I won't say there wasn't. Jesus Christ there were times when I thought I was going to go mad".

Additionally, Emma acknowledges that she did feel her mental health was affected as a consequence of her care giving role, however had to struggle on to fulfil her obligations

Emma: "And looking back on it, I do not know how I didn't end up myself, crazy. I was there, believe you me, but you just had to get on with it, there's nobody to help you, you, just have to do it".

Emma reported feeling “*so exhausted, I burst out crying in the chemist*”, feeling like she herself was “*crazy, I was there, believe you me*” while Mary described “*cracking up*” however despite this, they struggled on to fulfil their care giving obligations.

Carers struggled with the enormity of their situation attempting to be all things to all people, that of carer, mother, problem solver and liaising with many individuals coming and going in their family home. The multifactorial role had adverse effects on a carer’s ability to cope resulting in feelings of concern for their own mental health.

Mary: “Sometimes I get so mithered it’s like good God! Do you know when you have mother at you and then you will have let’s say [] other kids coming in and then you have home help coming in and you are all the time trying to solve all these other things coming in on top of you [] You are dealing with too many people [] so many people, you get Jesus, I am going to end up with it myself”.

1b. The Struggle to Care

Carers experienced a struggle throughout the caregiving trajectory, with the initial care giving period posing the greatest challenges to current carers. Dementia is a very unpredictable disease with no two individuals experiencing the same symptoms. Current carers identified the challenging behaviours associated with the dementia disease trajectory as very difficult to cope with, partly because carers were not aware of how to manage these unpredictable and unexpected side effects. Carers describe the uncertainty of not knowing what to expect from one day to the next, exacerbating their struggle providing care.

Fiona: “You just go from day to day and you just don’t know what is going to happen. [] It is a tough and a hard job and you are on your own”.

The following extract illuminates the struggle faced by a carer who described providing care as “an impossible situation”.

Jack: “What I was trying to do was, how I’ll put it to you is like, I was trying to deal with an impossible situation that was developing before me that I knew nothing about”.

The struggle to provide care was compared to a battle between those in authority who sanction resources and the carers themselves. Current carers described their experiences of 'them versus us' whereby any support carers received was resulting from a battle with 'them'. Kate illuminates that unless carers seek additional support or resources due to changing needs, support is not voluntarily offered to them

Kate: "You have to fight, I have to fight for it, I had to fight for every hour that I got. And I'm not finished yet [] I'll keep fighting, I mean I'm getting the same hours now that I was getting two or three years ago. So I think it's time that somebody did something about this situation, not my situation but the people like me who are looking after people like this".

1c. Burden of Care

Carers frequently reported dissatisfaction with having to take on extended roles and additional responsibilities, such as managing medications for the person with dementia. The burden of caregiving was experienced by both current and former carers however unsurprisingly this burden was higher with the current carer cohort.

Aaron: "and even with the medication now they say to me, they say well it's at your own discretion, you can up it if you like, you know, and I said no I couldn't do that, you know, I can't, I have enough responsibility because, you know, it's all responsibility, [] I'm not going to start prescribing medication here as well, you know, I can't do that"

Already feeling over burdened by their caregiving role, carers were unwilling to take on additional responsibilities, identifying their lack of knowledge and training in the pharmacological and medical field.

Emma: "So I brought her up to get her throat checked, and the doctor said to me "oh she has a cyst on her thyroid", "keep an eye on that" says he. And I'm thinking "what! How in fairness am I supposed to keep an eye on that? I'm not a doctor, I'm not a nurse". [] I cannot watch a cyst on the woman's thyroid, I cannot keep an eye on that. [] they were depending on me far too much, I'm not a medical person, and I can't be expected to be".

This is echoed by another carer who along with a professional carer would alter medications for the person with dementia as required until the correct dosage was achieved. The carer acknowledged that medication administration was not part of the role of the professional carer but because both she and the professional carer knew the person with dementia well, they felt best served to adopt this extended role instead of medical professionals.

Caroline: "all the different meds but I was the one that was left. I wasn't a nurse, but I had to try and get the balance right [laughing] and [] the carers that came in, [carer's name], and she was fantastic. And we'd do it between us. Now it wasn't their job but we'd try and work out the balance. [] Sometimes I'd lie about the whole thing because it wasn't worth going into it. [] Because really they didn't want to know either".

Male carers living in rural areas also had farms to maintain as well as their caregiving role. This is illustrated below by the geographical locations of a fragmented farm, coupled with the lack of free time and freedom, which heavily impacts on the role of carer for Aaron and his role of farmer. Aaron refers to time frequently in this excerpt emphasising how care giving impacts on his free time and highlighting how time limited he is to accomplish his farm work within the constraints of time afforded to him

Aaron: "Because our farm is fragmented, I use half my time just driving, you know, and it's so frustrating like and you're thinking I'm on the farm, I'm doing a bit of work, but you're looking and you're checking, I don't even wear a watch anymore but I check my mobile phone and I see the time is like, oh I've only fifteen minutes left because I have to be on the road, I have to allow twenty minutes and that's hoping that there's nobody with a truck on the road or somebody pulling a digger or something and you're there oh I can't pass them out and I'm going to be late back, the carer has another call, I don't want to be holding them up and it's, it's, it's very frustrating, living your life totally by the clock [] This thing, it's soul destroying".

Other carers also described how the burden of providing full time care resulted in having to withdraw from full time employment, social activities and ultimately sacrificing their freedom. Carers had enforced restrictions on their time and on their freedom, thus

exacerbating to their sense of social isolation. Lisa depicted how her life no longer belonged to her, it belonged to her mother and providing care for her mother

Lisa: "Not being able to do your own thing, have your own life. My life is not my own. My life is centred around mammy. If I even want to go to mass [] or if I wanted to go to the carers meeting on a Tuesday, if I want to go there I have to have everything arranged. I have to have somebody in to mind her".

In an effort to engage in outside activities, carers had to plan and organise a replacement to take over caregiving in their absence. Caregiving impacts not only on the carer but also on family life, resulting in dramatic changes to the way a family previously functioned. Both current and former carers identified how their caregiving role negatively affected relationships with their family and /or friends however this adverse impact was highlighted as a bigger concern for current carers.

Alec: "The other thing I wasn't ready for and I don't know if I spoke much to you about this, but our family life was absolutely turned upside down. And we couldn't do anything without first thinking".

The impact caregiving has on free time was detailed by both current and former carers, with the greatest time issues experienced by current carers. Ava further emphasises the difficulties associated with the restrictions on a carer's time and how this impacts adversely on family time or time spent with the children

Ava: "I know if I was not minding my mother I would have more time, [] but summer holidays as well that's when you would find it the most with the kids [] you know if the weather is good and you go to the beach, you have to be home. [] That's when you would find it with the kids but my biggest hurdle, what I find the hardest is the emotional aspect of it just getting your own head around it and accepting it, you know, there is nothing you can do, you are doing all you can and that's it".

Super-Ordinate Theme 2: Parenting the Parent

This super-ordinate theme details findings of the challenges faced by carers during the middle stage of the care giving journey where the ability of the person with dementia to carry out most activities of daily living had diminished. From the table below (Table 5.3), both current and former carers' experiences suggests a role change which evolved where the carer became the person parenting the parent. However, this role change was most significant with current carers who had only recently or who were in the process of adapting to this new role change. Coping strategies were adopted by carers to help deal with the enormity of the situation they found themselves in, in particular current carers who were actively caring for a person with dementia. In the absence of specific training or education which was identified in theme one, carers used experiential knowledge and common sense to care for the person with dementia.

	Caregiving status = Current	Caregiving status = Former
Parenting the Parent	292	179
Care for the Carer	38	23
Control	93	48
Coping Strategies	247	152
Personhood	25	22

Table 5.3. Parenting the parent codes and caregiver status

2a. Conflicted Parenting

Out of necessity, carers took on an unconditional and somewhat conflicted mothering or fathering role. Carers experienced a role reversal which was a novel experience for them and one which did not sit comfortably with current or former carers. Ava recalls a difficult time during care giving when she had to constantly tell her mother what she could or couldn't do, speaking to her like a child who needed guidance

Ava: "Em, it's hard. It is hard, it's very, very hard, its, in the beginning its emotionally traumatic how I think would be the only way to describe it. I used to tell my mother don't do this, don't do that, you can't have this, you can't have that, please come back, sit down, stop and you are speaking to your parent in a way that you were never reared to talk. We were told what to do by our mum and

dad, you didn't tell them what to do, and it's very, very hard in the beginning just coming to terms with the change".

Aaron further illuminates the role change encountered when he took on the role of parent for his father. However, this carer positively adopts the reverse parenting role, advocating that the relationship between both men was much closer than before, evidenced by him describing how losing his 'son' will be harder than losing his father

Aaron: "I've lost my father a long time ago, what I'm about to lose is my son, you know, and it's gonna be probably even harder to take, you know what I mean. [Pause] I didn't, I didn't envisage this in the beginning, you know, and I suppose nobody could have told me".

Carers referred to the person with dementia as a child or a baby, with their behaviours akin to those of a child and enjoyed the closeness the role reversal brought.

Fiona: "and you know she is gone back to like a child and a baby and its nice and you are looking after her and as she said the other evening 'where is mammy' and I didn't know how to answer her. And she looked at me and she said 'oh you are there', you know [] It's nice that you are able to give it back because she was a brilliant mother".

Maureen described how her mother had cared for her parents and now there was an expectation that she would care for her mother, a prospect which she welcomed. If there was mutuality within the dynamics of the dyad relationship, the situation seemed easier, more manageable for the caregiver

Maureen: "It is not all bleak really. You do get very close to the person in a different way almost like a mother and baby closeness again. That is one good thing".

Many carers were parents themselves and reported that parenting their parent was not always a negative experience however for Aaron, the role of parent was a novel and challenging role

Aaron: "I was never married and I never had children of my own but I have one now, I said I've a ten and a half stone baby really, you know [] Basically I had become a single parent".

Caregiving frequently involves providing intimate care for the person with dementia. Some male carers described the discomfort experienced having to change incontinence wear for their parent. There is evidential discomfort partly because the carer did not envisage having to take on a care giving role for their parent and also due to the discomfort of a son having to undertake such an intimate care giving role for his parent. As a means of coping with this task, Ben disassociates from the person receiving the care

Ben: "and to come to terms with it, there were days when I had to change a nappy and I couldn't believe this was happening to me and in the first stages it was hard to actually do something like that but then you just do it, you have to, because there is nothing there".

Contrary to professional advice, carers used experiential knowledge when it came to coping and providing effective care for their loved one with dementia.

Aaron: "Some professionals would say like oh don't ever treat a person with dementia or Alzheimer's like a baby but unfortunately there actually comes a time when it's better to do so because I'm a firm believer that if the person, if you can, if it's possible for you to keep that person content and happy then you will have a greater degree of success when it comes to doing other work with him".

2b. Quality of Care

In an effort to manage the inherited role of caregiver, carers were able to cope with the situation if they felt in control. Control was evident in this theme, that is, caregivers' perception of either being or not being in control of their situation. There were indications of feeling out of control, not knowing where to turn to or what to do next and feeling overwhelmed by the circumstances. This was especially evident with current carers. Findings revealed that male carers had greater issues with remaining in control of their unique circumstances (Table 5.4).

	Gender = Male (n=7)	Gender = Female (n=15)
Control	73	68

Table 5.4 Control and gender

Examples were also evident of great efforts made to remain in control; control was sought regarding where and when the person with dementia went to respite, keeping the person with dementia at home until the end of life, medication administration, dietary requirements and the co-ordination of professional carers who assisted in the care of the person with dementia.

Like most parents, carers wanted to protect their loved one with dementia and maintain their health. There was an evident mistrust of health care staff, hospitals, care facilities and respite centres. Carers provided a high standard of care for the person with dementia at home; however, based on past experiences in clinical settings, they felt that the quality of care would diminish once their loved one with dementia left their home.

Kate: “I would not let him go anywhere because he wouldn’t survive. He wouldn’t survive a week in a nursing home or you know if he went into respite care or anything, he wouldn’t survive because they’re not going to spend an hour giving him his breakfast, an hour, two hours giving him his dinner and dessert and glass of wine, they’re not going to have time for that [] So he wouldn’t have survived. And I wouldn’t. And anyway, if he was in a nursing home I’d be in there from early morning till last thing at night”.

Kate demonstrated how she maintained control over her husband’s care by taking on the role of gatekeeper, only trusting certain professional carers to assist with her husband’s care. Kate prided herself on the excellent care she had delivered over the years to her husband, evidenced by detailing how his skin or physical appearance had never been compromised by poor quality care.

Kate: “I only accept the best. And even with carers, if they’re not suitable they don’t come in here. And he, I mean [husband’s name], has never had a skin tear in his life, you know he’s never had bruising, because the carers I have are just wonderful []. But I just wouldn’t tolerate it any other way [] I wouldn’t have anybody who wouldn’t treat [husbands name] properly”.

Similarly, Aaron echoed the previous sentiment believing his father would be in danger if he was cared for by someone other than himself. Carers also need to feel in control of care provision at home and when the person with dementia goes to an alternative healthcare setting such as respite. In an effort to remain in control of the care provided to his father and to also assist healthcare providers deliver person centred care while in respite, Aaron provided a care plan to staff, with the aim that staff would continue to provide quality care to his father while in respite

Aaron: "I prefer to look after him here because I firmly believe that he's safer here with me than in the hospital, believe it or not, and that's a sad reflection on our society that that's the way things have gone [] Even when he goes to respite, I worry all the time. I created a four-page document, I've a care plan, in the hope that they will follow it exactly as I've things stated, but they don't, they never do".

The mistrust of respite care facilities was evident as Lisa detailed inspecting the facility in advance of her mother availing of respite. In addition, the carer was fearful that her mother would not be cared for adequately and despite understanding the need to trust the healthcare professionals delivering care to her mother, she was unconvinced the care would meet her standards.

Lisa: "I'm thinking now maybe I might go before mammy goes in, that's awful [] Yeah well now they said it's alright to me but just before she goes, just to make sure that, you know, she will be safe. Even with [respite] like mammy goes on a Friday, I'm on the phone on Saturday morning 'Is she OK?' and I might go Wednesday to see her. That's sad. Now I have stopped doing that. [] It's like, you know, your kids when they're with you you're fine and then you think oh somebody else is minding them, they won't do this and they won't do that [] but no I've stopped that now. [] I might go".

In a subsequent extract Lisa illustrates her belief that her mother is alive as a result of the care she is receiving at home.

Lisa: "and I wouldn't at this stage, that I have got her so far, that I am not going to bundle her off to a nursing home now because I know for a fact that she

wouldn't survive, she wouldn't, so as I said, I have done it so long now, I am just going to continue on with it".

2c. Parental Guilt

Guilt is a complicated emotion, commonly felt in the landscape of caregiving. Carers often feel guilty for recognising a need in them which is exacerbated if the carer acts on this need. In the case of Emma, she described feeling guilty about 'everything' with the worst guilt experienced when she recognised a need for respite. Despite acting on this need, the carer's guilt was immense, resulting in her not receiving the benefit of a break from her care giving role.

Ellie: "Guilt, guilt, guilt. [] Guilty she was like that, guilty for getting annoyed, guilty that I was getting frustrated that I was repeating everything, guilty that I wasn't doing enough, [] that I couldn't understand her, that she was frustrated, [] just guilty about everything. [] Do you know when I felt most guilty? When I was putting her into respite. I felt dreadful for leaving. [] And I didn't get over it for days".

Two participants (a couple) also discussed availing of respite and the guilt attributed to leaving their loved one with dementia in a respite facility. As well as guilt felt intrinsically by the carer, the person with dementia added to this guilt with verbal comments detailing their dissatisfaction with respite however as the dementia disease progressed and the ability to communicate decreased, the guilt experienced by the carer also reduced.

Alec: "The first time I took her into respite, ah I felt terrible after because she was, you know, how could you bring me here?"

Isobel: "[his father] would never have done that to me".

Alec: "Yeah and you know 'I'm very cross' []. I felt terrible. But you know as time went on it sort of, you know she didn't make any comments, she'd come out with, 'have I been somewhere', so she couldn't remember".

Alec: "You know so it got easier as it went on but the first year of you know, year or two was very hard".

Carers reported feeling compelled to provide the best care they could reflecting the care they received as a child and subsequent guilt of not being able to meet those high

standards. Carers felt a sense of duty to look after their parents as best they could in an effort to 'pay back' for the great care they received as children.

Irene: "and sometimes no matter what you do you feel guilty that you don't do enough. You know, that you aren't, when you are not patient its very, you just feel guilty. Because you know they are your parents and they have been the best in the world you know. So, you just kind of, you feel guilty about that".

Caregiver burden coupled with guilt is evident in the following extract from Helen. This carer illustrates the impact the care giving role has on her and on her family, placing her mother in the centre of the family circle, with everyone else on the periphery. Time plays a big part in her feelings of guilt and how she is conflicted between meeting the demands of caring for her mother against the demands of being a mother and a wife.

Helen: "The focus has to be on the individual, okay, it has to be on the person, [] I see here with the kids and the family and with everything else, [] all our lives were just totally focused around mum and dad prior to that, you know. And you had no time for anybody else and any time you had for somebody else, you were feeling so guilty that you should have being given it that way. You're so divided".

Divided time and demands of care giving are also present in the extract from Ava who experienced feelings of guilt for not having adequate time to spend with her younger children due to time spent caring for her mother

Ava: "It can be hard juggling, [] the two girls are ten and nearly nine, [] they have clubs, they have activities that they want to do, and I know this is nothing to do with [mother's name] illness, [] it's hard because you have to have someone minding her []. And to be able to bring the kids, you have to go and do the activities. Again, emotionally, you feel guilty for your children. Are they missing out a little bit cause you spend so much time minding your mother?"

Super - Ordinate Theme 3: Seeking Support

Participants detailed the supports they received and identified the need for additional supports to assist with providing care to the person with dementia. Current carers mainly discussed the input of professional support services, such as professional carers who assisted with caregiving (Table 5.5).

	Caregiving status = Current	Caregiving status = Former
Family Support	58	42
Negative examples of family support	33	22
Positive examples of family support	26	21
Financial support	9	3
Professional Support	210	109
Negative examples of professional support	107	57
Positive examples of professional support	93	49
Respite	21	6
Other support	27	9
Support Groups	11	7

Table 5.5. Support codes and caregiver status

3a. Support in the Form of Information

Carers were asked what they had known about dementia prior to taking up their caregiving role and findings revealed that the majority of participants had heard of dementia and / or Alzheimer's disease but most did not know the specifics of the disease. Emma details "*I know nothing, and knew nothing [] wouldn't have a clue*", while Derek asserts that he knew "*not a lot, [] just that her cousin had it [dementia] down the road so she would have been a first cousin of hers*". Michael had an awareness of the disease and its prevalence stating "*I don't know what it is but it's something that seems to be getting a lot more common, you see it, it's all around you now*".

When asked where carers obtained information, the responses were varied. Mary reported "*getting booklets myself*", while Lisa found information on "*Google I suppose, Google or the internet*". Several carers demonstrated their use of the internet for the purposes of seeking or obtaining information to assist with caregiving. Maureen highlighted

"I do courses online all the time []. I haven't seen any programme that shows you actually the practical things on handling somebody who is bedridden. That would suit me much better than going away for a day to do it".

Carers frequently discussed feeling alone and had to develop coping strategies to deal with the situations they found themselves in. With limited or no training or education about the disease or requirements of the role, they had to figure it out for themselves.

Emma: "Well, everything that I have done, I don't know, does it come with age or what, it's just common sense. You do it like you'd do it for a child. If you knew nothing about children, [] I don't know, its trial and error".

Carers expressed their need for practical information to assist them in their caregiving role. Workshops and training were offered to carers however certain factors such as the location, financial costs, previous negative experiences and not being free from caregiving prevented their attendance. Emma draws a direct comparison to her mother's energetic state akin to a 'Duracell bunny' that possesses an abundance of energy however this is in contrast to the fatigue that she feels both physically and mentally.

Emma: "[] you can't expect carers to go to things because they can't get out of the house to go to them. For me, I would have liked a package, a written information, that this is what you might expect, these are the symptoms. [] If she is walking around the house like a Duracell bunny, it's part of it. It's it, it's not her. It's not me, something I'm doing wrong. It's the disease. [] You are going to get exhausted, don't feel guilty about it".

Specific information and training requirements were identified by carers which would facilitate with care provision. Emma detailed her need for information on the disease and its trajectory.

Emma: "I think what to expect, what it is, you're not going mad, you really are not going mad, [] that this is what you might expect, these are symptoms, there is such a thing as sun-downing. [] Just educate people on the simple things. [] Give it simple, in simple terms. They're likely not to eat. That can happen. They're likely to lose weight. Watch out for urinary tract infections. Watch out for constipation. [] I know nothing, and knew nothing I should say about that – bed bath – wouldn't have a clue. Again, there probably are ways to do it, but you just, trial and error. Yea, the same with feeding. What do you feed her? I don't know, its trial and error".

Equally, Mary identified not having received the necessary information to provide care for her mother and instead depended on her own intuition. Mary also highlighted her lack of knowledge regarding the stages of dementia.

Mary: “with dementia you don’t really get information, it’s just learning step by step and once one stage happens, [] you know the stages hit you but you don’t really know what you are going through and I think that’s the biggest thing”.

Emma offered suggestions as to what carers need to know in terms of the available supports and services which are available to carers.

Emma: I didn’t know how I was going to go about getting help, who to ask, where to go. I didn’t know there was a Carers Association. [] I think it could be explained an awful lot better at the beginning. Tell people what help is out there. [] Tell you where to go. Tell you what is available. Tell you there is such a thing is as an occupational therapist. [] Tell you there is such a thing as a District Nurse. Tell you there are people in a hospital you can go and speak to and ask questions of. I only found this out in the last couple of months, that if she was in hospital, there is actually a staff nurse I could go to, to speak to.

3b. Accessing Formal Support and Services

A recurrent theme was the inherent difficulty carers experienced accessing support and services for people with dementia. When information and support was obtained, it was usually late into the care giving journey, with carers highlighting needing this support at the outset. Carers frequently reported learning about services and supports by ‘word of mouth’ from other carers. Kate details how any information she obtained was as a result of her searching for it owing to the fact that no one offered it to her.

Kate: “I don’t think anybody suggested it to me, I think I just found out for myself. I don’t think any doctor recommended it or anything you know [] But nobody comes to your door and says you can get help”.

Social isolation contributes to the burden of care. Carers cannot freely leave their caregiving role unless a replacement has been arranged in their absence. As a result,

carers were unable to attend information workshops and depend on informed professionals to call to their house to provide guidance and support.

Emma: “No, everything, everything, I found that out, everything is a trade secret until you hear about it from some other person, outside, or some other carer, which I was only, you know, was lucky enough to meet those carers [] because I’m not out, I’m not meeting people, so I’m depending on the medical crowd, or the district nurse, or somebody to tell me what I need, or where to go, or what to ask for”.

The struggle to access support and having to fight for entitlements was illuminated in the findings. The extract from Emma below likens her struggle for support to a conspiracy to prevent her receiving assistance. There is a sense of urgency in seeking support however support was not advancing at a pace fast enough to assist with the existing burden of care

Emma: “When I was looking for help, home help, I found them so, so unhelpful, and they didn’t want to tell you anything. She kept saying “well what do you want?” And I said “I’m sorry now, I’m so new to this, I haven’t a clue what I’m even asking for because I don’t know what there is, or what I’m supposed to be asking for? [] And I said “I just want somebody to come in and let me out, to get messages” [] Oh, I can’t tell you how long it was now, because time is nothing, but I’d say easily a year and a half, maybe two years [] After three years, asking for help!”

Mary further emphasised that unless carers requested help and information, it was not forthcoming. However, it was apparent that even asking for help may not yield the required results and instead carers had to demand the required supports to assist with care giving.

Mary: “You have to be able to fight your corner because if you are not able to fight your corner I think [] you are going to be left”.

Ben illustrated the extreme measures taken to demonstrate his desperation and urgent requirement for support, threatening to abandon his mother outside local administrative offices responsible for supporting carers. Depleted by the enormity of his care giving role,

Ben used similar terminology to Mary depicting the battle to be heard and to receive the required help to provide effective care at home.

Ben: "There were stages right throughout the 15 years that were absolutely horrific it actually played on my brain, there was no support there in the beginning coming in, I didn't get enough support and I had to fight for a homecare package, I had to fight with them, I had to fight with them. I literally told the HSE [Health Services Executive] one day on the phone that if they didn't come and do something for me, I was getting a wheelchair and bringing her [his mother] up there and leaving her outside their door and do whatever they wanted with her because I couldn't do it anymore. I was burned out, totally burned out".

Financial difficulties were discussed by most participants, highlighting the struggle to obtain any assistance to improve the burden associated with caring for a person with dementia. Helen described her dissatisfaction and the difficulty completing documentation to apply for financial assistance.

Helen: "I applied for the carers' allowance, I had to stop work, I just couldn't continue, and I have never got that and probably never will either. It's just everything comes back, 'sorry, insufficient' and you fill it all out again. It's all so much time that you don't really have [], so you're either entitled to it or you're bloody not entitled to it".

Carers reported having to make necessary modifications to their homes to make it fit for purpose to care for a person with dementia. Emma further emphasised the financial difficulties attributed to caregiving and how this role has impacted on her financial status. While financial support is available for carers in the form of a carers allowance and grants to assist with home modifications, applying and asking for this support is a difficult process and has made Emma feel embarrassed having to ask for this vital support.

Emma: "I'm trying to get on to the council to see if they'll help me with a grant. It is just constant, I feel like a beggar. Yea, you know, so difficult to get carers allowance. You're struggling with money, you know, you're struggling trying to get out and get messages [groceries]. The basics. The absolute basics [] You know, it's just so difficult".

Carers rely heavily on the support given by professional carers or community supports in their locality. Availing of formal support services allow carers receive vital time away from their caring role to fulfil other obligations. Professional support was identified by both current and former carers as instrumental to the carer in providing care and despite experiencing negative encounters with some professional carers, overall, professional support was viewed as a necessary assistance to allowing the person with dementia being cared for at home. Current carers expressed the Aaron discussed how day care was deemed no longer beneficial for his father, disregarding the enormous benefit it was to him. The support was withdrawn but not substituted with another form of support

Aaron: "This time last year my Dad stopped going to the local day centre. They said it was no longer of any benefit to him. No, but it was of huge benefit to me because it was like ten/twelve hours a week of farming and I've been really, really under pressure in the last year []. That was huge because [] when the bus would pick my Dad up, [] I had until about half-past four in the afternoon to get work done. I often skipped dinner [] on those days to try to make the best use of that particular day".

Cillian also emphasised the importance of receiving a break and time off to attend to other matters. The freedom from caregiving was likened to a divine intervention highlighting how important that break was to this carer.

Cillian: "We had [carers] about three hours a day or four some days and then Wednesday was a God send, because the bus used to collect her and she was back at four so you'd have ten until four to farm and then in the evening times usually my sister just at the village there would mind her, and I'd come home".

Despite the burden of care experienced, carers frequently reported a willingness to continue on this care giving journey with adequate supports available to them and aspired to provide this care until the end of life. Having given so much of themselves both physically and psychologically, to cease providing care at this late stage to the person with dementia would seem defeatist.

Lisa: "I mean it's like, you know, doing a race and getting to just the end of the line and all of a sudden you don't cross that line. I don't want her to go into

anywhere now, I'd love to be able to do it myself, but will I get any more help than I'm getting?"

3c. Informal Support: A help or a Hindrance?

Family support was identified as an important assistance in providing care to the person with dementia however not all carers had family involvement. Without the assistance of family to help shoulder the burden, carers experienced an overwhelming sense of pressure and accountability to ensure that the care provided was effectual.

Helen: "I don't find it very fulfilling, I'm always terribly conscious of the responsibility, I'm terribly conscious of trying to do it right and do the best I can but I find it very wearing. I'm the only one you see. Which is the thing, you know, it would be different, if there was somebody else, I think it would be a bit easier all right".

Frequently carers reported sporadic involvement or no involvement from siblings in the delivery of care to the person with dementia. Several carers would like to have had 'hands on' support or acknowledgement from their siblings for the role they were fulfilling. Aaron describes his desire for consistent input from his siblings however while he expressed the desire for further practical support, there was a greater need for positive reinforcement and appreciation for the care he provided to their father from his siblings.

Aaron: "No, I had nothing, nothing, just myself for the first few years and one of my sisters who would be calling two or three times a week, my other sister at that stage was calling irregularly, now she'd call every Saturday. My brother always kind of distanced himself, we didn't get on particularly well, there was trouble when he found out about the will, [] we didn't speak for a couple of years [] All I ever wanted was just appreciation from my own family for what I've done".

