



The Journey Through Death and Dying:

Families' Experiences
of End-of-Life Care in
Private Nursing Homes

*a report by Dr Mel Duffy
and Dr Eileen Courtney*



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Dedication

This report is dedicated to all individuals who care for older people in Irish society whether that is at home, in the community or in a formal care setting:

You know nobody has got a book on life, and on what to do or how to do it so I think you just try and do the best you can. [Aveen]

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Contents

Chapter 1: Background to the Study.....	3
Chapter 2: Methodology.....	6
Introduction	6
Aims and Objectives.....	6
Methodology.....	7
Gathering the Data.....	7
Data analysis	10
Ethical Consideration	10
Chapter 3: Literature Review	12
Introduction	12
End-of-Life Care	14
Achieving a Good Death.....	16
Death and Dying in Nursing Homes	17
Factors Influencing End-of-life Care in Nursing Homes	18
Families and Nursing Home Care	20
Supporting Families	21
Conclusion.....	23
Chapter 4: Transition: The Movement from Home or Hospital to the Nursing Home.....	25
Introduction	25
Coming to Terms with the Limitations of the Self	26
Struggling to Stay Afloat: Bringing Help into the Home	27
Surrendering to the Inevitable: Making the Decision to Use a Nursing Home.....	31
Where to From Here? Choosing a Home and Its Aftermath	33
Chapter 5: Being in a Nursing Home.....	39
Introduction	39
Settling In	39
Hyper-vigilance: Making Sure It's All O.K.....	39
Relaxing: A Home Away From Home	42
Recognised as Important: Caring for the Families.....	43
Bumps in the Road:.....	45

Experiences of Hospitals	45
Culturally Diversity or Cultural Competence	46
Chapter 6: Planning for the Future	50
Introduction	50
Discussing End-of- Life Care	51
What Does it Mean?	56
Partings	61
Chapter 7: Journeys End	68
After Death.....	69
Living Without the Nursing Home	71
Chapter 8: Conclusion and recommendations	74
Recommendations for Practice.....	77
Recommendations for Future Research	79
References	80
Appendix 1 Introductory Letter	94
Appendix 2 – Information Leaflet and Contact Consent Form	95
Appendix 3 – Interview Prompts	99
Appendix 4 – Written Consent for Participation in the Study	100

Chapter 1: Background to the Study

At a global level the age distribution of the world's population is undergoing a transformation, with many countries having to cope with substantial ageing of their populations, a process that is expected to continue indefinitely (United Nations, 2004, 2012). The issue of an ageing population is a major social factor across the whole of Europe which is likely to have significant economic and social impacts (European Commission, 2011), with the United Nations (2011, 2012) suggesting that population ageing is one of the most significant megatrends with implications for all societies. In Ireland the population of elderly people aged 65 or over increased by 14.4% over the 5 year period 2007 – 2012 to 11.6% of the total population (Central Statistics Office, 2013). Persons aged 80 and over as a proportion of persons aged 65 and over has risen steadily from 17% in 1981 to 24.1% in 2006 (C.S.O. 2007). Each year the total number of people over the age of 65 is now growing by around 20,000 persons (Department of Health, 2013) and projections suggest that this will continue to increase with the most notable increase in the oldest age band of 85 years and over which are due to more than quadruple by 2046 (C.S.O. 2013).

In parallel with population ageing the social environment within which ageing occurs is also rapidly changing. The size of families is decreasing, the role of extended families is diminishing, and perceptions in respect of intergenerational support and caring for older persons are rapidly changing (United Nations, 2007). These demographic and social changes clearly have major implications for the planning and provision of health services. Current government strategy proposes that investment in the supply of more and better care for older people in the community and in residential settings is a priority (Government of Ireland, 2011) so that services are developed to facilitate older persons to stay in their homes if desired, but also that the supply of formal long term care for older persons, including institutional living, is expanded. In 2011, 4.1% of men and 6.7% of women aged 65 and over in Ireland were in receipt of residential or long-term, with over two-thirds of patients (68.9%) aged 80 and over (Department of Health, 2012). The largest proportion of patients in long-stay units suffered with chronic physical illness or dementia (32.1% each), although Cahill *et al* (2012) suggest these figures are underestimated proposing that 63% of all residents in long-stay facilities have dementia. Over half of patients (53.8%) in long-stay beds were discharged during 2012 on death (Department of Health, 2012).

Based upon an analysis of mortality trends and future projections for the years 1974-2013 in the United Kingdom Gnomes and Higginson (2008) propose that, if recent trends continue, residential and nursing homes will be an increasingly important locus of care and death for older people.

Currently the majority of people in Ireland die in an institutional settings, with 1:4 older people dying in a long-stay facility (Mc Keown *et al*, 2010). Providing care for older people in long-term care settings presents significant challenges, not least in relation to the provision of good end-of-life care and palliative care. Based upon a review of the literature Wowchuk *et al* (2007) proposed these challenges include: lack of care provider knowledge about the principles and practices of palliative care; care provider attitudes and beliefs about death and dying; changing profile and disease trajectories of individuals admitted to nursing homes; staffing levels and lack of available time for dying residents; lack of physician support; lack of privacy for residents and families; families' expectations regarding residents' care; and hospitalisation of dying residents. More recent studies suggest that these factors remain salient (O'Shea *et al*, 2008; Payne *et al*, 2009; Casey *et al*, 2011; Österlind *et al*, 2011; Gorlen *et al*, 2013; Neilsen and Glasdam 2013; Hov *et al*, 2013; Handley *et al*, 2014).

In recent years, national policy agencies have become concerned with defining and measuring quality of care at end-of-life (O'Shea *et al*, 2006; HIQA 2008) including the way in which family and friends of the dying person are treated. Family members bear significant burdens in the long-term care of an individual even when that individual is resident in an institution (Williams *et al*, 2012) and can experience significant physical and emotional stress at levels that adversely affect their own health, especially when they are older or are physically vulnerable themselves (Berg-Klun, 2008). While it is generally acknowledged that families' experiences, and the way they perceive the patient being treated around and after death, forms a significant part of quality of life at end-of-life in a recent review of the literature Kendall *et al* (2007) found that there is relatively little research that draws on carers perspectives. This is important in the context of Steinhauser *et al*'s study (2000) exploring the factors considered important at the end-of-life by patients, families, and care providers which concluded that quality end-of-life care is a dynamic process that is negotiated and renegotiated among patients, families, and health care professionals, a process moderated by individual values, knowledge, and preferences for care.

Research focusing on families' experiences of end-of-life care in an Irish context is largely absent. In a recent comprehensive review of end-of-life care for older people in acute and long-stay care settings in Ireland, O'Shea *et al* (2008) excluded the perspective of families from the study. This study aims to reduce that deficit by exploring families' experiences and perceptions of the end-of-life care received by their loved in the context of a private nursing home setting. The report is comprised of discussions on: methodology; review of existing literature and interpretation of the data gathered thorough interviews of relatives who admitted a family member to nursing homes.

The data revealed how families noticed their loved 'grow infirm, they age' (Elias 1985 p.3) focusing on their journey through the ageing process. It uncovers the emotional journey of family members when they come to the realisation of the limitations of their ability to provide care for their loved ones. The majority of participants came to the realisation they could no longer provide the care their loved one needed. They had to navigate both the cultural ideology and promises made that nursing homes was the place of last resort for caring for a family member. Finding a nursing home is not easy and the majority of participants reviewed a number of nursing homes until they found what they were looking for. The decision to admit their loved one was based upon their initial instinctive reaction to the home for the majority 'it felt like home'. Life within a nursing home is unpacked, from the quality of life of residents to the quality of care and the process of partings. This report is centred on the stories people told of living with a loved one who was ill and how they journeyed with them until their death:

There are various ways of dealing with the fact that all our lives, including our own and those of the people we love, come to an end. This is the oldest and commonest form of the human endeavours to come to terms with the finiteness of life (Elias, 1985 p. 3).

Chapter 2: Methodology

Introduction

Population projections indicate that nursing homes are likely to increase in importance as a place of death for older people in the future. Consequently staff in the nursing home sector are providing care for residents with acute and chronic palliative care needs. Currently there is a lack of research in the Irish context exploring families' experiences of end-of-life care in private nursing homes. While the Health Services Executive [HSE] and Irish Hospice Foundation [IHF] conducted a national survey exploring families' experiences of the death of a relative in hospital in Ireland (2010) both the context of the study (acute and community hospitals) and the age range (18 – 100) and profile of those who died were significantly different to those in the current study. Additionally in a comprehensive mixed methods study involving 592 care facilities O'Shea *et al* (2008) exclude relatives from their analysis of end-of-life care in acute and long-stay care settings in Ireland. This study will help address the deficit in knowledge that currently exists in this area.

Engaging with families has been identified as an essential contributor to quality end-of-life care (Lawton *et al*, 2013) and while practitioners operate on the palliative care principle of caring for the family as a unit in practice it is frequently a struggle to operationalize this (Davies *et al*, 1995).

Aims and Objectives

The overall intention of this study is to provide a comprehensive description of how family members experience the process of palliative and end-of-life in a private nursing home setting.

The main objectives of the study are to:

1. Describe the experiences of family members of the end-of-life care provided to their relative
2. Investigate the meaning(s) that family members construct of that experience

These objectives were considered to be significant given the current lack of research exploring families' experiences in an Irish context.

Methodology

The methodology chosen for this study is from the qualitative framework which enables us to obtain an understanding of the experiences of family members through the stories that they tell. Bryman (2006) proposes that one facet of the distinction between quantitative and qualitative research is that the former is orientated to the specific concerns of the researcher and the latter to the perspectives of the research participants. A qualitative approach was required in order to ensure participants' perspectives remained central to the study and to ensure that through the voices of family members we can begin to understand their experiences. What a family member says is happening in her/his world is happening as s/he experiences and lives it for "It is in the co-disclosure of the shared world that issues of voice, reflexivity, identity, and understanding reveal themselves" (Kavanagh, 2006 p.252).

Gathering the Data

In keeping with the Qualitative methodology of the study purposeful sampling was used to recruit participants. The study required family members who have lived the experience being investigated, and families were eligible to participate in the study if they met the following inclusion criteria:

1. Had a relative who died in one of the nursing homes associated with the study between Jan – Dec 2012
2. Agreed to participate in the study.

This timeframe was chosen on the basis that it minimized the potential of recall bias but also excluded the very recently bereaved who may have found participation in the study distressing. Families were recruited through the four nursing homes involved in the study and a total of 67 families who met inclusion criteria 1 were identified. Each nursing home facilitated access to potential participants by issuing those eligible with an Introductory Letter [Appendix 1] and an Information Leaflet & Contact Consent Form [Appendix 2] on behalf of the research team. Families returned their contact details directly to the researchers if they agreed to be contacted about participation in the study. At no stage were the nursing homes aware of which families responded to the invitation to participate.

Twenty Six families returned completed consent forms agreeing for the research team to make contact, of which 24 could be contacted. During this initial telephone contact participants

were informed of the nature and purpose of the study, and the areas to be explored during the interviews. In this way participants had an opportunity to reflect on their experiences in their own time and space, prior to the interview. From this initial telephone contact 22 families agreed to participate, resulting in 15 individual interviews, 6 interviews with two family members, and 1 interview where three family members participated.

The total number of family members interviewed for the study was 30. Of these 22 were children of the deceased, 2 were spouses, 2 were siblings, 2 were daughters-in-law, 1 was a nephew, and 1 participant was mother to the deceased. Table 1 provides the pseudonyms of individuals who participated in interviews and their relationship to the deceased family member.

Table 1: Name of participant, relationship to deceased family member

Participants Name	Relationship to Deceased
Abbie	Daughter in Law
Cian	Brother
Holly	Daughter
Callaum & Dylan	Sons
Ciara & Ruth	Daughters
Iris & Lily	Wife and Daughter
Loran	Daughter
Hillary & Maisie	Wife and Daughter
Austin	Son
Jessica	Daughter
Silvia	Daughter
Daniel	Nephew
Sasha	Daughter
Alice	Sister
Sandra	Daughter
Corina & May	Daughters
Mandy, Joy & Zara	Daughters
Rosy	Daughter
Susan	Daughter
Tom & Mary	Son & Daughter-in-Law
Sean	Son
Brid	Mother

The deceased family members ranged in age from 40-97 ($m=84$, $sd=14$), 10 were male and 12 were female. Thirteen had been admitted to the nursing home directly from their own home and the remaining 9 had been admitted from an acute care facility. The majority had some form of Dementia (86%). The time spent in the nursing home prior to death ranged from 1.5 months to 120 months ($m=38.6$, $sd=36.2$). Table 2 describes the characteristic of the deceased family member including their age at time of death, diagnosis, whether they were transferred

from hospital or home to the nursing home and length of time that they lived in the nursing home.

Table 2: Demographic Characteristics of Deceased

No.	Age	Gender	Diagnosis	Time in N.H.	Source of Admission to N.H.
1	90	Female	Dementia	24 months	Acute Hospital
2	92	Male	Dementia	1.5 months	Home
3	59	Female	Locked in Syndrome	96 months	Home
4	97	Female	Dementia, CCF	24 months	Home
5	92	Female	Dementia	48 months	Home
6	96	Male	Dementia	6 months	Acute Hospital
7	87	Male	Dementia	18 months	Acute Hospital
8	82	Male	Dementia	24 months	Home
9	63	Male	Dementia	23 months	Acute Hospital
10	89	Male	Dementia	120 months	Home
11	85	Female	Dementia	30 months	Home
12	97	Female	Dementia	30 months	Home
13	89	Male	Dementia	60 months	Home
14	88	Male	Dementia	48 months	Home
15	92	Female	Dementia	42 months	Home
16	86	Male	Dementia	13 months	Acute Hospital
17	86	Female	CCF, Arthritis	8 months	Acute Hospital
18	78	Male	Dementia	84 months	Acute Hospital
19	40	Female	Multiple Sclerosis	120 months	Home
20	85	Female	Dementia	3 months	Acute Hospital
21	83	Female	Dementia	24 months	Acute Hospital
22	87	Female	Dementia	2 months	Home

Data gathering took place between June 2013 and September 2013 using unstructured interviews. Dinkins (2005) points out that the interviewer is the instrument through which data is collected. As previously stated most interviews conducted were one-to-one interviews (n=15), however in some cases two members of the family participated and in one case three members were interviewed. The interview opened with a single question –

- Can you describe your experience of the end-of-life care provided to your relative in the nursing home?

During the course of the interview, further questions arose from the information the interviewee imparted. These questions acted as prompts to enable the individual to develop their story [Appendix 3]. They were not used in every case.

The study was explained again in advance of the interview so that any questions could be answered or issues clarified. All participants provided written consent for the interview to

proceed and be recorded [Appendix 4]. When the interview consisted of two or three family members, each participant reminded and clarified for each other what was being said. In some cases the interviewer asked very little as family member began to tell their story speaking freely. Interviews ranged in duration from twenty minutes to 3 hours and took place in a setting chosen by the participant on the basis of convenience and comfort.

Data analysis

Interviews were recorded on an ipod and subsequently transcribed verbatim. These transcripts formed the basis of the data analysis, with each member of the team spending time with the data listening to family members describe their experiences while reading and re-reading the interview transcripts. Smyth *et al* (2007) suggest that working with the data is an “experience of thinking”. Each researcher spent time individually reviewing the data. This process took place initially as individuals and subsequently as a team. Data analysis was an iterative process.

Emergent themes were not necessarily similar for all participants; rather they represented “an understanding that we have something that matters significantly, something that we wish to turn the reader towards” (Smythe, 2007). It is something important that necessitates thinking about and gives an invitation to the reader to think further. Themes can be thought of in another way, they give ‘control and order to our research and writing’ (van Manen, 1990 p.79). Smythe (2005) states:

Within the experience of thinking there are no subheadings to categorize or arrange thinking. Thinking lives in rich, multidimensional ebb and flow, circling and recircling. Nevertheless, the written account demands a breaking down, and an order (p. 228).

Ethical Consideration

Lee (1993) informs us that when one undertakes sensitive research, it has implications at every point in the research process. He further argues that threats to the person can come in the form of intrusion into an individual’s life and social space; it can take many forms, from the perception of, to actual reality of, physical threat. Consequently each step of the sampling and data gathering requires the researcher to take steps to protect their participants. In this context pseudonyms were used to disguise the identities of family members in this study.

Ethical approval for the study was obtained from Dublin City University Ethics Committee. There are ethical considerations to be taken into account at every juncture of the research process and Sorrell and Dinkins (2006) inform us that: ‘ethics is concerned with the suffering humans cause one another and the related capacity of humans to recognize and address this suffering through empathetic virtues of sympathy, compassion, and caring’ (p. 310). These ethical considerations have been taken into account during the data gathering process and interpretation of the data.

Chapter 3: Literature Review

Introduction

The issue of an ageing population is a major social factor across the whole of Europe (European Commission, 2011). In Ireland the Central Statistics office (C.S.O. 2008) projects that the very old population (those aged 80 years and over) will more than double by 2026. Consequently dying in old age, in any setting, is one of the key public health challenges that Western countries face at the start of the 21st century (W.H.O. 2004a).