In contrast, other carers identified family siblings to be a hindrance, often judgemental of the care they provided which failed to offer any beneficial assistance. Ben depicted how his sister came and "looked at her in the bed and that's about it" while Aaron highlighted his family's lack of involvement stating that "there's never been a weekend where they've taken him".

Grace also illuminated the need for family involvement to assist her cope with the enormity of the role. This carer felt family involvement was essential to her survival.

Grace: "More time from the family, [] they were more supervisory than hands on and one sister in particular, [] she works fairly reasonable hours []. She could have said to me, well, I'm going to be in town on Saturday, I'll take mum into town, or I'll take mum out to our place and give her her tea []. That would have been nice, just to give me a few hours to catch my breath".

Despite many negative comments about family involvement, there were many carers who did receive good support from other family members, friends or neighbours.

Mary: "I have an aunt, and mother was a nurse and all her sisters were nurses, [] they are all good at fighting their corner. I am no good at fighting my corner. And the equipment, the hoist and stuff like this and the commode, they were all going to be very slow in coming, and I think [] my aunt [] really went after the nurse and said now these have to be here or you are going to have to get her into a nursing home if they are not going to be in this house within a week because there is no point taking in someone. [] And she did get them".

The extract from Mary above illustrates how assertiveness and strength of character enables the caregiving role. Being able to take control and 'fight their corner' ensured equipment required for her mother was received. There is a sense that because Mary was not a professional working outside of the home, was not strong or able to stand up for herself.

Participants living in rural areas identified neighbours as a valued additional support available to them. Seventeen participants lived in a rural setting versus six who lived in urban areas. Participants living in rural areas identified requiring more support from professional carers, family members, and greater respite hours. However, these findings may not be generalised to rural caregivers only because the proportion of rural carers are almost three times that of urban carers in this study. In many rural cases, neighbours were regarded as members of the extended family and were instrumental in supporting the carer to care.

Jack: "I have great neighbours, like any of them that knew there was anything wrong with her in the early stages, when she took to the road like, everybody looked out for her and you'd get a phone call or she'd be brought back in the car to you, you know".

Cillian also asserted that in addition to family members, having good neighbours was essential to effective caregiving

Cillian: "I was lucky again that her two sisters were there, and my own two sisters were close by and we had good neighbours and good friends. [] but the main thing about it is you need a support structure and you definitely need family and neighbours and friends and everything, you know".

3d. The Need for Social Support

Carers recognised the need for social support and to have time out to 'care for the carer', and while the desire was evident to have time away from caregiving, in the absence of adequate funding or either formal or informal carers to take over caring for the person with dementia, many carers had to forego any break available to them.

Grace: "...that is very important that you keep up and involve yourself in certain activities. [] You're very constrained for time when you are looking after somebody, but it's very important that you've some little bit of me time".

Lisa used her time to attend to farming duties or to walk for the hour when a professional carer was with her mother. The language used by Lisa detailing how she 'hit the roads' illuminates how she was able to take out her frustration or stress (on the road) by going for a walk. Thus, walking was used as a method of releasing built up tension attributed to caregiving. A sense of escapism was experienced by the participant during that hour of freedom which was maximised until the time where she had to return to her duties.

Lisa: "I usually go out cause we are farmers so I go out to feed the stock and do whatever I have to do in that hour, or if not, I will go for a walk for a full hour, I will hit the roads and I don't stop until I have to come back here again".

Many carers highlighted the difficulty attributed to leaving the home and due to the effort involved, the activity outside the home had to be worthwhile to entice them to go. Maureen also touched on escapism in her excerpt highlighting her desire to disconnect herself from anything associated with dementia or caregiving during her free time and instead engage with a pleasurable activity.

Maureen: "Going out, [] it has to be something really tempting now to get me to go out and enjoy myself because it is a hassle getting a carer in and it is very hard to totally unwind because it is just on your mind all the time. [] You are very careful of your spare time. [] I won't go to any carer's group because I only have a few hours. I will come into a movie or go to something totally different".

Like parents who leave their children in the care of others, carers in this study experienced the same anxiety about the welfare of their loved one with dementia and as a consequence, failed to enjoy time away from the home. This results from an inability to relinquish control or a mistrust of others to provide the same quality care as they do. Those with advanced dementia at home require 24 hour care, therefore participants in this study found it difficult to switch off when the opportunity was afforded to them.

Maureen: "I could go away but I don't think I really enjoy myself when I am away because of the situation, and I really can't chill out. You do to a certain extent, but I know that he doesn't like when I go and I am kind of sad about that, but I think I am getting a bit more callous about it now, this time I am just going to enjoy myself".

Due to the burden and physical demands of caring, Aaron opted to stay at home instead of socialising, isolating himself from family and friends

Aaron: "I don't go out, I hardly go out at all []. It gets to the point where it doesn't really bother you. Anyone I suppose that has children, and he's a child really now, they will say well if you go out at night and if you've to face that in the morning, the good is gone out of it, it takes the good out of your night".

Despite the presence of a carers' support group in close proximity to where Lisa lives, she failed to find it beneficial in terms of support and information tailored to her needs or

her age group. However, despite her informational needs not being met, her social needs were and she enjoyed socialising with another carer on conclusion of the meeting.

Lisa: "I didn't even know there was a carers group there, [] someone from the day care centre that said to me [] But it's just for the carers and that means they don't tell us anything about Alzheimer's in particular because it's not just carers for Alzheimer's, its people caring for all types of illnesses, [] and I get somebody in and I go, but in all fairness, I don't go to sit there talking, [] to sit with these 70 and 80 year olds who are looking after their husbands, I go because another young girl goes and we go for a drink afterwards and that's the truth, that's why I go []. We have two drinks in the pub when we come out and that's it and you know that's the best laugh we have".

Maureen also discussed not finding workshops or support groups for carers beneficial and found attending these to have the opposite effect. Maureen was disappointed that the workshop did not address her needs and consequently resented that her money was not spent well on something that would have benefitted her.

Maureen: "It is very depressing to talk to other carers. I have gone to some of these workshops. There was one arranged [] in [name of town] and it was very well arranged, a good variety of talks, but the stories were just heartrending and it didn't do me one bit of good. I had a carer for the whole day. It cost me a lot of money and I came home and I thought I can do a bit of mindfulness or I can do some other things that can make me feel good but that really hadn't. There was nothing new that we got out of it to help us to handle the situation. [] I had to get someone in for €25 per hour for the whole day and really when I came back I wish I had gone somewhere else for the day".

When a carer was prevented from leaving the house as a consequence of caring for their loved one with dementia, alternative activities and pursuits were sought. In an attempt to keep her mind active and fill her time, Maureen engaged in online pursuits.

Maureen: "I do online courses. There are very good courses. It started out from American Universities from the Ivy League Colleges and free courses online about 12 weeks each and they are really excellent. So I do two or three of those

at a time. So I would spend maybe an hour or two at the computer every day, and doing a language. I had been going into college to their short adult courses at night. They finish in December they only run September, October, November and they are finished then. So I do that. That keeps me going”.

Super-Ordinate Theme 4 – Death, Dying and Life after Death

This finding revealed little systematic variation between the experiences of death, dying and life after death between current and former carers or between those living in rural or urban locations (Table 5.6).

	Caregiving status = Current	Caregiving status = Former
Death, Dying & Life after Death	165	126
Death & Dying	47	57
Disembodiment	43	25
End of Life Care	47	53
Grief & loss	51	60
Regret	16	12
Role change	58	45
Temporality	27	20

Table 5.6. Death, dying & life after death codes and caregiver status

4a. Regret at not Discussing Death & Dying

Carers spoke of having regrets, one of which was not discussing death and dying with their loved one with dementia early in the disease trajectory while the person with dementia was able to communicate their wishes and feelings about death and dying. Due to being ill-informed about the progression of dementia, Caroline missed the opportunity to ascertain her mother’s wishes regarding end of life care or preferences after her death. This carer also describes being in denial about her mother’s imminent death.

Caroline: “I think what’s so important is [] that you make the most of the time you have. The stages, why didn’t I know mum would lose her speech [crying]? Because I should have spoken to her, I should have talked to her about death. I think the other thing I learned [] was they know they are dying. And we pretend, oh we can’t upset them. It’s not them we are afraid of upsetting, [] I’m disgusted

I didn't do that, [crying] but maybe I did know. I think I did to be honest. I just wasn't doing it. [] I thought the longer I put things off like that, mum was going to live longer. If you don't deal with it, put it on the long finger, and then it will all go away".

Irene also acknowledged missing the opportunity to discuss her mother's wishes about death and dying and regretted not paying attention to the subject when her mother requested to discuss it. It is noteworthy in the subsequent extract that Irene's mother wished to speak about her own mortality however the carer was not comfortable discussing it or accepting it was a reality. Further to this, Irene acknowledged she did not have the skill or expertise to discuss death and dying with her mother and as a result, chose to avoid the conversation completely.

Irene: "Well when you are talking about end of life, a few years ago she actually was talking to me about what she wanted to do with her end of life. And of course at the time [laughing] I wasn't in a place to hear it, so I told her 'stop that will you, no need to be talking about that, we'll look after that when it happens, forget about it'. And of course now, [] I would appreciate it if she started the conversation again because I think I'd write down if she had any things, any, requests, but I don't know how to broach it now you know. So it's a lost opportunity but at the time I wasn't, you know I wasn't in a place to talk about it, you know what I mean. I didn't think it was really that relevant".

Several other carers cited what they believed to be the person with dementia's opinions of dementia and the fear and anxiety the person with dementia had of developing this disease. There was a tangible sense of knowing their loved one with dementia and their loathing of the disease and wishes to die rather than live with it.

Ben: "When my dad was in the nursing home she used to say to me, 'look at that poor woman there, she is in a wheelchair, if I ever got that' [dementia], she used to say to me, 'I don't want to live', and then she got it".

Fiona and Ava both spoke candidly about their mother's wish to die by suicide rather than live with dementia. This extreme response emphasises carers' feelings and the feelings of their mothers towards having the disease. Fiona details how her mother spoke

about drowning herself but did not follow through on this threat. Fiona also acknowledged not having the skills or knowledge to communicate in an effectual way with her mother who had raised the issue of her mortality.

Fiona: "That time we didn't know any different and we were answering her back. And she said 'I am going down the road and I am going and drowning myself'. And we said 'off you go' and the two of us were looking at her and she went down there now along with her crutch and she went way past the bridge and she was walking and we were looking out but eventually she stopped and she came back up and she came in and she was fine, she was a different person".

Similarly, Ava also discussed suicide and illuminated how having dementia had changed her mother unrecognisably from the person she was prior to having dementia and believed her mother would have thought it preferable to die by suicide than live with the disease

Ava: "For a woman that was so vibrant and had a bubbly personality and embraced life with both arms its really, really horrendous to see them like this and if she had known the way things were going she would have gone off that bridge down there herself ten years ago before getting to this".

Fear associated with having a diagnosis of dementia was evident in Ava's account of her mother's request to die as a result of having dementia. Her mother's illness caused Ava to consider her own mortality and plan for her future, alluding to the implementation of an advanced care directive in the event that she herself should develop the disease. A distinction was made between a request to die by assisted suicide from a person with dementia versus a person without a cognitive impairment and the right to die for those who are *compos mentis* as opposed to those with dementia who may not be in a cognitive state to make such requests of decisions. Ava gives specific and graphic examples to support her beliefs in the following extract

Ava: "She often said that, the words would be 'shoot me', 'shoot me' 'put a bullet in me before I get like that', 'I don't want to be a burden on anybody'. And we would say, 'you are not a burden'. She is not a burden, she is still not a burden, its hard work, but she is not a burden. But I know I would put pen to paper for my own life and say get rid of me if I end up like that. I wouldn't want to be like that,

I know she didn't want to be like that, but I wouldn't do it, I wouldn't do it. If my dad had asked me years ago when he was suffering and he was in pain, if he had asked me to do it, I would have done it, because he was in his right mind and he would have known but I wouldn't take it from [mother's name]”.

When asked about their opinions on end of life care for people with dementia, both couples initiated a discussion surrounding the ethical dilemma of allowing the person with dementia to die naturally versus intervening with medical treatments. It is noteworthy that both Isobel and Donna had a medical background with prior knowledge and experience of caring for people with dementia in healthcare settings. As a consequence, both participants had theoretical and experiential knowledge of the ethical issues surrounding end of life care. However, despite this, both couples were conflicted in their decisions regarding the receipt of active treatment for the person with dementia versus the provision of comfort measures only.

Isobel: “It is a difficult one, are they obliged to leap straight in there and go ahead, or would that bit of common sense come to play, you know this could be the answer to this, you know this poor lady's condition, that she will be allowed to succumb, you know. I mean it's very much, no one wants to mention it, you know, people with dementia, you know, they're looking for a way out of it and you know these things crop up, chest infections or whatever and you know in a lot of ways I think they're denied the opportunity to die”.

Alec: “It's a very grey area and a difficult one and one that should you mention it, you know you kind of feel, oh you know I shouldn't be saying that”.

This dilemma is echoed by another couple who also discuss the end of life phase for people with dementia and offer their opinion of dementia being a life limiting illness.

Michael: “It's a difficult one, you have to take care of them, until nature takes its course basically. The only thing is that if they do get such a thing as pneumonia then you just let that...”

Donna: “But we do give her antibiotics”

Michael: “We do ya, we sure do”

Donna: “It's a difficult call because I have to say that is one thing that I found very difficult over these years was that, say the time she got the blood clot in the

leg and we took her to the hospital and the first doctor we met was kind of like, why are you here, why did you bother? [] Some people define it as a terminal disease, now I have cared for my father and the neighbour over the road with cancer and you know the terminal part of that you can see it, [] and you feel like it's ok to let them go, they are suffering. You don't see the same kind of thing, it's hard to call that as much as a terminal illness even though it is terminal"

Michael: "It's no more a terminal illness really than somebody that's ageing anyway, I suppose age is a terminal illness anyway, by the time you get to it".

4b. Striving for a Good Death

Despite caring for the person with dementia for many years, and seeing the declining progression of the disease, carers reported feeling surprised when their loved one died. While Grace was unprepared for the death of her mother, she was resolute that her mother had lived a long life and experienced a peaceful death. Interestingly, Grace highlighted that the shock of death to be greater in someone who was 'really ill' as opposed to someone who died with dementia.

Grace: "It always is a kind of a surprise, and I suppose it's even worse for someone who's kind of really ill, if you like. [] And I suppose with her, just going gradually in old age, she was ninety-one when she died. So I mean it was kind of, it was expected and like I say, she never suffered any pain. [] It was a natural progression in her case".

The surprise or shock felt by carers when death occurred was exacerbated by the lack of information on the disease process and what to expect in the final stages of life.

Alec: "So when she did finally die it was kind of a bit of a shock to us really, you know she just faded away really didn't she [] Oh yeah a nice peaceful death, you know you couldn't wish for, you know a better one. We hadn't a clue that that was going to happen".

Mary, who was an active carer for her mother, shared her fears and thoughts about what might come in the future for her mother. Mary detailed her uncertainty about the end stage of life and wished for a quick death at home for her mother. Additionally, Mary believed the arrival of death would come as a blessing for her mother.

Mary: "I don't know what's coming, I don't know how, how to care for, [] I hope, God forgive me, I hope it comes soon for her, I hope it comes when she is in her own home, you know in bed. My mother is alive but she is not living. She sits in a chair all day and watches the world go by. She doesn't interact. She has no quality of life, for the woman that she was, I do hope that the [] time comes quicker rather than later".

Home was identified as the ideal place for a good death in addition to having family present and being pain free.

Grace: "She died at home in her own bed surrounded by her family and with the priest on call and she wasn't in any pain, so if you want, if you like, it was as good a way as you could pick to go".

Owing to Maureen's acute awareness of a gradual decline in her husband's condition, she highlights his declining trajectory and has made plans for his end of life, identifying home as the optimal place for a peaceful death.

Maureen: "I think like most people who have somebody with Alzheimer's where I can see the deterioration, it is very slow but it is there, if I look back at last year I can see the deterioration, it is just awful to watch. I just hope he dies peacefully some night, no hospital".

4c. Life after Death

Carers experienced an additional role change after the person with dementia died. They were forced to re-invent their role within the family, in the work-place and in society as they no longer assumed the role of carer. Carers were so bound by time management and routine while their loved one was alive, they reported difficulty adjusting to the ample amount of routine - free time they now had.

Grace: "Well it's like I suppose if people retire, you know, all of a sudden from having your nine to five or whatever, and having your routine, all of a sudden there is no routine. So it does, it's kind of a bit of a culture shock, you have to get into recreating a routine. Haven't reached that stage yet but you know, you do have to kind of decide, right, I'm going to do this, that or the other thing today,

and create your own routine. Because if you don't, you can kind of slide, not only into depression”.

Aaron, an active carer for his father, considered the future and wondered how his life may change after his father died. Aaron pondered how he would occupy his time once this death occurred. Being a single man, living in a rural location, Aaron had a sense and perhaps a fear of the loneliness which would occur when his father died. There is a sadness to this excerpt revealing pre-death grief, not only for the loss of his father but also for his caregiving role

Aaron: “I often wonder how I will fill the void that’s going to be left behind when he’s gone, from this routine that I’ve been in for so long”.

Jack illuminated the emptiness and quietness that now filled his home and only recently noted the ticking of a clock as a result of the silence. The reference to time further emphasises his loneliness and lack of motivation to fill this time with meaningful activities. He no longer feels a sense of purpose due to the cessation of his caregiving role.

Jack: “You have no one to come, you have no one of your own, all you have as I said is cousins or relations, they are all in foreign countries, and all I have is my neighbours or friends there that come in to see me. When they leave here at night and you hear no sound coming there from the room and the heavy tick of the clock that you never heard when your mother was here with you, that’s when you know you’re on a lonely journey in your life, but there’s nothing you can do about it. Nothing. [] You have the time but you don’t want to do anything”.

4d. Already Grieving

In a previous theme, carers described not recognising the person with dementia any longer as their mother, father, or husband. The experience of grief and loss was greater in the former carer cohort. The probable cause of this is that while all participants may have experienced anticipatory grief, former carers have experienced an additional loss, that being the loss of the person with dementia following their death.

In this theme, carers described already grieving for their loved one despite them still being alive. Participants changed the way they interacted with and related to the person with dementia, no longer recognising them as their mother, father or husband. The relationship between the carer and their loved one with dementia had altered substantially causing family caring roles to be reversed. Participants articulated that the mother they once knew was no longer alive. It is paradoxical when participants state ‘that’s not my mother’ because although their mother was present with them, the mother they once knew was no longer there; the physical mother was present but the emotional mother was dead. There was an apparent disconnect between the way carers spoke about the person with dementia and how a person would speak about a loved one, often involving describing or comparing the person with dementia to an inanimate object. This further emphasises disconnect between caring for a living being who is dead inside.

Lisa: “I don’t know how long more, mammy, my mother could last another 10 years. [] I know the way she has gone downhill, [] I am very practical myself and I know she has not got 10 years left, maybe, I don’t know how long, and it’s not that I am going to be very remorseful about it either and of course I am very sad about it but it’s a celebration, but it’s not my mum, that’s not my mother sitting there, and I know now, that is not my mother, so that is why I distance myself”.

Ben also noted that the mother he used to know was no longer present. The language used by Ben to describe his mother’s current state as ‘do-lally’ has a negative and stigmatising viewpoint. The mother that he now cares for is unrecognisable to the mother she once was and alludes to the mother he once knew who had gone and taken the good part of him with her. Now both he and his mother were different people to who they were previously.

Ben: “And seeing someone with Alzheimer’s taking the best part with you, it’s not nice, you don’t recognise that person at all or who she is. But that is another point that I couldn’t come to terms with that this woman was gone totally do-lally with Alzheimer’s and this was not my mother”.

Lisa uses powerful imagery where she compares her mother to an egg. The shell of the egg represents the strong protective person her mother used to be. When the shell is taken off, the inside of the egg is vulnerable, penetrable, and in her mother’s case,

unrecognisable. This carer further illuminated how she had withdrawn from the pre-dementia relationship by the way she referred to her mother as ‘this’ or ‘it’

Lisa: “About two years ago when I saw this getting worse and I realised this is not mammy this is not my mother, my mother would never talk or carry on like this or soil herself and I know that’s all part of getting old [], but that’s not my mum, never has been, never would be. [] It’s like when you take a shell off an egg, you are left with this but this has nothing to do with me but I am minding it probably out of respect for the fact that my mother was very good to us [] So then you look at what am I minding, you know, there is a shell there, it’s like peeling an egg, isn’t it? You know, she is gone, the peel is gone and there is just this, there”.

Similarly, in an effort to cope with the loss of the person they once knew, Ava detailed having to emotionally draw back or pull away from her mother

Ava: “I know I have detached because for the sake of my kids I had to, [] you really do have to detach from the situation and realise that she’s, it’s a vessel, it’s not your mother anymore and she is really not, she doesn’t recognise me as her daughter and I don’t recognise her as my mother anymore, that might sound cold [] It’s honest”.

Carers adopt practical approaches to coping with situations, justifying detaching from the person with dementia to achieve a happier family life. Ava saw the detachment as reciprocal, whereby she no longer recognised her mother and her mother no longer recognised her

Ava: “We had a great home, between her and my dad we had a wonderful home growing up, a very happy home, we were a very close family [] but she is not my mum anymore, my mum is gone already and I reckon, it has been said to me before that you do grieve twice for someone with Alzheimer’s and I don’t think you do, I think you still only grieve the once because, you can’t grieve now because there is still something here. But you can’t be sad for what you’ve lost because you are too busy minding some, something else, and it’s not someone, it’s something else, it’s not what you had, it’s very different”.

In the extract above, Ava appeared conflicted in her opinions about grief and loss, acknowledging that her 'mum is gone already' however suggests that she is not or cannot grieve for her mother because her mother is still alive. The burden of care prevents carers from grieving for her mother.

Maureen experienced a similar loss, however still felt a connection, albeit in a different form of relationship. As well as grieving for her husband, she also mourned the loss of their relationship as a couple and the activities they enjoyed together

Maureen: "It is not your husband any more, it is somebody very close to you that, it is like looking after your father or somebody. And you have said good-bye to your husband really. It was very difficult in the beginning alright. But I guess time, you get used to things. And the hard part, is the social isolation, because you have no husband you don't have a partner, and a lot of things you would have gone to as a couple, you don't go to any more, and you are not light-hearted enough to take part in the usual things that groups of girls or groups of women do".

Helen details her grief for the person with dementia and her corresponding detachment from them. While she is still providing care, she views it as providing care to a person with dementia as opposed to her mother.

Helen: "I feel anyway with dementia you've lost the person such a long time before that, it's like as if they've died a long time ago and a lot of it, now this is being just entirely honest, a lot of it is going through the motions".

A similar strategy to cope with providing care to her husband with dementia is expressed by Maureen who no longer recognises the care recipient as her husband and has detached from him in an effort to cope with the grieving process.

Maureen: "It is not your husband any more [] you have said good-bye to your husband really. It was very difficult in the beginning alright. But I guess time, you get used to things".

Ava argued that you cannot grieve for someone that is still alive however she did acknowledge that the person she once knew as her mother is different to the person she was now caring for. She no longer recognised the person she was providing care to as her mother and had conflicted grief

Ava: "She is not my mum anymore, my mum is gone already and I reckon, it has been said to me before that you do grieve twice for someone with Alzheimer's and I don't think you do, I think you still only grieve the once because, you can't grieve now because there is still something here [] But you can't be sad for what you've lost because you are too busy minding some, something else, and it's not someone, it's something else, it's not what you had, it's very different".

Reflecting on the caregiving journey and the experience of death, Alec demonstrated the sadness and exhaustion experienced by his family immediately after the death of his mother. The sadness discussed was not as a direct result of the death of his mother, but a sadness as a consequence of the struggle of caring for the years preceding her death and due to the unhappiness experienced by his mother and the family during the care giving period.

Alec: "So it's nice to look after your parents, you know and do your best for them but I couldn't say it was a rewarding experience, you know when my mother died we thought we'd all have a great sense of relief, you know, that we'd all let out a big sigh, ah well she's at peace, but we just all sort of sat there and just felt kind of crest fallen really, like deflated. You know we thought it was going to be a great day when she did finally die, for herself and you're just, all we could come out with was just sadness [] In a few years we hope we'll remember her as she was, her fun, you know happy woman, you know it was always great fun. [] I mean the last three and a half years have been hard work, I can think of very few light, you know light bits of relief in the care of my mother really. So you know it's been a slog really".

5.1 Temporal Elements in the Research Findings

In addition, the findings revealed some temporal elements which are important to highlight here. In response to the first open ended question posed on commencement of each interview, all participants detailed their experience of caring for a person with

dementia from the time of initially suspecting and identifying changes in the behaviour of the person with dementia. Greater mental health issues were experienced by participants at the start of their caregiving journey, attributed to not being believed by others, issues surrounding a delay in receiving a diagnosis of dementia, not receiving support from family members, healthcare / organisational professionals and due to the challenging behaviours exhibited by the person with dementia. As the disease progressed, adverse mental health issues reduced, however the physical burden of care increased as a consequence of the requirement for full nursing care for the person with dementia.

Carers identified having greater financial pressures during the late stage of the caregiving journey. As a consequence of being unable to leave the person with dementia unsupervised in the home, it necessitated the carer having to resign from full time employment to become a full time carer. In addition, three male carers sold land and livestock to acquire funds and to lessen the workload and burden associated with farming.

Greater support was provided by friends and neighbours of the person with dementia in the early stages of the disease. However, it was noted that these friendships and meaningful relationships declined as the person with dementia displayed a deteriorating ability to communicate. The need for help from professional carers increased as the disease progressed into the late stages of dementia. More assistance with physical caring was required at this stage.

A final temporal finding identified was the emotional withdrawal of care by participants as the disease progressed. As the carer could no longer emotionally connect with the person with dementia, a protective coping strategy employed was to emotionally pull away from the relationship. This was identified by some carers during the final stages of the caregiving journey. The findings will be discussed in the next chapter.

Reflexivity involves openly reflecting on how our experience of the world is profoundly influenced by our assumptions, intentions and actions. Yardley (2000) advocates for researchers to consider how the aforementioned factors may have impacted on the process and product of research.

5.2 Reflection on Research Findings

Previously in section 4.8.4 Reflexivity, the researcher reflected on and considered how her experience and knowledge may have impinged on the research process. On completion of data analysis and interpretation of research findings, the researcher engaged in further reflexivity to identify any pre-conceptions of the research findings and how these prior assumptions may have been influenced by the researcher's knowledge. As well as reflecting on findings which were expected to emerge from the data, unexpected findings were also considered.

Despite having clinical and academic experience and following the completion of a literature review in the areas of dementia and end of life care, many of the research findings were unexpected and did not equate to any prior preconceptions. The researcher had a prior expectation that participants would highlight the burden of care attributed to caregiving however it was most surprising to hear of the magnitude of burnout and exhaustion revealed by participants and how much of a struggle it was to provide effective care. Despite the presence of organisations specifically relating to Alzheimer's disease and caregiving in Ireland, participants were mostly unaware or untouched by their existence which was an unexpected finding. Also surprising was participants' expressed mistrust in healthcare services, evidenced by many examples of poor quality care provided to the person with dementia and ineffective and inappropriate communication between healthcare providers and carers. As a nurse, this was difficult to hear and challenged my ability to analyse the data in an unbiased way. Reflective memos were recorded pertaining to this subject and discussed with the researcher's supervisor, which helped in minimizing the possible influence of such biases.

The finding which emerged as most unexpected was participants' regrets for not discussing death and dying with the person with dementia while the person with dementia still had the ability to communicate. Some participants described their loathing for the disease in quiet explicit terms, stating it was preferable to die by suicide rather than live with dementia. This was an unexpected revelation and was not identified in the literature review conducted. While a stigma exists surrounding the area of suicide (Cvinar, 2005; Pritchard & Hean, 2008; Scocco et al., 2012; Niederkrotenthaler et al., 2014), another stigma is reported around dementia (Devlin et al., 2007; Batsch & Mittelman, 2012; Gove et al., 2016; Woo & Mehta, 2017). However, carers' intimate knowledge of the person with dementia and how much the disease had taken from them, resulted in them

expressing a preference for the person with dementia to die rather than exist in their current state of cognitive ill health. This caused much reflection and detailed memos following these interviews allowing the researcher to consider her own feelings, experiences and views on suicide, the apparent stigma related to both suicide and dementia and the area of assisted suicide.

6. Discussion

As evidenced from the findings, carers described their experiences of providing care throughout the caregiving trajectory, detailing their journey from the time of diagnosis, to the current day and with former carers illustrating the death and dying experience. A number of models describe the caregiving trajectory in dementia (Wilson, 1989; Lindgren, 1993; Aneshensel, Pearlin, Mullan, Zarit & Whitlatch, 1995) with Lindgren applying the term 'caregiver career'. This encompassed 3 differing but overlapping stages: an encounter stage (the diagnosis and loss of previous life patterns), an enduring stage (managing extensive care routines and social isolation) and finally an exit stage (the relinquishment of caregiving through the death of a spouse or loved one or their admission into care) reflective of the stages experienced by these carers. Carers recounted their caregiving experience commencing with a detailed description of their encounter stage when the struggle to receive a timely diagnosis of dementia for their family member and the effort to provide care in the early stages was identified. During the encounter stage, carers experienced an initial role transition when they adopted a conflicted and enforced parent role. The middle stage of their caregiving journey is reflective of Lindgren's enduring stage when carers fought to receive support either formal or informal to assist with the burden of care. The final exit stage of caregiving was discussed by both current and former carers; current carers found themselves already grieving for the person with dementia while former carers recounted their experiences with death and dying and being ill prepared for life after death.

Carers identified 'home' as the preferred place of care for the person with dementia until the end of life. As the person with dementia's condition deteriorates, the hours of care required increases. This also poses a challenge for carers to manage a deteriorating patient, be responsible for the administration of medication, as well as assisting with activities of daily living. Making decisions or problem solving on behalf of the patient is also regarded as a clinical skill (Van Houtven et al., 2011). Carers recognise a lack of training or expertise to carry out these extended roles however do so to cope because if they do not do it, no one else will.

Sweeting & Gilhooly (1997) pioneered the application of the constructs of 'anticipatory grief' and 'social death' to the process of caregiving and dementia. Anticipatory grief is

experienced when there is forewarning or threat of loss before an actual death occurs (Coelho & Barbosa, 2017) while social death refers to the ways in which a person is treated as if they were no longer alive (Borgstrom, 2017). It is argued that people with dementia experience a loss of personhood as a consequence of their illness. In addition, since dementia is commonly linked with older age, people presume them to be approaching death and are “examples of individuals for whom life may not be worthwhile anymore” (Sweeting & Gilhooly, 1997, p.99)

Blandin & Pepin (2017) describe pre-death grief experienced by dementia family carers specifically as ‘dementia grief’ which is a particular form of anticipatory grief expressed in response to compounded serial losses of varying significance and evidenced by the ambiguity which characterises the experiences of loss in dementia. Carers recounted emotionally withdrawing from their caring role in an effort to cope with loss associated with the disease. Their inability to recognise the person with dementia any longer as their mother, father, or spouse was as a result of the profound changes in cognition, personality and physical disabilities now present and is an illustrative example of social death for the person with dementia. This ambiguous loss occurs due to an inability to identify personality characteristics or personal memories which lead to experiences of ambiguity in family members whereby the person with dementia does not appear to be emotionally accessible or the same person (Sanders & Corley, 2003; Large & Slinger, 2015; Blandin & Pepin, 2017).

Results from this study indicate that carers experience profound pre-death grief similar to post death bereavement as a consequence of experiencing the loss of the person they formally knew. This ambiguity was highlighted by one carer who stated “*that’s not my mother*”. Despite her mother being alive and having the physical appearance of her mother, the carer finds it difficult to remain emotionally connected to her mother as a result of her behavioural changes. This paradoxical disconnection between the psychological and physical losses, captures the crux of ambiguity in the receding of the known self in dementia grief (Blandin & Pepin, 2017). Pre-death grief occurs as a result of the physical and psychological response to the perceived losses in a loved one with dementia (Lindauer & Harvath, 2014). Significant losses are experienced by the carer before physical death, experienced as compounded serial losses (Chan, Livingston, Jones & Sampson, 2013; Santulli & Blandin, 2015) which increase in size and number as the disease advances.

Social and cultural factors have a strong influence on caregiving (Dongxia Xiao, Habel & De Bellis, 2015). Family customs which place high value and respect for older people and caregiving are usually motivated to take on the responsibility and duty of provide care for those who require it. In the US, 85% of care recipients depend exclusively on family and friends for assistance (Family Caregiver Alliance, 2015). In Europe, families provide more than two-thirds of long term care (de la Cuesta-Benjumena, 2010). Ireland has a strong tradition of possessing the same family focused values and desire to care for older or infirmed family members in the home. According to O'Shea, Cahill & Pierce (2018, p.8), "living at home in the community for as long as possible is a universal and desirable goal for us all", however homecare provision for those with dementia in Ireland is currently underdeveloped and family members are unsupported in their role of caregiver. The findings of this study revealed that the challenges of providing care to a person with dementia at home were more significant for current carers, living in a rural location. Nonetheless, despite experiencing adversity and challenges throughout the caregiving journey, participants in this study displayed determination and motivation to continue providing care at home until the end.

Carers' experience of uncertainty and helplessness, is congruent with the themes identified in a study by Szabo & Strang (1999) who identified that carers of those with dementia described feeling "out of control," trying to stay "in control," and spiralling "out of control". These findings are also consistent with Kellett (1999). Kellett's findings included five shared meanings in the caregiver experiences: experiencing a loss of control; feeling guilty, being disempowered, feeling a sense of failure, together with sadness and relief, and having to make negative choices. Akin to the findings of Kellett's study, and in an effort to remain in control of their current situation, caregivers in this research clearly stated that they intended to continue providing care at home until the end and would only contemplate long term care as a last resort when caregiving at home was no longer viable.

Immersed within all themes in this study, either implied or overtly stated in their conversations, was the reciprocal influence of the carer - person with dementia relationships, past and present, on their current circumstances. In pursuit of a deeper understanding of the contextual depth of the relationships between the carer and the person with dementia, Caron and Bowers' (2003) work proved valuable by highlighting two fundamental purposes of caregiving. The first purpose focused on maintaining the

long-term nature of the dyad relationship; in this context, the work being carried out was tailored toward protecting “what was.” In opposition, from a pragmatic perspective, the physical aspects of caregiving such as providing appropriate, adequate and high quality care was also focused on. According to Caron & Bowers (2003), as caregiving carried on and as the functioning of family member declined, transitions between the two purposes resulted. It was during these transition periods that caregivers grappled with surrendering what had been and what was now the present. Carers in this study demonstrated the challenges of such transitions. They experienced the dissonance associated with protecting and maintaining the relationship as it had been in the past while adapting and accepting the present situation of being the parent to the parent or spouse.

In general, carers of people with dementia require greater emotional support prior to the person’s death than afterwards therefore by receiving effective social support pre-bereavement, facilitates better adjustment post bereavement (Schulz et al., 2003; Shanley, Russell, Middleton & Simpson-Young, 2011; Sinha, Desai, Prakash, Kushwaha & Tripathi, 2017). Carers reported feeling isolated and left to ‘get on with it’. Difficulties included experiences accessing respite care for the person with dementia when required and there was also carers’ reluctance to avail of respite care due to a mistrust of respite facilities. As a consequence, carers had no experience of the person with dementia being away from the home for a prolonged period of time and carers had no break from their care giving role.

Carers highlighted the need for information surrounding the dementia disease process and ‘what to expect’ from time of diagnosis until death. Carers revealed having to find this information online or by word of mouth from other carers. Appropriate information and intervention strategies should be provided throughout the care giving trajectory so that the end of life phase is demystified and feared less (Adelman et al., 2012). Greater exploration into end of life decision making, adequate preparation for their loved one’s death, and measuring quality of life at end of life is required for family carers (Chan, Livingston, Jones & Sampson, 2012; Raymond, Warner, Davies, Illiffe & Manthorpe, 2014). Shock and devastation among carers after the death of their loved one is attributed with a lack of foresight (Hebert, Dang & Schulz, 2006).

Narratives from the findings illustrate former carers' regret for not discussing end of life and death preferences with their loved one early in the disease trajectory while the person with dementia had the ability to communicate their wishes. The unique aspect of ethical issues in dementia relates to the increasingly and unavoidable need for others to make decisions for the person with dementia. Decisions are based on evidence for the effectiveness of the particular action. However often decisions are complex involving clinical and ethical aspects. One such issue at end of life which raised an ethical discussion amongst carers was the provision or withdrawal of certain treatments such as antibiotic therapy. While carers understood that administering antibiotic therapy to treat infections was a life-prolonging measure, there was a reluctance to 'let nature take its course' and a view that non-intervention was an admission of failure or 'giving up'. These views are not unique to this research as Hennings, Froggatt & Keady (2010) reported family carers judging themselves responsible if death ensued following the withdrawal of treatment.

Prognosticators may suggest in certain cases that antibiotic therapy is required while in other cases it may be withheld in people with severe dementia. The distinction between ordinary and extraordinary means of treatment needs to be understood in the case of someone with dementia and when the burden imposed by the particular treatment against the likelihood of benefits accruing to the person concerned has traditionally found to be useful (Hanrahan, Luchins, & Murphy in Addington-Hall & Higginson (2001). Additionally, a failure to identify the end-of-life phase results in prolonged exposure to unnecessary treatments (Marsh et al., 2000). Ironically it is claimed that throughout the disease process people with dementia often receive 'too little' care, an example of which is the under treatment of symptoms such as pain (Martin et al., 2005; Herr et al., 2006; Sampson et al., 2006; Husebo et al., 2008; Barber & Murphy, 2011) whereas end of life care is often characterised by 'too much' (Small, Froggatt & Downs, 2007) specifically when people with advanced dementia are subjected to burdensome interventions such as tube feeding and parenteral hydration (Hertough, 2006; Arcand, 2015).

When it becomes unclear how to ascertain the person's autonomous wishes, carers are required to act in his or her best interests. Several countries legally recognise and support the use of advance healthcare directives which have been devised by the person with dementia while they were deemed cognitively able to make decisions about their future care (de Boer et al., 2011). In Ireland, The Assisted Decision Making (Capacity) Act 2015

was signed into law in December 2015, however the Act has not yet been introduced. This Act will support decision making and maximising a person's capacity to make decisions. Part 8 of the Act allows for the introduction of advance healthcare directives (Mental Health Commission, 2018). The purpose of which are to enable an individual to be treated according to their will and preferences and to provide healthcare professionals with essential information about the person in relation to their treatment choices even when the person no longer has decision-making capacity to make decisions (Health Services Executive, 2018). Findings from this study revealed caregiver anxiety pertaining to decisions made for the person with dementia particularly regarding end of life preferences. The introduction of advanced healthcare directives into practice will come as a welcome measure for those with dementia and their carers who wish to document future care preferences which will facilitate carers with a guide to the decisions made on behalf of the person with dementia. This will go a long way to reducing the guilt and caregiver burden highlighted by participants in this study. This Act will safeguard the dignity and autonomy of those with capacity impairment and will positively impact the human rights of those with dementia (Alzheimer's Society of Ireland, 2015)

Collaborative communication between the person with dementia, their family and healthcare professionals should be continuous and models of shared decision making need to be employed. Even in the latter stages of dementia, the person with dementia should still be consulted regarding decisions about their care. Through improved communication and advanced care planning, end of life care wishes can be ascertained, individualised care delivered and decision making lightened for carers in the end of life period (Hennings et al., 2010).

Carers discussed the concept of euthanasia and assisted suicide for their loved one as well as citing the person with dementia's preferences for dying by suicide instead of dementia. Belgium and the Netherlands are the only two countries to legally recognise euthanasia within a number of patient categories (Gastmans & de Lepeleire, 2009). In addition, The Netherlands legally recognises advanced healthcare directives for euthanasia of incompetent people such as those with dementia as part of the 2002 Euthanasia Law (de Boer, Dröes, Jonker, Eefsting, Hertogh et al., 2011). Carers expressed their desire for the suffering of their loved one to cease and deemed it kinder for death to occur sooner rather than later. Carers wished to avoid an undignified death for their loved one and acknowledged their poor quality of life as a consequence of the disease.

Involving carers is paramount in ethical decision making especially at the end of life stage when complex ethical issues may be frequent. The principle of autonomy must be adhered to and education involving a detailed discussion of how death comes about is required. The concept of the person helps to justify and should encourage greater willingness to involve carers in decisions concerning death and dying (Chan, 2004). This mirrors part of the palliative care approach and the philosophy of palliative care that carers should be involved in decisions especially in dementia (Hedley & Hughes, 2004).

Literature on caregiving in dementia suggests that carers generally consider the person's death as a relief (Shanley et al., 2011; Chan et al., 2012; Raymond et al., 2014) in contrast to general literature on bereavement (Earle, Komaromy & Bartholomew, 2009; Eliot, 2014; Thomas, Hudson, Trauer, Remedios & Clarke, 2014). However, findings from this research suggest otherwise, with carers expressing surprise and shock when death occurred, despite knowing that death was imminent. The overwhelming burden and routine driven care provided over a protracted period of time, resulted in caregivers failing to recognise that the person with dementia was in the dying phase of life. Carers previously highlighted being inadequately educated on the disease trajectory and requested specific information about the stages of dementia, which would assist in their knowledge and identification of the end of life stage.

Larkin (2009) identifies three post bereavement phases encountered by bereaved carers: the post-caring void, closing down the caring time and constructing life post-caring. Carers described an innate sadness following the death of the person with dementia while in their post-caring void. During this 'wind down' period, carers undertook closure activities however struggled with the lack of routine and abundance of free time now available to them. Another role transition occurs reconstructing life and reinventing the self in the post-caring phase. Blandin & Pepin (2017) term this state of transition as liminality and while the end result may be positive, the process is unstable and ambiguous. Assistance is required in the pre-death period to help carers plan for their post-caring lives while still caring (Larkin, 2009) such as maintaining leisure activities and undergoing education and training to develop skills. Several carers in this study engaged in online courses on computer literacy and care skills. Equally, it is imperative that those healthcare professionals who had contact with carers during their caregiving career, continue this relationship with follow-up visits in the post-death period. This facilitates former carers discussing the challenges associated with the post-caring phase

and reduced the incidence of complicated grief. There is strong evidence to suggest that the physical, psychological and social health of caring may leave family carers poorly equipped for life after death. When care giving ends due to the death of the person with dementia, carers often struggle to deal with this significant change in their life circumstances.

According to Shear (2010) complicated grief results after a loss and is defined as a severe form of grief which includes intrusive thoughts, separation distress and the inability to resolve a loss. Twenty per cent of dementia caregivers suffer from complicated grief following the physical death of the person with dementia (Holland, Currier, & Gallagher-Thompson 2009; Blandin & Pepin, 2017). Dementia caregivers with high levels of pre-death or dementia grief are more likely to have post-death complicated grief (Schulz et al., 2006). Therefore, adopting interventions to lessen stress and caregiver burden, decreases the level of post-death depression and complicated grief (Blandin & Pepin, 2017).

7. Conclusions, Strengths, Limitations and Recommendations

The focus of this chapter is to draw conclusions from the research, consider the strengths and limitations of the study and to make recommendations for future research and practice.

7.1 Conclusions

The purpose of this study was to gain an understanding and insight into family carers' experiences of providing end of life care for a person with dementia at home. The outcome of the research was to uncover themes related to this topic which will inform practice and improve the supports currently available to carers. The findings have significance both nationally and internationally and for researchers, practitioners and educators. From this research, the following key points emerged which relate to the research question:

What facilitates or hinders caring for a person with dementia at home?

Carers identified unusual behaviours, changes in personality and signs of dementia years before a formal diagnosis was made. Despite carers reporting these concerns to other family members and medical professionals, frustration was felt, which was exacerbated by the perceived dismissal of their expertise. Carers expressed discontent with medical professionals throughout the dementia disease trajectory, particularly during the initial phase related to receiving support and a diagnosis of dementia. There is an onus on medical professionals to trust carers' judgement when concerns are expressed pertaining to changes in behaviours or health conditions of their family member.

Due to the enormity of their care giving role, carers experienced immense stress and felt overwhelmed, which adversely affected their own mental health. Carers reported feeling like they were "cracking up" and had "difficulty coping" with their "impossible situation". Carers struggled throughout the caregiving trajectory, with the initial caregiving period posing the greatest challenges. A greater requirement to 'care for the carer' is necessitated to allow carers to break away from their caregiving duties for a period of time. This cannot occur without the support of either formal or informal carers to take over caregiving in the absence of the carer.

Caregiver burden is not a novel concept and carers in this study frequently reported dissatisfaction with having to take on extended roles and additional responsibilities, such as managing medications for the person with dementia. Healthcare providers must ensure that medication regimes are reviewed regularly for effectiveness and titrated accordingly in response to feedback from family carers. Community supports, such as a community liaison nurse should be available for carers to access for concerns and queries regarding medications and other therapeutic interventions.

Carers described how the burden of providing full time care resulted in having to withdraw from full time employment, social activities and ultimately sacrificing their freedom. Financial difficulties were also identified by most participants, highlighting the struggle to obtain any assistance to improve the burden associated with caring for a person with dementia. While government funded financial assistance is available to carers in the form of carers allowance, home help and homecare packages, they are not statutory entitlements. The application process is lengthy and carers reported finding the form filling exercise as laborious. All primary carers should be in receipt of non-means tested funding to assist with this role.

Stigma surrounding dementia was identified by participants in this research. However, this stigma is not unique to Ireland and is prevalent across European states, but has lesser impact in countries with more established and wide ranging dementia care services (Vernooij-Dassen et al., 2005). Misconceptions profoundly impact on care provision and the isolation felt by the person with dementia and their carer. Healthcare professionals and those involved in aging services networks can play a vital role in reducing fear and stigma surrounding dementia by encouraging those with dementia and their families to talk with healthcare providers about concerns related to the disease. Moreover, to enhance the public's knowledge and understanding of the disease, it is imperative to involve those with dementia in planning and developing policies, practices and programmes that affect individuals with dementia.

Time plays a big part in terms of feeling guilty especially when the carer is conflicted between meeting the demands of the person with dementia against the demands of being a mother / father / wife / husband. Having more time away from caregiving will facilitate the carer to invest this time with other family members.

What are participants' experiences of supports available or required to facilitate caring for a person with dementia at home?

A recurrent theme was the inherent difficulty carers experienced accessing support and services for people with dementia. When information and support was obtained, it was usually late into the caregiving journey, with carers highlighting needing this support at the outset. Carers frequently reported learning about services and supports by 'word of mouth' from other carers. Information needs to be made available to the person with dementia and their families at the time of diagnosis. In addition to information about dementia, carers need to be made aware of the available support services, financial assistance and put in touch with a named health care provider who can be contacted regarding questions pertaining to their relative with dementia.

Carers relied heavily on the support given by professional carers or community supports in their locality. Availing of formal support services allowed carers receive vital time away from their caring role to fulfil other obligations. There is a greater need for additional home help hours to be made available to carers who require it.

Frequently carers reported sporadic involvement or no involvement from siblings in the delivery of care to the person with dementia. Greater 'hands on' support would be welcomed from their siblings for the role they were fulfilling. On receipt of a diagnosis of dementia, a family meeting should be held to discuss the future care needs and wishes of the person with dementia. A primary carer should be identified at this early stage and an agreement between all family members on the support they can provide to assist with future care provision.

Many carers recognised the need for social support and to have time out to 'care for the carer', and while the desire is evident to have time away from caregiving, in the absence of adequate funding or either formal or informal carers to take over caring for the person with dementia, many carers had to forego any break available to them. Additional home help hours and greater family involvement is required to allow the carer receive a break from caregiving.

Despite carers experiencing high levels of stress and burden, engaging in everyday activities and routines were essential to maintaining a sense of stability and continuity in everyday life. Carers not only looked after or cared for the person with dementia, they

also set and adapted everyday activities for them regardless of what stage of the dementia disease trajectory the person with dementia was at. This had a two-fold benefit; as well as maintaining a sense of self, personhood and control for the person with dementia, it also extended to benefit their own. Literature suggests that if carers feel inadequate and unable to manage their relative's everyday activities, it often results in a decision to admit the person with dementia to a long term care facilities (Yin Fan Chung, Ellis-Hall & Coleman, 2017). Participants expressed a reluctance to avail of long term care services consistent with their beliefs that caring for a parent or spouse is a family responsibility. In addition, participants had provided care for many years and navigated through the challenges and adversities encountered along the way, thus carers were determined to see the journey through until the end. Despite all of the battles fought, carers were reluctant to admit defeat.

Notwithstanding the existence of carer support groups in local areas to where carers resided, these were not deemed as beneficial in terms of support and information as they were not tailored to dementia carers' needs or differing age groups. Dementia carer specific support groups are required to meet the needs of this cohort of care givers. This finding has international relevance and on-line international support networks for carers could be developed, modelled on current international on-line networks accessed by cancer patients and carers with less common cancers whose support needs are not met by generic cancer support group networks.

There was an evident mistrust of health care staff, hospitals, care facilities and respite centres. Carers prided themselves on providing a high standard of care for the person with dementia at home; however, based on past experiences in respite and clinical settings, carers felt they were not in control of the care delivery and believed the quality of care would diminish once the person with dementia left their home. This finding has international relevance and recommends that all healthcare providers working with dementia patients receive dementia specific education and training. This will result in enhanced care provision and a renewed trust in the services provided.

Healthcare professionals should be cognisant of the factors associated with caregiver burden and psychological well-being to provide effective care and support and promote a healthy transition in the caregiving role and through the course of the dementia disease.

Carers reported failing to receive post bereavement support following the death of the person with dementia. In accordance with international recommendations and guidelines (Schulz et al., 2015; Nielsen et al. 2016), pre-death education is required to facilitate a better post death adjustment to life after caregiving.

What are the specific end of life care / palliative care needs for individuals with end stage dementia?

Carers spoke about having regrets, one of which was not discussing death and dying with the person with dementia early in the disease trajectory while the care recipient was able to communicate their wishes and feelings about death and dying. Due to being ill-informed about the progression of dementia, carers missed the opportunity to ascertain the person with dementia's wishes regarding end of life care or preferences after death. Internationally, several countries recognise and support the use of advance healthcare directives to assist with decision making regarding future care. Once introduced in Ireland, the Assisted Decision Making (Capacity) Act 2015 will allow for the introduction of advance healthcare directives to enable an individual to be treated according to their will and preferences, including those with dementia. In the short term, families should be encouraged to discuss end of life care preferences during the early stages of the disease trajectory while the person with dementia can still make informed decisions and can communicate their wishes.

The pursuit for a good death for the person with dementia was reported with home identified as the ideal place for a good death in addition to having family present and being pain free. Early discussions about preferences for place of death will allow family members to ascertain where the person with dementia wishes to die. Having adequate support from family and healthcare professionals facilitates the person with dementia to die peacefully at home.

Participants changed the way they interacted with and related to the person with dementia, no longer recognising them as their mother, father or husband. The relationship between the carer and the person with dementia altered substantially causing family caring roles to be reversed. Participants articulated that the mother / father / husband they once knew was no longer alive. Carers withdrew from the pre-dementia relationship in an effort to cope with the loss of the person they once knew, by emotionally pulling away from the person with dementia. There is a requirement for greater information, education and

support to be provided to carers. Education about the stages of dementia, coping with behaviours that challenge and information regarding pre-death grief adequately equips the carer to a variety of situations as they present.

Carers experienced an additional role change after the person with dementia had died. Carers reported difficulty adjusting to life after the death of their loved one. They were forced to re-invent their role within the family, in the work-place and in society as they no longer assumed the role of carer. As previously mentioned, pre-death education and post death bereavement / follow up support will facilitate carers to cope with dying, death, and life after death.

What are the educational and training needs of families and carers?

Dementia is a very unpredictable disease with no two individuals experiencing the same symptoms. Carers described the uncertainty of not knowing what to expect from one day to the next, exacerbating their struggle providing care. Information on the stages of dementia, dietary advice, knowing what to expect, available support services, and coping with behaviours that challenge were identified by carers. This information needs to be delivered at the time of diagnosis, tailored to the needs of each carer and provided in the home face to face, in written form or online.

Carers expressed their need for practical information to assist them in their caregiving role. Workshops and training were offered to carers, however certain factors such as the location, financial costs, previous negative experiences and not being free from caregiving prevented their attendance. Social isolation contributed to the burden of care. Carers cannot freely leave their caregiving role unless a replacement has been arranged in their absence. As a result, often carers are unable to attend information workshops and depend on informed professionals to visit them in their homes to provide guidance and support. The need for information and training has been clearly highlighted from the findings of this study. However, support or respite is required to allow the carer to attend workshops and training. The value of these workshops or training events cannot be underestimated for not only the information they provide but also from a social aspect. Carers benefit hugely from interaction with other carers in similar situations. Of international relevance, this finding identified the need for online support and education for carers who may not be able to attend such events in person but who have a desire and

need to receive information and remain connected with others. Offering a variety of educational platforms allows carers to remain in control of their learning needs.

Carers reflected on how life would change again after the person with dementia died and worried how they would occupy their time once death occurred. The issue of pre-death grief needs to be addressed with carers before the death of the person with dementia occurs to prepare them adequately for life and loss after death.

7.2 Strengths and Limitations of the Study

A critique of methodological approaches and a review of the study's rigour was previously presented in chapter four. This section will consider the strengths and limitations imposed by the research design.

This is the first known study to provide a comprehensive account of the background, issues and challenges relevant to carers who provide end of life care to those with late stage dementia at home in Ireland. In relation to former carers, the study supports an earlier conceptualisation of a post-caring trajectory (Larkin 2009). There was congruence between 'post-caring void' and the loss of the carers former role of carer and reconstructing life post-caring'. What is noteworthy is that to date, Larkin's (2009) work was the only one that focused on post-caring following the death of the care recipient. This study begins to address the dearth of research on post-caring and care transition experiences due to death. The study findings add to the limited knowledge base surrounding this topic.

This research is the first of its kind in Ireland to employ IPA as a methodology to explore this area. Methodologically, an IPA study involves a highly detailed analysis of the participant's verbatim accounts, which relies on the researcher's skill to reflect on and make sense of the participant making sense of their experience (Smith, Flowers & Larkin, 2009). The researcher ensured sufficient extracts were presented to provide evidence from all four themes.

This study had a sample size of 23, which could be perceived as a limitation however IPA studies typically have small sample sizes and it was not the researcher's aim to make generalisations from the findings. Considerable time was spent using a systematic

approach to data collection and analysis to ensure a transparent audit trail, safe-guard the transferability of the research finding and illuminate the study's rigour.

The age of participants ranged from 30 – 79 and years spent caring ranged from 0 – 19 years which may be deemed as being too wide ranging. However, those who were the recipients of care were all in the late stage of dementia, and all carers lived in the West or North-West of Ireland, thus increasing the homogeneity of the study.

Carers aged between 50 – 59 years constituted the largest group of caregivers in this study. The greatest period of time spent caring was five to nine years. Despite participants having a range of educational qualifications, and residing in rural and urban areas, their experiences of caregiving was similar. While carers living in rural areas experienced more challenges in providing care and required additional support, there were almost three times more carers living rurally as opposed to those in urban areas. Unsurprisingly current carers experienced more challenges providing care than former carers, while former carers described experiencing further grief and loss than current carers. The data from the dyadic interviews was integrated with data from the individual participant interviews, thus was not analysed separately. See appendix 13 for additional tables and graphs evidencing systematic variations between variables.

The data from the dyadic interviews was integrated with data from the individual participant interviews and was not analysed separately. No systematic exploration of differences in themes emerging from the individual or couple interviews were revealed.

Both couples presented on the day of the interview as a couple and the researcher responded to the situation in the most appropriate manner she felt which was to interview them as a couple.

The findings of this study are limited to the West and North-West of Ireland and may not have widespread international application. However, given that the majority of participants were recruited by gatekeepers of national dementia and health related organisations, it is reasonable to assume that the experience is not uncommon to other carers who may share many of the same experiences and issues. This research also highlights that further research focusing on examining this experience nationally and

internationally is important along with efforts designed to support the specific needs of carers providing care in the late stage of dementia.

This research clearly outlines the specific challenges carers have throughout their care giving career, including the challenges faced by carers after the death of the person with dementia. The findings have significance for practitioners, educators and researchers nationally and internationally.

7.3 Recommendations

7.3.1 Recommendations for Practice

While there is a growing trend towards an inclusive community approach to dementia care, the findings from this research have implications for the creation of dementia friendly communities across the country which will aid reducing stigma associated with the disease and help reduce social isolation for the person with dementia and their carer.

A dementia diagnosis should be followed by immediate access to a named and appropriately trained contact person who will support and empower the carer, assist the carer maintain independence and autonomy, avert future problems and provide continued advice and information. In addition, carer-specific post diagnostic support structures need to be developed to support families and acknowledge the role played by caregivers in Ireland.