For some older people with increasing frailty comes the need to move into care-homes, and subsequently nursing homes have become common sites for the provision of end-of-life care (Department of Health, 2012). Moving to a long-stay care facility represents a major life transition for many older individuals (Reed *et al*, 2002; Payne *et al*, 2009), with most people admitted to such settings dying there, or be transferred somewhere else to die (Department of Health, 2012). While the duration of this process depends largely upon the individual's diagnosis and illness trajectory (Murray *et al*, 2005), several stages associated with end-of-life care in long-stay settings have been identified including: living with loss; living with dying; the actual dying and death; and the bereavement that follows a person's death (Froggatt, 2004; Payne *et al*, 2009). As a result end-of-life care in this context requires a longer-term perspective than just the death of the individual and the time period immediately preceding it (Froggatt & Payne, 2006; O'Shea *et al*, 2008; Bern-Klug, 2009).

A "good death" in a nursing home had been described as involving individualised care, interdisciplinary teamwork, and advanced care planning to avoid unnecessary interventions and hospitalisation (Waldrop & Kirkendall, 2009). Essential to achieving good quality care at the end-of-life for older people is the provision of individualised care that acknowledges and respects the values and preferences of the individual and their families, and this is achieved through a process of shared decision making and clear communication (Hanson *et al*, 2002; W.H.O 2004b; O'Shea *et al* 2008; HIQA, 2009). Regardless of the diagnosis, or location of care, the general attributes of a good death include pain and symptom management, awareness of death, patient's dignity, family presence, family support, and communication among patient, family and health care providers (Lawrence *et al*, 2011; Granda-Cameron & Houldin, 2012). Teno *et al* (2001; 2004) propose that high quality end-of-life care results when health care

professionals ensure physical comfort and emotional support for the dying person and treat them with respect; promote shared decision making; provide information and emotional support to family members, and coordinate care across settings. These concepts are congruent with the WHO (2002) definition of palliative care and the principles upon which this is based –

an approach that improves the quality of life of patients and their families facing the problems of 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, physical, psychosocial and spiritual (Sepulveda *et al*, 2002 p.1.)

At a national level the past two decades have seen the publication of a number of reports, plans and strategies which have directly impacted on, or have significant implications for, the development and provision of palliative care services in Ireland (DOH, 1994, 1996, 2001, 2001a, 2004, 2008, 2010). Possibly the most significant and far-reaching of these has been the publication of the seminal *Report of the National Advisory Committee on Palliative Care* (DOH&C, 2001) which made several recommendations regarding the development of specialist palliative care services based upon the principles of equity, accessibility, and the adoption of a coherent and comprehensive national policy framework. The National Advisory Committee on Palliative Care [NACPC] differentiate three distinct levels of palliative care (DOH&C, 2001:32), and proposed that palliative care services should be structured to accommodate these levels of ascending specialisation [Table 3]:

Table 3 – Levels of Palliative Care

Level 1	Palliative Approach	Involves engagement in the principles of palliative care, where required, by all health professionals
Level 2	General Palliative Care	Viewed as the intermediate level of expertise, with engagement in palliative care being part of the health professional’s caring role but not defining it.
Level 3	Specialist Palliative Care	Practice involves palliative care as its core activity and is directed towards caring for patients with complex and demanding palliative care needs.

The NACPC makes a clear distinction between “specialist” and “generalist” palliative care, with the former referring to the palliative care philosophy or approach to care rather than to the specialist care delivered by a particular service or place of delivery. This distinction is upheld and supported by the palliative care programme working group of the Health Services Executive [HSE] and the Irish Association for Palliative Care [IAPC] who define generalist palliative care providers as all those services who have a primary “first-contact” relationship with the person with life-limiting illness and palliative care needs, including staff of residential services (HSE & IAPC, 2012 p4). Palliative care is concerned with the suffering, dignity, holistic care needs and quality-of-life of individuals with life-limiting illness; it is also concerned with the care and support of their families and friends (WHO, 2004a). The idea that a general palliative care approach is a vital and integral part of all clinical practice, whatever the illness or its stage, applicable to all individuals and families facing life-threatening or life-limiting illness, in all care settings, has been widely endorsed both nationally and internationally (WHO, 2002; 2004a; 2004b; Council of Europe, 2003; DOH, 2001; 2005; 2010; HSE & IAPC, 2012). Both the National Council on Ageing and Older People [NCAOP] and the Irish Hospice Foundation [IHF] advocate that the philosophy and principles of palliative care should be evident in all facilities for older people (IHF & NCAOP, 2008).

End-of-Life Care

Despite calls for extending palliative care provision the concept of palliative care is not necessarily well understood and its timing, particularly in the context of the uncertain trajectory associated with many chronic or progressive life-limiting illnesses, remains problematic (Murray *et al*, 2005; Fitzsimons *et al*, 2007; Sampson *et al*, 2011). Prognostication is poor and imprecise for most conditions, leaving patients and caregivers struggling to cope with illness for years, often with different trajectories of functional decline and escalating levels of need (Mularski *et al*, 2007). There is also conceptual confusion between palliative care and end-of-life care with the terms frequently used interchangeably. Clark and Seymour (1999) suggest that distinctions between palliative care and end-of-life care are becoming increasingly blurred as palliative care expands through all facets of medicine and diversifies into different settings and populations.

However, like palliative care, defining end-of-life care also is subject to operational and temporal challenges. Despite the increasing use of the term there is no agreed and unambiguous definition of “end-of-life” since, to date, there is no distinct and precise clinical indicator to

predict time of death (Christakis, 1999; Seymour *et al*, 2005; Fitzsimons *et al*, 2007; Sampson *et al*, 2011). The lack of medical and scientific evidence to support the clinical indications characterising a specific time-frame as “end-of-life” makes it impossible, and perhaps even unreasonable, to mark a date as the beginning of an end-of-life period.

It is therefore unsurprising to find divisions about when end-of-life care begins in policy documents since the term has been interpreted in both broad and narrow conceptualisations (Ross *et al*, 2000; WHO, 2002; National Institute for Clinical Excellence, 2004; Lorenz *et al*, 2005; General Medical Council, 2010; HSE & IAPC, 2012; Izumi *et al*, 2012). In the United Kingdom the General Medical Council considered that people “are approaching the end-of-life when it is thought that they will die within the next 12 months, and includes those who may die in a few days or hours” (General Medical Council, 2010, p.86). However within an Irish context The Palliative Care Programme Working Group propose that end-of-life care should be defined in a much shorter temporally-bounded way in order to differentiate it from the concept of palliative care. They define end-of-life-care as a “continuum of palliative care and usually used to describe the care that is offered when death is imminent, and when life expectancy is limited to a short number of days, hours or less” (HSE & IAPC, 2012, p.3). In support of the WHO position (2002) they propose that the term “end-of-life care” is a quantitative rather than qualitative descriptor that excludes the purpose of care. Steinhouser *et al* (2000) however hold a contrary position and recommend a broader conceptualisation of the life to death trajectory suggesting that relaxing the time period that constitutes dying would facilitate a more thorough evaluation of patient’s and families’ perceptions of the dying experience. Similarly, in the context of nursing homes, Johnson (2005) asserts that if clinicians try to identify an exact time at which a resident is dying then the opportunity for palliation is often missed and residents and their families are not receiving optimal palliative care.

While there may be no agreed definition of “end-of- life”, the Irish Hospice Foundation (IHF, 2008, p. xiii) propose criteria which evidence the need for “end-of-life care”. These include the existence of a chronic disease, or symptoms, or functional impairments, that persist but may also fluctuate; or the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional), or informal (unpaid), care and can lead to death. The most recent reference to end-of-life care in official government policy documents is its inclusion as an explicit standard in the *National Quality Standards for Residential Care*

Settings for Older People in Ireland (HIQA, 2008). By law, all public, private and voluntary long-stay facilities are required to be registered with HIQA and compliant with its standards (Gov of Ireland, Health Act, 2007). The standard on end-life care states that each resident should ‘continue to receive care at the end of his/her life which meets his/her physical, emotional, social and spiritual needs and respects his/her dignity and autonomy’ (p.23) thus linking end-of-life care to palliative care services where appropriate but without reference to a defined timescale.

Achieving a Good Death

End-of-life care is a core component of palliative care and is central to the provision of good general care, yet it is not a singular entity with a universal experience and well agreed upon course. Every person’s end-of-life trajectory is unique and needs fluctuate in intensity and quality over time (Hasson *et al*, 2002). The quality of care provided at the end-of-life care has become an important issue for health care professionals, researchers and policy makers.

Writing in the first century AD the Stoic philosopher Seneca 70 states, ‘A prolonged life is not necessarily a better one, but a prolonged death is necessarily worse’ (cited in Campbell, 1969) and a significant element of modern palliative and end-of-life care is assisting individuals to die well. The debate about dying well pivots on definitions of a “good death”, a concept which has changed significantly over time as the contexts and causes of death have altered (Walters, 2003) and for which many surrogate terms have been used (Granda –Cameron & Houldin, 2012). Several researchers have explored the concept of a “good death” and the notion of ‘dying well’ in a wide variety of clinical settings (Steinhauser *et al* 2000; Neuberger, 2004; Faber *et al* 2004; Paddy, 2011; Allen & Watts, 2012; Lawton *et al*, 2013). Notwithstanding philosophical arguments centred on whether the very concept of a good death is an oxymoron since all deaths involve the loss of something valuable and irreplaceable (Walters, 2004; Woods, 2007; Scarre, 2012) it is generally accepted that some deaths are worse than others.

In medical and nursing literature a good death has essentially been defined by its attributes. While there is evidence that social and professional roles substantially shaping the views of what constitutes a good death (Steinhauser *et al* 2000) there is also evidence to support considerable shared common ground amongst patients, health professionals and families. These common components include pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person (Holloway, 2007).

It is essential to remember however that the concept of a good death is both individual and fluid (Allen & Watts, 2012; Hayes *et al*, 2014). Because what is significant and important to one person may be trivial or inconsequential to another healthcare professional play a crucial role in determining what a good death means to the individual (Sherwen, 2014). Sandman (2005) suggests that given the complexity and heterogeneity of the world there is not, and possibly never can be, a singularly adequate account of the good death. Similarly Redding (2003) cautions us to remember that, as we struggle as a society to find a better way to provide care at the end-of-life, it is imperative to remember that death belongs to the dying who are ultimately the only people who can tell us what is needed.

Death and Dying in Nursing Homes

Much of the research on end-of-life care in nursing homes focuses on the experiences of people with dementia and their families. This is significant since, although there have been no comprehensive prevalence studies on dementia carried out in Ireland, Cahill *et al* (2012) estimate that 63% of all residents in long-stay facilities in Ireland have dementia. While there is little Irish research focusing specifically on end-of-life care in nursing homes the available evidence from international studies suggests that people with dementia receive poor quality care and suboptimal palliation at the end of their lives. Sampson *et al* (2011) suggest that people in the advanced stages of dementia may experience poor end-of-life care because they are often not perceived to have a terminal illness. Prognosis is frequently overestimated (Mitchell, Kiely and Hamill, 2004) making the timing of palliative care difficult. While Sloane *et al* (2008) noted no difference between individuals with dementia and those without dementia in terms of pain, psychosocial status, family involvement in care, advance care planning, use of most life-prolonging interventions, and hospice use in a residential care setting, in a comprehensive analysis of the current research evidence van der Steen (2010) concludes that, relative to people with other terminal illnesses, people with dementia are at risk of under-treatment of physical symptoms and overtreatment with burdensome and possibly non-beneficial interventions. It is possible that while there is little difference between groups in residential settings, there is a considerable difference between residential settings and other populations.

Data indicate that residents dying with dementia in long-term care facilities commonly experience a wide variety of physical problems and inadequate symptom control at the end-of-life. In a cross-sectional study of 198 deceased residents with dementia in 69 nursing homes

Vandervoot *et al* (2014) identified that, regardless of the dementia stage, many residents developed serious clinical complications and symptoms in the last phase of life, posing major challenges to the provision of optimum end-of-life care. Difficulty swallowing and pain were reported most frequently in the last week of life. Physical restraints were used in 21.4% of cases. Vandervoot *et als* findings (2014) support previous which reported that long-term care residents dying with dementia commonly experience inadequate pain control, develop pressure ulcers, are treated with feeding tubes and other potentially inappropriate treatments, and are underrepresented in the palliative care population (Kayser-Jones *et al*, 2003; Mitchel *et al*, 2004; Volicer, 2005; Sloane *et al*, 2008; van der Steen 2010).

Findings from Irish studies appear to show mixed results. In a comprehensive mixed methods study using both a survey of 675 acute and long-stay facilities and interviews with 35 direct care staff and 30 patients O'Shea *et al* (2008) report that there were both positive and negative aspects to best practice in symptom management with evident gaps in knowledge around pain management. Conversely in a small scale qualitative study of 16 elderly caregivers whose spouse had died from dementia in a long-stay facility Cahill *et al* (2010) reported high levels of satisfaction amongst carers in respect of the end-of-life care their spouse received. None of those interviewed in this study reported that their spouse had been undertreated and only one respondent reported that the deceased had been overtreated. The difference in the sample, both in size and composition, may account for the apparent disparity in the findings of these studies, in addition the inclusion of acute care facilities in O'Shea *et als* study may have influence the findings. In a later exploration of death in acute hospital wards in Irish hospitals Buhagiar *et al* (2010) conclude that people with dementia and their families are seldom included in end-of-life discussions leading to poorer symptom management.

Factors Influencing End-of-life Care in Nursing Homes

According to Frogatt and Payne (2006) the characteristics of end-of-life care in care homes for older people can be considered in four domains: the managers' understanding of end-of-life care; the presence of dying and death in this setting; the attributes of the resident population living in these care homes; and the availability of resources to support the provision of end-of-life care in this setting. Quality end-of-life care therefore is at least partially dependent on the culture and philosophy of the organisation. Several studies suggest that suggest that the organisational routine of a long-term setting can make it difficult for staff to find the time to

spend with dying patients (Costello, 2001; Katz, 2005; Casey *et al*, 2011). In addition direct care staff in a study by Hill *et al* (2005) cited additional organisational challenges to providing quality end-of-life care in nursing homes, namely inadequate staffing and high staff turnover which impacted continuity of care.

The need for palliative care education and training for staff has long been recognised as essential to the provision of end-of-life care (Frogatt, 2002; Higgson, 2005; Larkin, 2005, Livingstone *et al*, 2012). Greater nursing home palliative care knowledge appears important both in terms of overall symptom management O'Shea *et al* (2008), and in terms of reducing terminal hospital and emergency department admission. In an analysis of 4149 nursing homes in the US, collecting data using the validated Nursing Homes Palliative Care Survey, Millar (2014) reported that for each 1-point increase in nursing home staff knowledge score residents had a 10% lower likelihood of a hospital admission at the end-of-life and a 6% lower likelihood of an accident and Emergency department visit. Inadequate knowledge and skill levels are frequently cited as an impediment to achieving quality end-of-life care for residents in long term facilities by the staff themselves (Hill *et al*, 2005).

The general attitudes of staff to death and dying can also be influential in the care residents receive at the end-of-life with international studies on the death of elderly nursing home residents demonstrating the complexity in the understanding of the professionals who care for the dying (Nielsen and Glasdam, 2013). Leclerc (2014) found significant differences between upper-level professionals and managers (registered nurses, physicians, and clinical managers) vs the hands-on caregivers (nursing assistants) with regard to attitudes related to some aspects of the care of the dying concluding that the attitudes of all staff need to be considered in long term care facilities, and that hands on staff seem most likely to benefit from training and support programs.

Quality end-of-life care cannot be achieved by technical intervention alone, in addition to knowledge and skills achieving this goal requires cooperation, communication and good coordination by and between health and social care professionals. Teamwork is an essential principle of palliative care (WHO, 2000) and collaboration in the assessment and delivery of end-of-life care to nursing homes residents is important for achieving quality outcomes for the resident and the family (Rurup *et al*, 2006). Within this context nurses frequently play key roles in facilitating collaborative decision making, drawing together resident, family, and practitioner

perspectives as they strive to create a plan of care acceptable to family members and doctors, and most comfortable for residents (Lopez, 2009). Because the trajectory of death is often difficult to ascertain, effective on-going communication between providers and between providers and families is vital (Morrison, 2009) yet studies report communication difficulties within the nursing home setting as a barrier to the delivery of quality end-of-life care from both the perspective of staff (Livingstone *et al*, 2012) and from the perspective of families (Cohen *et al*, 2012).

In a qualitative study of 58 staff Livingstone *et al* (2012) reported that care staff, nurses and doctors did not see themselves as a team and communicated poorly with relatives about approaching death. The staff used opaque euphemisms and worried about being blamed. The staff also found talking with relatives about dying uncomfortable. When asked directly by relatives, they avoided words such as ‘death’ and commented on appetite and mood instead. They also worried about the accuracy of what they told relatives, it not being appropriate for carers or nurses to give information and of saying too much or too little then being held to account. It is unsurprising then that family members of long-term care residents report dissatisfaction with communication at the end-of-life (Cohen *et al*, 2012), and feel that they are not sufficiently informed or prepared for the dying process (Caplan *et al*, 2006).

Families and Nursing Home Care

There is a volume of research exploring the nature of the relationship between staff and family caregivers of residents in nursing homes. Research related to the experiences of carers at the end-of-life however is limited.

Research reports that family members continue their involvement and sense of responsibility for care for their loved when they are transferred to a nursing home (Lopez, 2009; Habjanič & Pajnkihar, 2013). This involvement takes a multitude of forms from providing hands-on care to planning, decision making, and the monitoring of quality of care (Isoal *et al*, 2003; Logue, 2003; Bern-Klug & Forbes-Thompson, 2008). In addition to providing care families may be called upon to make decisions or advocate on their relatives behalf (Lloyd-Williams, Morton & Peters, 2009). However Bauer (2006) suggests that family carers occupy an ambiguous position within nursing homes where, although inclusive models are acknowledged, families continue to be perceived as ancillary to care and attitudes which depict family roles as adversarial are still evident. Families usually want to be involved in their relatives’ care (Bauer

and Nay 2011), but such involvement is not always supported by staff (Davies and Nolan 2006; Bauer 2006, 2007).

Being a close relative or next of kin of someone in the final phase of life is often complicated. Small exploratory and descriptive studies predominate the published literature. From the available evidence, it appears that family carers find themselves in an unfamiliar situation lacking adequate communication (Kaarbø, 2010), and about which they lack knowledge and experience (Hennings, Froggatt & Keady, 2010).

Because the trajectory of death is often difficult to ascertain, effective on-going communication between providers and family members is vital (Morrison, 2009). Information sharing and communication with families is essential for quality care at the end of life, yet several studies express concern about the quality of communication with family carers at this time. In interviews with 461 bereaved family members Hason et al (1997) report that nursing homes received the smallest proportion of positive comments on terminal care relative to all other sites with families emphasising the need for greater communication with and access to the physician. Almost 2 decades later Hasson *et al* (2002) also report communication challenges experienced by families in nursing homes in relation to comprehensive advance care planning that addresses prognosis, emotional preparation, and appropriate use of medical treatments. Similar findings in relation to initiating discussions around end-of-life care were reported by Cartwright (2002) who reports that families expected staff to raise the issue but they failed to do so. Similar findings are reported in other studies which highlighted a perceived lack of support for relatives when their loved one's death was imminent, lack of informational and emotional support and a general lack of communication which increased conflict between staff and family members (Teno *et al* 2004; Caplan *et al*. 2006; Gjerberg *et al* 2011).

Supporting Families

The quality of life of the person confronting the end stages of life may be severely compromised without the support of family caregivers, indeed Hudson and Payne (2011) suggest that people requiring palliative care would not be able to fulfil their preferences without significant family input and consequently health services are mandated to support the family alongside the individual. Research into end-of-life and dying in nursing homes from the family carer's perspective is limited, however from the available evidence it appears that family carers find themselves in an unfamiliar situation about which they lack knowledge and experience

(Hennings, Froggatt & Keady, 2010), and are often uninformed about what to expect in the dying process (Sheild *et al*, 2010).

While the “right way” of supporting caregivers is still to be established, Simonič *et al* (2012) suggest that consideration of caregivers' roles as co-providers and co-recipients of care offers a promising model for clinical practice. It is also proposed that many of the needs of such families could be addressed through improved application of the principles of advance care planning (Gessert *et al*, 2001; Andershed *et al*, 2006; McConville, 2011). Advance care planning (ACP) is a process of discussion that usually takes place in anticipation of a future deterioration of a person’s condition (Henry & Seymore, 2007). It is proposed that it can the frustration and pain felt by families at the end-of-life caused by insufficient discussion of goals of care, including end-of-life care, in nursing homes (Gillick, 2004; Furman *et al*, 2007). Although its legal status has been unclear the analytical evidence suggests that ACP discussions can reduce the need to consult out of hours medical support, reducing the need to transfer to acute services with non-emergency events, and provide greater satisfaction for patient’s/ families at end-of-life (Gessert *et al*, 2000/2001, Andershed *et al*, 2006). It is perceived positively by both staff and families (Goodard, Schiff & Hall, 2010). Advanced care planning is considered a central component of good quality palliative care and especially relevant where individuals lose capacity to make their own decisions at the end-of-life (Detering *et al*, 2010; Meussen *et al*, 2011; McConville, 2011; Vandervoort *et al*, 2013) where it can improve the quality of dying. Vandervoort *et al* (2014) report that where residents wishes are written down relatives report lower levels of emotional distress at the end-of-life¹.

However advance care planning for those with advanced dementia is difficult, as relatives feel that they lack adequate information and emotional support in making medical decisions on

¹ Currently advanced care planning is a common feature of nursing home end-of-life care. However advanced directives have no legal standing in Ireland. However following a national public consultation which concluded on March 07th the DoH&C published a draft general scheme for Advance Healthcare Directives (DoH, 2014b) which will be one provision to be included in the Assisted Decision-Making (Capacity) Bill 2013. This Bill changes the existing law on capacity, shifting from the current binary approach to a flexible functional one, whereby capacity is assessed on a context-specific and time-specific basis (Department of Justice and Equality, 2013). The DoH defines an advanced care directive as “a statement made by a person with capacity setting out his / her will and preferences regarding treatment decisions that may arise in the future in the event that he or she lacks the capacity to provide consent to or refuse those treatments” (2014, p.1) and proposes to introduce legislation to enable an adult with capacity to make a legally binding Advance Healthcare Directive and refuse any form of treatment up to and including life-sustaining treatment.

someone else's behalf (Livingston *et al*, 2010), or felt that staff did not talk to them about death in advance and did not explain directly when it was imminent (Caplan *et al*, 2006).

Conclusion

There have been extensive and increasing calls to extend the principles of palliative care to all individuals with life-limiting illnesses regardless of their diagnosis and quality standards for end-of-life care for people in nursing homes and long-stay facilities are now part of official policy documents. The appropriate timing of palliative care continues to pose a challenge in the context of chronic and life-limiting illness however, as many illness trajectories are difficult to predict with any degree of accuracy.

Advanced dementia is not perceived as a terminal illness and prognosis is frequently overestimated (Mitchell, Kiely & Hamill, 2004). As a result many individuals receive poor quality care and suboptimal palliation at the end of their lives. Downes *et al* (2006) propose that too much or too little is often provided in environments which hinder rather than support optimal care. Large scale cross-sectional and cohort studies suggest the people with dementia experience considerable morbidity at the end of their lives with unresolved symptoms and unnecessary futile interventions, yet small scale studies of carers present a different picture.

Although various elements of palliative care in nursing homes has been increasingly researched and reported assessing the quality of end-of-life care in long term facilities is complex. Opinions of staff and family are frequently used as a proxy indicator of the care received, however Caprio *et als* (2008) comparison of staff and relatives perception of symptom control suggest that assessment between staff and family members does not correlate well at the end-of-life. While there is emerging evidence that the use of standardised assessment tools can enhance the quality of palliative care in dementia (Volicer, Hurley & Blasi, 2001; Thompson *et al*, Munn *et al*, 2007; 2011; van Soest-Poortvliet *et al*, 2011; Krumm *et al*, 2014) these have yet to be systematically described or compared in a large scale.

In an exploratory study of bereaved relatives of people with dementia and healthcare providers in the U.K. Lawrence *et al* (2011) propose that a good death for someone with dementia in residential care is one that is physically comfortable and where the individual is surrounded by those who are close to the person with dementia. They conclude that in order to achieve this health professionals need to move beyond basic physical care tasks and prioritise planning and communication with families. These are not necessarily highly complex goals,

however, in an ethnographic study of dying in care homes Komaromy (2009) suggests that the rhetoric of a good death is not always the reality as the main focus of care continues to be physical to the detriment of holistic approach that is the signature of the palliative approach to care.

Chapter 4: Transition: The Movement from Home or Hospital to the Nursing Home

Introduction

Barrett *et al* (2011 p.2) point out that in Ireland at present ‘there is little evidence on what families provide to older adults’. Chapters 4 - 6 discusses the findings from participants’ interviews and reveals one reality of “what families provide for older adults” from an end-of-life care perspective. The findings are presented in the chronological sequence in which participants told their personal stories. This followed a linear model for although the focus of the opening question was on nursing home care at the end-of- life all participants began their narrative with the decision to admit their relative to the nursing home. This demonstrates the significance of this event in the care trajectory as a marker for the beginning of end- of- life care for many families.

The living reality of families providing care for older adults has been called the ‘sandwich generation’. This is the generation who epitomise the intergenerational caring relationship as they are in the 50+ age bracket and are caring both for children under 18 and for parents over 70 (Kamiya & Timonen, 2011). This has led to the development of new patterns of family reciprocity (Chambers, 2012). This study suggests that these patterns include giving substantially of the self in terms of time, energy and in some cases financial assistance to both sets of dependents in their lives. It also necessitates making decisions regarding the well-being of both generations.

In the case of the older generation these decisions can relate to complex issues around capacity, capabilities and the level of assistance that the older person requires. It can also involve recognising when the care giver can no longer provide this care. Participants’ stories illustrate that being part of the ‘sandwich generation’ places enormous strain upon individuals, and when it comes to making care choices families make choices in accordance to their own abilities.

Prior to the illness that was ultimately to lead to their admission to residential care all individuals in this study had achieved what Layte, Sexton and Savva (2013) describe as successful ageing with a good quality of life. For carers making the decision to admit a relative to a nursing home was a difficult and often painful one and was made only after all possible strategies to maintain their loved one in their own home had failed. Eventually a time arrived

when families realized they could no longer provide the type of care their loved ones required and they needed to begin the search for care facilities that they could live with as well as their loved one.

Coming to Terms with the Limitations of the Self

The overarching theme that will be explored in this chapter is ‘coming to terms with the limitations of the self’. This describes how carers and families eventually come to the realisation that there are limitations to the kind of care they can provide for their loved one. All of the participants in this study provided care on different levels for loved ones. This included physical and emotional care, as well as making decisions about their needs when the older person could no longer do so for themselves. Relatives described a process of growing awareness that their loved one was changing as the taken-for-granted aspects of everyday life were becoming increasingly difficult for their relative. As these needs intensified relatives were prompted to go outside their realm of knowing into the unfamiliar and often complex arena of health and social care to seek assistance to facilitate the care of their loved ones.

Participants described the sense of loss associated with the new role they found themselves in as care providers for their relative. It required a new way of “being” with their loved ones, and undertaking actions that are not normally associated with being a relative such as intimate care. Their sense of self was continually challenged as they attempted to adjust to the changing nature of the relationship with their relative. Heidegger (1962) suggests that human beings are always entangled in the everyday world of experience and the participants in this study existed within the world of their ill relative and not outside of it. The ‘world’ for Heidegger:

Is the interconnected context of involvements that give meaning to everything on encounters within one’s individual world (Johnson, 2000 p.137).
Sartre’s (1969) develops this further suggesting in the world of our experience we are always becoming and never complete, thus the self is continuously being transformed by the others in our life:

He needs the other, not only to live and make the species live, but also to assert himself, to get recognition, as a child by his parents or the artist by his public, and to enter collaboration (Dufrenne, 1965 p.55)

From a Sartrean point of view the participants can only become aware of their self in collaborating with others in this case both their ill relatives and the health care providers.

Elements of coming to terms with the limitations of the self-include: ‘struggling to stay afloat: bringing help into the home’; ‘surrendering to the inevitable: making the decision to use a nursing home’; ‘being put at ease’ and understanding the ‘difference between hospital care and nursing home care’.

Struggling to Stay Afloat: Bringing Help into the Home

One of the significant points along the journey of coming to terms with the limitation of the self is the decision to bring outside help into the home, whether that was the home of the relative, or the home of the carer (when the relative was resident). Participants were motivated to make this decision on the basis that it would maintain their loved one in the home environment, however making provision for outside help acknowledged that there were limitations on their abilities to facilitate the care needs of their relative.

Many participants talked about noticing the changes in their relative that prompted the decision to seek additional help and support and how they dealt with these changes. Dylan’s mother moved in with him three years after his father died and lived with him for a further fourteen years. He tells the story of sharing his life with his mother:

For the most part she was a very independent woman. She was a very thoughtful woman...up to her mid-80’s she was quite competent at doing the housework and so on. We had a lady who came in twice a week who came in to do the heavier work. I can’t remember quite when but I suppose about 7 or 8 years ago we began getting some help. A lady to come in and make the dinner and we noticed at some stage that my mother was beginning to show some sign of dementia. In the summer of 2006 they advised that we get in a residential help and we got a carer in here, she lived in Monday to Friday and we had other people then covering the weekends... lady was here for about 18 months [Dylan].

Dylan’s story illustrates the trajectory of life for his mother, how she moved from being an independent woman to being totally dependent on others. Dylan witnessed his mother’s life develop and how growing older necessitated the need for assistance initially in the form of obtaining help for light house work to eventually requiring full-time residential help in the home. Dylan’s story, like those of many participants, demonstrates a family’s willingness to provide care for their close relative at home and the extraordinary lengths families will go to in order to maintain their relative at home (Biegel *et al*, 1991).

Silvia had a similar experience with her mother, however the difference between Silvia's story and Dylan's is that Silvia's mother lived alone in the house she had inhabited since she was 30

She had lived alone, she was there (in nursing home) for about 2 and a half years. So she had lived alone till just before her 95th birthday, in the house on her own. She was in that house since she was in her 30's but we had a lot of support. I used to be a social worker in my former life so I had been able to get a lot of support for her. I had somebody calling 3 times a day and then I had somebody else staying at night for almost the last 3 years before she moved into a nursing home [*Silvia*].

Silvia's mother was an independent woman who had the capacity to care for her own needs. When the time came to provide support Silvia used her knowledge as a former social worker to put in place the support system that her mother required. The process mirrored Dylan's experience: beginning with the provision of daily in-home support to eventually providing full-time twenty four hour care. This escalating trajectory of care requirements was reported all participants in the study.

Similar to the stories above Loran experienced her father as an active, socially adaptable man. He had cared for his wife during her illness and as a widower enjoyed life. Loran identifies a hip replacement as the start of the decline in her father. She states:

He got his hip replaced and from then we noticed his behaviour starting to deteriorate. Kind of a nervous sort of behaviour. Not as confident as he normally would be. And we were putting this down to age. He rang me that Saturday morning and he was very upset. Possibly depressed which I didn't connect it with depression at the time but thinking back I put it down to that now. And he said don't put me into a home please don't put me into a home and I could not understand where this was coming from. But dad I won't put you into a home. When it comes to that time you need help you come and live with me. [*Loran*]

Loran's narrative illustrates the fear that some older people have in relation to nursing homes it also provides an insight into some older people's awareness of their declining health. Iris and Lily (mother and daughter) describe the following poignant exchanged when their loved one tried to explain his increasing forgetfulness to his wife:

and after six months of him getting it really badly he said to me "sit down there I want to tell you something", and this is the way he always went on like "sit down there" if it was really important you know. I said "right". He said "I can't remember things", and I said "I know that". He said "I want to tell you what it's like", he said "that wall is full of my

memories like on a blackboard and someone came along with a duster and he wiped it all off...and now I can't remember". It was absolutely terrible, and that was his summing up of it. [*Iris*]

Where this awareness exists it may lead some older people to try to negotiate their future care needs and extract a promise, whether realistic or not, that they the relative will not place them in a nursing home. Loran found herself in this situation and she made the promise suggesting that it was made as she was:

... trying to kind of take the worry out of his head. But really that made me think a lot after that. [*Loran*]

While Loran reassured her father that he would not be 'put in a home' she did so to alleviate his worries but it also caused her to stop and think about what he was asking of her. Unlike Silvia, who could trade on her insider knowledge of health and social care services, Loran did not obtain support she required. As a result the family of six siblings set up a rota which required all members to give the self to their father in terms of time and energy beyond the normal interaction that they would have had:

So then we tried to get support for him through the health system that wasn't great. So we had a rota system whereby each of us went to my dad every day with the added facility of external private help. We did this for 6 months and we realised we can't continue [*Loran*].

However, Loran's fathers declining health created increasing demands on her family, and after six months of intensive care they began to question the sustainability of the arrangement eventually realising that they could not continue and the promise that was made had to be broken.

Many participants reported negotiating complex family care-rotas in an effort to meet the care requirements of their loved one. Similar to Loran, Jessica and her six siblings cared for their mother at home after her diagnoses of Alzheimer's disease:

There are seven of us in the family, five brothers and one sister and my mum had Alzheimer's and we had looked after her at home a couple of years after she was diagnosed. Between the seven of us staying at night and looking after home helps and that. [*Jessica*]

Jessica's story illustrates what O'Connor (1998 p.89) proposes is the family as "an important symbol of identity, unity and security. However, even within large families there is a need to find

outside support to facilitate the keeping of an elderly parent at home. There is always a stage when the family can no longer provide the care that is required or that situations present that cannot be accommodated. Jessica explains:

And it just got to the stage where we couldn't look after her. The seven of us work and she needed full-time, full-time care. And I think the final the straw that broke the camel's back was there was always a gap kind of maybe between 5 and 6 o'clock where she would be on her own and then we got up one evening and I kind of sat in the car and it was January and I said "oh Jesus what is going, what am I going to face into here you know". She was crying and she said "I can't stay here anymore" she said. "It's too lonely and I have to go home". So at that stage she didn't know where home was. [*Jessica*]

Jessica came to the painful realisation that she and her family could not continue with the intensive family support system they had set up. Her story echoes those of many participants and illustrates the demand that is made on families when they provide informal care (Broback *et al*, 2003) resulting in little time for the self as they work, provide for a family, and try to maintain personal relationships evidencing what families provide to older members (Barrett *et al*, 2011).