Service providers should receive education and guidance to help understand the causes of challenging behaviours, the stages of dementia and the supports to facilitate caregiving in the home. Findings revealed that carers developed strategies to overcome barriers to providing care in the absence of support, knowledge or training. This is despite carers being constantly challenged by complex and ever-changing circumstances, which include behavioural difficulties. It is noteworthy that carers who had no formal training, took on an enabling role, which was once considered to be a clinical role undertaken by trained staff. It is important for practitioners to recognise the coping strategies employed by carers and to ascertain if carers feel that the strategies they are using are useful or not and to be able to suggest alternative strategies which could lead to a successful intervention.

It is also helpful for carers if they could identify which strategies were not useful which could lead to frustration and failure.

Carers have a wealth of experiential and tacit knowledge which can enable professionals to gain insight into the mechanisms of support for family carers. This understanding and insight is crucial if professionals are to work collaboratively with carers to develop an individualised care plan for those with dementia.

This study highlights an unmet need to care for the carers and the need for an outreach / liaison service specifically addressing carers' needs. This service must be specific to dementia carers as it has been highlighted that generic carer support groups / services are fail to address the specific informational and supportive requirements of dementia carers.

7.3.2 Recommendations for Education

The provision of timely post-diagnostic support services for people with dementia and their carers is important. Information regarding information services, signposting, counselling and psychological supports are key elements in the early stages of the disease (O'Shea & Monaghan, 2017). This information should be tailored to the needs of the person with dementia and their identified primary carer.

Information needs to be provided in a variety of formats. Written material, face-to-face education or information provided online should be made available according to carers' preferences. Practical information to assist carers provide physical care to the person with dementia is required. Workshops and training which are free of charge should be offered to carers, ideally in carers' homes or at a location convenient for carers.

Pre-death bereavement support should be provided to adequately prepare carers for the end of life phase and to facilitate a better adjustment to life and loss after death. In addition, accredited formal training in dementia care is a requirement for all medical, nursing and allied healthcare professionals at both undergraduate and postgraduate level.

Integration of the findings of this research into the curricula at both undergraduate and postgraduate level for physicians, nurses and health care assistants can help develop knowledge, understanding and critical awareness in the workforce.

7.3.3 Recommendations for Policy

The National Dementia Strategy has invested heavily in the Home Help and Home Care Packages schemes, however findings from this study reveal that services are inadequate. In addition, owing to the fact that these services are non-statutory, not all carers can avail of the services and have to rely on their personal finances to fund home help hours. Universal statutory entitlement to home care is a pre-requisite to the transformation of care for people with dementia in Ireland and should be a priority for government (O’Shea, Cahill & Pierce, 2018).

As a consequence of home help hours being so short, there is a tendency for staff to rely on a task allocation method of care to “get things done” rather than “do things with” the person with dementia. This results in neglecting the psychological aspect of caring, disempowering their individuality and failing to communicate effectively with the person with dementia. Kelly (2017) notes that with the introduction of Ireland’s new Assisted Decision Making Act (2015) the preferences and will of those with impaired cognitive capacity will be placed at the centre of decision making for their personal care as well as their property and affairs.

7.3.4 Future Research

Based on the findings of this research and the literature reviewed, a number of areas present themselves as potential areas for future research.

Carers are ideally placed to be involved in public and patient involvement (PPI) research which will further explore the needs of caregivers to those with dementia living in the home.

This research was conducted in the West and North-West of Ireland. A larger scale study sampling participants from across Ireland and from countries outside of Ireland would be

worthy of research. The focus would compare and contrast carers' experiences with a larger sample size from diverse backgrounds. This would have implications on using IPA as a methodology however, and other design methods suited to larger sample sizes should be utilised.

Carers in this study reported little, or no family involvement in the care of the person with dementia. Research examining the factors affecting sibling involvement in the delivery of care is an area warranting further investigation.

Participants in this study consisted of spouses and children of a person with dementia. A worthwhile study exploring the experiences of spouse caregivers versus child carers would illuminate the specific experiences of both cohorts.

Carers indicated the negative impact their caring role had on family life particularly highlighting the throughput of people (such as professional carers) in the family home and having to divide their time between providing care to the person with dementia with being a wife, husband, mother or son. Research examining the impact on spouses and children when the person with dementia is being cared for in the family home by a primary caregiver is warranted.

Findings revealed that carers felt unsupported by their GP, PHN or allied healthcare providers despite identifying their apparent struggle to provide care. Carers also detailed not having access to sufficient information or training required to provide quality care. Research examining GP / PHN / support organisations understanding of the needs of carers and their knowledge of appropriate interventions / information and their own confidence in supporting carers is required.

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9. Appendices

Appendix 1: Search Strategy for the CINAHL Database

Interface – EBSCOHost

Database – CINAHL Complete

# Search Number	Search Terms	Limiters/Expanders	Results
S1	Carer* OR caregiver* OR care giver* OR family carer* OR family caregiver*	Search modes - Boolean/Phrase	58,842
S2	Loved one* OR spouse OR children OR patient* OR individual* OR people	Search modes - Boolean/Phrase	2,231,713
S3	S1 AND S2		44,936
S4	Dementia OR Alzheimer*	Search modes - Boolean/Phrase	70,716
S5	End of life OR end of life care OR palliative care OR terminal care OR care of the dying	Search modes - Boolean/Phrase	53,571
S6	Death OR dying OR grief OR grief and loss OR loss	Search modes - Boolean/Phrase	282,349
S7	(MH “Home+”)	Search modes - Boolean/Phrase	67
S8	S5 OR S6 OR S7		320,942
S9	Advanced stage OR late stage, OR severe OR end stage OR terminal stage	Search modes - Boolean/Phrase	152,913
S10	S4 OR S9		220,189
S11	S3 AND S8 AND S10	Limiters - Abstract available; Published Date: 2012-2015, Language: English, Search modes – Boolean/Phrase	212
S12	S3 AND S8 AND S10	Limiters - Abstract available; Published Date: 2015-2018, Language: English, Search modes – Boolean/Phrase	93

Appendix 2: Ethical Protocol for Dealing with Distress

This procedural protocol is for the participant in this study to ensure that their wellbeing and rights are protected. The steps outlined below are for participants benefit in the event that they become distressed while being interviewed.

The interview will be terminated if:

The participant decides to terminate the interview

The participant decides to participate in the interviews at another time or place

The researcher will intervene if the participant is:

Experiencing anxiety or distress during the interview. The participant will be asked if they would like to take a break and if they wish for the recorder to be switched off.

Continuing to be upset, they will be asked if they wish the interview to end and if they would like the researcher to call someone to spend time with them, such as a son or daughter or spouse.

Unduly distressed. The researcher will remain with the participant until they are calm and composed and they may decide if they wish to continue with the interview or not.

The researcher will, with the participant's consent:

Refer to others if they request

Ask if it is ok to call them later in the day or the next day to make sure they are ok. Alternatively, the researcher will ask if they would like a family member or someone from the local community (e.g. priest, public health nurse) to call them to make sure they are ok.

Contact details of useful numbers and support groups will be offered to the participant if they require them such as Alzheimer's Society of Ireland (1800341341), The Carers Association (057 9322920), and the local public health nurse.

Appendix 3: Interview Guide One (Current Carer)

Describe your experience of providing care for someone who has dementia?

Tell me what makes providing care easier for you?

What are the barriers or obstacles that you feel prevent you from providing care?

What do you know about Dementia?

What training or education do you think you would like to have to help you provide care for the person with dementia at home?

What would be important for somebody to know who is starting out caring for someone with dementia?

What support services are available to you to allow you to provide care at home?

Appendix 4: Interview Guide Two (Former Carer)

On reflection, describe your experience of providing care for someone who has dementia?

What did you know about dementia?

What helped you to provide care / what made providing care easier for you?

Can you identify what obstacles hindered the care you provided?

What training or education would have helped you provide better care?

What support services were available to you when you were providing care?

What support services would you like to have been available to you that would have helped you provide better care?

What are your views on the involvement of palliative care when someone has significant dementia being cared for at home?

What are your views on end of life care for those with dementia?

What was the biggest challenge for you providing care?

What were the benefits of caring?

Appendix 5: Participant Invitation letter (Current Carer)

Dear Carer,

My name is Laura Dempsey and I am undertaking a PhD in the School of Nursing & Midwifery at the National University of Ireland, Galway. I am a qualified general nurse and now work as a nurse lecturer in the School of Nursing & Midwifery at the National University of Ireland, Galway. My job involves teaching student nurses and also directing a palliative care programme to qualified nurses. My research interest is in the area of dementia and palliative care and I have been involved in several major national studies on dementia over the past few years.

Purpose of the study

For my PhD I am conducting a study looking at the experience of family carer's who provide care to those with dementia who are at end of life. Dementia is a long term illness and much has been written and discussed about how people with dementia, especially at the end of their illness, have difficulty accessing specialist services and are not receiving end of life care (from health care professionals) even though dementia is a life limiting illness.

You have been asked to participate in this study as you are a family carer looking after someone with dementia. The aim of this study is to understand your experience of providing care at home for a family member with significant dementia who is approaching end of life. I would like to ask you questions about your experiences providing care, so that I can understand what this experience is like for you. I would also like to identify what helps you provide care and also what obstacles makes providing care difficult for you at home.

How do I take part?

If you choose to take part, I will interview you twice, on two separate occasions. The interviews will take place at a location and time suitable for you as I understand how hard it may be for you to get away from your caring responsibilities. In the first interview you will be asked to describe your experiences of providing care for a family member who has significant dementia and is approaching end of life.

With your consent, the second interview would take place approximately 6-12 months after your loved one has passed away. The purpose of the second interview is to allow

me to understand what the experience was like for you, looking back at it, and for you to be able to tell me what helped you give this care and what prevented you giving care. I would also like to discuss with you what you knew about dementia and what you feel would be important to know about dementia which would have helped you provide care. In the second interview, I am trying to see if your experience of providing care has changed from when you were actually providing the care, to now having gone through the process, what it was like looking back and what you feel is important for carer's to know and what help you would like to have had at the time of providing care.

If you decide to take part, you are still free to withdraw at any time and without giving a reason.

What are the possible disadvantages of taking part?

This study includes two interviews which discusses your experiences of caring for a family member with significant dementia who is at the end of their life. You might find while you are describing your experiences you may become upset. If this happens, the interview will be stopped and will only restart if you are happy to do so. After the interview you may like to talk to someone about some of the issues it raises. I am happy to recommend someone suitable to you.

What are the benefits of taking part?

Taking part in this study will provide me with valuable information on family carers' experiences of caring for a person with significant dementia at end of life. This information will be used to educate healthcare providers (nurses, doctors, physiotherapists, occupational therapists) on the needs of carer's in the community, and to inform other carer's about the experiences of others who also care for a family member at home with dementia. Above all I want to find out what end of life care is / was available to your loved one with dementia, and what supports and services were offered to you to make your job of caring a little easier as your loved one with dementia reaches end of life. It is by highlighting your experiences and having actual evidence of your caring journey, allows me to share the facts through publishing articles and speaking at health care conferences on this topic.

Many thanks for taking the time to read this and I look forward to hearing from you.

Please telephone or text me on [REDACTED] or Email [REDACTED]

Laura Dempsey

Appendix 6: Participant Invitation letter (Former Carer)

Dear Carer,

My name is Laura Dempsey and I am undertaking a PhD in the School of Nursing & Midwifery at the National University of Ireland, Galway. I am a qualified general nurse and now work as a nurse lecturer in the School of Nursing & Midwifery at the National University of Ireland, Galway. My job involves teaching student nurses and also directing a palliative care programme to qualified nurses. My research interest is in the area of dementia and palliative care and I have been involved in several major national studies on dementia over the past few years.

Purpose of the study

For my PhD I am conducting a study looking at the experiences of family carer's who provide care to those with dementia who are at end of life. Dementia is a long term illness and much has been written and discussed about how people with dementia, especially at the end of their illness, have difficulty accessing specialist services and are not receiving end of life care (from health care professionals) even though dementia is a life limiting illness.

You have been asked to participate in this study as you were a family carer who looked after someone with advanced dementia at home. The aim of this study is to understand your experience of providing care at home for a family member with significant dementia who was approaching end of life. I would like to ask you questions about your experiences of providing care, so that I can understand what this experience was like for you. I would also like to identify what helped you provide care and also what obstacles made providing care difficult for you at home.

How do I take part?

If you choose to take part, I would like to talk to / interview you. The interview will take place at a location and time suitable for you. In the interview you will be asked to describe your experiences of providing care for a family member who had advanced dementia and was approaching end of life. The purpose of the interview is to allow me to understand what the experience was like for you, looking back at it, and for you to be able to tell me what helped you give this care and what prevented you giving care. I would also like to discuss with you what you knew about dementia and what you feel would be important to know about dementia which would have helped you provide care.

If you decide to take part, you are still free to withdraw at any time and without giving a reason.

What are the possible disadvantages of taking part?

This study includes an interview which discusses your experiences of caring for a family member with advanced dementia who was at the end of their life. You might find while you are describing your experiences you may become upset. If this happens, the interview will be stopped and will only restart if you are happy to do so. After the interview you may like to talk to someone about some of the issues it raises. I am happy to recommend someone suitable to you.

What are the benefits of taking part?

Taking part in this study will provide me with valuable information on family carers' experiences of caring for a person with significant dementia at end of life. This information will be used to educate healthcare providers (nurses, doctors, physiotherapists, occupational therapists) on the needs of carer's in the community, and to inform other carer's about the experiences of others who also care for a family member at home with dementia. Above all I want to find out what end of life care is / was available to your loved one with dementia, and what supports and services were offered to you to make your job of caring a little easier as your loved one with dementia reaches end of life. It is by highlighting your experiences and having actual evidence of your caring journey, allows me to share the facts through publishing articles and speaking at health care conferences on this topic.

Many thanks for taking the time to read this and I look forward to hearing from you.

Please telephone or text me on [REDACTED] or Email [REDACTED]

Laura Dempsey

Appendix 7: Participant Information Sheet (Current Carer)

Title of the study: The Experience of providing Care for those Dying with Dementia: Family Carers' Perspectives.

Invitation

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. This participant information sheet will tell you about the purpose, risks and benefits of this study. If you agree to take part, we will ask you to sign a consent form. If there is anything you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read it. You should only consent to participate in this research study when you feel that you understand what is being asked of you, and you have had enough time to think about your decision. Thank you for reading this.

Who is doing the research?

The research is being conducted by Laura Dempsey, a PhD candidate from the School of Nursing & Midwifery at the National University of Ireland, Galway. I am a qualified general nurse and now work as a nurse lecturer in the School of Nursing & Midwifery at the National University of Ireland, Galway. My job involves teaching student nurses and also directing a palliative care programme to qualified nurses. My research interest is in the area of dementia and palliative care and I have been involved in several major national studies on dementia over the past few years.

Purpose of the study

You have been asked to participate as you are a family carer looking after someone with dementia. The aim of this study is to understand your experience of providing care at home for a family member with significant dementia who is approaching end of life. I would like to ask you questions about your experiences providing care, so that I can understand what this experience is like for you. I would also like to identify what helps you provide care and also what obstacles makes providing care difficult for you at home. Finally, I would like to talk to you about dementia and find out what training or education you think would help you give this much needed and vital care.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep, asked to sign a consent form and post it back to me in the stamped addressed envelope provided. If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way.

How do I take part?

If you wish to take part, you will be required to return the consent form enclosed by posting it in the stamped addressed envelope provided. I have asked for your contact telephone number on the consent form so that I can phone you to arrange an interview at a time and place convenient for you. I will be the only one who will have access to your details, so confidentiality will be ensured.

What will happen to me if I take part?

If you choose to take part, you will be required to undertake two interviews in total. These interviews will take place at a location and time suitable for you. In the first interview you will be required to describe your experiences of providing care for a family member who has significant dementia and is approaching end of life. The second interview will take place approximately 6-12 months after the person you provided care for has passed away. The purpose of the second interview is to allow me to understand what the experience was like for you, looking back at it and for you to be able to discuss what helped you give this care and what prevented you giving care. I would also like to discuss with you what you knew about dementia and what you feel would be important to know about dementia which would have helped you provide care.

The interviews will be recorded and I will be the only person permitted to listen to these recordings.

How long will my part in the study last?

You will only be required to attend two interviews, each lasting approximately 30-45 minutes.

What do I have to do?

There are no special requirements/ restrictions prior to attending this interview.

What are the benefits of taking part?

Taking part in this study will provide me with valuable information on family carers' experiences of caring for a person with significant dementia in the final months or weeks of life. This information will be used to educate healthcare providers (nurses, doctors, physiotherapists, occupational therapists) on the needs of carers in the community, and to inform other carers about the experiences of others who also care for a family member at home with dementia.

What are the possible disadvantages of taking part?

This study includes two interviews which discuss your experiences of caring for a family member with significant dementia who is at the end of their life. You might find while you are describing your experiences you may become upset. If this happens, the interview will be stopped and will only recommence if you are happy to do so. After the interview you may like to talk to someone about some of the issues it raises. I am happy to recommend someone to you, such as the Alzheimer's Society, Carers Association or Bereavement Counsellors.

What happens at the end of the study?

The interview will be recorded so that I can transcribe exactly what you said during the interviews. This ensures an accurate representation of the interview is achieved. The interviews will be typed by myself and then analysed. Common themes generated from the data will be identified and published within a dissertation, at conferences and in health care journals. Your name will not be included within this publication, and as I will be the only one who interviews you, every effort will be made by me to ensure confidentiality and anonymity in the presentation of the research findings.

What happens if I change my mind during the study?

If at any time you wish to withdraw your participation from this study you may do so, if this is following the interview any information you have provided will be destroyed and will not be included.

What if I have a complaint during my participation in the study?

If you have any concerns about this study and wish to contact someone in dependant and in confidence, you may contact the chairperson of the NUI Galway Research Ethics Committee, C/O Office of the vice president for research, NUI Galway, ethics@nuigalway.ie

If you have further concerns, please contact me:

Telephone: [REDACTED]

Email: [REDACTED]

Many thanks for taking the time to read this.

Laura Dempsey

Appendix 8: Participant Information Sheet (Former Carer)

Title of the study: The Experience of providing Care for those Dying with Dementia: Family Carers' Perspectives.

Invitation

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. This participant information sheet will tell you about the purpose, risks and benefits of this study. If you agree to take part, we will ask you to sign a consent form. If there is anything you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read it. You should only consent to participate in this research study when you feel that you understand what is being asked of you, and you have had enough time to think about your decision. Thank you for reading this.

Who is doing the research?

The research is being conducted by Laura Dempsey, a PhD candidate from the School of Nursing & Midwifery at the National University of Ireland, Galway. I am a qualified general nurse and now work as a nurse lecturer in the School of Nursing & Midwifery at the National University of Ireland, Galway. My job involves teaching student nurses and also directing a palliative care programme to qualified nurses. My research interest is in the area of dementia and palliative care and I have been involved in several major national studies on dementia over the past few years.

Purpose of the study

You have been asked to participate as you were a family carer who looked after someone with dementia. The aim of this study is to understand your experience of providing care at home for a family member with significant dementia who was approaching end of life. I would like to ask you questions about your experiences of providing care, so that I can understand what this experience was like for you. I would also like to identify what helped you provide care and also what obstacles made caregiving difficult for you at home. Finally, I would like to talk to you about dementia and find out what training or education you think would have helped you provide this much needed and vital care.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep, asked to sign a consent form and post it back to me in the stamped addressed envelope provided. If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way.

How do I take part?

If you wish to take part, you will be required to return the consent form enclosed by posting it in the stamped addressed envelope provided. I have asked for your contact telephone number on the consent form so that I can phone you to arrange an interview at a time and place convenient for you. I will be the only one who will have access to your details, so confidentiality will be ensured.

What will happen to me if I take part?

If you choose to take part, you will be required to undertake 1 interview. This interviews will take place at a location and time suitable for you. In the interview you will be required to describe your experiences of providing care for a family member who had significant dementia and was approaching end of life. The purpose of the interview is to allow me to understand what the experience was like for you, looking back at it and for you to be able to discuss what helped you give this care and what prevented you giving care. I would also like to discuss with you what you knew about dementia and what you feel would be important to know about dementia which would have helped you provide care.

The interviews will be recorded and I will be the only person permitted to listen to these recordings.

How long will my part in the study last?

You will only be required to attend two interviews, each lasting approximately 30-45 minutes.

What do I have to do?

There are no special requirements/ restrictions prior to attending this interview.

What are the benefits of taking part?

Taking part in this study will provide me with valuable information on family carers' experiences of caring for a person with significant dementia in the final months or weeks

of life. This information will be used to educate healthcare providers (nurses, doctors, physiotherapists, occupational therapists) on the needs of carers in the community, and to inform other carers about the experiences of others who also care for a family member at home with dementia.

What are the possible disadvantages of taking part?

This study includes an interview which discusses your experiences of caring for a family member with significant dementia. You might find while you are describing your experiences you may become upset. If this happens, the interview will be stopped and will only recommence if you are happy to do so. After the interview you may like to talk to someone about some of the issues it raises. I am happy to recommend someone to you, such as the Alzheimer's Society, Carers Association or Bereavement Counsellors.

What happens at the end of the study?

The interview will be recorded so that I can transcribe exactly what you said during the interviews. This ensures an accurate representation of the interview is achieved. The interviews will be typed by myself and then analysed. Common themes generated from the data will be identified and published within a dissertation, at conferences and in health care journals. Your name will not be included within this publication, and as I will be the only one who interviews you, every effort will be made by me to ensure confidentiality and anonymity in the presentation of the research findings.

What happens if I change my mind during the study?

If at any time you wish to withdraw your participation from this study you may do so, if this is following the interview any information you have provided will be destroyed and will not be included.

What if I have a complaint during my participation in the study?

If you have any concerns about this study and wish to contact someone in dependant and in confidence, you may contact the chairperson of the NUI Galway Research Ethics Committee, C/O Office of the vice president for research, NUI Galway, ethics@nuigalway.ie

If you have further concerns, please contact me:

Telephone: [REDACTED] Email: [REDACTED]

Many thanks for taking the time to read this, Laura Dempsey.

Appendix 9: Consent Form

**Title of project: The Experience of providing Care for those Dying with Dementia:
Family Carers' Perspectives.**

Name of Researcher: Laura Dempsey

Participant identification number:

**Please read the following statements and sign at the bottom if you agree to take
part in this study.**

I confirm that I have read the information sheet dated for the above study and
have had an opportunity to ask questions.

I am satisfied that I understand the information provided and have had enough time to
consider the information.

I understand that my participation is voluntary and that I am free to withdraw at any
time.

I agree to take part in the above study

Name of Participant:

Contact Telephone Number:

Date:

Signature:

Appendix 10: Demographics Form

Demographics

Participant Code:

1. Gender

Male Female

2. Age

Age 20-29 30-39 40-49 50-59 60-69 70+

3. Supports you currently have for caring for the person with dementia:

Respite Record how often available/availed of: _____

Day Care Record how often available/availed of: _____

Professional carers Record how often (per day/per week): _____

Family/other carers Record how often (per day/per week): _____

Other (explain) _____

Years of caring for the person with dementia:

0 -4 5-9 10-14 15-19 20-24 25+

4 – Highest Level of Education Attained:

No Formal education	<input type="checkbox"/>	Primary Education	<input type="checkbox"/>
Secondary	<input type="checkbox"/>	Post leaving Cert	<input type="checkbox"/>
Third Level- Non Degree	<input type="checkbox"/>		
Technical/Vocational Qualification	<input type="checkbox"/>	Please Specify	_____
Third Level- Degree or above	<input type="checkbox"/>	Please Specify	_____
Professional Qualification	<input type="checkbox"/>	Please Specify	_____
Other	<input type="checkbox"/>	Please Specify	_____

Appendix 11: Letters to Gatekeepers

The Experience of providing Care for those Dying with Dementia: Family Carers' Perspectives.

School of Nursing & Midwifery,
National University of Ireland, Galway
Galway
September 2nd 2011

Dear [REDACTED] (Policy and Research Officer, Alzheimer's Society of Ireland)

I am a lecturer in the School of Nursing & Midwifery at the National University of Ireland, Galway and have just commenced a PhD examining the experiences of providing care to individuals who are dying with dementia from the perspective of the family carer. I hope to invite 25 participants to be involved in this study to uncover their lived experience of providing care in the home to their family member with end stage dementia.

I am contacting you to enquire whether you could assist with access to potential participants who would be known to The Alzheimer Society of Ireland through the organisations work of supporting and caring for individuals with dementia and their families. If this is something you could help me with, I would be most grateful to you and your organisation as this is a very important study which will highlight the needs of family carers and those with dementia at end of life.

If your organisation personnel are willing to give potential participants information packs to family carers who meet the inclusion criteria outlined below, I will send this information to you. Potential participants can then decide whether they wish to participate in this study and can contact me at their convenience.

The inclusion criteria for participants is that they must:

- be the main care provider for someone with end stage dementia
- Provide care at home
- be cognitively and physically able to participate

If you have any questions or concerns about this study, please contact me.

Yours Sincerely

Laura Dempsey

Phone: [REDACTED]

E mail: [REDACTED]

The Experience of providing Care for those Dying with Dementia: Family Carers' Perspectives

School of Nursing & Midwifery

National University of Ireland, Galway

Galway

February 15th 2012

Dear Director of Public Health Nursing,

I am a lecturer in the School of Nursing & Midwifery at the National University of Ireland, Galway and have recently commenced a PhD examining the experiences of providing care to individuals who are dying with dementia from the perspective of the family carer. I hope to invite 25 participants to be involved in this study to uncover their lived experience of providing care in the home to their family member with end stage dementia.

I am contacting you to enquire whether you could assist with access to your public health nurses who may be able to identify family carers in the community. If this is something you could help me with, I would be most grateful to you and your public health nursing teams as this is a very important study which will highlight the needs of family carers and those with dementia at end of life.

If your public health nursing teams are willing to give potential participants information packs to family carers who meet the inclusion criteria outlined below, I will send this information to you. Potential participants can then decide whether they wish to participate in this study and can contact me at their convenience.

The inclusion criteria for participants is that they must:

- be the main care provider for someone with end stage dementia
- Provide care at home
- be cognitively and physically able to participate

If you have any questions or concerns about this study, please contact me.

Yours Sincerely

Laura Dempsey

Phone: [REDACTED]

E mail: [REDACTED]

The Experience of providing Care for those Dying with Dementia: Family Carers' Perspectives

School of Nursing & Midwifery
National University of Ireland, Galway
Galway

February 15th 2012

Dear Director of Nursing (Palliative Care),

I am a lecturer in the School of Nursing & Midwifery at the National University of Ireland, Galway and have recently commenced a PhD examining the experiences of providing care to individuals who are dying with dementia from the perspective of the family carer. I hope to invite 25 participants to be involved in this study to uncover their lived experience of providing care in the home to their family member with end stage dementia.

I am contacting you to enquire whether you could assist with access to your palliative care home care nurses who may be able to identify family carers in the community. If this is something you could help me with, I would be most grateful to you and your home care nursing teams as this is a very important study which will highlight the needs of family carers and those with dementia at end of life.

If your home care nursing teams are willing to give potential participants information packs to family carers who meet the inclusion criteria outlined below, I will send this information to you. Potential participants can then decide whether they wish to participate in this study and can contact me at their convenience.

The inclusion criteria for participants is that they must:

- be the main care provider for someone with end stage dementia
- Provide care at home
- be cognitively and physically able to participate

If you have any questions or concerns about this study, please contact me.

Yours Sincerely

Laura Dempsey

Phone: [REDACTED]

E mail: [REDACTED]

The Experience of providing Care for those Dying with Dementia: Family Carers' Perspectives

School of Nursing & Midwifery
National University of Ireland, Galway
Galway

October 10th 2012

Dear [REDACTED] (CEO Carer's Association),

I am a lecturer in the School of Nursing & Midwifery at the National University of Ireland, Galway and am conducting research exploring carers' experiences of providing care to a person with late stage dementia at home. I hope to invite 25 participants to be involved in this study to uncover their lived experience of providing care in the home to a person with dementia.

I am contacting you to enquire whether you could assist with access to potential participants who would be known to The Carer's Association through the organisations work of supporting and caring for individuals with dementia and their families. If this is something you could help us with, we would be most grateful to you and your organisation as this is a very important study which will highlight the needs of family carers and those with dementia in the community.

If your organisation personnel are willing to give potential participants information packs to carers who meet the inclusion criteria outlined below, I will send this information to you. Potential participants can then decide whether they wish to participate in this study and can contact me at their convenience.