All of the stories above are set in the context of siblings caring for parents. They demonstrate the importance of family and infrastructural supports in the context of maintaining older people in their own homes. The situation may be different for individuals who do not have a child, spouse, or capable family member to provide the kind of support necessary to maintain them at home. Cian's story illustrates this point. His sister was in her late 50's when she began to need care:

She wasn't married. A very independent woman all her life never had to answer to anybody. If she wanted to go somewhere she went. She didn't have to ask for anybody's permission. Our parents were deceased but when she came down with a debilitating illness ... It meant she lost her faculties over time. She had been diagnosed and it came to a head when she fell in work, broke a small bone in her back. Ended up in the XX hospital for 3 months and they knew that getting her home was going to be a difficulty because at that point she had sort of crossed the point with everybody that she wasn't going to be able to cope with the illness as well [*Cian*].

Cian's sister was a single, working, independent woman; she was also the main carer for a brother who lived with a mental illness and with whom she resided. When she became ill it was impossible to facilitate her being cared for at home as she lacked two essential resources: carers and appropriate housing.

She lived with a brother but he was a schizophrenic so he was barely able to look after himself. My sister looked after him but it meant when she was ready to be released from hospital he wasn't going to be able to look after her. So because she had no children and no family and nobody else in the house that could really look after a small 2 up 2 down she would have had to put a bed downstairs which would have taken up the front room she was effectively left with no option and ended up in a nursing home. [*Cian*]

Ungerson (1987) proposes that informal care rests upon the twin edifices of 'labour' and 'love' - it is both work and the expression of a relationship. Sinding (2003) suggests that when considered in terms of labour, distinctions between "caring" and the usual tending within social networks are difficult to draw, however Twig and Atkin (1984 p.8) propose that informal care can best be understood as involving supportive tasks that go "beyond the normal reciprocities" between adults. The core feature that underlines all caregiving, according to Twigg and Atkin (1994), is the sense of being responsible for the cared-for person. These narratives illustrate how far families are willing to go.

Surrendering to the Inevitable: Making the Decision to Use a Nursing Home

In a meta-ethnographic study exploring families' experiences of admitting a relative to a nursing home Graneheim *et al* (2014) concluded that the process of relinquishing care is similar to a crisis process: beginning with a turning point, followed by a coping phase and finally the outcome of the process. Dellasega and Mastrain (1995) suggest that the decision to admit a loved one to a nursing home is a long and agonizing one for families, similarly Rodgers (1997) suggests that placing a family member in a nursing home is one of the hardest decisions that many adults face and the findings of this study would suggest that little has changed in the past two decades. All participants described the extraordinary lengths they went to in an attempt maintain their loved one at home and to ameliorate the challenges they encountered in the face of declining self-care abilities. Even though they knew they could not manage it still did not make it easy to place a loved one in a nursing home. Similar to Loran's family, Holly illustrates how her family made every effort to continue homecare for her mother:

And my mother was living at home and which was just up the road from me and we were trying as much to keep her at home. But she had multi, she had diabetes and she had dementia and she had heart problems and all the rest. And it was becoming more and more difficult besides the fact that we had more and more nurses and care workers whatever [*Holly*].

Despite consistent and sustained efforts eventually the level of personal commitment required could be sustained no longer, or relative's care needs became so overwhelming, that admission to a nursing home was the only realistic option for the continued care of their loved one. For most families making this decision was not an easy task. This was particularly evident where the participant has been asked by their loved one not to do so. Susan's mother had been transferred to a nursing home from an acute care facility; tearfully she described the following exchange:

she said to me "I looked after you so much, please don't leave me here and I will never, ever, ever forget that [*Susan*]

Similarly Dylan and Callaum had promised their father on his death bed that they would take care of their mother:

We had been under orders from the boss before he left to look after her you see [*Callaum*]

A promise that was made to their father prior to his death was becoming increasingly difficult to keep. This can become problematic when the reality of the situation presents itself and caring for their mother at home becomes almost impossible. This is similar to Loran's story above who also promised her father not to admit him to a nursing home. Unlike Callaum and Dylan, Loran's promise derived from a decision to remove any worry and angst from her father but like Callaum and Dylan the reality of the promise was unsustainable.

So while the decision to admit a loved one to a nursing home was never made lightly, and in some cases it was complicated by participants feeling they had failed to live up to commitments and promises made, it was made in the realisation that their loved one's care demands now exceed the family's capabilities and that there was simply no other option available to the family:

She was in the hospital ... and wanted to go back home but we just knew it wasn't possible. She had lived on her own actually up to that but things were getting very complicated with her. You know what I mean she was in her 90's [*Abbie*]

We knew we could not manage. He was very sick and we knew we could not manage [*Brady family*]

For many participants, and despite their best efforts, this was associated with feelings of tremendous guilt and of somehow having failed-

I always felt he thought I let him down. Which maybe he did but then we'd always talk about things before we did them and we didn't talk about this [*Iris*]

The family's acknowledgment that they can no longer maintain the level of care required begins the process of finding a nursing home. This also points to the authenticity of their humanity as Heidegger suggests (1962 p.68)

As modes of Being, *authenticity* and *inauthenticity* are both grounded in the fact that any Dasein² whatsoever is characterized by mineness (emphasis in the original)

By 'mindness' Heidegger means 'I am' or 'you are', it is mine or yours, it belongs to me or you and therefore it cannot be given to me or you. From this we could suggest that family members can only give themselves their authentic self, by choosing their own possibility, by saying 'I am a carer who can no longer provide that care'. No other person can do this for them in a Heideggerian sense and so each family had to come to terms with their own limitations.

Where to From Here? Choosing a Home and Its Aftermath

The participants who took part in this study had different stories to tell about the journey to the nursing home. In nine families their relative was admitted to the nursing home from an acute care facility, while the remaining 13 families admitted their relative directly from home. Choosing a nursing home was a significant challenge, although easier for those who had previous experience to draw on. There was consensus that the following factors were critical: the location, an open access visiting policy, a good reputation and the attitudes of the staff. Families felt significantly reassured where staff were friendly and welcoming as this was interpreted as an indication of the type and quality of care their loved one would receive if resident in there. When families were satisfied that these elements were in place they began to consider the "fit" between the environment and their loved one. In order to achieve this many families visited several nursing homes before making a decision about where to place their loved one: for example Loran explains that her father had always been an "outside person" and they picked their nursing home because it "was out in the countryside" they wanted a nursing home where he could have the:

freedom to walk and not feel he's locked on a floor and he feels that he can get out.
[*Loran*]

² Dasein is Heidegger's term which refers to the human being in the world.

Susan described her mother as “very social all her life, always singing, always dancing”, her mother’s nursing home was chosen on the basis that it provided such activities even though her mother could no longer join in. Ultimately, when it appeared that all things were equal, the final decision was based largely on an intuitive feeling about the nursing home itself. Thus the final decision was both rational and intuitive. Families reported that in the end “you just know”. Austin exemplifies this when looking for a nursing home for his father. After visiting several nursing homes with what he described as “a mental checklist” he comments:

it wasn’t just about the nurses and the attendees and the doctors, it was a total, you know. You know when you walk in – is it more nursing than it is home – and then that ethos runs across everything it does. But in X it’s like we have a house, we’ve got old people in it, we look after the old people [*Austin*]

Alternatively Dylan, a primary carer, was not involved in the process of choosing a nursing home for his sister. This decision was made by two other siblings suggesting that Dylan found it difficult to participate in the process:

So Callaun and my brother visited a number of homes and they came to the conclusion that G was probably the most suitable. It was about you know where it is. It is not too far from here. And eventually we brought her there. Before she went there the matron came here, they just interviewed mother and myself and I think my brother [health care professional] came as well just to inform them what medication she was on. So that interview went very well and then she went there. [*Dylan*]

While Dylan was not part of the selection of the nursing home he was part of the decision making process when his mother went into the nursing home. The use of the phrase ‘eventually brought her there’ indicates the dis-ease he had in placing his mother in a home. However even though Callaun and his brother had secured a place for their mother Dylan was more comfortable after the house call the matron of the nursing home made. This alleviated Dylan’s fears and it was then that his mother was admitted.

Sean describes considerable family conflict in the choice of his mother’s nursing home. Sean, a single man who worked full time, was the sole carer for his widowed mother who was suffering from Dementia. He assumed this role by default as he was the only member of his family still living in Ireland, and consequently bore full responsibility for organising every aspect of his mother care over several years. Sean was obviously devoted to his mother but the role he assumed had impacted greatly on his life both socially and financially. He spent every evening and weekend with his mother which resulted in his becoming very socially isolated, and the cost

of providing support for his mother while he was at work was significant. When Sean's mother was admitted to an acute care facility after an accidental overdose while he was at work it became apparent that full-time residential care was the only realistic option for both of them. For Sean one of the most important factors in choosing his mother's nursing home was that it be close enough for visiting:

I wanted her close and she wanted to be close to me [*Sean*]

However Sean's brother was a healthcare professional, and contacted the hospital directly to negotiate the nursing home arrangements. Sean describes the anger, fear and frustration he felt:

They went behind my back and made an arrangement between the two of them that she would go to X and so I exploded. I had a very, very bad time. And they promised me that they wouldn't send her anywhere without contacting me but then they rang me back an hour later saying that she was on her way, and you know there are a few very good nursing homes around here and all within walking distance. But my brother for a long time had this fixation on getting her up to X and I point blank refused on the grounds that they are never here and they don't have to visit. I was trying to explain that if my mother is out in X it will take me forever to get there, and like she will be sitting there on Christmas Day and nobody able to get to her, and she will go berserk because she will think she has been abandoned or she will be so very, very lonely. So anyway they chose X and then she was moved out to X [*Sean*]

Sean's story is unique amongst the families who participated in this study but it highlights an important issue in the context of the palliative care principle of the family as the unit of care: not all families function as cohesive units, and this may pose a significant challenge for end-of-life care planning where families are required to act as proxy decision makers.

Susan's mother was admitted to a nursing home from an acute hospital. She describes an additional stress in her search for a suitable nursing home placement for her mother - the constant pressure she was under from the hospital to move the process along. Despite the involvement of the hospital social worker she reports that it was "very, very difficult to get the Fair Deal through". This significantly delayed her mother's discharge which appeared to cause the hospital to run out of patience:

I don't know who the man was but they said they had a bed for my mother in M. I went to see it and you would want to see where they wanted to put my mother, I nearly screeched. She would have been dead in four weeks. I got so upset, and the administrator said like "I knew this would not suit your mother". Now if my mother has been really bad with a different form of Dementia maybe it wouldn't have been a problem. But not my mother, I mean it would have killed her. Then we were threatened by the hospital that

they were going to discharge her. Discharge her because I wouldn't accept what they decided was good enough for my mother [*Susan*]

Susan continues to describe her frenzy as she attempted to locate a nursing home placement that was suitable for her mother. She talks about the shame and frustration she felt with media reports of older people occupying hospital beds:

And I remember on the television they were always saying that the elderly were overcrowding the wards in hospitals. I felt like screaming at them saying "I'm trying to get my mother out of (hospital) and I can't [*Susan*].

Susan eventually found a nursing home which she felt was compatible with her mother's needs. Her mother had been in hospital for 3 months at that stage.

Finding a suitable nursing home was only the beginning of this part of the journey for families in this study. Although locating a suitable place for their loved ones was a challenge for all families, for some the process of relaying this information to their loved one was significantly more difficult. The difference between admitting that you can no longer care for your loved one and informing your loved one of this fact is immense.

As Loran had made a promise to her father never to put him in a home, she informed him that he was going into a hospital:

a type of hospital where they were going to sort out his chest [*Loran*]

Many families report the use of a similar strategy. When her mother was admitted to the nursing home Susan realised she would be upset by the move, she reports:

so I told her she was going to a holiday home. To recuperate. That she hadn't been very well [*Susan*]

Sasha too describes how her father was discharged from an acute care facility and was waiting for admission to the nursing home. He did not want to go.

he could have gone before, but he wouldn't go. He wanted to stay at home. And looking back now I think we said he was going in for respite but I think he knew he wasn't. He was leaving his home of sixty years [*Sasha*]

It is obvious that talking to relatives about admission to a nursing home is a significant challenge, with many families unable to face the conversation. Families economy with the truth

was based on the belief that it was better not to inform their relative for fear of upsetting them. Austin provides an insight into the struggle, he explains:

that was a real, real challenge you know. Because the only way you win it is with deceit, and that you know is the sad reality of the situation [*Austin*]

While this strategy proved effective for some families, for others it was less so. The day after admitting her father to the nursing home Loran had to face the reality of the deception. He confronted her:

I didn't think you would do this to me Loran I didn't think you'd be the one to put me in a home [*Loran*]

The decision to admit their loved one to a nursing home did not sit comfortable with many carers. Many families felt the need to justify their decision by emphasising how friends and other family members were in agreement that they could no longer continue with home care in the interests of their own health or their relatives' health. It would appear that the emotional turmoil of the decision to institutionalise a loved one continues long after the decision has been made. Iris understood that her husband would not want to go to a nursing home but also knew that she had no choice as the care he needed she could not provide. She called upon her daughter to reinforce the case:

You were worn out mam... everybody has their limits. Like we all helped with it. Mam used to have the weekend off. We'd all take it in turns. A weekend each and we'd come in and say ok mam off you go and she'd go off to a friend or out somewhere with her sister. And we used to go in and stay there and like I'd be absolutely shattered coming home on a Sunday. Because it was hard. Like mammy had that for 5 days and 5 nights because he wouldn't sleep properly and he'd be wandering [*Lily*]

In an exploration of the perspectives of older people and their carers Nolan *et al* (1996) propose a 4-stage typology of admission to residential and nursing homes: the positive choice, whereby the relative was fully informed in the decision making process; the rationalised alternative, where there was less choice but the older person was able to create and sustain a perception that the admission was legitimate and/or reversible; the discredited option, which starts as a positive choice or rationalised alternative but after admission the resident finds that the situation is not as they expected it to be; and the *fait accompli*, described as the worst case scenario where virtually all the basic conditions for an acceptable move are absent. This typology does not fit with the

circumstance of the families in this study possibly because of the limited capacity of the individuals involved. Schermer (2007) suggests that categorical statements about the legitimacy of deceiving or lying to individuals with Dementia are not warranted and that those who know the patient well should therefore make such decisions. Families in this study justified this deception on the basis of respect for the subjective world of their loved on and in the context of the pain truth telling would cause both parties. The strategy appeared to persist throughout the nursing home residency:

Whereas I did go through one evening I told him he couldn't go, and I went through the whole reason why he was there and he was crying and he was upset. I came home bawling and the next day he didn't remember the conversation and I just thought I'm not having that conversation again. There is no point. It is only upsetting us [*Hillary*]

Chapter 5: Being in a Nursing Home

Introduction

The focus of this chapter is an exploration of how an individual who is admitted to a nursing home and their relatives negotiate the living and dying within that setting. When it comes to the end of our lives:

We might see it as our task to make the end, the parting from human beings, when it comes, as easy and as pleasant as possible, for others as for ourselves; and we might pose the question of how this task is to be performed (Elias, 1985 p.3).

While Elias (1985) articulates this in relation to the individual coming to terms with their mortality, this can also be applied in the context of the nursing home setting. Nursing homes have increasingly become a site of elderly care and consequently end-of-life care. For most of the individuals who are admitted to a nursing home there are two elements to their care: providing a quality of life for the living and providing quality of dying when the time comes.

Settling In

Once their relative was admitted to the nursing home a period of settling in occurred. For relatives settling in appeared to involve two distinct phases: hyper vigilance and relaxation.

Hyper-vigilance: Making Sure It's All O.K.

Most of the families in this study describe a period of hyper vigilance in the period after their relatives' admission to the nursing home. This period involved frequent visiting, observation of the staff (usually covert) and observation of their loved one. It appeared to serve two functions: most importantly to ensure their loved one was receiving the appropriate standard of care; and confirming that the right decision had been made with regards to the choice of nursing home.

One of the most significant factors for families in this period was the open visiting policies of the nursing homes:

What I really loved about it, really loved 'cause it was very reassuring, was that you could drop in at any time of the day. Any time of the day you could go in [*Susan*].