The inclusion criteria for participants is that they must:

- be the main care provider for someone with end stage dementia
- Provide care at home
- be cognitively and physically able to participate

If you have any questions or concerns about this study, please contact me.

Yours Sincerely

Laura Dempsey

Phone: [REDACTED]

E mail: [REDACTED]

The Experience of providing Care for those Dying with Dementia: Family Carers' Perspectives

School of Nursing & Midwifery
National University of Ireland, Galway
Galway
October 10th 2012

Dear [REDACTED] (CEO, Western Alzheimer's Association, Ballindine, Co. Mayo)

I am a lecturer in the School of Nursing & Midwifery at the National University of Ireland, Galway and have recently commenced a PhD examining the experiences of providing care to individuals who are dying with dementia from the perspective of the family carer. I hope to invite 25 participants to be involved in this study to uncover their lived experience of providing care in the home to their family member with end stage dementia.

I am contacting you to enquire whether you could assist with access to your respite care nurses who may be able to identify family carers in the community. If this is something you could help me with, I would be most grateful to you and your home care nursing teams as this is a very important study which will highlight the needs of family carers and those with dementia at end of life.

If your respite care nurses are willing to give potential participants information packs to family carers who meet the inclusion criteria outlined below, I will send this information to you. Potential participants can then decide whether they wish to participate in this study and can contact me at their convenience.

The inclusion criteria for participants is that they must:

- be the main care provider for someone with end stage dementia
- Provide care at home
- be cognitively and physically able to participate

If you have any questions or concerns about this study, please contact me.

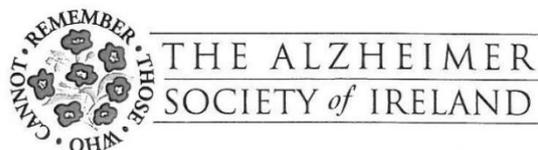
Yours Sincerely

Laura Dempsey

Phone: [REDACTED]

E mail: [REDACTED]

Appendix 12: Letter of Support from The Alzheimer's Society of Ireland



Ms. Laura Dempsey
School of Nursing and Midwifery Studies
NUI Galway
Galway

15 September 2011

Dear Ms. Dempsey

Thank you for sharing your research idea with the Alzheimer Society of Ireland.

As the main patient organisation supporting people with dementia and their carers in Ireland, we would be pleased, in principle, to support your fellowship application and the research process. This is a subject matter that is of significant interest to us as an organisation and we are pleased to see it becoming a topic of research in order to add to the evidence base here in Ireland.

We look forward to working with you.

Yours sincerely

Grainne McGettrick

Policy and research Officer

Patron: Mary McAleese, President of Ireland
Directors: Mr. Kevin Norton, Chairman • Mr. John Clifford • Mr. Finbarr Fitzpatrick • Mr. Brian Holland • Ms. Tess Hogan • Mr. Shane Molloy • Mr. Maurice J. O'Connell • Mrs. Lillian Sullivan
Mr. Maurice A O'Connell, Chief Executive, Company Secretary

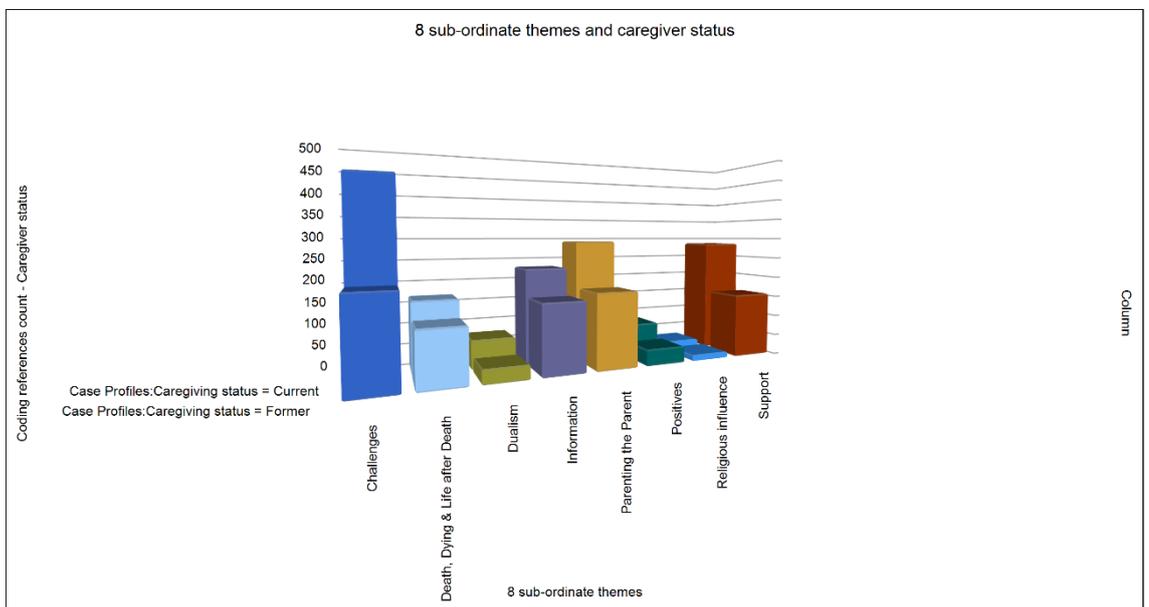
Alzheimer Society of Ireland, National Office, Temple Road, Blackrock, Co. Dublin
Phone: 01-207 3800 Fax: 01-210 3772 E-mail: info@alzheimer.ie Website: www.alzheimer.ie
A Limited Company, Registered in Ireland No. 102700 Registered Charity No. CHY 7868

Appendix 13: Sub-ordinate / Super-ordinate Themes and Demographic Variables

Sub-ordinate / Super-ordinate themes and years of caring	Years of Caring = 0-4 Years	Years of Caring = 5-9 Years	Years of Caring = 10-14 Years	Years of Caring = 15-19 Years
Challenges/Experience of Dementia Grief	185	313	83	66
Anger	25	11	5	13
Burden of care	14	55	22	20
Difficulty attending medical appointments	0	3	0	1
Fight for your rights	2	2	1	5
Going Crazy	2	3	0	1
Medication administration	12	0	0	0
Your house is not your own	3	4	0	1
Challenging behaviours	5	19	1	0
Anxiety - Agitation	7	7	3	1
Dressing & Washing	0	13	4	0
Eating & Drinking	3	11	11	1
Emotional	10	10	7	1
Hallucinations & Delusions	8	8	3	0
Mobility	6	10	13	2
Money	1	6	0	0
Pain	5	0	1	0
Physical	1	13	0	1
Remembering the past	1	10	7	0
Repetition	4	9	0	0
Safety	1	14	18	6
Sleep	5	15	3	3
Toileting	3	9	3	0
Verbal	8	12	14	2
Wandering	1	7	11	3
Change in body function	40	46	22	7
Contradiction	32	27	7	15
Examples of poor professional care	33	17	13	11
Family or Friends or Relationship impact	70	115	15	4
Fear	5	18	4	3
Financial & Legal Affairs	38	45	5	11
Frustration	35	26	8	10
Guilt	14	12	1	1
Risk taking	1	10	4	2
Self image	5	9	2	2
Social Isolation	5	6	3	5
Stigma	8	21	4	6
Struggle	21	17	13	8
Time	22	38	16	5
Death, Dying & Life after Death	97	117	47	32
Death & Dying	46	40	12	8
Disembodiment	25	18	16	11
End of Life Care	45	31	17	9
Grief & loss	43	50	15	5
Regret	9	16	2	3
Role change	30	51	16	8
Temporality	11	26	7	5
Parenting the Parent	131	193	90	59
Care for the Carer	7	45	9	2
Control	45	47	20	31
Coping Strategies	110	158	81	52
Personhood	16	20	10	3
Support	138	163	74	68
Family Support	27	45	21	9
Negative examples of family support	19	25	6	7
Positive examples of family support	9	21	16	3
Financial support	3	9	1	1
Professional Support	107	103	55	56
Negative examples of professional support	67	44	20	35
Positive examples of professional support	36	51	32	25
Respite	9	14	5	1
Other Support	6	18	4	10
Support Groups	6	9	4	1

	Caregiving status = Current carer	Caregiving status = Former carer
Challenges	442	203
Death, Dying & Life after Death	165	126
Dualism	68	33
Information	228	163
Parenting the Parent	292	179
Positives	76	39
Religious influence	22	14
Support	285	156

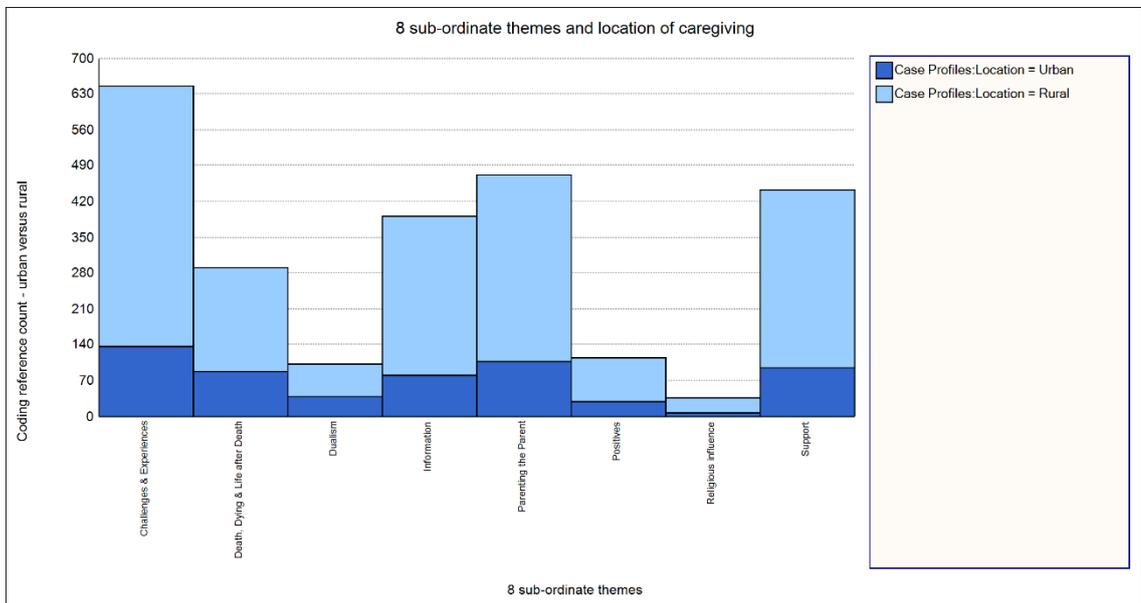
Eight sub-ordinate themes and caregiver status



Eight sub-ordinate themes and caregiver status

	Location = Urban	Location = Rural
Challenges	137	508
Death, Dying & Life after Death	87	204
Dualism	37	64
Information	80	311
Parenting the Parent	107	364
Positives	27	88
Religious influence	7	29
Support	94	347

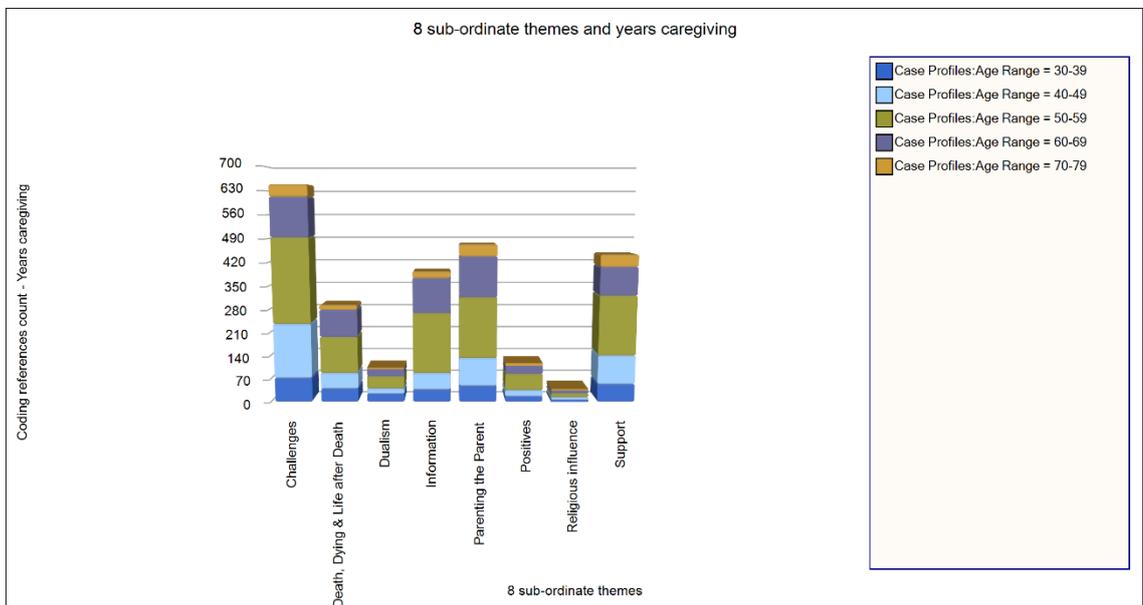
Eight sub-ordinate themes and location of caregiving



Eight sub-ordinate themes and location of caregiving

	Age Range = 30-39	Age Range = 40-49	Age Range = 50-59	Age Range = 60-69	Age Range = 70-79
Challenges	74	164	257	118	35
Death, Dying & Life after Death	41	48	110	81	14
Dualism	25	16	38	22	3
Information	38	51	182	104	19
Parenting the Parent	50	85	183	121	35
Positives	17	19	50	25	7
Religious influence	5	9	12	10	3
Support	55	87	181	85	36

Eight sub-ordinate themes and age of participants



Eight sub-ordinate themes and age of participants

Appendix 14: Published Papers

The unmet palliative care needs of those dying with dementia

Laura Dempsey, Maura Dowling, Philip Larkin and Kathy Murphy

Abstract

An estimated 33.9 million people are living with dementia worldwide. The overall estimated median survival time from onset of dementia to death is 4.1 years for men and 4.6 years for women, with longer survival times in those with early-onset dementia. Much has been discussed about the needs of this vulnerable group of people particularly in terms of their health-care and end-of-life care (EoLC) needs. However, the literature suggests that people with end-stage dementia are still not receiving adequate or appropriate EoLC. Difficulty diagnosing dementia, a stigma surrounding the disease, lack of education of the dementia disease process and the ability to identify complications encountered at end-stage dementia by health-care providers, families and carers are some of the factors preventing those with dementia receiving effective EoLC. Great strides have been made to improve dementia palliative care; however, this cohort of patients still receive fewer referrals to appropriate palliative care services than other terminally ill patients.

Key words: Dementia ● Unmet needs ● Palliative care ● Good death

This article has been subject to double-blind peer review.

Laura Dempsey, Lecturer and Programme Director for the Postgraduate Diploma in Nursing (Palliative Care); **Maura Dowling**, Lecturer and Programme Director for Masters Programmes in the School of Nursing and Midwifery, both at National University of Ireland, Galway, Ireland; **Philip Larkin**, Associate Professor of Clinical Nursing (Palliative Care) at the School of Nursing, Midwifery and Health Systems, University College Dublin and at Our Lady's Hospice, Ireland; **Kathy Murphy**, Lecturer and Professor of Nursing, School of Nursing and Midwifery University of Ireland, Galway, Ireland.

Correspondence to:
Laura Dempsey
laura.dempsey@nuigalway.ie

An estimated 33.9 million people are living with dementia worldwide (Barnes and Yaffe, 2011; World Health Organization, 2012) with this number expected to double every 20 years, reaching 81.1 million by 2040 (Ferri et al, 2005). Dementia is ranked as the sixth most common cause of death in high-income countries, accounting for 3.4% of the total deaths worldwide in 2004 (World Health Organization, 2008). Dementia prevalence rates for Ireland using EURODEM calculations suggest a present figure of 38 000 to over 100 000 by 2036 (O'Shea, 2007).

People with end-stage dementia require specialist end-of-life care (EoLC) to improve comfort and quality of life (Nazarko, 2009). The World Health Organization (WHO, 2002) defined palliative care as:

'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through

the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems'.

WHO Europe (2004) further state that every person with a progressive illness has the right to palliative care. National Institute for Health and Care Excellence (NICE) guidelines (2013) recommend that people with dementia receive palliative care from the time of diagnosis to the point of death. The approach to treatment advocated by NICE aims to improve and enhance the individual's quality of life and allow the person to die with dignity in an appropriate environment. NICE recommends that palliative care is holistic, meeting the physical, psychological, social and spiritual needs of the person with dementia. There is an emphasis on adopting a person-centred approach to care, involving the individual with dementia, their views on treatment options and care provision while the person still has the ability to make decisions and communicate effectively (NICE, 2013).

In Ireland, a report commissioned jointly by The Irish Hospice Foundation (IHF, 2008) entitled *Palliative Care for all – Integrating Palliative Care into Disease Management Frameworks* asserts that it is imperative that an integrated, co-ordinated and person-centred model of service provision is provided to those with dementia which is flexible to adapt and respond to the changing needs of the individual. Each person with dementia will have their own complex and unique experience of the disease. This report also highlights the need for education and training for families who provide care and timely palliative care provision. Recognising the need for palliative care in dementia, the European Association for Palliative Care (EAPC) commissioned a research-based position paper producing the first evidence-based consensual definition of palliative care in dementia (van der Steen et al, 2013). International experts from palliative care, dementia and palliative care in dementia

specifically participated in the Delphi study (van der Steen et al, 2013), aiming to describe core domains and defining optimal palliative care in dementia. Full consensus was achieved immediately in 8 out of 11 domains; after revision, full consensus was achieved on a 9th domain; and moderate consensus was achieved on the final 2 domains, those being nutrition and dehydration, and dementia staging in relation to care goals. In identifying research priority domains important to palliative care in dementia, this white paper (van der Steen et al, 2013) presents a framework to provide guidance for clinical practice, policy and research in the provision of palliative care in Europe and elsewhere.

Obstacles to accessing palliative care for those with dementia

A plethora of literature exists advocating that people with dementia should have access to palliative care and hospice services (Mitchell et al, 2007; Birch and Draper 2008; Shega et al, 2008; Treloar et al, 2009; van der Steen, 2010; de Vries and Nowell, 2011). However, it is clear from the literature that people with end-stage dementia do not receive adequate or appropriate EoLC for a number of reasons; end-stage dementia is difficult to diagnose and dementia is often viewed as part of the natural ageing process (Phillips et al, 2011; Illiffe et al, 2013). Furthermore, there is a lack of education of the dementia disease process itself and the ability to identify complications which are encountered in end-stage dementia by health-care providers, families and carers (Brodaty et al, 2003; Shega et al, 2003; Chang et al, 2005; Birch and Draper, 2008; Barber and Murphy, 2011; Illiffe et al, 2013).

As well as additional complications of bowel and bladder incontinence, pyrexia, infections and decubitus ulcers, terminally ill dementia sufferers have multiple complications with as high as 91% having a co-morbid condition (Moss et al, 2002; Mitchell et al, 2007). Co-morbidities complicate the clinical picture and may create a need for palliative care at any stage of the dementia process, since most people die with dementia rather than from it (Brunnström and Englund, 2009). The evidence base to guide practice with those dying with dementia is less well developed, although is now evolving (Boogaard et al, 2013; Illiffe et al, 2013; van der Steen et al, 2013). Gove et al (2010) in association with Alzheimer's Europe established practical and consensual recommendations for EoLC of people with dementia. The aim of their recommendations is to provide a basis for understanding and action with regard to EoLC not

only for family caregivers but also for professionals, policy makers and anyone with an interest in palliative care.

Access to hospice and palliative care is also an issue for dementia sufferers. A retrospective case note audit of EoLC for people with dementia in an acute hospital setting conducted by Sampson et al (2006) found that dementia patients received significantly fewer referrals to specialist palliative care and less palliative medication than cancer patients, despite research indicating that symptom burden in those with advanced dementia and those with cancer was comparable (64% of dementia patients experienced pain and 57% loss of appetite) (McCarthy et al, 1997).

Similarly, Afzal et al (2010) examined 75 clinical case notes of people aged over 65 years who had died in an Irish hospital within a 6-month period, revealing that 18 patients were recorded as having dementia, 32 were documented as not having dementia while the remaining 25 patients notes did not specify cognitive status. Findings revealed that dementia patients were less likely to be referred for palliative care, have carer involvement in decision making, or receive palliative medication and suggested that those with dementia may be receiving different EoLC to those who are cognitively intact (Afzal et al, 2010).

A UK study by de Vries and Nowell (2011) audited internal case notes of patient admissions to one UK hospice. The hospice admission policy was inclusive of all terminally ill patients including those suffering from non-malignant disease; however of the 288 case notes audited, only 9% of hospice patients had a primary diagnosis of dementia or suffered from dementia as a co-morbidity to another terminal condition. Hospice referrals came from GPs (13), hospitals (12) and community matrons (2). The figure of 9% is much higher than found in earlier studies by McCarthy et al (1997) and Houttekier et al (2010) but is more consistent with the US data which is currently around 11% of hospice admissions (de Vries and Nowell, 2011).

The problem of variable quality of palliative care is particularly, although not exclusively, evident in community settings such as care homes (long-term care facilities) and primary care services (Lawrence et al, 2011). A pan-European study found a similar pattern across Europe (Piers et al, 2010). Access to palliative care services and social support are two factors (alongside environmental and material resources) that determine whether older people with dementia can remain living in their own homes at the end of life (Rolls et al, 2010) or necessitate hospital/long-stay care admission.

‘Access to palliative care services and social support are two factors ... that determine whether older people with dementia can remain living in their own homes at the end of life.’

‘Early diagnosis of dementia by physicians is imperative for contact with specialist services to be initiated ...’

Difficulty diagnosing dementia and end-of-life dementia

Early diagnosis of dementia by physicians is imperative for contact with specialist services to be initiated so that timely decisions about treatment and preferences can be made. However, between 28% and 42% of GPs report difficulty disclosing a diagnosis of dementia (Downs et al, 2002; Cahill et al, 2012). As dementia progresses, the person’s cognitive and communication abilities decline, making it more difficult for lay and professional carers to accurately ascertain the wishes and needs of the person with dementia. Koch and Iliffe (2010) identified that dementia is not diagnosed in time and there is a reluctance to diagnose dementia due to diagnostic uncertainty, fear of labelling or stigma within families or the community, lack of support, time and financial constraints. Identifying dementia as a progressive terminal illness allows those with dementia and their carers to consider palliative care approaches more readily and at an earlier stage (Mitchell et al, 2004; Aminoff and Adunsky, 2006; de Vries and Nowell, 2011).

The transition from living to actively dying for people with dementia can be protracted. This uncertainty affects how preferences and priorities are discussed, by whom and when, and whose opinions carry the most weight (Goodman et al, 2013). There can be an imbalance between the individual’s perspective, the system of care they are in (for example a nursing home), and wider systems that provide EoLC (Froggatt et al, 2011). The difficulty of identifying those at high mortality risk underlines the need to consider the possibility of death with dementia, even in the earlier or mild stage of the disease (van der Steen et al, 2013).

In order to provide high-quality care to people with dementia, including the appropriate level of palliation, ‘it is essential to identify and develop validated, reliable, sensitive, and accurate prognostic tools that can be used to identify end-stage dementia and that allow for advance preparation and planning’ (Brown et al 2013: 390). Clinical prognostic indicators (CPIs) for EoLC are tools which help provide a guide to estimating when a person with advanced disease is in the last 6 months or year of life. When interpreted as part of the holistic assessment, it can assist to alert health and social care professionals when a patient may require EoLC. CPIs are advocated within the Gold Standards Framework (Thomas, 2000) and are also included within generic standards for palliative care. In addition, they are useful in understanding disease trajectories and can help predict how needs may develop over time.

A US study by Mitchell et al (2004) revealed that only 1% of patients with advanced dementia admitted to a nursing home were perceived by staff being at end of life with a life expectancy of less than 6 months, yet 71% died within that 6-month period. Tools to improve mortality predictions have been developed for and validated in patients with advanced dementia (Mitchell et al, 2010; van der Steen et al, 2010). Potter et al (2013) conducted a systematic review of policy, guidelines, publications and position documents aimed to identify evidence-based signs and symptoms of end-stage dementia. From this review, 8 signs and symptoms associated with worsening function and increased mortality were identified and incorporated to develop the REACH toolkit to assist staff to identify people with dementia who were at end of life allowing for a palliative approach to care to be implemented.

Specific prognostic markers for advanced dementia, focusing on a life expectancy of 6 months, have been developed and are based on scales which have attempted to classify the progression of dementia into stages such as the Global Deterioration Scale (Reisberg et al, 1982) or the Functional Assessment Staging Test (FAST) scale (Reisberg, 1988). A recent systematic review by Brown et al (2013) attempted to identify accurate prognosticators of mortality in elderly advanced dementia patients. In total, 7 studies met their inclusion criteria, 5 of which were set in the US and 2 in Israel. Methodology and prognostic outcomes varied greatly between the studies. All but one study found that Reisberg’s (1988) FAST scale, widely used to assess hospice admission eligibility in the US, was not a reliable predictor of 6-month mortality. The most common prognostic variables identified related to nutrition or eating habits, followed by increased risk on dementia severity scales and co-morbidities. Brown et al (2013) conclude that although the majority of reviewed studies agreed that the FAST scale criterion was not a reliable predictor of 6-month mortality, and a lack of prognosticator concordance across the literature exists.

Care pathways for those with dementia

Palliative care for people with dementia is less well systematised (in the sense of having structured care pathways) than that for people with cancer and the evidence base to guide practice in palliative and EoLC for people with dementia is limited (Iliffe et al, 2013).

Integrated care pathways (ICPs) set out steps in the care of patients with specific conditions and describe expected progress of the patient as their

condition advances. Care pathways aim to support the integration of clinical guidelines into clinical practice while also promoting better communication with the patient by giving them information about their care which is planned and progressed over time. ICPs have assisted in the management of chronic conditions but there is a need to recognise palliative care and EoLC as a unique and ultimate period within a person's pathway of care. Palliative care should be integrated within the patient's care pathway so that their care is planned and seamless.

Specific integrated care pathways and programmes were developed and implemented in the UK for patients who are approaching end of life such as the Gold Standards Framework (GSF) (Thomas, 2000) and the Liverpool Care Pathway for the Dying Patient (Marie Curie Palliative Care Institute, 2001). The GSF is a systematic evidence-based approach to optimising the care for patients nearing the end of life in the community and care homes, so that people are enabled to live and die where they choose. The Liverpool Care Pathway (LCP) was developed as a mechanism for dying patients, and their relatives and carers, to receive a high standard of care in the last hours and days of life. The LCP was originally developed by the Marie Curie Palliative Care Institute in Liverpool for cancer patients in the acute environment, but was adapted for use in all generic care settings irrespective of diagnosis (Ellershaw and Wilkinson, 2011). It encouraged a multi-professional approach to the delivery of care that focused on the physical, psychological and spiritual comfort of patients and their relatives, and had been implemented by both non-specialist and specialist palliative care providers (Ellershaw, 2007). However, in 2012, the LCP received serious media criticism, highlighting reports of bad practice and professional concerns, mainly regarding hydration of dying patients, possible hastening of death, and consent and communication issues (Watts, 2013). An independent review into the use of the LCP in the UK recommended that the LCP be replaced by a personalised EoLC plan backed up by disease-specific good practice guidance (Neuberger et al, 2013).

According to Shipman et al (2008) there is a need to define good practice, and more needs to be known about the context of provision. A generic model for palliative care in dementia, suitable for use in different health and care systems as a guide to service quality is required, for appropriate outcomes to be identified, so that good care can be characterised in terms of quality indicators and benchmarks, and the effects of interventions can be measured (Iliffe et al, 2013). Iliffe et al

(2013) devised one such generic model of palliative care for people with dementia which captures commonalities and differences across Europe (IMPACT project). The model includes features deemed important for the systematisation of palliative care for people with dementia, which are: the division of labour among practitioners of different disciplines; the structure and function of care planning; the management of rising risk and increasing complexity; boundaries between disease-modifying treatment and palliative care and between palliative and EoLC; and the process of bereavement. The model of palliative care for people with dementia has placed the person needing palliative care within a landscape of services and professional disciplines (Iliffe et al, 2013).

NICE (2013) quality standard for supporting people to live well with dementia guideline outlines a palliative care pathway for people with advanced dementia and emphasises the need for the adoption of a palliative care approach from diagnosis until death to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing. Palliative and EoLC pathways are informed by the regional community facing model, which when implemented effectively, supports the delivery of quality palliative and EoLC.

The concept of a 'good death' in dementia care

At the heart of palliative and terminal care lies the concept of a 'good death'. One of the primary outcomes of EoLC should be the experience of a good death by the patient and the family. Efforts have been made to conceptualise a good death; however, literature suggests that no one definite, clear, shared understanding of what constitutes a good death exists. It is based on the idea that a good death is not a single event, but a series of social events (Kendall et al, 2007). Closely related concepts such as quality of life at end of life, quality of care at the end of life, and quality of dying cause confusion (Kehl, 2006).

The concept of a good death is highly individual and dynamic, and can be dictated by faith or culture. Some feel that death while sleeping is preferable, while others prefer to be awake and alert at the time of death (Pierson et al, 2002). This example of contrasting opinions of a good death echoes research findings that what one person considers a good death, may be in complete opposition to another. This suggests that clinicians and caregivers should consider the wishes and opinions of the patient and family as to what they consider a good death, and caution must be emphasised to clinicians and caregivers ensuring that their own per-

‘Palliative care should be integrated within the patient's care pathway so that their care is planned and seamless.’

‘... what one person considers a good death, may be in complete opposition to another.’⁹

ceptions of a good death does not bias or overpower the opinions of the patient and family.

A dearth of qualitative research has been conducted in an effort to conceptualise a good death for terminally ill patients (Seale, 1991; Steinhauer et al, 2002; Tong et al, 2003; Beckstrand et al, 2006; Kehl, 2006; Rietjens et al, 2006; Miyashita et al, 2008); however, due to the complexity and vulnerability of these participants, experiences of families and caregivers on this topic tend to appear more frequently in the literature (Morita et al, 2002; Bosek et al, 2003; Teno et al, 2004; Shiozaki et al, 2005; Papastavrou et al, 2007; Sampson, 2011; Lee et al, 2013; van der Steen et al, 2013).

Vig et al (2002) described good deaths as being pain free, dying in one’s sleep, quickly, without suffering, and without knowledge of impending death. Bad deaths were characterised as being in pain, having a prolonged course of dying and being dependent on others. However, numerous studies suggest that a high proportion of patients at end of life die in pain (Steinhauer et al, 2002; Vig et al, 2002). Moreover, an abundance of literature exists to demonstrate that pain is undiagnosed and untreated in patients with dementia (Martin et al, 2005; Herr et al, 2006; Sampson et al, 2006; Horgas, 2010; Husebo et al, 2008; Barber and Murphy, 2011).

An encouraging Dutch study by van der Steen et al (2013) analysed possible trends in families’ evaluations of the quality of EoLC and the quality of dying in dementia. Individual patient data of 372 residents with dementia in 38 nursing homes and 13 residential homes over the period 2005–2010 was analysed. Outcome measures were the End of Life in Dementia-Satisfaction With Care scale (EOLD-SWC; range: 10–40) to assess quality of, or satisfaction with, EoLC, and the EOLD-Comfort Assessment in Dying scale (EOLD-CAD; range: 12–42) to assess quality of dying (comfort). Findings revealed a positive trend of increased satisfaction with EoLC. Families of those with dementia at end of life reported a possible increase in residents’ end of life comfort and the emotional support provided for families, and families reported lower levels of emotional distress in residents. van der Steen et al (2013) suggest that ongoing surveillance of outcomes measuring end-of-life quality is important in view of the increasing health-care budget constraints, which is a universal issue, which has a knock on effect on care provision.

Several authors have linked a good death to the place of death (McNamara, 1994; Low and Payne, 1996; Payne et al, 1996; Semino et al, 2014). When addressing the needs of the termi-

nally ill, it is important to identify where people die and where people choose to die. McNeil (1998: 6) presented a very balanced view of whether home deaths should always be held up as the gold standard for a good death, wisely stating that it ‘matters less where we die, than how we die’. While the choice of where a person dies is an individual one, ultimately, there have to be resources available to allow that decision to be taken. This is echoed by Vig et al (2002), whose findings reported that the location of preferred death was irrelevant, however, it was clear that patients’ preferences for EoLC need to be established from the patient themselves from an early stage in order for a good death for the individual to ensue. This is particularly pertinent in the case of people with dementia. Health professionals need to be more proactive in initiating early discussions around care planning and specifically advanced care planning to ensure that the needs of those with dementia are met (Burns, 2005). Advance care planning allows for improved communication and shared decision making, reducing unnecessary hospitalisation, the use of burdensome interventions such as tube feeding, and parenteral hydration in advanced dementia (Hertough 2006) and also facilitates discussion around place of death with the person with dementia.

The IHF (2011) recently launched their ‘Think Ahead’ programme which encourages people to think about important issues, talk to others about them (family, GP, etc) and tell key people in their lives about their decisions and preferences in relation to these matters. This method of advanced care planning is vital in the case of those with dementia so that their treatment and care preferences are adhered to at the end of life. It must be noted, however, that Ireland has no legislative provision for advanced care planning at this time.

The increasing requests from patients and families to die at home has put considerable responsibility and pressure on primary care and palliative care teams, as the patient and their family depend on their support and management of the final stages of the patient’s life. With national and international publications such as *Palliative Care For All* (IHF, 2008), End of Life Care Strategy and NICE quality standards for supporting people to live well with dementia and EoLC for adults (NICE, 2011; 2013) endorsing and supporting this initiative, more and more patients are being afforded the opportunity to die at home. Effective guidelines such as the GSF assists to optimise care provision and fulfil the wishes of patients nearing end of life through improved communication and advanced care planning (Tapsfield, 2006). However, Shaw et al (2010) caution that its use is

variable and the GSF's direct impact on patients and families, especially where dementia is present, is not yet known.

Exley and Allen (2007) in a critique of 'home' as the preferred place for EoLC, observe that 'home' is not merely about physical space but the social and emotional relationships that are experienced there. The need for meaningful relationships, purpose and feeling safe for people with dementia in long-term care settings at the end of life are known (Birch and Draper, 2008; Hall et al, 2009; Ryan et al, 2009). Goodman et al (2013) concurs with this with residents in a care home in the UK identifying that relationships made them feel at 'home'.

Several studies have examined the experience of dying with dementia in a nursing home or residential care setting from the family member or health professional's perspective. Bosek et al (2003) interviewed 57 family member caregivers of a person with Alzheimer's disease whose loved one had died in a US nursing home. Despite the fact that all family members reported their loved one died with dignity, 28% believed that their family member had not experienced a good death. Family members cited a good death as one that conformed to the patient's preferences regarding when and where to die, if the death had occurred with the patient being comfortable, or if the experience by the family member of the dying process was a positive one. Bosek et al (2003) highlighted some proactive recommendations to improve the quality and process of the death. These include aggressive pain and symptom management, provision of information for family on the signs and symptoms of the anticipated death, maintaining familiar surroundings, providing accommodation for family presence, and an examination of family and caregiver's attitudes, beliefs, and expectations about death.

More recently, Goodman et al (2013) explored the end-of-life preferences and priorities of people with dementia residing in a nursing home in the UK. Findings revealed that place of death was not a priority for these residents, but the relationships formed with the people around them made them feel at 'home'. Living and dying with dementia extends beyond any physical care needs and decisions about preferred place of care and according to Moriarty et al (2012), the challenge is how to develop practice and processes that reflect the fact. Goodman et al (2013) emphasise the necessity of documenting the end-of-life priorities of people with dementia at an early stage, as early as on admission, and for this discussion to be ongoing in order to facilitate the wishes and needs of the person with dementia at end of life.

Conclusions and implications for practice

From the available literature highlighting the palliative care needs of people with dementia, it is clear that adequate or appropriate EoLC is not received by this vulnerable group. While great strides have been made to improve dementia palliative care, they still receive fewer referrals to appropriate palliative care services than cancer patients (Sampson et al, 2006). While excellent EoLC is attainable, greater efforts are required of health-care staff to firstly recognise dementia as a terminal illness, to initiate the dialogue on EoLC at an early stage of the illness, allowing the individual to take the lead on determining their own wishes and preferences of care. A good death with dementia according to Lawrence et al (2011) is being pain free and being surrounded by those closest to the person with dementia; these are not unachievable or particularly technical goals but necessitate effective communication, cooperation and coordination by health professionals.

With reference to the increasing number of people who will require care as they die with dementia, service models to improve care must be adopted and implemented carefully, taking into account the variety of settings in which people with dementia die, as well as cultural, staff, organisation and budgetary factors, with due consideration to what may work best for whom and in what circumstances (Sampson et al, 2011). van der Steen (2013) purports that not all dementia sufferers require specialist palliative care, only if it is required for those with complex problems; however, a palliative care approach is required as a baseline for those without complexities (van der Steen 2013). Furthermore, not all palliation occurs with palliative care. Health-care providers offer their own palliation in the treatment of difficult symptoms associated with dementia or as a result of other co-morbid factors. As dementia is mainly as disease of older age, principles and practices of gerontological medicine and nursing should also apply.

The aim of this paper is to highlight that there is still a need for health-care providers to recognise the eventual terminal nature of dementia, anticipate specific needs which will change over time, throughout the disease trajectory, and that a baseline palliative care approach for all is adopted, irrespective of the type or stage of dementia. Implementing a palliative approach to dementia care facilitates in the appropriate identification of any unmet needs of people with dementia while also promoting a continuum of care focusing on quality of life and values the uniqueness of the person (IHF, 2013). 

'... emphasise the necessity of documenting the end-of-life priorities of people with dementia at an early stage ...'

Declaration of interests

The authors have no conflicts of interest to declare.

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Sensitive Interviewing in Qualitative Research

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Abstract: In this paper we focus on important considerations when planning and conducting qualitative interviews on sensitive topics. Drawing on experiences of conducting interviews with dementia caregivers, a framework of essential elements in qualitative interviewing was developed to emphasize study participants' needs while also providing guidance for researchers. Starting with a definition of sensitive research, the framework includes preparing for interviews, interacting with gatekeepers of vulnerable groups, planning for interview timing, and location, building relationships and conducting therapeutic interactions, protecting ethically vulnerable participants, and planning for disengagement. This framework has the potential to improve the effectiveness of sensitive interviewing with vulnerable groups.

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Keywords: qualitative research; caregivers; dementia; sensitive topics; vulnerable populations; recruitment; hidden population; protection of human subjects

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Much of nursing and health research focuses on aspects of living that may be considered sensitive (Enosh & Buchbinder, 2005). While all research topics have the potential to be sensitive (Corbin & Morse, 2003), some studies elicit more distress than others, often causing the risk of harm to participants and evoking emotional responses such as sadness, anger, anxiety, and fear (Elmir, Schmied, Jackson, & Wilkes, 2011). Furthermore, when sensitive research is being undertaken, reasonable and appropriate safety measures must be taken to reduce the risk associated with breaches of confidentiality and invasion of privacy (Mealer & Jones, 2014).

For sensitive topics, many researchers choose a qualitative design using in-depth interviews (Liamputtong, 2007). Face-to-face interviews are an ideal method of data collection when exploring sensitive topics (Elmir et al., 2011; Taylor et al., 2011). Interviewing requires the skill of conducting an incisive interview that yields rich and meaningful data, while at the same time allowing participants to

feel safe and at ease discussing difficult or sensitive experiences with a stranger (Knox & Burkard, 2009).

In this paper we describe the experience of gaining access to and conducting interviews with family carers who provided end-of-life care for individuals with end-stage dementia. Using examples from field notes, reflections and extracts from interview transcripts, we detail some of the challenges encountered when interviewing family carers and how these influenced the recruitment process and quality of our data. We provide some suggestions for improving access to participants and conducting sensitive interviews with this vulnerable population through the use of a framework (Table 1) developed to guide and assist novice researchers.

Study Context

Our study was designed to increase understanding of family carers' experiences of providing end-of-life care for

Table 1. Framework of Essential Elements in Qualitative Interviewing

Elements	Considerations	Action
Preparation, planning and implementing an interview schedule	Preparation is vital. Select the correct research methodology and data collection tool/s to acquire data from participants. Develop an interview schedule and have a thorough knowledge of this interview schedule. Use the interview schedule flexibly as a guide to facilitate meaningful discussion between the researcher and participant.	Liaise with research supervisor or research team to decide which research methodology best addresses the study's research question, aims, and objectives. Develop an interview schedule with predetermined questions focusing on the study's research question and aims. Conduct pilot interviews to troubleshoot issues with interview schedule questions. Pilot interviews will aid skilful and effective questioning.
Accessing vulnerable groups	Consider issues with accessing gatekeepers of vulnerable groups and negotiating access to participants. Participants require sufficient information to make an informed decision to participate. Consider how participants may contact researchers to self-select to participate in a research study (text message, telephone call, or return postal consent form).	Meet gatekeepers in person to facilitate relationship building, develop trust, allow questions to be asked and clarification to be sought. Explain to gatekeepers the perceived benefits of taking part in research. Provide detailed study information to potential participants and contact names and numbers if they wish to partake in the research. Consider utilizing social media to recruit participants.
Time and location of interviews	Flexibility on the part of the researcher.	Conduct interviews at a time and location which is suitable for the participant.
Rapport and relationship building	Consider how to deal with distress and emotions. Care is required for the participant and researcher. Interviews may be therapeutic for participants. Relationship development which is mutually trusting and positive facilitates discussing sensitive topics.	Effective listening is required. Support structures may be required to deal with distress. Rapport development and a trusting relationship are key to facilitating discussion of sensitive topics.
Therapeutic interviewing	Know your interview questions so that your schedule is a guide, allowing free flow of conversation. Develop skills in empathic listening and being comfortable with interview silences. Consider how you will deal with distressed participants. Location of the interview is key to allow for free flowing discussion. Consider the need for refreshments and tissues during interviews.	Thorough knowledge of interview questions is required for free flowing conversation between researcher and participant. Avail of qualitative interviewing training. Develop a distress protocol. Source a quiet, private interview location free from interruptions. Provide water and tissues to participants to promote comfort.
Concluding interviews	Closing of relationship after data has been collected. Ensure positive closures for the participant and the researcher. Reflexivity is required to consider values, beliefs, perceptions which may influence the research process.	Debriefing with participant after interview has ended. Provide contact numbers of support services as required. Meet with supervisor or research team to discuss the interview process. Bracket interviews: meet with a critical friend/supervisor/research team to challenge self-deceptions, keep a reflective diary.
Ethical considerations	Trust. Informed Consent. Anonymity and Confidentiality.	Devise a risk assessment and distress protocol. Adhere to ethical research principles.

those dying with dementia at home. While qualitative studies have been conducted on the experiences of family carers of a person with dementia, they have mostly been conducted in nursing homes or long-term care settings. Less is known about family carers' experiences of providing end-of-life care to persons with dementia at home or the impact of providing end-of-life care to a family member with dementia (Dempsey, Dowling, Larkin, & Murphy, 2015; Hennings, Froggatt, & Keady, 2010).

The research was guided by interpretative phenomenological analysis (IPA). This research design was selected over alternative qualitative approaches as the most appropriate methodology to address the research question. Methodologically, IPA concerns itself with examining the lived experience and how individuals make sense of their experience (Smith, Flowers, & Larkin, 2009).

Purposive sampling was used to select participants who provided care for a family member with end-stage

dementia at home. Participants were selected for homogeneity and diversity, including men and women who lived in urban and rural locations. Participants were primary caregivers to persons with end-stage dementia or who had been carers for persons with dementia who died at home in the previous 12 months. Participants included 15 current carers and five past carers for a family member with dementia. The first author conducted semi-structured interviews in participants' homes.

A Sensitive Topic and a Vulnerable Population

Sensitive research is difficult to define but has been associated with taboo topics or those "laden with emotion or which inspire feelings of awe or dread" (Lee, 1993; p. 6). Renzetti and Lee (1993) defined sensitive research topics as those which intimidate, discredit, or incriminate the participant. Health researchers conduct research on a wide variety of topics that could fall into these categories, such as research focused on rape, post-traumatic stress disorder, drug use, death, grief, or birth (Lowe, Chan, & Rhodes, 2011; Mealer & Jones, 2014; Taylor et al., 2011). Dickson-Swift, James, Kippen, and Liamputtong (2008, p. 2) favored the definition, "research which potentially poses a substantial threat to those who are or have been involved in it," acknowledging that all who participate may be affected. The topic itself may be perceived as sensitive, or the research may evoke emotions from those participating in it. Researchers also may be affected and should prepare to disengage both physically and psychologically on completion of the research. Studies of this nature require careful planning and consideration on the selection of an appropriate research design and data collection method (Ashton, 2014; Dickson-Swift et al., 2008).

Although sensitive topics do pose an element of risk to participants, avoiding this research may be seen as evasion of responsibility and disempowering to the individuals involved (Dickson-Swift et al., 2008; Sammut Scerri, Abela, & Vetere, 2012). Often, researchers cannot predict how participants may be affected because some issues are not always apparent at the outset (Corbin & Morse, 2003). Dickson-Swift et al. (2008) contended that the experience of participating in such research may bring about a change in participants, which may be positive or negative.

The benefits of undertaking sensitive research must outweigh the risks. Ethical guidelines provide useful advice when planning research on sensitive topics (Ashton, 2014). Corbin and Morse (2003) recommended following a code of ethics to guide the research process, from framing the research question, to selecting participants, through to writing up and disseminating findings. The moral complexities of the research relationship need to be addressed and sensitivity shown for participants' needs throughout the research process (Hewitt, 2007).

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The term "vulnerable" when referring to target populations for research is often used interchangeably with other terms, such as hard-to-reach, sensitive, or hidden populations (Liamputtong, 2007). Vulnerable groups may hold a social status that diminishes their autonomy and marginalizes their lives. Participants in the dementia carers study were vulnerable as members of a population known to experience mental and physical illness, social isolation, financial difficulties, stress, and difficulty coping (Flynn & Mulcahy, 2013; Jones, Tudoe Edwards, & Hounsome, 2014). The population also is emotionally vulnerable due to their involvement in end-of-life care.

A Framework for Sensitive Interviews With Vulnerable Groups

Qualitative researchers must attend to special considerations when planning and conducting interviews on sensitive topics to ensure a good outcome for both the interviewer and interviewee. The framework described here (Table 1) was developed by the first author after revisiting reflective field notes on the challenges presented when conducting such interviews. The framework encourages researchers to plan for a variety of considerations before embarking on data collection, to improve the effectiveness of sensitive interviewing with vulnerable groups and to avoid omission of critical information.

Access to vulnerable groups and participant satisfaction may be enhanced with a standardized framework for sensitive interviewing. In addition, strengthened interpersonal relationships between the researcher and gatekeepers may result from an approach that places the participants' needs at the forefront. In this framework, we offer points for consideration prior to starting the research, in hopes of guiding interviewers through the swampy lowlands of data collection and avoiding common pitfalls along the way.

Preparation, Planning, and Implementing an Interview Schedule

Qualitative researchers aim to understand people's lives as they are lived generating deeply contextual accounts of participants' experiences and their interpretation of them (Schultze & Avital, 2011). The participant has experiential expertise and should be the sole focus of the researcher's attention (Smith et al., 2009). By listening intently to the participant's story, the researcher conveys interest in what the participant is saying and facilitates the conversation to flow freely.

Semi-structured interviews are the most common type of interviews used in qualitative research (Holloway & Wheeler, 2010). In-depth interviews can be conducted on a one-off basis, however, many authors suggest that researchers should develop a relationship and rapport prior

to conducting sensitive interviews (Liamputtong, 2007; Liamputtong & Ezzy, 2005; Murray, 2003).

Development of an interview schedule is advised, especially for novice researchers, but it should be used in a flexible manner as a guide, incorporating ideas of how best to phrase questions and how to move from broader issues (emic) to more specific and sensitive (etic) topics (Doody & Noonan, 2013). In the dementia carers study, after four pilot interviews, it was found that having a predetermined schedule of questions in front of the researcher was off-putting to participants and made the interview more formal and less conducive to open and free flowing discussion. Therefore, we recommend having an interview schedule as a guide but remembering that the researcher's role is that of active listener and in the case of vulnerable participants, it is often preferable to set aside the structure to fully concentrate on the participants' needs instead (Smith et al., 2009). The onus is on the researcher to be sufficiently familiar with the interview questions in advance so as not to rely on the schedule during the interview.

Naturally, an interview does not have to follow the sequence of the schedule. The participant may move completely away from the schedule and follow an alternative course. Probes are valuable to find out more on interesting topics (Doody & Noonan, 2013). This requires intent listening on the part of the researcher to be ready to ask relevant follow-up questions (Smith et al., 2009). Knowing when to probe and how to choose the correct probe requires skill and an understanding of the purpose of each question (Polit & Beck, 2012). Nondirective probes refocus the discussion in a natural way, eliciting more detailed information from the participant.

In this study, it was the first author's intention to make participants feel at ease in the familiar surroundings of their own homes and facilitate a conversation between two people, as opposed to a question and answers type session between strangers. Therefore having a thorough knowledge of the interview questions and topics prior to data collection was crucial.

The researcher asked participants at the start of each interview to "describe your experience of providing care for your family member who has dementia." This broad question allowed scope and flexibility for each participant to tell his or her personal story. When participants discussed topics which were of particular interest to the research, the researcher probed further by asking, "Can you tell me a little more about that?" or "You mentioned how difficult this has been for you, can you explain what these difficulties are?"

Accessing Vulnerable Groups

Accessing participants for research purposes is often problematic if the sample is seen as vulnerable or the research topic under investigation is sensitive in nature. Gatekeeping is the process by which researchers are permitted access

to a research setting under investigation and/or to the participants in that setting (Kawulich, 2011). Obtaining the support of gatekeepers when conducting research with minority groups or vulnerable groups is vital (Berg, 1999). Gatekeeping means more than meeting the right people to open doors; involving gatekeepers can have great benefits in that they may have local influence and power to add credibility and validity to research by their acceptance of it (Seidman, 2013). However, gatekeepers can also block research and prevent access to participants (Sixsmith, Boneham, & Goldring, 2003).

Two problems have been identified in relation to gatekeepers and the consent of study participants. The first concerns the over-protectiveness of gatekeepers, which may result in people being denied the opportunity to participate in research (Heath, Charles, Crow, & Wiles, 2007). The second concerns a failure of gatekeepers to provide opportunities for potential participants to exercise choice in participating in research (Miller & Bell, 2002), which may occur in schools or institutional settings. Seidman (2013) classified gatekeepers into two groups: absolutely legitimate (to be respected) and self-declared (to be avoided), cautioning that self-declared gatekeepers may be working to their own agenda, attempting to influence the research process by selecting participants approved of by themselves.

While gatekeepers correctly serve to protect individuals in their care, Alderson and Morrow (2004) highlighted that this may also exclude and silence potential participants without consulting with them in person and may result in a biased sample. Access to participants may be denied by gatekeepers due to pressures of time and inconvenience, reluctance to expose organizations or institutions to public scrutiny, or inappropriateness of the research topic and/or its methods (Heath et al., 2007). The latter reason must be respected, as it is acknowledged that the role of gatekeeper is to prevent harm and protect those in their care. Researchers have little choice but to respect gatekeepers' judgments but may on occasion seek to contest them (Heath et al.).

The first strategy is to secure access to the organization from which participants will be recruited. Researchers often must negotiate access to a research site with influential gatekeepers at multiple points or with multiple gatekeepers in different sites. When the researcher or others from the researcher's organization have conducted research in the institution, positive relationships may have been formed before recruitment begins, but novice researchers should consider strategies to gain access to organizations and participants in advance of data collection.

Negotiating access is based on building relationships with gatekeepers, which is an "ill-defined, unpredictable and an uncontrollable process" (Wanat, 2008, p.192). Having knowledge of the organization and the appropriate gatekeeper to contact will assist in negotiation, keeping in

mind that lower-level gatekeepers may not appreciate feeling ordered to co-operate by their superiors. LeCompte and Preissle (1993) advised meeting gatekeepers in person, which is integral to acquiring cultural or organizational knowledge. Developing a rapport is vital to fostering research relationships that are honest and respectful to both parties (Kawulich, 2011). In a face-to-face meeting, information about the research can be shared in an open and transparent way. Any questions pertaining to the research can be answered and clarification provided. This meeting allows the gatekeeper to evaluate the researcher's professional suitability and allows the researcher to emphasize the value of his or her personal contributions (Shenton & Hayter, 2004).

Researchers should detail the level of involvement required of gatekeepers. Gatekeepers may decline to be involved in research if it will add burden to their workload. Co-operation is often influenced by what gatekeepers perceive as a benefit or a threat to participation (Kawulich, 2011). If gatekeepers recognize the benefit of the research to themselves or participants, they may be more likely to co-operate. However, they may be less likely to take part if they feel a threat to themselves personally or to their role. Furthermore, gatekeepers can avoid cooperation, shift responsibility to other organizations, control communication, request additional information, or forget to follow through on promises of assistance.

Shenton and Hayter (2004) posited that entry is best ensured if the researcher is in a position to offer something back to the organization and participants. This reciprocity may take the form of incentives to gatekeepers or participants or sharing study findings with the collaborating organizations. In the dementia carers study, the researcher endeavored to provide a sense of reciprocity by offering gatekeepers copies of published papers from the research data and bringing a cake and flowers to each participant's home. Giving back to the participants who share their experiences is customary because without their stories, the research would not exist (Kawulich, 2011). Each research setting is unique, and it is noteworthy that gaining permission from an authority does not mean that entry has been achieved (Kawulich, 2011). However, these strategies may result in greater cooperation (Wanat, 2008).

The recruitment process for the present study relied on gatekeepers who selected individuals deemed suitable. Initial contact by telephone was made with gatekeepers (managers of carer support groups, home help services, or nurse managers working with people with dementia) to describe the study in detail and its potential benefits to participants. Without doubt, speaking to gatekeepers and allowing an opportunity for them to ask questions and seek clarification on aspects of the study facilitated access. Once the gatekeepers understood what was involved and had information about the first author's background and

experience in this area, they were extremely encouraging of the research and willing to provide access to suitable participants. Gatekeepers then distributed research information letters to potential participants, which allowed them to self-select to take part in the research by contacting a named researcher.

One gatekeeper denied access to potential participants, deeming those who satisfied the entry criteria to be "too vulnerable." While this was frustrating and disappointing, the gatekeeper had a good knowledge of the individuals and of their situations, and the decision was respected, despite awareness that potential participants were not afforded the opportunity to make an informed decision.

Timing and Location of Interviews

Successful interviewing requires meticulous planning, and the location of interviews needs careful consideration. It is important for participants to feel safe, comfortable, and at ease during interviews (Elmir et al., 2011). The environment should be private and free from interruptions, particularly when discussing sensitive issues. Interviews should always be conducted at a place and time selected by the participant (Doody & Noonan, 2013). Interviews in participants' homes and give researchers entry into a private part of participants' lives (Dickson-Swift, James, Kippen, & Liamputtong, 2007) but also place the participant in a position of some control (Doody & Noonan).

Time dependence burden of caregiving is significant and influenced by the degree of impairment and caregiving involvement (Hoskins, Coleman, & McNeely, 2005). This was true for carers for persons with end-stage dementia. A plethora of evidence exists on caregiver burden (Flynn & Mulcahy, 2013; Hawkins, McAiney, Denton, & Ploeg, 2013; Van Vliet, De Vugt, Bakker, Koopmans, & Verhey, 2010) and its impact on family carers. Etters, Goodall, and Harrison (2008) attributed depression, ill health, and decreased quality of life to caregiving, and lack of social support and isolation are among risk factors of this role (Flynn & Mulcahy).

Participants in this study were offered the opportunity to be interviewed at any location suited to them, and all participants opted to be interviewed at home. Reasons were varied; most participants were current carers who did not have an abundance of free time and were not in a position to leave the home or their caring duties. Some did not have other family members or supports to facilitate social outings. Former carers also selected to be interviewed at home.

When carers made contact with the researcher by text message or telephone to consent to be interviewed, they typically requested that the interview take place the following day or within a few days of this first contact. A great degree of flexibility was required to organize interviews with participants who were current carers. By virtue

of their ongoing and intense caring role, these participants often were not in a position to plan very far in advance. Therefore, interviews had to occur within a day or two of the first contact. Initially, this required a great deal of reorganization of the researcher's work schedule to facilitate these requests. The researcher had to prioritize interviews over other work and block off periods of free time over a number of days, to ensure that participants had a choice of days and times for the interview.

Rapport and Relationship-Building

Researchers enter other people's lives, often at a time of crisis and stress, and ask them to discuss their experiences (Liamputtong, 2007). This can be for an extended period of time, such as with repeat interviewing or as a one-off event. The process of conducting qualitative research may be complex, personal, and intense. Interviewing people considered vulnerable about sensitive topics makes the establishment of a trusting relationship with the researcher especially important (Murray, 2003). Investigation of a sensitive topic may precipitate participants' intense emotions. Researchers must consider the vulnerability of their participants and devise a plan to provide appropriate support when required. Ensuring researchers have a good understanding of the appropriate boundaries of the researcher-participant relationship and the ethical issues that may arise will lead to a mutually beneficial experience to both parties (Murray).