Although as time progressed this was assumed to be a welcome pragmatic convenience in the initial stages after admission it was taken an indication that:

everything was open, nothing was hidden [*Austin*]

Relatives used this as an opportunity to ensure that standards of care were consistent for their loved one with some families describing a deliberate strategy of visiting at various times of the day by different family members. For many it was also considered an opportunity to watch how staff interacted with resident who had no visitors, and by extension how they would interact with their loved one in their absence. Many families commented on how “gentle” and “patient” staff were with other residents, with these covert observations providing considerable reassurance for families.

Daniel recalls observing the treatment of other patients when there was no relative present as a barometer for the care his uncle might be receiving in his absence:

He was 4 years in the home never worried about his care or about him you know like that people seemed to be concerned that we were there. Because I could go in at any time of the day you know there was no restrictions on us at all the time I was there you know the way you could pick up an atmosphere in the place? You know people can't just turn it on like that. Because you are there and I noticed like the others and I watched them all the time how they were dealing with the other patients some of who were quite disabled and I never saw any sort of impatience or raised tone of voice or anything. I was very aware of trying to pick up on that. You know that the underlying atmosphere was good you know which I thought it was. But sure you can always be wrong but I just went on what I saw myself. [*Daniel*]

Daniel gives voice to the worries many relatives expressed in this study: does the care given in your presence correspond with the care in your absence? For reassurance Daniel employed a few strategies: firstly he arrives at different time; secondly he observes the care of other patients and finally he concludes that the atmosphere cannot be created on demand and therefore it must be a permanent aspect of the home. Many respondents employed similar strategies with similar results. Nursing homes were acting and behaving in a consistent manner regardless of the presence of relatives.

Although many families reported that their relative experienced difficulties with the transition to the nursing home, eventually, for some more quickly than others, this appeared to settle. Observation of the treatment of their loved during this period was critical and the term “dignity” was used by almost every family who participated in the study. Upholding dignity was considered to be the pinnacle of care. Maisie stated:

dignity that was the one thing with the whole thing in there. [*Maisie*]

Dignity was evidence in various ways: in the interactions between staff and residents; the attendance to medical care and bodily functions; and in the manner in which staff assisted residents in their presentation of self. Alice reflects on her sister's experience in the nursing home, how her needs were met:

My sister was in G and she was there for 3 and a half years and she got absolutely excellent care. She was looked after in every way possible from you know medical care to the care of understanding to helping her to keep her dignity all of that. [Alice]

Goffman (1959) proposes that dignity is also maintained thorough the presentation of self, and for families in this study this was significant. Masie continues:

You know he was always immaculately shaven and you know teeth spotless and he was such a proud man like such a proud man. [Maisie]

Her father was a man who all his life presented himself to the world as a man who took care of his appearance. Maisie commented that his teeth were kept clean as well as been shaven, these are the things that relatives notice the ordinary day-to-day activities of bodily maintenance. Hilary reflects on these aspects of her husband's treatment in the nursing home comparing it to their experience in a hospital:

I just think small things like that make such a difference. Like you can't have that personal touch in a hospital but you know for a home. [Hilary]

Alice reflects on her experience of quality of life of her sister in the nursing home, how her needs were met and her dignity upheld:

My sister was in G and she was there for 3 and a half years and she got absolutely excellent care. She was looked after in every way possible from you know medical care to the care of understanding to helping her to keep her dignity all of that. [Alice]

The upholding of her sisters dignity, is Alice's recognition of the negative aspects of the ageing body with resultant inability of the individual to care for the self which requires others to undertake body maintenance. Lawton (1998, p.132) writes about this aspect of care within a hospice setting which can be applied to nursing homes:

Issues of dirt, decay, disintegration and smell are rarely, if ever, written about by hospice professionals or covered in media representations of hospice care. Rather, they are 'glossed over' as 'symptoms' requiring 'control'.

Alice recognises these elements and constructs them as the maintenance of her sister's dignity.

Relaxing: A Home Away From Home

When families were reassured that they had made the right choice what they wanted for their loved one was effectively a "home away from home" and the degree to which the nursing home could achieve this was essentially judged to be a critical indicator of success. There were two components: trust in staff providing care; and the environment in which this care took place. There was no participant in this study who suggested that this was not achieved.

Cian's sister was in a nursing home for a number of years. He considered it a priority that nursing staff understood his sister to the point that they knew her better than he or his family did. This sat well with him as he states:

But one of the great things from our point of view as a family was that the two guys [nurses] that looked after her in particular knew her better than we did. It was more important that they knew her views and as her faculties well sorry not her faculties her mind was always there as we understand it but it was just her ability to communicate became less and less. And the two boys assured me and I would have seen bits of from time to time myself if my sister was unhappy with something you would have got a sense of it and they were able to pick up on those things better than I was at the end. And that was far more important to me because while I was family these people were looking after her every day. So from that point of view of that vague feeling of guilt anybody has when somebody goes into a nursing home you know I was able to reassure myself that where she was the right place for her [*Cian*]

Within this vignette Cian describes the trust that builds between family and the nursing staff. He illustrates his comfortableness with the nursing staff when he uses the affectionate term 'the two boys'. Cian notices the care staff can 'pick up' his sister's unhappiness quicker than he can thus enabling him to acknowledge he had made the right decision in placing his sister in the 'right place'.

Also significant for families was that the nursing home looked and felt like home – a factor influential in the original choice of the site. Abbie articulates this as the feeling of "comfortableness", becoming integrated into the fabric of the nursing home, getting to know not only the staff but other residents and their families. Many families reported similar stories: a blurring of the boundaries between themselves, nursing home staff and other residents:

Now the way it worked like, all the staff welcomed you, everybody said "hello", whether it was the chef or the cleaners, we all knew each other, and like I love the elderly so I would sit for hours, and I used to bring them all up sweets like [*Susan*]

It was important that the nursing home had a feeling of home. Many families commented on the “warmth” of the environment. The word ‘warmth’ is suggestive of comfort and security. The intuitive nature of this knowledge seems to be pertinent; they feel the warmth, it is not quantitative knowledge, it is qualitative. Another important issue in selecting a nursing home was the extent to which the nursing home it differed from a hospital. The focus of this for Maisie was odour:

It wasn't like a hospital at all; I don't know how they keep out that hospital smell in it.
[*Maisie*]

This was also an issue commented on by Corina and Mae when they stated:

It did not smell like a nursing home [*Mae*]

Also important in the concept of “just like home” were the opportunities for social engagement that were available for relatives. Susan's mother had been very socially engaged all her life; she was a well-travelled woman who loved singing and dancing. Susan reports:

my mother loved company, she loved singing and dancing, and every six weeks they'd bring I a band...they'd bring them all down to this big room and my mother would be dancing....I cannot fault X...it was so nice to see her happy [*Susan*]

Social opportunities were considered important even for those who chose not to participate. Not everyone was as social as Susan's mother. Some families described how, despite the range of activities available and the encouragement of family and staff, some relatives simply did not want to engage. Rosy describes her mother:

She was very old school. Her whole life was her family and she didn't have friends as such. Her only interest was in her home and her family. It wasn't as if she used to go anywhere [*Rosy*]

Rosy's mother never availed of the activities on offer in the nursing home, but what was important to the family was that they were available if she changed her mind.

Recognised as Important: Caring for the Families

Relatives' encounters with the nursing home were driven solely by the needs of their loved ones, yet a surprising consequence of this encounter for many of the participants in this

study was the unexpected level of personal and affirmation support they received as a result of this encounter:

I would have to say they were as equally concerned about myself and my sister as they were for my father [Austin]

This for Austin was an unintended and unanticipated consequence of his father's admission to the nursing home. Ciara similarly commented:

But not just for his needs but for ours. You know they got to know from the first day they knew all our names. [Ciara]

For many participants this was the distinguishing feature between the hospital experience and the nursing home. Within the nursing home relatives felt they mattered as much as the older person in their care. Ersek and Wilson (2003) propose that inclusiveness is an asset to nursing homes in their effort to provide high quality care, and this was evident in the narratives of families in this study.

Families describe the many ways in which they felt valued by the nursing home staff. From the friendly atmosphere; the encouragement to make themselves at home and the provision of facilities to allow them to do so, to the manner in which they felt they were encouraged to be involved in the decisions about their loved ones care. These were considered to be indicative of the esteem in which nursing home staff held them, and they were greatly appreciated.

Ancillary practical benefits were also accrued. Abbie got involved in the activities of the nursing home which made her feel good and she developed a set of acquaintances in a similar situation helping to remove the loneliness she experiences as primary carer and providing her with a circle of individuals in a similar situation who understood and provided mutual support (Wittkowski and Carlsson, 2004).

Care for families was also demonstrated in other ways through occasionally protecting them from their loved one. Ruth and Ciara's father could become aggressive and the staff in the nursing home took care of him thus enabling them to maintain a relationship with their father:

getting me out when he was very aggressive with me. They would distract him and they'd go to me you know behind his back out you go. [Ciara]

The nursing staff managed the situation enabling Ciara to remove herself from his presence thus taking care of her. They would also warn Ciara and Ruth regarding his mood prior to their

entering his room, so that they were prepared for what they may face. This allowed them to avoid unpleasant situations and manage their expectations for their visit.

Bumps in the Road:

Although the adjustment period after admission appeared challenging for both their loved one and themselves most families reported a period of relative stability after the transition. In the period between settling in and the death of their loved ones significant challenges were rare but families reported two issues that were significant.

Experiences of Hospitals

Several of the families in this study described their experience of engagement with acute hospital services. Families encountered these services either as the referral agency for the relatives' admission to the nursing home, or as a consequence of their relatives admission to the hospital during their stay in the nursing home (some individuals had multiple admissions in the early days of their residency in the nursing home). Without exception there were no positive experiences of these encounters reported.

Susan's story of the pressure she was put under to find a nursing home for her mother has been previously described. Here the Brady family describes their experience of hospital care:

He went into the nursing home on the 31st of December, New Year's Eve having spent a week at home after his discharge from X hospital.

... after being dumped by X hospital on Christmas eve, they sent him home Christmas eve.

He was at home for a week. To live on his own. He really wasn't well

He didn't eat

No Christmas day he wouldn't go to any of us. He was to go to you that Christmas day. He wouldn't leave the house [Brady family]

This vignette exposes the difficulties that families face when caring for a relative who is very ill and is discharged from hospital. Andershed and Ternstedt (1999) observed relatives being expected to care for their loved one who are signed out from hospital quicker and sicker irrespective of their capacity to care for them. The Brady's father lived alone and was unable to care for himself however they felt that the hospital had abandoned him. This was felt as particularly poignant as it was Christmas time.

Many families reported fear of their loved one having to go to hospital on the basis of their previous experiences. Brid's daughter had a progressive neurological disease and was resident in a nursing home for almost 10 years before her death. She would go in to see the consultant twice a year. Brid dreaded every visit:

God love her she'd be just lying there...just lying there. It's pathetic when someone can't speak for themselves.. She couldn't even scream for herself. And the so called medical staff, I mean they are just walking backwards and forwards...but she was lying there, and she was stone cold, and a good few old people were looking at her and saying "that's a shame, that little girl, she's so ill". But you know she still wasn't seen until half nine that night. [Brid]

Brid's story contains the elements that all families described in relation their relatives' experiences with acute hospital services: prolonged discomfort, long waits, and a lack of respect and consideration. However, Jessica reports an additional and crucial difference:

Now those few days that she was there were awful. She was just a number. Not really properly looked after and I was really happy when she was transferred back. Because she was back with the nurses that knew her and loved her [Betty].

Culturally Diversity or Cultural Competence

1990's Ireland began to see the development of a multi-cultural nursing workforce which was reflected in the nursing home sector. As an organisation the culture of the nursing home is predicated upon a shared set of assumptions and values that guide the everyday behaviours of organisation members (Schein, 1992). Nursing homes socialise nurses and health care assistants into the rules and regulation of caring with elderly people so that there are carried out proficiently. As May and Pukis (1995 p.285) put it: 'Perhaps the most important effect of professional socialization is its function as a process, by which disparate actors learn things in the same way'. Some participants in this study recognised cultural diversity in the nursing home workforce reflecting that they adhered to shared norms and values (Vandenberghe and Peiro, 1999). Other participants questioned this thus positive and negative perspectives emerged. On the one hand some participants reported that the staff who came from different cultural backgrounds were unable to provide the same care as Irish staff as they lacked the same cultural competencies or concerns that the residents displayed. On the other hand several participants seemed to believe that nursing staff of diverse cultural backgrounds were able to provide superior care as a result of their cultural ethos.

Ciara and Ruth, for example, draw attention to the fact that, despite facing what they perceived as the ‘obstacle’ of being ‘foreign’, the staff in G were more than capable of looking after their father:

You know they have a really good ethos and they seem to take good care in the staff that they pick that the staff actually whether they are foreign or Irish that they are, that they know how to look after somebody in Ireland. It doesn’t matter. [Ruth]

Ruth suggests that the nursing home provides care on a multitude of platforms: care in choosing staff; care of the staff as employees; care of the residents and care of the relatives. It is this circle of caring ethos that leads to the atmosphere created in nursing homes that participants have commented upon. Hilary and Maisie also reported that nursing staff from diverse culture backgrounds:

are just so caring and so even just knowing all our names and knowing when the kids [*grandchildren*] would come in like and I just think small things like that make such a difference. [Maisie, italics are mine]

In this situation Hilary and Maisie are impressed by the care that is provided by the staff and their cultural background is not seem as an obstacle, if anything these individuals provide high quality care. Susan concurs:

the foreign staff were fantastic.....no disrespect to the Irish now but they were just so caring [Susan]

Other participants mentioned that staff in the nursing home, where their loved one was resident, came from diverse cultural backgrounds but this did not seem to be of any significance to them or to the care their loved one received. They mentioned it only in passing and then moved on in their narrative and so it may be assumed that they did not believe that this had much relevance to their loved one’s care.

Participants’ recounted ethnicity was not a barrier to the quality of the nursing care provided to their relatives. There appeared to be a shared set of assumptions, norms and values of the organisation which guided the behaviours (Schein, 1992) of the staff particularly the nursing staff. However some participants questioned the level of cultural competence within the nursing home. One area that this presented itself was the use of jokes. Iris and Lily knew how far their loved one would take a joke or the kind of humour he had. Iris explained that her husband in his youth was nicknamed ‘psyche’ but he did not like it. Lily continues:

so a X [names the country] nurse or a carer came in and she kept calling him psyche [Lily]

Iris indicated that she had asked that the nurse stop:

I'd given her a warning I said don't tease him, don't go any further [Iris]

However she did not which led to conflict between the family and the nurse. Iris and Lily viewed this as irritating their loved one but more importantly a lack of cultural understanding.

Callaum and Dylan did not question the cultural diversity of the nursing home staff but wondered about the ability of all staff regardless of ethnicity to empathise with Irish residents:

One comment I would make and it's something somebody said that a number of the staff out there were from abroad. And there was a question of the empathy of these people with Irish people you know that somebody native would probably be a little bit closer to our culture and so on. [Dylan]

While Dylan highlighting this as an issue both he and his brother Callaum insisted that this was not a nursing care issue rather an issue of nursing staff understanding the cultural nuances of their mother's reality. It is the cultural memory that some older people bring to the fore which Dylan is focusing on. As a culture Ireland has experienced many transitions which this cohort of residents would have experimental knowledge and at times require staff that would have a shared knowing.

Silvia found it to be the case that the multi-cultural staff at G lacked cultural competence, while at the same time being "brilliant nurses". Silvia felt it was "a pity there weren't more Irish on the staff". She explores this comment concluding that from her perspective a lack of Irish staff members led to a deficit in holistic care:

these are all elderly people and who you know when you talk about dementia you are talking about people that you are trying to remind them about their childhood and their memories and their you know with their kind of what their lives were like or whatever and you know ... She's just from X [names culture] to here and was doing her job and was fantastic like and was fantastic at her job but had no idea of the background of the people you know and I though now they have they had staff doing singing and dancing and whatever with them you know. [Silvia]

Silvia expands the concerns of Dylan and Callaum shedding light on the needs for a cultural knowing to exist within a nursing home. Elderly residents' particularly residents living with dementia may speak from memory bringing to the fore a life that has been lived inviting the care staff into their world. Silvia points to some of the difficulties a deficit of a shared memory

within a multi-cultural nursing workforce. The staff that worked within G could take care of the nursing duties capably but when it came to looking after the leisure activities that they offered to residents Silvia felt that their knowledge was lacking. This assessment was based on the assumption that dementia care involves helping those who live with dementia to remember their earlier lives. The presence of ethnically diverse staff who themselves may not have grown up in Ireland may destabilise from Silvia's perspectives the work of families in maintaining a line of communication with their relative. Further, the fact that personnel from a multi-cultural background are leading residents in activities that maybe distinctly Irish could from Silvia's observations create problems of knowing a complete playbook that is reflective of particular Irish subcultures.

Chapter 6: Planning for the Future

Introduction

Lloyd-Willaims (2009) proposed that end-of-life care plans facilitate a nursing home in providing care for residents, enables families to make decisions and where necessary advocate on behalf of their relative. Future care planning is considered a critical feature in achieving end-of-life care for individuals with Dementia (McConville, 2011; IHF, 2013) and all of the nursing homes from which families were recruited to this study had a specific policy on end-of-life care planning for residents. This policy included open discussions with families about how they would like their relative's care to proceed and what goals were appropriate during the dying phase. The discussion cumulated in the signing of an official End-of-Life Care Plan which was reviewed as required and at least every three months.