Paramount to building an effective research relationship is initiating a rapport-building process from the outset, which will facilitate access to a participant's narrative (Dickson-Swift et al., 2007) by helping participants feel at ease to disclose intimate and sensitive information. A strategy to ensure that the researcher-participant relationship is non-hierarchical is reciprocal sharing of personal stories by both participant and researcher (Liamputtong, 2007). This creation of a level playing field enhances rapport as well as showing respect for participants and validating their stories. In research on sensitive topics, the frequency and intensity of researcher disclosure may differ (Lee, 1993; Renzetti & Lee, 1993) and has the potential to make researchers feel vulnerable (Fontana & Frey, 2005).

When questions are posed to researchers with a healthcare background, a role conflict arises (Ashton, 2014). Although the researcher is there as data collector, it is difficult to shed nursing knowledge and experience and enter the field with a blank curriculum vitae (Johnson & Macleod Clarke, 2003). In such cases, sustaining an impartial data gatherer role is difficult, and nurses with experience and training will act on instinct and answer clinical questions, discuss concerns with participants, and refer on if required. While according to Jack (2008), information provided by nurse-researchers has the potential to influence participants' responses or discourage the participant from openly sharing more information, refusing to answer

health-related questions also may adversely affect the interview. Britten (1995) advocated deferring requests for answers or information until the end of the interview, and, if a need for further intervention is identified, referring the participant to another health care professional.

While researchers must be empathic to the participants' needs, they should remember that they are researchers and not counselors (Hennink, Hutter, & Bailey, 2011). Murray (2003) advocated retaining clear boundaries with participants, to prevent nurse researchers from becoming nurse therapists. Empathic distance is required to engage with participants without becoming too involved (Valentine, 2007). Nonetheless, nurse researchers can draw on experience to spot signs of distress (Ashton, 2014). Dowling (2006) highlighted the difficulties in separating the nurse from the researcher and contended that participants may consent to partake in research studies as a result of being a healthcare user, or in this case, the carer for a healthcare user. Dowling found it unjustifiable to use the role of the nurse to recruit participants and then abandon this identity once the study commences.

Etherington (2004) affirmed that researchers are intimately involved in both the process and the product of research, but to maintain credibility and objectivity, the researcher is required to be reflexive and aware of influences on the researcher's internal and external responses as well as the relationship to participants and the research topic. The researcher is obliged to self-reflect (Carolan, 2003) or to self-critique, explaining how his/her own experiences, values, beliefs, and perceptions have or have not influenced the research process (Koch & Harrington, 1998).

Carers in this study asked the first author about her feelings on end-of-life care and about the dementia disease trajectory. They were aware that the researcher was a registered nurse, based on information provided in the information letter. On occasion, the first author was asked medical questions with the belief that, "well you are a nurse so you understand." One participant was discussing a dilemma of whether or not to allow administration of antibiotic therapy to her mother with end-stage dementia. The participant asked the researcher, "What would you do if you were in my situation?" The researcher responded by saying, "That is a very difficult situation to be in, and one that I would find hard making a decision. Perhaps we can discuss this further when the interview has finished?" This response acknowledged the difficulty faced by the participant and showed empathy. However, the researcher was aware that engaging in a discussion about this topic could change the interview's focus.

Therapeutic Interviewing

Any interview is sensitive because disclosing information about the self makes the respondent vulnerable to emotional turmoil (Drury, Francis, & Chapman, 2007).

Qualitative researchers encourage participants to provide rich data by eliciting underlying emotions and listening intently to participants' utterances. Despite the potential for participants' upset or distress, cathartic disclosure can be a revelation or prompt a new understanding of past or recent events (Birch & Miller, 2000). The researcher should create a space in which a participant can relive difficult emotions, providing relief and reinforcement of participants' experiences (Ashton, 2014).

Although therapy is not the purpose, and even researchers from a healthcare background may not be trained counselors or therapists (Ashton, 2014; Valentine, 2007). Holloway and Wheeler (1995) suggested that research interviews can be therapeutic. Birch and Miller (2000) used the term therapeutic to represent a process (which is sometimes emotional) by which an individual reflects on and comes to understand previous experiences in different ways, promoting a changed sense of self with new understandings. Both qualitative interviews and therapeutic practice involve disclosing aspects of the self, revealing intimate personal experiences in the presence of an effective listener.

The endeavor to create a successful interview can be likened to the work of counselors and therapists involved in therapeutic practice. Allowing participants the space to reflect on, re-order, and give new meanings to past experiences is the essence of much therapeutic work (Sammut Scerri et al., 2012). Social theorists have highlighted the merits of therapeutic or expressive culture, appreciating the value of expressing feelings and not keeping them bottled up (McLeod, 1997). Therapeutic change, according to Rose (1991), requires the resolution and release of repressed emotions. A therapeutic relationship is founded on empathic listening, witnessing the expression of emotions and the disclosure of a more private self, and acknowledging the participant's experience of self-determination and self-worth (Shamai, 2003).

In this study, having developed an interview schedule prior to data collection allowed the first author to anticipate the likelihood of emotional responses and to adequately prepare for them. This gave rise to the creation of a distress protocol (Table 2), which could be implemented to protect participants in the event that upset did occur. Indeed, some participants did become upset, but all agreed to continue and found being able to express emotion and discuss their role as carer as cathartic. One participant spoke about agreeing to participate in the research, as it was a chance for her to talk about herself: "This is the first time anybody has ever actually asked me about me, because any time anybody comes in the door it's 'how is your Mum,' but nobody has ever said 'how are you, Elizabeth'?"

How researchers deal with distress and emotional situations is based on personal style. Much has been written on how researchers should deal with such events (Ashton, 2014; Hewitt, 2007; Walls, Parahoo, Fleming, &

Table 2. Distress Protocol

The interview will be terminated if:	<ul style="list-style-type: none"> • The participant decides to terminate the interview. • The participant decides to participate in the interview at another time or place.
The researcher will intervene if the participant is:	<ul style="list-style-type: none"> • Experiencing anxiety or distress during the interview. The participant should be asked if they would like to take a break and if they wish for the audio-recorder to be switched off. • Continuing to show signs of upset. The participant will be asked if they would like the interview to end and if they would like the researcher to call someone to spend time with them, such as a family member or friend. • Unduly distressed. The researcher will remain with the participant until they are calm and composed. The participant may then decide to continue with the interview or not.
The researcher will, with the participant's consent:	<ul style="list-style-type: none"> • Refer to others if they request. • Gain permission to call them later in the day or the following day to ensure they are no longer distressed. Alternatively, the researcher may ask if they would like a family member or someone from the local community to call them to offer support. • Contact details of useful numbers and support groups will be offered to the participant if they require them.

McCaughan). Roulston, deMarras, and Lewis (2003) advised that if researchers become uncomfortable dealing with participant emotions, changing topic can be a useful tactic, but they cautioned that this may be a lost opportunity for knowledge to be gained. In one case, the first author acknowledged a participant's upset by saying, "I see that you are upset, would you like to take a break from the interview for a while?" Mitchell (2011), however, encouraged acknowledging the participant's upset by maintaining eye contact, and attempting to talk through the issue. Emotions expressed during an interview enhance our understanding of the participant's experience and are as epistemologically

beneficial as other data, allowing the researcher to enter into the lifeworld of that person. Hoffman (2007) advocated for a greater emphasis on reporting, expressing and understanding of emotions during interviews, to increase sensitivity to such situations and yield more meaningful interpretations of data.

Concluding the Interview

After an interview, Ashton (2014) advised allowing participants time to regain composure and to allow for feedback and discussion. Emotional interviews also can affect the researchers' physical and emotional health (Dunn, 1991) and leave them emotionally drained and burned out (Gerrish, 1991). Hammersley and Atkinson (1995) noted that researchers conducting sensitive interviews rarely leave the field unscathed. Preparation and planning for such events is imperative. Researchers should plan for self-care and informal support networks (Holloway & Wheeler, 1995).

Disengaging from the research field may be more of a process than a single event, particularly if the study involves repeat interviews with participants. Participants' involvement in research may have lasting effects on them, particularly after discussing sensitive topics. In addition, participants and researchers may become close through the passage of time. Researchers attempt to construct a social relationship of reciprocity, friendship, and shared understandings, in an effort to uncover a deep meaning of the topic under investigation (Birch & Miller, 2000). A blurring of boundaries may occur, whereby participants may see the researcher as a friend, which may be a reason for concern. Burns (2000) suggested withdrawing gradually, returning to participants during the write-up and analysis stages to recheck and clarify points before finally concluding the research relationship.

Corbin and Morse (2003) reported that no evidence had emerged that participants have suffered negative long-term effects or have been referred for counseling as a result of being interviewed, and that anecdotal evidence suggests that interviews are more beneficial than harmful. That being said, participants should be afforded the opportunity for feedback and discussion of their feelings on completion of an interview (Murray, 2003), spending time discussing the interview experience and the impact it may have had on them. Sammut Scerri et al. (2012, p. 107) also advocated debriefing with participants on completion of sensitive interviews, to "help the participant back to a normal state of arousal from the intensity of the interview." The researcher is responsible to identify additional support needs and provide contact details on sources of support as required.

In the present study, one of the final questions asked during interviews was, "What is good about being a carer for someone dying with dementia?" Interviews conducted on this topic have the potential to focus only

on the negative aspects of being a carer, and refocusing on the positive aspects of their caring role allowed for a positive ending to the interview. Not all participants identified many/any positives, but the majority did identify good points, such as feeling good about being able to fulfill a promise to care for their loved one at home, having the opportunity to get to know their family member better, and doing what felt right by them and for them in their time of need.

Ethical Considerations

Topics studied using IPA or other qualitative approaches include those central to the unique life experiences of individuals and may be classified as sensitive areas of investigation, due to the potential for intrusion into people's private lives. Even talking about sensitive issues to participants may constitute harm for them.

In addition to ethical approval from institutional ethics committees, qualitative research also requires sustained reflection and review (Smith et al., 2009). Researchers are obliged to uphold beneficence and non-maleficence, or doing good and avoiding harm to participants. In an effort to protect a participant's identity, transcripts of interviews should only be viewed by the research team, and data for wider use such as for publication should be carefully edited for anonymity. Smith et al. (2009) contended that anonymity is all that qualitative researchers can offer; by saying that something is confidential is to say that no other individual will see it, which is not the case. Researchers can represent participants and make their voices heard within an academic or professional forum, but this should not be achieved at the cost of anonymity. Because total anonymity is impossible in a face-to-face interview, data must be stored and reported in a way that the source is unidentifiable. This is ensured through coding personal data to protect participants' identity and storing data securely.

Risk assessment is important when conducting research on sensitive topics. Despite efforts to predict risks at the outset of a study, researchers cannot know what an interview will uncover. A risk assessment should be completed and a distress protocol developed prior to data collection in sensitive contexts (Sammut Scerri et al., 2012) to ensure that researchers consider any potential distress participants may experience during the course of the study and develop strategies to deal with upset if it occurs. Researchers should ask themselves questions such as, is this study likely to cause any discomfort or distress, either physically or emotionally? If the answer is yes, then the researcher should estimate the degree and likelihood of discomfort or distress and the precautions needed to minimize them. Participants should be provided with access to appropriate supports in the event of becoming upset during an interview.

Researchers may have feelings of guilt related to the interview process, the effects of the research on the

participants, or the data collected (Dickson-Swift et al., 2007). Researchers do not set out to exploit or use" participants (Edwards, 2009), but researchers may feel simultaneously excited and guilty about the data (Dickson-Swift et al.; Sammut Scerri et al., 2012). Lofland and Lofland (1995) referred to this as an ethical hangover. Qualitative researchers must acknowledge the power granted to them when participants trust them to report and disseminate their personal narratives with the wider public (Shamai, 2003). Research supervisors or team members can be of great help in dealing with feelings of guilt, upset, or vulnerability. Supervision and self-care are important to deal with the stress and strain of sensitive interviews (Mitchell, 2011).

Any qualitative researcher is challenged to explore how their experiences and assumptions influence the development of knowledge. Bracketing is advocated by Smith et al. (2009) for researchers employing IPA as a methodology. Bracketing, which originates from Husserl's descriptive phenomenology, prompts researchers to set aside their own understandings and assumptions in an effort to allow the phenomenon under investigation to speak (Crotty, 1996). Bracketing interviews, in which the researcher is interviewed on the topic of study, can uncover the researcher's personal and professional experiences during data collection and analysis. Bracketing allows the researcher to "hold the tension of the dialectic process of investigating the nature of the participant's experience, at the same time as holding her own experience" (Rolls & Relf, 2006, p. 286). According to Myerhoff and Ruby (1992), bracketing requires an ability to reflect on oneself, the supportive environment and reflective skills, and Ahern (1999) suggested reflective diaries and journals to aid this process.

A great degree of reflexivity and bracketing of assumptions was required of the first author, who was a registered general nurse with knowledge of the dementia disease trajectory and of palliative care. Bracketing assisted the researcher to objectively explore any hidden or blind assumptions, so that data were collected and analyzed in ways that did not prejudice the subject matter (Crotty, 1996). Field notes and reflections were detailed immediately after each interview, with the intention to document initial thoughts and feelings for discussion with the research team.

Conclusions

The framework presented here may assist researchers in conducting sensitive interviews with vulnerable groups, by directing focus to the participant's needs as well as points for researchers to consider before embarking on their data collection journey. In this paper, we detailed the experiences of a novice researcher conducting sensitive interviews with vulnerable participants and examined the complexities of negotiating access to these participants. The role of a

defined interview schedule, the importance of developing relationships, and the issues arising when discussing the sensitive area of the end of life with participants also were explored. While adhering to the ethical principles of beneficence and non-maleficence, researchers must acknowledge that all qualitative interviews have the potential to cause distress, and even talking about sensitive issues to participants may constitute harm for them. Researchers are advised to conduct a risk assessment and devise a distress protocol prior to data collection in sensitive contexts. Assessing participants for signs of distress during research of a sensitive nature and identifying strategies for minimizing discomfort are fundamental to good ethical practice (Walker, 2007). While avoiding entering into the role of nurse counselor, nurse researchers can draw on experience in an effort to spot signs of distress (Ashton, 2014).

The framework will require further use to evaluate its effectiveness as a tool for novice researchers in particular when planning for and interviewing on sensitive topics. Moreover, further implementation of the framework will need to be carefully evaluated to determine actual application of the model and acceptability in practice by researchers. Meanwhile, incorporating these essential elements may improve the effectiveness of sensitive interviewing with vulnerable groups and avoid loss of critical information.

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Providing care for a person with late-stage dementia at home: What are carers' experiences?

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Abstract

Background: It is widely reported that carers who provide care for a family member with dementia endure physical and psychological burdens. Not only do they fulfil an important role for the person with dementia but also for the wider society. This study aims to explore the experiences of carers who provide end-of-life care for a person with late-stage dementia at home.

Method: Semi-structured interviews were conducted with 17 current carers and 6 past carers of a family member with late-stage dementia. Data was analysed using interpretative phenomenological analysis.

Results: Four super-ordinate themes were identified which described the challenges faced by carers at different stages of their care giving journey: (1) The experience of dementia grief; (2) Parenting the parent; (3) Seeking support; (4) Death, dying and life after death.

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Conclusion: Dementia grief was experienced by carers as a result of a relationship change and an inability to recognise the person with dementia as their mother, father or spouse. A role transition ensued resulting in the carer adopting the role of parent. Carers expressed a desire to provide care for the person with dementia at home until the time of death; however, support is required in this area at both individual and community level. Family carers require education to help identify the dying phase which will assist to minimise the shock of death. Strong evidence suggests that the burden of care may leave family carers poorly equipped to adapt to life after the death of the person with dementia. Greater pre-death support is required to facilitate a better post bereavement adjustment.

Keywords

carers, dementia, end-of-life care, family carers, palliative care

Background

In Ireland, it is estimated that there are approximately 55,000 people living with dementia in the community (Pierce, Cahill, & Carney, in O'Shea, Cahill, & Pierce, 2017). According to Cahill, O'Shea, and Pierce (2012), there are currently an estimated 50,000 family carers in Ireland, caring for someone with dementia or a symptom of dementia; however, due to a reduction in family size and more women returning to the workforce, this figure is expected to decline in the coming years (O'Shea & Monaghan, 2016). At present, community-based services in Ireland are fragmented and limited despite government policy to support people with dementia to remain at home. The latest Irish Central Statistics Office (2016a, 2016b) figures reveal that 92.1% of those aged 65 years and over live at home and for those individuals with dementia, the burden of care largely falls on family and friends. This results in significant costs on caregivers who receive little or no financial support. In addition, without adequate support for caregivers and the improvement of community-based services, continued reliance on family carers may be untenable in the longer term.

Cahill et al. (2012) estimated that the overall median daily provision of care received by a person with dementia (PWD) from a family carer was 8.33 hours duration. Carers reported needing greater relief and more support to assist with the ongoing burden of care provision. While it is not clear from Cahill et al. (2012) report what stages of the dementia disease process these care receivers were at, it may be assumed that greater care requirements would be necessitated at end of life stage, which inevitably increases carers' stress and strain.

Caregiver burden is the most commonly studied topic in clinical gerontology (O'Rourke & Tuokko, 2004) and equally it is well documented that women account for the majority of informal caregivers (Chiao, Wu, & Hsiao, 2015; Schulz & Martire, 2004; Stieber Roger, 2006). Tretteteig, Vatne, and Mork Rokstad (2017) echo this, reporting that as well as providing care, women are more likely to attend to housekeeping duties than male caregivers and experience a greater burden from caregiving. Chiao et al. (2015) also contend that spouse caregivers and adult children caregivers experience higher levels of burden compared with other informal caregivers of people with dementia. Studies focusing on the issues of dementia care illustrate the burden family members bear, with common findings including risk of mental and physical illness, social isolation, stigmatisation, financial difficulties,

stress and difficulty coping (Orgeta, Lo Sterzo, & Orrell, 2013; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Reily, Evans, & Oyeboode, 2018).

Carers can experience profound pre-death grief similar to post death bereavement. This reaction is as a consequence of experiencing the loss of the person they formally knew and an inability to recognise them as their mother, father and spouse. This paradoxical disconnection between psychological and physical losses, captures the crux of ambiguity in the receding of the known self in dementia grief (Blandin & Pepin, 2017) and is a response to the perceived losses in a loved one with dementia (Lindauer & Harvath, 2014). Significant losses, experienced as compounded serial losses are a feature of the carer's experience (Chan, Livingston, Jones, & Sampson, 2013; Santulli & Blandin, 2015) and these losses increase in size and number as the disease advances.

Studies have also been conducted on the experiences of family carers of a

PWD in a care home or long-term care setting (Hennings, Froggatt, & Keady, 2010; Schulz et al., 2003; van der Steen et al., 2013); however, less attention has been focused on family carers' experiences of providing care to the PWD in the home or on the impact of providing end-of-life care to a family member with dementia on the carer. Research has been overlooked on this topic in Ireland and knowledge about the experience of providing end-of-life care to a PWD at home is required to develop this field of research.

Method

Aims and objectives

This study aimed to illuminate the experiences of family carers who provided end-of-life care for those with late-stage dementia at home. The objectives of the study were to gain an understanding of (a) what facilitates or hinders caring for individuals with late-stage dementia at home; (b) participants' experiences of supports available or required to facilitate caring for individuals with late-stage dementia at home; (c) the educational and training needs of family carers; (d) specific end-of-life care needs for individuals with late-stage dementia.

Study design

Interpretative phenomenological analysis (IPA) was selected as a research design over alternative qualitative approaches as it is consistent with the epistemological position of the research question. The principal aim of IPA research is to ascertain how people make sense of their experiences. The focus of IPA is on 'the detailed examination of personal lived experience, the meaning of experience to participants and how participants make sense of that experience' (Smith, 2011, p. 9).

Participants and setting

Given the sensitive nature of the research and the potential difficulty to recruit family carers who would be willing and able to participate, the small, idiographic, homogenous sample size typically used in IPA was appealing. Participants were selected if they were the main carer for a family member with late-stage dementia at home, were physically and cognitively able to participate, were aware of a dementia diagnosis for the PWD (all types of dementia were included) and were aware that the PWD was in the late stage

of dementia. For the purpose of this study, past carers also had to satisfy the same inclusion criteria; however, an additional criterion was that the PWD had died within the last 6–12 months.

Gatekeeping is the process by which researchers are permitted access to a research setting under investigation and/or to the participants in that setting (Kawulich, 2011). Gatekeepers were instrumental and of paramount importance in the selection of participants for this study. Initial contact was made with gatekeepers (managers of carer support groups, home help services or nurse managers working with PWD) by telephone. Once the gatekeepers understood what the study involved, and had information about the first author's background and experience in this area, they were willing to provide access to participants deemed suitable for the study. Gatekeepers then distributed information letters to potential participants, allowing participants the opportunity to self-select to take part in the study by contacting the first author.

Procedure

Semi-structured interviews were conducted by the first author in participants' homes. All interviews were audio-recorded and ranged in length from 30 minutes to 1 hour and 53 minutes. While interviews were being conducted, the PWD was present in the home or in a respite facility. Two interview schedules were developed and utilised in this study; one for current carers and the other for past carers. Interview schedules were used in a flexible manner and acted as a guide; however, the researcher's role was that of active listener and it was often preferable to set aside the structure and to fully concentrate on the participant's needs instead (Smith, Flowers, & Larkin, 2009). Questions posed reflected the aims and objectives of the study. In addition, interview schedules were developed in consultation with experts in IPA, those with expertise in the area of interviewing people with dementia and from questions based on an examination of previous literature.

Data analysis

Smith et al. (2009) contend that the core of IPA rests in its analytic focus; that focus directs analytic attention to the research participant's efforts to make sense of their experiences. The analysis moves from 'the particular to the shared, and from the descriptive to the interpretative' (Smith et al., 2009, p. 79). A sequential series of steps to analysis was developed by Smith et al. (2009) which acted as a framework for analysis used flexibly and innovatively. Each transcript was read and re-read before initial notes were made. Emerging themes and sub-ordinate themes began to develop leading the analyst to identify connections across emerging themes. The researcher then moved to the next case and repeated this process for each transcript. Finally, patterns were sought across cases leading to the identification of super-ordinate themes.

Results

The experience of providing care to a person with late-stage dementia can be a protracted and difficult journey. The challenges of providing care to a person with late-stage dementia at home were the overarching theme to emerge from the analysed data. However, the challenges were abundant and varied depending on where the carer was situated within the caregiving trajectory. Participants included 17 current carers and

Table 1. Demographic profile of participants.

Carer's pseudonym	Age range	Gender	Years of caring	PWDs relationship to carer
Mary	40–49	Female	5–9 Years	Mother
Lisa	50–59	Female	0–4 Years	Mother
Kate	70–79	Female	15–19 Years	Husband
Maureen	60–69	Female	5–9 Years	Husband
Fiona	60–69	Female	10–14 Years	Mother
Ava	30–39	Female	0–4 Years	Mother
Donna	50–59	Female	10–14 Years	Mother
Michael	50–59	Male	10–14 Years	Mother-in-law
Derek	50–59	Male	10–14 Years	Mother
Alec	50–59	Male	0–4 Years	Mother
Isobel	50–59	Female	0–4 Years	Mother-in-law
Caroline	50–59	Female	0–4 Years	Mother
Cillian	50–59	Male	5–9 Years	Mother
Ben	30–39	Male	15–19 Years	Mother
Grace	60–69	Female	5–9 Years	Mother
Jack	60–69	Male	10–14 Years	Mother
Aaron	40–49	Male	5–9 Years	Father
Emma	50–59	Female	0–4 Years	Mother
Hannah	50–59	Female	5–9 Years	Mother
Helen	50–59	Female	0–4 Years	Mother
Natalie	30–39	Female	0–4 Years	Mother
Ellie	70–79	Female	5–9 Years	Husband
Irene	50–59	Female	5–9 Years	Mother

PWD: person with dementia.

6 past carers for a family member with dementia (Table 1). Twenty-one interviews were conducted in total, two of which were with couples while the other 19 interviews were one-to-one interviews ($n = 23$). A brief demographic form was utilised to collect information pertaining to the participant's age, gender, number of years caring, and support services used by the PWD. Almost three quarters of participants were female ($n = 16$), the average age of a carer was between 50 and 59 years, the average length of time caring was between 5 and 9 years and the majority of participants cared for their mother ($n = 17$). All current carers resided with the PWD. Past carers also resided with the PWD prior to their death.

Four super-ordinate themes collectively describe the challenges faced by carers at different stages of their caregiving journey (Table 2).

Super-ordinate theme 1: The experience of dementia grief

Questioning the self and their own sanity. This theme highlights the struggles experienced by carers to provide care during the initial stage of their caregiving journey. Carers identified unusual behaviours, changes in personality and signs of dementia often years before a formal diagnosis was made. Despite carers reporting these concerns to other family members and medical professionals, they felt unheard, disbelieved and frustrated. Carers expressed their discontent with medical professionals throughout the dementia disease

Table 2. Super-ordinate and sub-themes.

Super-ordinate theme 1	The experience of dementia grief <ul style="list-style-type: none"> • Questioning the self and their own sanity • The struggle to care • Burden of care
Super-ordinate theme 2	Parenting the parent <ul style="list-style-type: none"> • Conflicted parenting • Being in control • Parental guilt
Super-ordinate theme 3	Seeking support <ul style="list-style-type: none"> • Support in the form of information • Accessing formal support and services • Informal support: A help or a hindrance • The need for social support
Super-ordinate theme 4	Death, dying and life after death <ul style="list-style-type: none"> • ‘That’s not my mother’ • Regret of not discussing death and dying • Place of death • Life after death

trajectory, especially in the initial phase related to receiving support and a diagnosis of dementia.

Fiona (daughter): I must be two years telling them but they didn’t believe me. Because you see things, you know your mother. [] Then I remember being at the doctor and I said ‘I don’t know, there is something not right’ []. But he put it down to old age [], then I went in to him, I had enough, [] and I told him that, that there was something not right. But eventually he had to, so he brought her in and it was vascular dementia.

As a result of having an intimate knowledge of the PWD, carers reported instinctively knowing there was something amiss with the PWD, however, found it difficult to articulate exactly what that problem was. Frustration was evident when other family members dismissed the carer’s concerns. Ben described having to almost set a trap to catch his mother out in an effort to prove to his family that his concerns were justified:

Ben (son): They would deny it and it felt like I was putting her under pressure to find something wrong with her, when I knew there was something wrong with her but I couldn’t find it and like everybody else was in denial about it, but I could see her.

Carers struggled with the enormity of their situation attempting to be all things to all people, that of carer, mother, father, problem solver and liaising with many individuals coming and going in their family home. The multifactorial role had adverse effects on a carer’s ability to cope resulting in feelings of concern for their own mental health. Emma acknowledged that

her mental health was adversely affected as a consequence of her caregiving role, however, had to struggle on to fulfil her obligations:

Emma (daughter): They thought it was me. They thought I had Alzheimer's []. I couldn't go to the toilet on my own, I wasn't sleeping on my own, she was with me 24 hours a day, with no break, and deteriorating in front of my eyes, physically and mentally. And they were all looking at me as if I was exaggerating, as if I was going mad. [] And looking back on it, I do not know how I didn't end up myself, crazy.

The struggle to care. Dementia is a very unpredictable disease with no two individuals experiencing the same symptoms. Carers described the uncertainty of not knowing what to expect from one day to the next, exacerbating their struggle to provide care.

Fiona (daughter): You just go from day to day and you don't know what is going to happen. [] It is a tough and a hard job and you are on your own.

Jack (son) described caregiving as *'an impossible situation that was developing before me that I knew nothing about'*.

The struggle to provide care was compared to a battle between those in authority who sanction resources and the carers themselves. There was a sense of 'them versus us' whereby any support carers received was due to a battle with 'them'. Kate illuminated that unless carers sought additional support or resources due to changing needs, support was not voluntarily offered to them.

Kate (daughter): You have to fight, I have to fight for it, I had to fight for every hour that I got. And I'm not finished yet [] I'll keep fighting, I mean I'm getting the same hours now that I was getting 2 or 3 years ago. So I think it's time that somebody did something about this situation.

Burden of care. Already feeling over-burdened, carers frequently discussed their dissatisfaction with having to adopt extended roles and responsibilities, such as managing medications for the PWD. Carers identified their lack of knowledge and training in the pharmacological and medical field.

Aaron (son): And even with the medication now they say to me well it's at your own discretion, you can up it if you like and I said no, I couldn't do that, I can't. I have enough responsibility []. I'm not going to start prescribing medication here as well, I can't do that.