Despite the implementation of this policy, and reporting discussions with nursing home staff, not all families appeared to be aware that such a plan existed. When asked about his involvement of end-of-life care planning for his father Austin reported:

I would have to say I wasn't conscious of a care plan. Resuscitation obviously yes you know with the standard you know "do you want to resus or do you not want to resus etc?" and we signed forms in that regard quite regularly. Erm similarly because he was in a wheelchair and with a belt we had to sign some restraining forms quite regularly [*Austin*]

Worryingly, the significance of the end-of-life care plan does not seem to have registered with Austin – like a constraint form it was perceived as just another "standard" form to be signed.

Only two families reported that end-of-life care had been discussed with their relative beforehand.³ The remaining families who participated in the study indicated that they made the decisions on end-of-life care. This was done in consultation with other family members and based on what they believed their loved one would want. In some cases families suggest this was heavily influenced by the staff in the nursing home.

Despite the drive in favour of open conversations on end-of-life issues with people with dementia (McConville, 2011), Silvia suggests that conversations in this context are extremely difficult:

³ Both of these discussions had taken place in the hospital much earlier in the individuals illness trajectory.

issues like this I was very aware that she had not made a will, and that you know her expressions of what she wanted is something we should do and as much as I knew all that I chickened out of the conversation. And you know I chickened out because having that conversation when she was able to speak was effectively starting off conversation by saying well you know you are going to die soon so get your house in order. And it appeared to me that she never wanted to have that conversation. I couldn't bring myself to have it. Everybody talks about capacity and the difference in talking to people and all the rest, in the real world it is very, very different to have to sit down and have that conversation with somebody and say we both know what we understand by having that conversation which is you know you are going to die. I just couldn't bring myself, partly because I just felt she never wanted to have that conversation [*Silvia*].

Discussing End-of- Life Care

While Maisie reported that the conversation occurred relatively quickly after her mother's admission to the nursing home this seems to have been initiated by Maisie herself. She recounts the following:

well it would have started I suppose in terms of end-of-life discussion when I brought her into the nursing home originally I had said that if at all possible I would like her to avoid X hospital because we had a couple of experiences that in which she got very confused and very disorientated so if at all possible I asked them if they could care for her in the nursing home you know. And I also signed something at that stage about palliative care you know that didn't want to end to the extraordinary means. In relation to her care so I signed something very early on [*Maisie*].

In this instance Maisie was the one to initiate the conversation. Past experiences with her mother had help crystallise in Maisie's mind what she expected for her mother at the end of her life. Other families also introduced the issue, generally when they saw some level of deterioration in their loved one and became concerned at what might happen if medical intervention was required. Other families indicated that where the issues was raised by staff it tended to occur after an acute episode of illness

Some participants recounted an experience of embattled advocacy suggesting this emanated from their loved one's care, which had been proposed or supported by the their primary physician, being undermined either though being changed, challenged or simply ignored. One such incident was reported by Hilary and Maisie who experienced their loved one prescribed antibiotics despite the fact a care plan was in place which indicated that no aggressive treatment should be given. When they brought this to the attention of the nursing staff the antibiotic was stopped immediately. It was the reaction of staff to their request that lead Hilary to

feel both that she was being judged and forced to justify her actions and the kind of care that she required her husband to receive:

one of the staff came in who was not medical and said to me oh I believe you are not having J [her husband's name] treated anymore? You are not having him on antibiotics anymore.....I don't think they should come in and comment to me [*Hilary*]

Staff members making comments about her decision resulted in Hilary encountering a moral narrative which put her in a position where she felt she had to defend her actions. From Hilary's perspective she was enacting the care plan that she and her husband's doctor had agreed upon. Hilary experienced herself as being looked at:

The Other's look makes me be beyond my being in this world and puts me in the midst of the world which is at once this world and beyond this world (Sartre, 1969 p.261).

Hilary experienced the look of the Other which placed her in the world she was inhabiting and beyond that world as the world that would exist beyond her husband. Hilary experienced what Cooley (1996 p.90) suggested as 'we always imagine and in imagining share the judgements of the other mind'. The comments of the staff resulted in the imagined judgements of the 'other mind' becomes a reality. Another staff member wondered:

do you not think maybe he would have changed his mind? [*Hilary*]

Hilary's husband could no longer articulate his needs and Hilary became his advocate having shared her life with him resulted in a knowing of her husband that enabled her to make difficult decisions. This reflects Rurup et al (2006) assertion that relatives have a knowing that emanates out of close association and for Hilary that derived from their marriage. She stated:

You went in and had very definite ideas about what he wanted and what he didn't because I knew it would get to a stage and that would be the end of that. But he didn't want to be where he was. He knew that was what he didn't want. He didn't want to be left cause literally where he could do nothing and we had discussed it with his specialist when he was in the H [names hospital] for 11 weeks before he went into the home and they were all in agreement it would be more like a palliative care that he wouldn't be aggressively treated for infections and when he went into the nursing home it was the same with the doctor who was taking care of him in there. He would treat him as he thought but aggressively if he got bad chest infections it would get to a stage where he would say no but there was a time when he was away and the other doctor was in the nursing home, [*Hilary*]

Hilary and her husband had spoken about her husband's illness and had a clear plan of how his life would progress. To her mind the admittance to the nursing home and the care that her husband would receive would be palliative. However the plan did not always work when the doctor for the nursing home was away and an alternative doctor made decisions which did not adhere to the care plan exposing poor communication between the nursing home and the on call G.P. (Neergaard *et al*, 2008). Knowing how her husband wanted his life to progress and move into the phase of leaving her behind Hilary found it difficult to advocate on his behalf when her decisions were questioned:

Now I don't think that was her place but it was hard enough for me to fight for what he wanted. [Hilary]

This segment implies that there are only certain roles within the nursing home which legitimately allow the questioning, or enabling, of decision making by relatives. Hilary is suggesting here that a non-medical staff member were overstepping the boundaries of her position by commenting on her decisions. As well as having to bear the burden of her own distress regarding her loved one's situation, she had to defend or explain her motivations to the staff at the nursing home. Hilary construed this as her motivation being judged – a suggestion that perhaps she was acting out of self-interest and not in the interest of her husband:

That was the only the main things I found very, very hard. This is what she wants and maybe it is not what he wants. [Hilary]

In short, Hilary faced obstacles in her attempts to advocate for her husband's wishes. Sartre (1969 p.58) suggests:

We have to deal with human reality as a being in which is what it is not and which is not what it is.

Hilary acts through the knowledge of her situation which has developed through decision being made to facilitate her husband's desires. She finds herself in a situation advocating for her husband not to be aggressively treated thus presenting herself to others as what she is not and which is not what she is. In other words Hilary is being constructed as the 'bad wife' not caring for her husband while in reality she is adhering to his wishes even when they are difficult.

Ciara and Ruth experienced being advocates for their father resulting in the disconnect in medical care between the nursing home doctor and the weekend service provided by d-doc. Ciara

and Ruth disagreed with the medical decision made by d-doc who attended their father and maintained that their father needed hospital intervention. Ciara and Ruth perceived their father as having a palliative care plan with the nursing home. Neither of the sisters wanted their father to be admitted to a hospital on the basis that the action of moving him to an unfamiliar place would cause him distress. Ruth recalls:

I didn't know what things were in place that gave us the right to say no and this doctor was very, very pushy. [Ruth]

The doctor was insistent on the diagnoses made and the outcome be followed thus negating and disrespecting their knowing leading to conflict (Dreyer *et al*, 2009). Ciara and Ruth recollects that the doctor refused to read their loved one's file as the decision reached was based upon an examination of the patient that is their father.

would not read his notes, just kept saying I've seen him, I've made up my mind. [Ruth]

Ruth's nursing background allowed her to offer an opinion regarding how her father's care should proceed which ran contrary to that of the doctor. Ruth being a health care provider experienced health care as a service user. Her intervention was not well received, with the doctor expressing shock that her professional opinion was being questioned. Ciara explains that they were well aware of the care plan and had renewed it on a number of occasions:

we had met with the doctors and in fact we had renewed the care plan because daddy when he went in we thought it was going to be very short and then as it went on you know daddy recovered because he was very strong and we had another meeting with the team and we went over the care plan again and said exactly what we wanted to be done. And I have Power of Attorney for my father and I was prepared because I knew what my dad wanted. [Ciara]

Ciara and Ruth experienced their father's recovery which enabled them to revisit their father's needs. Ciara's father had made his wishes to her about his end-of-life care. Knowing these wishes resulted in an embattled advocacy with the d-doc. However Ciara suggested that Ruth's knowledge led to a positive outcome:

the doctor wouldn't listen and the only thing that saved us was that Ruth knows the law and she knows the different initiatives that have been set up and she challenged her. [Ciara]

The implication being that if Ruth did not have the knowledge she had they would not have been able to adhere to their father's wish and the care plan that had been made. However Ruth was put in the position of challenging the expertise of the doctor.

While advocacy in these cases presented itself in relation to medical practitioners and comments made about relative's decision making, Holly's experiences emanated from her mother's medication and her need to advocate on behalf of her mother given her medical knowledge:

She had a stormy few days no actually what did happen and I'm always a bit worried saying this was her medication was rationalised. They took her off a lot of her medication including diuretics and she had fairly severe heart failure. So of course she did go in even though she wasn't eating or drinking that much she did go into failure. And I sort of was a bit upset about that because I thought bloody hell who would take them off diuretics at this stage because it did I felt precipitate things. Anyway then she was reviewed regularly by the general practitioner who was wonderful. She was going down and couldn't take anything orally. They were giving her some Medazalin luckily and that was helping matters to settle her down and then they eventually put her up on a syringe driver and that helped things. Certainly for a few nights I stayed with her during the night and it was difficult because she was getting a lot of secretions and it was difficult. You are also then very aware [Holly]

Holly's frustration derived out of a decision made in relation to her mother's medical regime without consultation. In her experience it did not make any sense to remove diuretics. She questioned who made the decision concluding that it should not have been made. Holly's story demonstrates family members' involvement in the care of their loved ones and how they are key decision makers at all times (Vig and Pearlman, 2003). Holly found this period difficult and only relaxed when the syringe driver was introduced into her mother's medical routine; however this experience made her very aware of her mother's care.

While some participants faced advocating for their loved one with the medical profession other sites of conflict was within the family itself. Jessica explores the difficulty of obtaining agreement between all seven siblings in her family. She recounts her mother was a regular attendee to A&E and a point came when the question 'who is this for' had to be answered. The realisation was it was for the siblings they all agreed bar one to cease this practice.

we did have one brother who kind of was a bit iffy about oh Jesus not treating her and that. The May bank holiday when she went down that weekend and his daughter was getting married. I said to him right I'm not going to hospital; I said I'm going to X for the

weekend you are going to have to go with her. So when he actually saw himself the distress that she was in and I mean distress you know climbing out over the rails of the bed. Pulling the drips out of her arms it was just you know and it was the time band between transfusions was getting shorter and shorter. [Jessica]

To enable her brother come to terms with their mother's health situation Jessica hatched a plan whereby he would have to take her to A&E. Her brother's experience in A&E lead to the cessation of regular transfusion and the entire family engaging with the nursing home regarding their mother's care.

Confrontations can be experienced in a multitude of formats deriving from the nursing home in relation to nursing staff, general practitioner or other members of the nursing home workforce. It can also be experienced amongst families when members are not ready to come to terms with their loved ones failing health.

What Does it Mean?

The majority of the participants in this study spoke about 'the care plan' and how this facilitated them in coming to terms with the inevitable parting with their loved one.

I had a meeting with his doctor and like say the senior sister and the lady who would be coordinator. And it was basically saying we are not going to do this or this or that. You know they had gone in, they had assessed him before they took him and they were in agreement with everything [his doctor] had said they would treat him not palliative but you know it wouldn't be aggressive. You know they wouldn't continue to treat him. He kept getting chest infections and kidney infections but yeah they were the doctor there was no hassle there. And he had said you know I had said you know I don't want it treated aggressively and he had said I agree with you but if I didn't agree with you he said I would let you know. So it wasn't he was doing it because I was saying that's what I wanted, he agreed that. [Hilary]

Hilary was happy that there was clarity around the end-of-life care of her husband, his wishes acknowledged and agreed to, this, she perceived was the reason for the care plan.

Corina and Mae did not undertake a care plan for their mother when she went into the nursing home as she had been 'fairly well' however a particular incident warranted a plan:

My mother had to be taken to hospital for a period of two weeks when her condition deteriorated and she was struggling to breathe. This is when a discussion about end-of-life care with the home, in which the woman in charge assured them that the nursing home would be able to care for their mother if a similar situation arose in the future. We had not talked before about such care with anyone at the nursing home. [Mae]

Corina and Mae illustrate the belief that a care plan is unnecessary for those who are 'fairly well'. For this family it became necessary to avoid unnecessary hospitalisation and accept that the nursing homes could manage their mother's needs. Ackermann and Kemle (1999) found, nursing homes were not only capable of providing care that was necessary to avoid hospitalisation; families had to be comfortable with that situation. Care plans, it would appear, enable families to come to terms with this.

Jessica's family developed a plan relating to her mother's care once all members of her family agreed that there would be no more A&E interventions:

we met the doctor and we said look at you know this is what we think, what do you think. And he brought us through the whole thing of palliative care and they can do this in the nursing home now and what happened the next time the blood went down and she wouldn't be brought to hospital. They went through the whole process with us and if necessary the Palliative Care Team would come in from X [names the area] that when her breathing went that they would have the morphine there and whatever we wanted. [Jessica]

The family found that once they had placed their mother at the centre they were able to develop a plan for her care in conjunction with the nursing home. They found that nursing homes could facilitate a Palliative Care Team to care for their mother. Palliative care no longer is the prerogative of hospice care rather it is seen as one aspect in a menu of options available at the end-of-life provided by nursing homes.

Sasha was appreciative that the nursing home discussed all options with her family about the end-of-life care of her father as she considered:

it was inevitable I suppose was the word so I appreciated that the nursing home discussed those options with us because you know somebody is suffering and going back and forth to hospitals they were very negative experiences so to have you know something in writing you know although that took a long time because my dad kept going back and forth about his end-of-life. [Sasha]

Sasha was aware that her father's life was coming to an end and she was appreciative of the openness of the nursing home in discussing all aspects of his care. However, while they had one

in writing, that is, a care plan, her father was of sound mind and thus able to make decisions which regularly changed:

You know mentally he was still with it so after coming back from a negative hospital experience he would then change you know he'd say yeah DNR and I don't want to go back to an emergency room and then he would they would check in with him a few months later and he would change his mind. .. but you know they were on top of it. They kept you know checking in with it and different things. Do you mean like their actual plan in a book like and what we had all agreed on and that kind of stuff. Because that's what they had, that's what they had [*Sasha*]

While the nursing home had to adhere to her father's wishes it was a difficult time for Sasha as it kept changing in accordance to his experience. The nursing home were adapt at dealing with the ever changing environment.

but it changed all the time because for example he was lucky that he had insurance. He was a retired H [names his profession] and they had their own insurance and sometimes he would go into not kidney infections but he would get a lot of urinary tract infections. They were what made him really sick and that was a few trips to the A & E for that but when the homecare team could come and take care of him in the nursing home that was perfect, that was really good so we would do that up to a point but it was a little difficult the gp that he had at the nursing home he insisted sometimes on him going to the hospital where we would have preferred him to stay. Because we didn't see the point. All they would do is take blood leave him on a trolley for 2 days and then he'd be begging to go back [*Sasha*]

Sasha unpacks the difficulty that relatives face when their loved ones go back and forth between the nursing home and A&E. From Sasha's perspective the nursing home were well equipped in caring for her father but:

no it wasn't the nursing home's fault it was the gp. I suppose he wanted to cover himself as well. And it is a very tricky thing. The responsibility lay with me I suppose in the end of the day as to whether we got him further care or got him comfortable. And that was my responsibility which is huge because you are making these big decisions. And there were some occasions where we said DNR if you know this is going to happen and then other incidents one time I was in an A & E and they said DNR and I said well he's conscious he's with us if you asked him this minute he'd say keep going with everything so you know it went back and forth a lot but in the end I'm just trying to think back in the end ... they double checked a few times where we stood with the care plan you know the end-of-life care plan and that he was comfortable and that he was getting whatever he could in the nursing home you know that he wasn't going to go back to the hospital this time so it worked you know [*Sasha*]

While Sasha voices the complications in enacting a care plan and having adhered to when there is conflict between a GP and the nursing home. However, this story illustrates how the nursing home works closely with the resident and the family and facilitates the wishes of both (Ersek and Wilson, 2003). However this story also demonstrates the difficulty for family members being responsible for the care of their loved one. She suggests they are weighty decision as they are 'huge' and 'big' which are not ordinary everyday decisions are made. They are life and death decisions even to the point of when to enact a DNR order.