Other carers described how the burden of providing full time care resulted in having to withdraw from full time employment, social activities and ultimately sacrificing their freedom. Carers had enforced restrictions on their time and on their freedom. Lisa detailed not being in control of her life any longer:

Lisa (daughter): Not being able to do your own thing, have your own life. My life is not my own. My life is centred around mammy.

In an effort to engage in outside activities, careful planning was required and organisation of a replacement to take over caregiving in the carers absence. Caregiving impacts not only on the carer but also on family life, resulting in dramatic changes to the way a family previously functioned.

Alec (son): The other thing I wasn't ready for, but our family life was absolutely turned upside down. And we couldn't do anything without first thinking.

Super-ordinate theme 2: Parenting the parent

Conflicted parenting. This theme details findings of the challenges faced by carers during the middle stage of the caregiving journey where the PWD's ability to carry out most activities of daily living had diminished. Out of necessity, carers took on an unconditional and somewhat conflicted mothering or fathering role. A role reversal was experienced which was an evolving and novel experience for carers and one which did not sit comfortably with them. Ava recalls a difficult time during caregiving when she had to constantly tell her mother what she could or couldn't do, speaking to her like a child who needed guidance.

Ava (daughter): It is hard, it's very, very hard, its, in the beginning its emotionally traumatic would be the only way to describe it. I used to tell my mother don't do this, don't do that, you can't have this, you can't have that, please come back, sit down, stop; and you are speaking to your parent in a way that you were never reared to talk. We were told what to do by our mum and dad, you didn't tell them what to do, and it's very, very hard in the beginning just coming to terms with the change.

Many carers were parents themselves; however, for Aaron, the role of parent was both novel and challenging:

Aaron (son): I was never married and I never had children of my own but I have one now, [] I've a ten and a half stone baby really. Basically I had become a single parent.

Contrary to professional advice, carers used experiential knowledge when it came to coping and providing effective care for the PWD:

Aaron: Some professionals would say oh don't ever treat a person with dementia or Alzheimer's like a baby but unfortunately there actually comes a time when it's better to do so because I'm a firm believer that if it's possible for you to keep that person content and happy, then you will have a greater degree of success when it comes to doing other work with him.

Not all carers reported negative feelings towards their role change. Some positively adopted the reverse parenting role, found satisfaction in caring and observed the relationship between the PWD and themselves flourishing and strengthening. Aaron illuminated the role change encountered when he took on the role of parent for his father and articulated

how the relationship between both men had become closer than before as a consequence of this role change.

Aaron (son): I've lost my father a long time ago, what I'm about to lose is my son, you know, and it's gonna be probably even harder to take, you know what I mean. [Pause] I didn't envisage this in the beginning, and I suppose nobody could have told me.

Quality of care. In an effort to manage the inherited role of caregiver, carers were able to cope with the situation if they felt in control of where and when the PWD went to respite, medication administration, dietary requirements and the co-ordination of professional carers who assisted in the care of the PWD. There was an evident mistrust of healthcare staff, hospitals, care facilities and respite centres. Carers provided a high standard of care for the PWD at home; however, based on past experiences in clinical settings, they felt that the quality of care would diminish once the PWD left their home.

Kate (wife): I would not let him go anywhere because he wouldn't survive. He wouldn't survive a week in a nursing home or if he went into respite care, he wouldn't survive because they're not going to spend an hour giving him his breakfast, an hour, two hours giving him his dinner and dessert and glass of wine, they're not going to have time for that.

Similarly, Aaron believed his father would be in danger if he was cared for by someone other than himself. In an effort to assist healthcare providers deliver person centred care to his father while in respite, Aaron provided a care plan to staff, with the aim that staff would continue to provide quality care to his father while in respite:

Aaron (son): I prefer to look after him here because I firmly believe that he's safer here with me than in the hospital, believe it or not, and that's a sad reflection on our society that that's the way things have gone []. Even when he goes to respite, I worry all the time. I created a four-page document, I've a care plan, in the hope that they will follow it exactly as I've things stated, but they don't, they never do.

Parental guilt. Guilt is a complicated emotion, commonly felt in the landscape of caregiving. Carers often feel guilty for recognising a need in them which is exacerbated if the carer acts on this need. In the case of Ellie, she described feeling guilty about 'everything' with the worst guilt experienced when she recognised a need for respite. Despite acting on this need, the carer's guilt was immense, resulting in her not receiving the benefit of a break from her care giving role:

Ellie (wife): Guilt, guilt, guilt. Guilty he was like that, guilty for getting annoyed, guilty that I was getting frustrated that I was repeating everything, guilty that I wasn't doing enough, [] just guilty about everything. [] Do you know when I felt the most guilty? When I was putting him into respite. I felt dreadful for leaving. And I didn't get over it for days.

Carers reported feeling compelled to provide the best care they could reflecting the care they received as a child and subsequent guilt of not being able to meet those high standards:

Irene (daughter): And sometimes no matter what you do you feel guilty that you don't do enough. Because you know they are your parents and they have been the best in the world you know. So you just kind of, you feel guilty about that.

Caregiver burden coupled with guilt is evident in the following extract from Helen. This carer illustrates the impact the caregiving role has on her and on her family, and how conflicted she feels attempting to meet the demands of her mother against the demands of being a mother and a wife:

Helen (daughter): the focus has to be on the individual, it has to be on the person. [] All our lives were just totally focused around mum and dad prior to that. And you had no time for anybody else and any time you had for somebody else, you were feeling so guilty that you should have being given it that way. You're so divided.

Theme 3: Informal support. A help or a hindrance?

This theme examines the supports carers had available to them to assist with caregiving. There was an apparent lack of certain vital supports which would have made the caregiving role less arduous. Ten carers have some form of sporadic family support in the delivery of care while the remaining 13 carers provided care on their own. Several carers would like to have had 'hands on' support or acknowledgement from their siblings for the role they were fulfilling.

Aaron (son): I had nothing, nothing, just myself for the first few years []. All I ever wanted was just appreciation from my own family for what I've done.

Family siblings were frequently identified to be a hindrance, often judgemental of the care that was provided and failing to offer any beneficial assistance. Ben (son) depicts how his sister comes and 'looks at her in the bed and that's about it' while Aaron (son) highlights his family's lack of involvement stating that 'there's never been a weekend where they've taken him'. Grace also illuminated the need for family involvement to assist her cope with the enormity of the role:

Grace (daughter): More time from the family, [] they were more supervisory than hands on and one sister in particular, [] she could have said to me, I'll take mum out to our place and give her her tea []. That would have been nice, just to give me a few hours to catch my breath.

There were many carers who did receive good support from other family members and friends. Participants living in rural areas identified neighbours as a valued additional support available to them. Seventeen participants lived in a rural setting versus six who lived in urban areas.

The need for social support. The need for social support was recognised by many carers and the requirement to have time out to ‘care for the carer’. While the desire is evident to have time away from caregiving, in the absence of adequate funding or either professional or informal carers to take over caring for the PWD, many carers have to forego any break available to them.

Grace (daughter): that is very important that you keep up and involve yourself in certain activities. [] You're very constrained for time when you are looking after somebody, but it's very important that you've some little bit of me time.

Carers highlighted the difficulty and effort attributed to leaving the home and were resolute that the activity outside the home had to be worthwhile to entice them to go.

Maureen (wife): It has to be something really tempting now to get me to go out and enjoy myself because it is a hassle getting a carer in and it is very hard to totally unwind because it is just on your mind all the time. [] You are very careful of your spare time.

Despite the presence of support groups in close proximity to where carers lived, some opted not to attend as they found the group to be of no benefit in terms of support or information. Additionally, the support group was not tailored to meet their specific needs.

Maureen (wife): It is very depressing to talk to other carers. I have gone to some of these workshops [] but the stories were just heartrending and it didn't do me one bit of good. I had a carer for the whole day. It cost me a lot of money []. There was nothing new that we got out of it to help us to handle the situation. [] I had to get someone in for €25 per hour for the whole day and really when I came back I wish I had gone somewhere else for the day.

Super-ordinate theme 4 – Death, dying and life after death

‘That’s not my mother’. Participants changed the way they interacted with and related to the PWD, no longer recognising them as their mother, father or husband. A paradox exists in the subsequent extract when Lisa states ‘that’s not my mother’ because despite her mother being present with her, the mother she once knew was no longer there:

Lisa (daughter): I don't know how long more, mammy, my mother could last another 10 years [] and it's not that I am going to be very remorseful about it either and of course I am very sad about it but it's not my mum, that's not my mother sitting there, [] so that is why I distance myself.

Also

Ben (son): And seeing someone with Alzheimer's taking the best part with you, it's not nice, you don't recognise that person at all or who she is. But that is another point that I couldn't come to terms with, that this woman was gone totally do-lally with Alzheimer's and this was not my mother.

There was an apparent disconnect between the way Lisa spoke about her mother comparing her to an inanimate object. Lisa used powerful imagery likening her mother to an egg.

The shell of the egg represented the strong protective person her mother used to be. When the shell is taken off, the inside of the egg is vulnerable, penetrable, and in her mother's case, unrecognisable. Lisa further illuminated how she had withdrawn from the pre-dementia relationship by the way she referred to her mother as 'this' or 'it':

Lisa (daughter): about 2 years ago when I saw this getting worse and I realised this is not mammy this is not my mother, my mother would never talk or carry on like this [], but that's not my mum, never has been, never would be. [] It's like when you take a shell off an egg, you are left with this but this has nothing to do with me. But I am minding it probably out of respect for the fact that my mother was very good to us [] So then you look at what am I minding, you know, there is a shell there, it's like peeling an egg, isn't it? You know, she is gone, the peel is gone and there is just this, there.

Similarly, in an effort to cope with the loss of the person they once knew, Ava experienced conflicted grief and detailed having to emotionally draw back or pull away from her mother. Carers adopted practical approaches to coping with situations, justifying detaching from the PWD to achieve a happier family life. Ava saw the detachment as reciprocal, whereby she no longer recognised her mother and her mother no longer recognised her:

Ava (daughter): I know I have detached because for the sake of my kids I had to, [] you really do have to detach from the situation and realise that she's, it's a vessel, it's not your mother anymore and she doesn't recognise me as her daughter and I don't recognise her as my mother anymore, that might sound cold [] It's honest.

Also

Helen (daughter): I feel anyway with dementia you've lost the person such a long time before that, it's like as if they've died a long time ago and a lot of it, now this is being just entirely honest, a lot of it is going through the motions

Maureen experienced a similar loss, however, still felt a connection, albeit in a different form of relationship. As well as grieving for her husband, she mourned the loss of their relationship as a couple and the activities they enjoyed together.

Maureen (wife): It is not your husband any more, it is somebody very close to you that, it is like looking after your father or somebody. And you have said good-bye to your husband really. It was very difficult in the beginning alright. But I guess time, you get used to things. And the hard part, is the social isolation, because you have no husband you don't have a partner, and a lot of things you would have gone to as a couple, you don't go to any more.

Regret of not discussing death & dying. Carers spoke of having regrets, one of which was not discussing death and dying early in the disease trajectory while the PWD was able to communicate their wishes and feelings. Due to being ill-informed about the progression of

dementia, Caroline missed the opportunity to ascertain her mother's wishes regarding end-of-life care or preferences after her death:

Caroline (daughter): I think what's so important is [] that you make the most of the time you have. Why didn't I know mum would lose her speech [crying]? Because I should have spoken to her, I should have talked to her about death. I think the other thing I learned was they know they are dying. And we pretend, oh we can't upset them. It's not them we are afraid of upsetting. [] I'm disgusted I didn't do that, [crying] but maybe I did know. I think I did to be honest. I just wasn't doing it.

Irene also acknowledged missing the opportunity to discuss her mother's wishes about death and dying and regretted not paying attention to the subject when her mother requested to discuss it. The subsequent extract depicts how the PWD wished to speak about their own mortality; however, it was the carer who was uncomfortable discussing this topic or accepting that this was a reality.

Irene (daughter): a few years ago she actually was talking to me about what she wanted to do with her end of life. And of course at the time I wasn't in a place to hear it, so I told her 'stop that will you, no need to be talking about that, we'll look after that when it happens, forget about it'. And of course now, [] I would appreciate it if she started the conversation again because I think I'd write down if she had any things, any, requests, but I don't know how to broach it now you know. So it's a lost opportunity but at the time I wasn't, you know I wasn't in a place to talk about it. I didn't think it was really that relevant.

Several others cited what they believed to be the PWD's opinions of dementia and the fear and anxiety the PWD had of developing this disease. There was a tangible sense of knowing the PWD and their loathing of the disease and wish to die rather than live with it. Fiona spoke candidly about her mother's wish to die by suicide rather than live with dementia. This extreme response emphasised the feelings of the PWD towards having this disease:

Fiona (daughter): she said 'I am going down the road and I am going drowning myself'.

Similarly, Ava also discussed suicide, illuminating how having dementia had changed her mother unrecognisably from the person she was pre-dementia and believed her mother would have thought it preferable to die by suicide than live with the disease:

Ava (daughter): For a woman that was so vibrant and had a bubbly personality and embraced life with both arms its really, really horrendous to see them like this and if she had known the way things were going she would have gone off that bridge down there herself ten years ago before getting to this.

Ava gives specific and graphic examples to support her beliefs in the following extract:

Ava (daughter): She often said that, the words would be 'shoot me', 'shoot me' 'put a bullet in me before I get like that', 'I don't want to be a burden on anybody'. And we would say, 'you are not a

burden'. She is not a burden, she is still not a burden, its hard work, but she is not a burden. But I know I would put pen to paper for my own life and say get rid of me if I end up like that. I wouldn't want to be like that, I know she didn't want to be like that, but I wouldn't do it, I wouldn't do it.

When asked about their opinions on end-of-life care for people with dementia, both married couples initiated a discussion surrounding the ethical dilemma of allowing the PWD to die naturally versus intervening with medical treatments. It is noteworthy that both Isobel and Donna had a medical background and prior knowledge and experience of caring for people with dementia in healthcare settings:

Isobel (daughter in law): It is a difficult one, are they obliged to leap straight in there and go ahead, or would that bit of common sense come to play, [] no one wants to mention it, you know, people with dementia, you know, they're looking for a way out of it and you know these things crop up, chest infections or whatever and you know in a lot of ways I think they're denied the opportunity to die.

This dilemma is echoed by another couple who also discussed the end-of-life phase for people with dementia and offered their opinion of dementia being a terminal illness:

Michael (son): It's a difficult one, you have to take care of them, until nature takes its course basically. The only thing is that if they do get such a thing as pneumonia then you just let that. . .

Donna (daughter in law): But we do give her antibiotics []. It's a difficult call because I have to say that is one thing that I found very difficult over these years was that, say the time she got the blood clot in the leg and we took her to the hospital and the first doctor we met was, why are you here, why did you bother? [] Some people define it as a terminal disease, now I have cared for my father and the neighbour over the road with cancer and you know the terminal part of that you can see it, [] and you feel like it's ok to let them go, they are suffering. You don't see the same kind of thing [with dementia], it's hard to call that as much as a terminal illness even though it is terminal.

Striving for a good death. Despite caring for the PWD for many years, and seeing the declining progression of the disease, carers reported feeling surprised when death occurred. The shock felt by carers when the PWD died was due to a lack of information on the disease process and what to expect in the final stages of life:

Alec (son): So when she did finally die it was kind of a bit of a shock to us really, you know she just faded away really didn't she []. Oh yeah a nice peaceful death, you couldn't wish for a better one. We hadn't a clue that that was going to happen.

Mary detailed her uncertainty about the end stage of life and her wish for a quick death at home for her mother. The arrival of death would come as a blessing for her mother.

Mary (daughter): I don't know what's coming, I don't know how to care for, [] I hope, God forgive me, I hope it comes soon for her, I hope it comes when she is in her own home, you know in bed.

My mother is alive but she is not living. She sits in a chair all day and watches the world go by. She doesn't interact. She has no quality of life, for the woman that she was, I do hope that the [] time comes quicker rather than later.

Two carers identified home as the ideal place for a good death, in addition to having family present and being pain free.

Grace (daughter): She died at home in her own bed surrounded by her family and with the priest on call and she wasn't in any pain, so if you want, if you like, it was as good a way as you could pick to go.

Maureen (wife): the deterioration is very slow but it is there. If I look back at last year I can see the deterioration, it's just awful to watch. I just hope he dies peacefully some night, no hospital.

Life after death. Carers experienced an additional role change after the PWD died. They were forced to re-invent their role within the family, in the work-place and in society as they no longer assumed the role of carer. Carers were bound by time management and routine while the PWD was alive, and reported difficulty adjusting to the ample amount of routine – free time they now had.

Grace (daughter): Well it's like I suppose if people retire, you know, all of a sudden from having your 9 to 5 or whatever, and having your routine, all of a sudden there is no routine. So it does, it's kind of a bit of a culture shock, you have to get into recreating a routine.

Being a single man living in a rural location, Aaron reflected on how his life would change after his father died and had an awareness of the loneliness which would occur. There is a sadness to this excerpt revealing pre-death grief, not only for the loss of his father but also for his caregiving role:

Aaron (son): I often wonder how I will fill the void that's going to be left behind when he's gone, from this routine that I've been in for so long.

Similarly, Jack was also a single man who lived in an isolated area and detailed the emptiness and quietness that now filled his home, only recently noting the ticking of a clock as a result of the silence following his mother's death:

Jack (son): You have no one, you have no one of your own, [] and all I have is my neighbours or friends that come in to see me. When they leave here at night and you hear no sound coming there from the room and the heavy tick of the clock that you never heard when your mother was here with you, that's when you know you're on a lonely journey in your life but there's nothing you can do about it. Nothing. [] You have the time but you don't want to do anything.

Reflecting on the caregiving journey and the experience of death, Alec demonstrated the sadness experienced by his family immediately after the death of his mother. The sadness discussed was not as a direct result of the death of his mother, but a sadness as a

consequence of the struggle of caring for the years preceding her death and due to the unhappiness experienced by his mother and family during the caregiving period:

Alec (son): So it's nice to look after your parents, you know and do your best for them but I couldn't say it was a rewarding experience, you know when my mother died we thought we'd all have a great sense of relief, that we'd all let out a big sigh, ah well she's at peace, but we just all sort of sat there and just felt crest fallen really, like deflated. You know we thought it was going to be a great day when she did finally die, for herself and you're just, all we could come out with was just sadness.

Discussion

As evidenced from the findings, carers described their experiences of providing care throughout the caregiving trajectory, in addition to former carers illustrating the death and dying experience. A number of models describe the caregiving trajectory in dementia (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Lindgren, 1993; Wilson, 1989) with Lindgren applying the term 'caregiver career'. This encompasses three differing but overlapping stages: an Encounter stage (the diagnosis and loss of previous life patterns), an Enduring stage (managing extensive care routines and social isolation) and finally an Exit stage (the relinquishment of caregiving through the death of a spouse or loved one) reflective of the stages experienced by these carers.

Sweeting and Gilhooly (1997) pioneered the application of the constructs of 'anticipatory grief' and 'social death' to the process of caregiving and dementia. Anticipatory grief is experienced when there is forewarning or threat of loss before an actual death occurs (Coelho & Barbosa, 2017) while social death refers to the ways in which a person is treated as if they were no longer alive (Borgstrom, 2016). It is argued that people with dementia experience a loss of personhood as a consequence of their illness. In addition, since dementia is commonly linked with older age, people presume them to be approaching death and are 'examples of individuals for whom life may not be worthwhile anymore' (Sweeting & Gilhooly, 1997, p. 99).

Correspondingly, Blandin and Pepin (2017) describe pre-death grief experienced by dementia family carers specifically as 'dementia grief' which is a particular form of anticipatory grief expressed in response to compounded serial losses of varying significance and evidenced by the ambiguity which characterises the experiences of loss in dementia. Carers recounted emotionally withdrawing from their caring role in an effort to cope with loss associated with the disease. This ambiguity was highlighted by one carer who stated 'that's not my mother'. Despite her mother being alive and having the physical appearance of her mother, the carer finds it difficult to remain emotionally connected to her and unable to recognise the PWD any longer as her mother as a result of the profound changes in cognition, personality and physical disabilities now present and is an illustrative example of social death for the PWD. This ambiguous loss occurs due to an inability to identify personality characteristics or personal memories which lead to experiences of ambiguity in family members whereby the PWD does not appear to be emotionally accessible or the same person (Blandin & Pepin, 2017; Large & Slinger, 2013; Sanders & Corley, 2003).

In general, carers of people with dementia require greater emotional support and respite care prior to the person's death than afterwards therefore by receiving effective social support pre-bereavement, facilitates better adjustment post bereavement (Schulz et al., 2003; Shanley, Russell, Middleton, & Simpson-Young, 2011; Sinha, Desai, Prakash, Kushwaha, & Tripathi, 2017). Carers reported feeling isolated and left to 'get on with it'. Difficulties were experienced accessing respite care for the PWD when carers needed it while others expressed their reluctance to avail of respite care due to a mistrust of respite facilities. As a consequence, carers had no experience of the PWD being away from the home for a prolonged period of time and no experience of a break from their caregiving role. Greater exploration into end-of-life decision-making, adequate preparation for their loved ones death, and measuring quality of life at end of life is required for family carers (Chan et al., 2013; Raymond, Warner, Davies, Illiffe, & Manthorpe, 2014). Shock and devastation among carers after the death of the PWD is attributed with a lack of foresight (Hebert, Dang, & Schulz, 2006). Carers in this study also highlighted the need for information surrounding the dementia disease process and 'what to expect' from time of diagnosis until death. Carers reported having to find this information online or by word of mouth from other carers. Appropriate information and intervention strategies should be provided throughout the care giving trajectory so that the terminal phase is demystified and feared less (Adelman et al., 2014).

Carers expressed their regret not discussing end of life and death preferences with the PWD early in the disease trajectory while the PWD had the ability to communicate their wishes. The unique aspect of ethical issues in dementia relates to the increasingly and unavoidable need for others to make decisions for the PWD. Decisions are based on evidence for the effectiveness of the particular action. However, often decisions are complex involving clinical and ethical aspects. One such issue at end of life which raised an ethical discussion amongst carers was the provision or withdrawal of certain treatments such as antibiotic therapy. While carers understood that administering antibiotic therapy to treat infections was a life-prolonging measure, there was a reluctance to 'let nature take its course' and saw non-intervention as an admission of failure or 'giving up'. These views are not unique to this research as Hennings, Froggatt, and Keady (2010) reported family carers judging themselves responsible if death ensued following the withdrawal of treatment.

Prognosticators may suggest in certain cases that antibiotic therapy is required while in other cases, it may be withheld in people with severe dementia. The distinction between ordinary and extraordinary means of treatment needs to be understood in the case of someone with dementia and when the burden imposed by the particular treatment against the likelihood of benefits accruing to the person concerned has traditionally found to be useful (Hanrahan, Luchins, & Murphy in Addington-Hall & Higginson (2001)). Additionally, a failure to identify the end-of-life phase results in prolonged exposure to unnecessary treatments (Marsh, Prochoda, Pritchett, & Vojir, 2000). Ironically, it is claimed that throughout the disease process, the PWD often receives 'too little' care, an example of which is the under treatment of symptoms such as pain (Barber & Murphy, 2011; Herr et al., 2006; Husebo et al, 2008; Martin, Williams, Hadjistavropoulos, Hadjistavropoulos, & MacLean, 2005; Sampson, Gould, Lee, & Blanchard, 2006), whereas end-of-life care is often characterised by 'too much' (Small, Froggatt, & Downs, 2007) specifically when advanced dementia patients are subjected to burdensome interventions such as tube feeding and parenteral hydration (Arcand, 2015; Hertough, 2006).

Carers discussed the concept of euthanasia and assisted suicide for the PWD as well as citing the PWDs preferences for dying by suicide instead of dementia. Carers wished to avoid an undignified death for the PWD and acknowledged their poor quality of life as a consequence of the disease. Belgium and the Netherlands are the only two countries to legally recognise euthanasia within a number of patient categories (Gastmans & de Lepeleire, 2010). In addition, The Netherlands legally recognise advance directives for euthanasia of incompetent people such as those with dementia as part of the 2002 euthanasia law (de Boer, Dröes, Jonker, Eefsting, & Hertogh, 2011).

Involving carers is paramount in ethical decision-making especially at the end-of-life stage when complex ethical issues may be frequent. The principal of autonomy must be adhered to and education involving a detailed discussion of how death comes about is required. The concept of the person helps to justify and should encourage greater willingness to involve carers in decisions concerning death and dying (Chan, 2004). This mirrors part of the palliative care approach and the philosophy of palliative care that carers should be involved in decisions especially in dementia.

Literature on caregiving in dementia suggests that carers generally consider the persons death as a relief (Chan et al., 2013; Raymond et al., 2014; Shanley et al., 2011) in contrast to general literature on bereavement (Earle, Komaromy, & Bartholomew, 2009; Eliot, 2014; Thomas, Hudson, Trauer, Remedios, & Clarke, 2014). However, findings from this research suggest otherwise, with carers expressing surprise and shock when the PWD died, despite knowing that death was imminent. There is strong evidence to suggest that the physical, psychological and social health of caring may leave family carers poorly equipped for life after death. When caregiving ends due to the death of the PWD, carers often struggle to deal with this significant change in their life circumstances. Larkin (2009) identifies three post bereavement phases encountered by bereaved carers: the post-caring void, closing down the caring time and constructing life post-caring. Carers described an innate sadness following the death of the PWD while in their post-caring void. During this ‘wind down’ period, carers undertook closure activities, however, struggled with the lack of routine and abundance of free time now available to them. Another role transition occurred reconstructing life and reinventing the self in the post-caring phase. Blandin and Pepin (2017) term this state of transition as liminality and while the end result may be positive, the process is unstable and ambiguous. Assistance is required in the pre-death period to help carers plan for their post-caring lives while still caring (Larkin, 2009) such as maintaining leisure activities and undergoing education and training to develop skills. Several carers in this study engaged in online courses on computer literacy and care skills. Equally, it is imperative that those healthcare professionals who had contact with carers during their caregiving career, continue this relationship with follow-up visits in the post-death period. This facilitates former carers discussing the challenges associated with the post-caring phase and reduced the incidence of complicated grief.

According to Shear (2010) complicated grief results after a loss and is defined as a severe form of grief which includes intrusive thoughts, separation distress and the inability to resolve a loss. 20% of dementia caregivers suffer from complicated grief following the physical death of the PWD (Blandin & Pepin, 2017; Holland, Neimeyer, Boelen, & Prigerson, 2009). Dementia caregivers with high levels of pre-death or dementia grief are more likely to have post-death complicated grief (Schulz, Boerner, Shear, Song Zhang, & Gitlin, 2006). Therefore, adopting interventions to lessen stress and caregiver burden, decreases the level of post-death depression and complicated grief (Blandin & Pepin, 2017).

Strengths and limitations of the study

This is the first study to examine the experiences of carers who provide end-of-life care to those with late-stage dementia at home in Ireland and the findings add to the limited knowledge based on this topic. Methodologically, an IPA study involves a highly detailed analysis of the participant's verbatim accounts, which relies on the researcher's skill to reflect on and make sense of the participant's sense-making of their experience. The findings presented here have addressed the need for sufficient extracts providing evidence of the four themes.

The findings are limited to the West and North-West regions of Ireland and may not have widespread international application. However, given that the majority of participants were recruited by gatekeepers of national dementia and health-related organisations, it is reasonable to assume that the experience is not uncommon to other carers who may share many of the same experiences and issues. This study had a sample size ($n=23$) which could be perceived as a limitation; however, IPA studies typically have small sample sizes which result in rich data. The age of participants ranged from 30 to 79 and years spent caring ranged from 0 to 19 years. However, all care recipients were in the late stage of dementia, and all carers lived in the West or North-West of Ireland, thus increasing the homogeneity of the study.

Conclusion

This study highlights the challenges faced by carers who provide end-of-life care for a PWD living at home. The supports carers require to provide care were outlined, providing valuable clinical insights for healthcare providers and organisations working with this cohort of people. Carers want to provide care for the PWD at home until the time of death. The support currently available has been described as inadequate and not addressing the specific needs of Irish carers or the PWD. Enhanced support is required in this area at both individual and community level and the findings should be considered when developing carer support services and education programmes to meet the needs of carers as well as the PWD. Findings from this research can additionally inform future research which could include larger samples of carers, comparing the caregiving experiences in different countries, or different cultural groups.

Author contributions

LD conceived and conducted the study. MD, PL and KM supervised the study. LD wrote the first drafts of this paper. All authors contributed in critiquing and proof reading this paper.

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The author(s) declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethical approval

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