Similar to Sasha, the Brady family found there was contradiction in the care of their father between health care providers. As a family, they were clear about their father's care needs:

Before he went back we went out to talk about you know the different the change of circumstances and we said look what'll happen if he's you know if he gets very ill again or whatever will he be moved

Cause he'd end up in X hospital

We don't want any more of this you know. So there was a discussion around how what the system would be and how they dealt with these things in the nursing home and that once they knew what our wishes were and what his wishes were that you know that wouldn't happen. That they would the hospice would be involved. Their understanding at the time was the hospice would be involved because we were told at the time by the F hospital that the hospice would be involved. So they assumed the hospice would be involved and there would be a discussion about what the right thing to do in the circumstances. But he was in so they were really very helpful and they gave us time and they were reassuring us and they you know they were kind of in a nice way trying to you know saying we have to prepare him and we have to prepare you and I thought they were kind. [*Brady family*]

Within this vignette the family took control over the care of their father. They directed the conversation clearly stating what their wishes were which derived from their knowing, gleaned from previous experience. They felt they were listened to, reassured that they finally had a health care plan in place for their father which they were contented with. The Brady family experienced the nursing home as:

Committing yourself to dialogue with people is more than recognizing their inherent dignity and defending their rights; it's being willing to allow their voice to count as much as yours (Frank, 2004 p.44).

The Brady's experienced of having their wishes respected granted equal authority of voice with the nursing home. For the first time they were satisfied with the care of their father.

Sandra demonstrates how the nursing home speaks with all members of the family to make sure that everyone is not only aware but also in agreement with the care plan:

first meeting that they had organised and they wanted as I say a family meeting The meeting didn't take too long. But we put down what our wishes were in relation to end-of-life care for dad. We didn't want any unnecessary interventions. We didn't want them to put him into hospital if there was any chance he'd have to go to hospital. And we were happy with the care there. We were happy for him to be looked after. [Sandra]

Sandra's story elucidates the clarity a care plan brings to end-of-life care for everyone involved. Sandra's family were 'happy' with the care their father was receiving and were contented for the nursing home to provide the care at the end of his life.

Where the vignettes about demonstrate the value of clarity, some families reported confusion about what an end-of-life care plan actually involved. There was considerable confusion about the meaning of the term "Palliative Care" (some families reporting that they thought palliative care was only for cancer patients), and there also confusion and misinterpretation about what the phrase palliative care actually implied. Susan's mother suffered with Alzheimer's disease. She had been in the nursing home for 2 years when she became acutely ill. After being transferred to an acute hospital for a short stay she was subsequently discharged back to the nursing home. Despite all efforts on the part of the staff and the family she refused to eat. Her condition weakened and she suffered recurrent chest infections. Susan recounts the following interaction with the doctor in the nursing home, and what she perceived were the consequences of the intervention:

we were all there and the two doctors came in and said "we've decided that your mother needs palliative care", *we've* decided...now I didn't know what palliative care *was*..I mean I thought it was that they'd look after them, but I *never* thought that they would take them off medication. And then one day I'm here and they took the drip off her – I said "Jesus, what are you *doing*"? They didn't kind of say anything, and normally I'm very kind of extrovert but I was so stressed, so *emotionally overwhelmed* by it all. God I got so exhausted, and I never asked "*why* are you taking this water off? And then my mother started to die [Susan⁴]

Susan's narrative emphasizes the importance of both language and understanding. The term palliative care, although widely used, had different meanings for Susan and the nursing home staff. Knowing and being kept informed eases the situation for relatives (Thompson *et al*, 2008). Susan found herself on the outside looking in thus she had: no collaboration with health care

⁴ Italics indicate Susan's own emphasis

providers; support for the situation she was in; shared goals for the mother's care or emotional preparation for things to come, which are required for positive family adaptation to a declining relative's health (Hanson *et al*, 2002). Equally it illustrates her vulnerability as she tried to understand the situation she found themselves in:

As an existential state that may belong to any one of us, but which is characterised as a negative attribute, a failure to self-protection that opens the self to the potential of harm (Shildrick, 2002 p.1)

The overwhelming sense Susan perceived in Shildrick's (2002) terms that she failed to protect her mother, however in the face of the knowledgeable health care providers she had no choice but to trust that they knew the health care her mother required. As Thiede (2005 p.1456) indicates, 'trust is always rooted in experience' which leads to both 'emotional and cultural security'.

Most families in this study however experienced nursing homes as aware of all family members need to be part of the care planning process for their loved one. This leaves no room for ambiguity between family members, this clarity in turn assists nursing homes in the provision of end-of-life care

Let us try to assume out fundamental ambiguity. It is the knowledge of the genuine conditions of our life that we must draw our strength to live and our reason for living (de Beauvoir, 1976 p.9).

De Beauvoir points out that human existence is always ambiguous, and it always has more than one meaning. This is something that nursing homes understand, they are aware of the ambiguity within families where the truth of their loved one's situation is known, and they enable families live with that.

Partings

In an exploration of death in acute hospital wards Buhagiar *et al* (2010) conclude that people with dementia and their families are seldom included in end-of-life discussions leading to poorer symptom management. This was a finding of this study where a collaborative care plan enabled the nursing home to care for residents in particular when it came to end-of-life. However, perhaps because of the unexpected improvements many families reported following admission of their loved one to the nursing home, the process of rapid deterioration that marked the very end-of-life came as a shock to many families. This was true even for those families who

had been actively involved in the care planning process. This section will explore how participants experienced the partings with their loved ones in the nursing home environment.

Families' descriptions of the death of their loved one ranged from "o.k." [Aveen] to "the Rolls Royce of exits" [Callaum & Dylan]. Aveen's description of an "o.k." death appeared to be related more to the fact that any death can, at best, be described in this way. She recalls:

I think we were probably lucky and he was lucky. That it was he really just slipped away. There was nothing really upsetting. Vague agitation but to be with him and try to keep him relaxed you know, it was just in as much as death can be ok it was [Aveen]

Like Aveen most families reported that their loved one "slipped away" There were no reports of uncontrolled pain. Several families recall the fact that their relative had access to specialist palliative care although the credit for a peaceful death was generally attributed to the nursing home staff. Ciara and Ruth recount:

well they were brilliant. The palliative plan I suppose they arranged it in advance. They told us what was going to happen. They said about the pump and what they were going to put into the pump to make him comfortable [Ciara and Ruth]

Loran to found comfort and solace in achieving the goals they had set for her father at the end of his life. She had been concerned about the possibility of him being transferred to a nearby hospital

We were delighted that we had an option of leaving him where he was and to die kind of peacefully without pain and suffering and that's all we wanted [Loran].

Hilary and Maisie reported being cared for and their needs met in relation to the provision of refreshments, arrangement of space in which the family could grieve, and their privacy upheld. However, they were uncomfortable as they felt their loved one suffered unnecessarily

It was just there was a point can we did not give him something because we knew it was happening and it was just to a case of like flexible cause you could hear he was drowning like in his chest and his throat like [Maisie]

Maisie wondered if her father was drowning and speculated if he could have been made more comfortable, as Maisie was aware that her father was dying. Hilary viewed this from the perspective of the limitations of a nursing home:

I think it is to do with the nursing home they said I can't give him anymore...I think had he been in hospital I think they would have definitely given him something but other than that they were amazing [Hilary]

Hilary thought had her husband been in a hospital he would have had more pharmaceutical intervention. The process of dying for Hilary was unnecessarily long as her husband was grappling with life for the entire day:

But I do think that had he been in the hospital the last day they wouldn't have let him suffer as he did. He was dying from 10 o'clock in the morning and he didn't die until 10 o'clock at night [*Hilary*]

Hilary viewed this struggle as suffering (Society, 1998), suggesting that a hospital might not have allowed this to happen hence the process may have been shorter and in some ways easier. While Hilary questioned the medical intervention, she was satisfied that her husband had good nursing care:

but the nurses were in and out and they would check him and they would turn him and change him and you know he had on the oxygen so they had him kind of propped up but they were brilliant but I just I didn't want you know....I feel they could have given him something extra so that he wasn't I don't know whether he was aware [*Hilary*]

Hilary expressed concern around the comfortableness of her husband and upon reflection thought he required 'something extra'. This concern emanated from her disquiet that he might have been aware and she did not want him to have a negative experience. Maisie and Hilary's experience is not unique as families posing questions relating to pain management and comfortableness of relatives at the end of their life has been found by Johnson (2005) Won et al (1999) and Ferrell et al (1995).

The Brady family recall being unaware that their father was close to death and were startled when they received a call from the nursing home:

At the very end. Well you see we didn't realise that he was as bad as he was. And there was a call on the Sunday morning that his breathing was bad

His breathing was poor

They obviously knew I mean they had never phoned to say anything. Any other time. They phoned K who would have been the nearest.

And I think she phoned S because she lived beside it and she'll go out she said what the situation is she didn't realise.

That was the message because I didn't go I was in the supermarket at the time.

I waited till S got out there and well I didn't rush like and I was here and S rang me just as we were going out the door but I think he was dead at that stage

They didn't tell us or you know the fact [*Brady family*]

The Brady family suggests that the nursing home had never phoned them before and when the phone call came they were unprepared for the message. However they surmised the nursing home was aware that their father was near death and wanted to inform the family (Ersek and Wilson, 2003). They also suggest that if they knew that their father was dying they would have arrived quicker and not waited for a report from another sister on their father's status. What this story illustrates is that no matter how much knowledge a family has of their loved ones health the passing comes as a surprise with the comment 'we didn't realise that he was as bad as he was'.

In this study some participants spoke of how nursing homes listened to their concerns. In some cases the nursing home informed them when the individual in their care began to show signs that their departing was near:

I was in to see him on Thursday and my sister was in to see him on the Saturday, felt he wasn't that well. I think she may have been in there on the Sunday. At that stage he really wasn't well. She felt she had to call their attention to the fact he wasn't well and they put him on an antibiotic and then the following morning I was on my way out and they called me to see whether I was coming out. They probably called me the previous night to see if they could put him on an antibiotic because they always did that as a matter of course. I was on my way out on the Monday morning and they called me to see was I on the way out and I said yeah and they said are you bringing your mum out and I said yeah. And I said why is he very unwell and they said yeah and they weren't really telling me. And I said you know maybe put the doctor on to me he was there and I said what's the situation is he very ill and is he going to die. And they said yes he probably was so obviously I contacted all the family and that was the Monday. [*Sandra*]

While the nursing home listened to Sandra's sisters concerns and dealt with the situation when it came to informing her that her father was dying, a hierarchy emerged. The nursing staff in the nursing home could not inform Sandra that her father was dying it had to come from the doctor. This could cause problems for other families if a doctor was unavailable and families found themselves in a conflict situation of whether they could go to the nursing home or not. While Sandra and her family all gathered to be with her father he had to be moved to a different area of the nursing home:

they moved him to their end-of-life unit. Maybe in a slightly undignified fashion I think they had him in a wheelchair and he really was very unwell. You know I felt it was slightly undignified. [*Sandra*]

Sandra's experience of this procedure as 'undignified' and she felt the final journey of her father could have been undertaken differently.

In most cases nursing homes recognising that people in their care were close to the end of their life, and informed relatives to enable them to make decisions about their presence. Austin reported the nursing home looked after his sister for three weeks prior to his father's death including providing her with meals so that she could be present during that period:

I would have to say they were equally concerned about myself and my sister as they were for my father. My sister chose because she had been away for so long to stay with my father each evening. They looked after her. They fed her. I would have to say the care was just superb and that ran for three weeks like you know because he was a stubborn old man you know. [Austin]

Austin perceived his father's long departing as resulting from his father being 'stubborn' but throughout the process the nursing home enabled the family to be present. The nursing home enabled his sister to make the choice to be with her father.

Daniel had full confidence in the nursing home staff pointing to the foresight of the nursing manager regarding his uncle's decline filled him with confidence regarding his care. Daniel felt included in his uncle's dying process:

Oh no quite the opposite the erm, I don't think they are called the matrons anymore the nursing manager what's her name, X, was excellent you know. And she knew she said 'he's making his way' was the way she kind of put it you know. She knew he was getting weaker and weaker he'd had various infections. [Daniel]

Foresight regarding his uncle's outcome and knowledge regarding his decline was taken to signify good care in the sense that she had kept a close eye on his uncle progression.

Silvia also appreciated the foresight of the nursing home in anticipating her mother's death, as they called her brother to inform him, giving him an opportunity to be present:

the nursing home had called my brother and he was on his way in the morning when she died. So in terms of end of care very pleased about how they dealt with the whole thing. [Silvia]

Silvia lived abroad and was unable to be with her mother when she died, however, her brother was on his way to the nursing home but their mother had passed away prior to his arrival. Even though neither Silvia nor her brother was with her mother, Silvia had no complaints about the end-of-life care her mother received.

Jessica spoke of the care the nursing home took of the family during the time that her mother was dying:

Oh they were so good they really were so unbelievably good down there and you know every one of us said the same thing. You know they were just and they explained everything along every step of the way and then the time came to give her the morphine and they called us in and they told us you know this was, this was what was going to happen. But she had her whole family around her for 3 weeks. It wouldn't have happened at home. We wouldn't have got and yet we knew that if we needed someone we just had to ring the bell and they were there and they weren't intrusive. You know. You couldn't say enough ... as far as we are concerned she died in her own bed at home. She was relaxed. [*Jessica*]

Jessica reported a good experience for her and her family during the period her mother was dying. She also perceived that her mother had a good death. This was important for her. The nursing home enabled the family to be with their mother to such an extent that Jessica believed that: 'It wouldn't have happened at home'. Jessica and her family were afforded the space to be with and be present to her father. Jessica's family experienced the nursing home grounding the essence of presence for their father. As Heidegger (1977 p.9) stated 'lying before and lying ready characterize the presencing of something that presences'. Central to the presencing of something that presences within the nursing home was the ringing of the bell and being non-intrusive as a means to an end as well as the human activity (Heidegger, 1997) of the nursing home and the family and their father around it.

Rosy stated that her family did not have a care plan as her father did not need one when he was admitted. However she was more concerned about the end-of-life process and sought out guidance of what to expect from her aunt (her father's sister).

So she's 80 now, 82 probably. So as I said I looked for guidance on what happens and then I could sort of see the progress because I would visit Dad and you'd see it with other people that were in there before him. Things that might have happened you know and you were sort of saying that this seems to be the next step and then you think you're prepared for it but you're actually not, you know what I mean. You think it's going to be okay or it is okay but it's not so. [*Rosy*]

Rosy's aunt who she turned to for guidance on the process of dying was in her 80's. Rosy gives voice to wanting to know and understand the process of dying almost as a step by step process. She wanted to be aware and ready for when the time came but realised that you can never be prepared. Losing a parent is not easy no matter how it happens and there is no blueprint as Rosy

discovered. Rosy was the person in her family who was delegated as the decision maker in relation to her father and found this difficult hence her need to make sure she was doing right:

And again I'd ask a sister and stuff like that so they would have said, look; maybe Dad mightn't have wanted it plus the complications of it. You know because Dad was an awful man for pulling stuff out, needles everything, when he'd be in the hospital so. All our decisions like give you the phone numbers if you wanted to ring them and just check, you know what I mean that it wasn't just my decision, you know. [Rosy]

Even though Rosy had the sole responsibility for decision making regarding her father's care she checked with other members of her family thus drawing them into the decision making process (Pala-Lopez, 2009). Rosy had seven siblings and her mother but the final decisions rested with her as her parents were separated. This added another dimension to the process of caring for her father and needing to aware of every step of the way. However Rosy was unable to be with her father when he died:

you know they knew I had a family as well to come home to and stuff like that and things to do. So I went home because I was happy enough that both of them [named nursing staff] were there you know so. And then throughout that night then I think they had said they'd ring and let me know and it's very hard I suppose to know when anybody is going to pass away. And they said that there was a nurse sitting there I think, I don't know whether it was with him or outside the door, I forget, but it would have been about a quarter to five I think when I got a call to come up, by then he had passed away so. As I said they were very good. [Rosy]

Rosy was assured that her father did not die alone and that someone was with him.

Similarly Ciara and Ruth were unable to be with their father when he died as they made the decision not to be there. From Sartre's (1985) perspective Ciara and Ruth made a choice:

In one sense choice is possible, but what is not possible is not to choose. I can always choose, but I ought to know that if I do not choose, I am still choosing (Sartre, 1985 p.41).

In Sartrean terms we can choose one way or another, they can choose to be with their loved one or not but they make their choices in the social setting they find themselves in. Ciara and Ruth explained that at the time of their loved one's death there was even a flu outbreak in the nursing home and restrictions had been placed on visitors. They report being the only family allowed in during this outbreak so that they could be with their loved one at his death. The night before their father's death the nursing home staff had asked for a suit for their loved one and enquired

whether or if not they would like to be called if he died during the night. They declined this offer taking into account the flu outbreak in the nursing home:

... so we knew it was imminent and the night sister had said to me will I ring you during the night and I said listen don't the place is in lock down because of the infection control. It is not going to make any difference to us if it is 3 in the morning or 8 in the morning. So they did check and we said no. [Ciara]

They received a call at five to eight in the morning to say that their father had died deciding not to go immediately but rather provided the nursing home an opportunity to get everything sorted before they went in to see him.

Chapter 7: Journeys End

The withdrawal of the living from the moribund, and the silence that gradually spreads around them, are continued when the end has come. This is seen, for example, in the treatment of corpses and in the care of graves. Both have today passed largely out of the hands of the family, relatives and friends, and into the hands of paid specialists. The memory of the dead person may remain fresh (Elias, 1985 p.25).

This chapter explores Elias' observations from the perspective of the stories some participants told of their journey through the final stages of being with their loved one in the nursing home. It also examines how relatives move forward and undertake their life post nursing home.

After Death

The participants in this study spoke of the care their relatives received after they had died. Abbie and her husband were away when their mother-in-law/ mother died.

she was brought to the funeral home and then she was brought back to G and they were so good and that to the family and so respectful of her when she did die and that. She was laid out in the special room that they have there and that and even on the morning that she was going to the church was absolutely beautiful because they did a guard of honour and sang. It was lovely and then some of the staff came to the funeral and that. [Abbie]

Abbie's account of after-death care of her mother-in-law reflects Elias' (1985) assertion that the treatment of the body has been removed from the family in to the hands of specialist. This is seen in Abbie's mother-in-law been removed to a funeral home and then returned to the nursing home. The care of the body is concealed from the family through the intervention of the funeral home and nursing home and they present the dead to families in an acceptable manner. This can be interpreted as another step in the letting go of the loved one in the process of death.

In a similar manner Jessica and her family accepted the accommodation provided by G for her mother. Whatever her expectations were the nursing home surpassed it:

She died on Friday night the undertaker came and took her off on Saturday morning and they rang me at 2 o'clock to say she was back. Now I expected her to be in the little mortuary down there, the little chapel. And when I went down they had the room cleared out, her bedroom cleared out and they had the coffin in her bedroom and that was on Saturday and they kept her until Monday morning. We removed her from there straight to the church on the Monday morning. So you know we had all that and on Monday morning we had a few people who met us down there a few people that were going to accompany us up home and they had tea and coffee and you know it just and it was just they were so good. [Jessica]

For Jessica the nursing home took care of her and her family during the period prior to the removal of her mother to a Church. Jessica indicates that this was a service provided to her family by the nursing home which she had not expected. The availability of tea and coffee for Jessica's family and friends prior to the removal of her mother rendered her speechless. This for

her is contrasted with her experience of her father-in-law's death in a different nursing home. Jessica and her husband received a phone call from the nursing home informing them that:

Your father X had bitten the bullet. Well I mean we laugh, we laughed since. He had bitten the bullet. He has bitten the bullet. He obviously heard that expression and thought this is how you tell people. [*Jessica*]

Jessica appreciates the experience of her mother's passing and after care when she contrasts it with her father-in-law. The care and attention that she received in G contrasted strongly with the poor communication of her previous experience which she stated 'has since closed down'. Jessica's story illustrates previous experiences of nursing homes shape people's perceptions when they encounter another one.

Sandra indicated that time was given to her and her family to be with her father after he died. This for her was an important aspect of his care. However she suggested that once he was removed from the nursing home the nursing home was keen to have his personal possessions removed by his family.

They gave us plenty of time to be with him and no pressure a couple of days later they started trying to get rid of his belongings and sort that out so we had to go in and pick those up. [*Sandra*]

Sandra suggests that she was under pressure to collect her father's possessions as she indicates that they 'started trying to get rid of his belongings'. By using the words 'we had to' suggests that she was not ready to go back to the nursing home and perhaps would have appreciated more time prior to this.

Callaum also accepted to have his mother waked in the nursing home removing her straight to the church:

She died very peaceful death. I was there with Dylan and H (names staff member of the nursing home) was there with us and so was Z (another staff member) and you know they of the religious brigades. And we had her anointed beforehand by the priest who comes to say mass there for them. He anointed her in January so I mean she as far as we were concerned it was a Rolls Royce exit all the way. And then we had her waked in that place then because there were a lot of people coming from Y (names area) and all over so we used the room at the very end of the corridor as the if you like a reception room where the remains were and where cousins came and we had sandwiches and we all went off then to the church. So like they couldn't have been more helpful to us. [*Callaum*]

Callaum and Dylan chose the nursing home to wake their mother because they were comfortable with her death and all the facilities that was afforded to them. They had all their family around them prior to the removal to the church.

Unlike Callaum and Dylan, Loran elected not to have her father waked in the nursing home. Loran was also offered a room to wake her father by the nursing home.

after that how G you know I suppose gather up his stuff and they had a room available to us to say prayers, they made a place available to us if we wanted family members to come and kind of like a wake or you know that kind of a thing. We didn't go for that we went to the funeral home basically and had people come to the funeral home [Loran]

When she went into the nursing home after his death they had all his belongings available for his family. Loran family elected to take control and made arrangements for their father's funeral.

Living Without the Nursing Home

Some participants in this study found it difficult not only to reconcile themselves to the loss of their deceased family member but to get used to the broader life changes that went hand in hand with this, such as no longer visiting the nursing home on a regular basis and interacting with staff that they may have had long-standing relationships with. A number of the participants had been visiting the same nursing home for years as a result of the fact that their loved ones were suffering from chronic conditions or terminal illnesses. Holly remarked that:

I found it a huge part of my life had gone because I had gone up there every day. Well probably 6 to 7 days a week for 2 years except for an odd break and I became I knew everybody....It was like a big family that they sort of put their arms around to and suddenly that was gone [Holly]

Holly experienced the loss of her relationship with the care staff as akin to that of losing a family due to the large amount of time she spent there and the care that they provided to herself and her mother while her mother was resident there. Holly even contemplated going back there to help out in order to keep in contact with the staff there:

I found that really hard to the point that I was nearly saying oh I think I'll even come up here and do the teas or something or whatever. But it was a huge part of my life that suddenly went because I think when even though Mum was dying they were giving us as a family as much care as they you know. They were that sort of the spine that held you up straight. [Holly]

Holly missed the support that was provided for the family by the nursing home and contemplated volunteering there in an effort to regain the support that they offered there. While palliative care services may provide adequate support when their loved one is dying it may be the case that continuing this support for a time after the death of their loved one may be beneficial. In any case there does appear to be some need for support after care service for relatives of those in end-of-life care.

Holly's story encapsulates what Heidegger (1962) stated as the bringing close of the world:

If Dasein discovers the world in its own way [eigens] and brings it close, if it discloses itself to itself its own authentic Being, then this discovery of the 'world' and this disclosure of Dasein are always accomplished as a clearing-away of concealments and obscurities, as a breaking up of the disguises with which Dasein bars its own way (Heidegger, 1962 p.167).

The world that was being brought close was bereavement for her mother. Holly was part of the nursing home world and the death of her mother removed her from that world. The clearing away of her concealments happened when she attended a mass for former residents. To herself she had not grieved for her mother to the point she found it difficult to travel the road of the nursing home.

I was now I found it on my on a personal level I just found it really hard to go back to G but they had at Christmas in November they have a day for all the deceased a mass which was fantastic. Because I even had like this is so stupid you know I even find driving along the road by it was as if my mother died and you know I it was like my father died and then a month later my mother fell and broke her hip and it all started. Everything happened. And then suddenly my mother died. And then actually what happened I became very ill last summer ... I just didn't deal with my mother's death. Until I went to G for that day. [Holly]

Holly's experience is reflected in the literature as it is reported that relatives find it difficult to cope with the death of their loved ones (Hasson *et al*, 2010). The nursing home that Holly's mother was in could be seen as providing a service to families enabling them to grieve for their loved one.

Cian also acknowledged that he missed visiting the nursing home as his sister was there for a number of years:

I've been back since myself and my brother were back since for the annual mass there just to meet staff and chat to them again because it's funny how they're such a part of

your life for such a long period and then once the person in the middle goes your connection is absolutely cut. [*Cian*]

It is this severing of the connection built over a period of time, for some, years that can be difficult to deal with. While families have to cope with the loss of a loved one, they also have to deal with the loss of others who have come into their lives through caring for their loved one. In some way it is also a loss

Other participants spoke about sharing nursing home stories with friends and relatives.

Abbie concluded:

And speaking to other people that have had people in nursing homes you know I realise how lucky we were. My own mother a couple of years back we didn't have the choices what we had with this Fair Deals for my mother in law you know. And you get such a nice place you know what I mean. [*Abbie*]

Abbie realised that the changing system of providing nursing home care through the Fair Deal programme enabled her mother-in-law to have a better experience than her own mother. Through the stories others in her circle told she realised concluded that she was 'lucky'.

Ciara and Ruth also make mention of the fact that the staff become a part of your life while your loved one is resident there and that you miss them afterwards. They states:

They were just like a family up there. [*Ciara*]

Ciara voices what a number of participants stated nursing homes became part of their family particularly when a loved one was a long term resident.

Chapter 8: Conclusion and recommendations

Stories are not models of correct responses to dilemmas, told so that others can act that way in similar situations. They teach us how to be serious about how we act wherever we find ourselves. If they are models of anything, the stories model moral sensitivity to what makes each situation unique and each decision difficult (Frank, 2006 p.7).

The purpose of this report was to develop an understanding of families' experiences and their perceptions of the end-of-life care their loved one received in a nursing home setting. The research approach taken sits within a rich research tradition whereby we "always question the way we experience the world, to want to know the world in which we live as human beings" (van Manen, 1990 p.5). Within this study the lived experience of relatives in the world of end-of-life care in a private nursing home was explored, how they constructed and gave meaning to the situation they found themselves in. While it was the world of the nursing home that was originally the beginning point of the study the story began for most relatives recalling the journey they undertook from the moment they realised that there was something not quite right within the world of the relative. Thus the report illustrates how families understand and give meaning to their situation: first in caring either in their own home or their relatives home and eventually moving to the next juncture in their journey, the admission of their relative to the private nursing home.

The following lists the main findings of the study:

1. This study provides some understanding to the level of care provided by families for their loved one. It unfolds the intergenerational family interaction within Irish society.
2. All participants spoke about making an initial intervention into their relatives' lives by providing the care their loved one could no longer provide for themselves. Spouses, children, sisters, mothers and daughter and sons –in-law relayed their stories of negotiating the changing relationship with their loved one.

3. Participants related stories of learning to live with loss: the loss of the former relationship they had with their relative; their ability to keep the promises they had made to their loved one; their ability to negotiate all strands of life from work to family commitments; and their own personal lives.
4. The majority of participants spoke about negotiating the unfamiliar realm of health care to seek assistance in providing care within the home.
5. The majority of participants told the story of their personal struggle in seeking a nursing home and how it was the last resort in providing care for their loved one. This in itself negates the idea that families no longer care for their elderly.
6. Choosing a nursing home was based upon both rational and intuitive factors. Essentially what was required was a home away from home.
7. Families engaged in strategies to ensure that their loved one was cared for: frequent visiting; non-set time of visiting; observation of staff and observation of their loved one.
8. An unintended consequence of nursing home care reported by families was the care provided to family members in addition to that provided to their relative.
9. The majority of participants in this study acknowledge that level of professionalism in the care of their relative however for some there was a cultural competence issues relating to understand the nature of Irish society and culture.

10. Families advocated on behalf of their loved ones from the perspective of their lived knowledge of the individual accrued over a lifetime of shared experiences.
11. This report illustrates disconnect between professional knowledge and lexicon and the lay knowledge which is expressed through love and belonging.
12. All participants expressed contentment with the care provided to their loved one at the end of their life.
13. Families recounted the after death experience in a private nursing home was positive.
14. Some relatives in this study struggled with life after the nursing home as it had become a feature of life. It left a void which was more acute for those who became isolated through the care of their loved upon re-entering society as a non-primary carer.

In conclusion this report provides an insight into what families provide to older adults in Ireland. Families intervene in the lives of their loved one to provide care and support when it is necessary. The patterns of family reciprocity this study uncovered included substantially giving of the self in terms of time, energy and in some cases financial assistance. Some participants emanated from what is termed 'the sandwich generation' thus providing care for both their offspring and their older adult members of their family. In an Irish context this study would suggest that while originally a nursing home was considered a place of last resort the majority of participants had positive experiences both for themselves and their loved ones in the private nursing home sector.

Recommendations for Practice

We advocate that the following recommendations be implemented with immediate effect. This will benefit all members working in a nursing home environment.

1. Understanding the ‘why’ of choosing a nursing home

We recommend that healthcare professionals need to be sensitive to the range of feelings associated with surrendering a loved one to nursing home care and the emotional turmoil many families experience during this transition.

2. Cultural Training

We recommend that all Nursing Homes whether private or public implement a cultural competence training programme for all individuals working in the nursing home environment. This programme should be developed to create Irish cultural awareness amongst staff regardless of culture of origin.

3. Taken-for-granted language

We recommend that health care professional demystify the taken-for-granted language of everyday life in a nursing home. In particular this pertains to language used to discuss end-of-life care issues.

We recommend that all health care professional working with older members of Irish society actively remove negative language from their lexicon when public utterance are made by elderly care practitioners. Phrases such as ‘bed blockers’ are both inflammatory and discriminatory towards older people in a hospital setting.

4. Caring for their loved one

We recommend that the nursing home creates a real partnership of care when it comes to end-of-life care.

5. Family dynamics

We recommend that nursing homes take cognisance of family dynamics so that the individual who were the primary carer prior to nursing home care do not get marginalised when it comes to decision making.

We recommend that matters relating to securing a nursing home place should be discussed with the primary carer even if they are not part of the initial enquiry, this would alleviate the notion of a nursing home being foisted upon an individual as a fait accompli.

6. Revisitation of the End-of-Life care plan

We recommend that the end-of-life care plan is revisited regularly particularly where the resident is enabled to have a voice.

7. Creating a connection between community, hospital and nursing home

We recommend easier routes to find access information to maintain a relative in their home.

We also recommend access to information regarding nursing homes that would enable relatives to make decision without feeling pressured to choose by hospitals.

8. After death supports

We also recommend that where possible relatives are facilitated to remove their loved ones possession within a time-frame that accommodates bereaved parties.

We recommend that a longer period of after death support be provided for family members.

Recommendations for Future Research

- A. We recommend that an in-depth study on the experiences of health care professional working in nursing homes be undertaken.

- B. We recommend further research on the nature of lay and professional knowledge of elderly care in acute hospital setting.

- C. We recommend that research be carried out to evaluate cultural competence training within the nursing home setting.

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Appendix 1 Introductory Letter

Dear [Participants Name]

My name is Eileen Courtney and I am a nurse and a lecturer in nursing in Dublin City University. Together with my colleague, Mel Duffy and our research assistant Barry Kestell, we are working on a research study exploring the experiences of families who have had a relative who died in a nursing home. We are especially interested in your experience of being involved in the care of your relative at the end of their life and we are conducting the study to see if this process could be improved in the future. We are writing to ask for your help with this study.

Our request has been forwarded to you by [Name of Nursing Home] who agreed to contact you on our behalf. We do not have any details about you or your relative and [Name of Nursing Home] will not be aware of who agreed to take part in the study.

Please take the time to read the Information Leaflet enclosed with this letter. It provides important information about the study and what you would be asked to do if you agree to take part. You do not have to be part of the study if you do not want to, and if you agree and then change your mind and you can choose to withdraw from it at any time if you wish without having to explain your decision.

If you have any questions about the study please feel free to contact either myself, Eileen Courtney, or my colleague Mel Duffy. Our contact details are included with the Information Leaflet. If you would like to contact an independent person about the study please contact – The Secretary, Research Ethics Committee, Dublin City University, Dublin 9.

Thank you for reading this letter. We hope that you will consider being part of our study as we greatly value your experience.

Yours Sincerely

Dr Eileen Courtney

Dr Mel Duffy

Appendix 2 – Information Leaflet and Contact Consent Form

What is the study about and why have you contacted me?

What is the Study About and Why is it Being Done?

This study is about exploring the experience of families who were consulted in planning the care for their relative at the end of their life. We hope that by better understanding these experiences we can help to improve this process for other families in the same situation in the future.

Who is Doing the Study?

The study is being undertaken by –

Dr Eileen Courtney a Nurse and a Lecturer in Nursing in Dublin City University.

Dr Mel Duffy a Sociologist and a Lecturer in Sociology in Dublin City University.

Mr Barry Kestell a Research Assistant in Dublin City University

Why Have I Been Chosen?

You have been asked to be involved in the study because of your experience in this area. You are one of a number of families who have been asked to participate in the study.

How Did You Contact me?

Our request has been forwarded to you by [Nursing Home Name] who agreed to send on this letter on our behalf. [Nursing Home Name] did not give us any information about you or your relative and they will not know who agreed to be part of the study.

What does taking part in the study mean?

What Will Happen If I Agree to be Part of the Study?

If you agree to be part of the study one of the research team will telephone you to arrange to meet with you to talk about your experience. You can talk to us on your own or if you prefer you can have another family member (or members) present. We will arrange the interview for a place and time that suits you.

We will need to record the interview so that we can listen to it again and write out what you say. This will help us to remember your story and make sure that we do not forget any important information that you give us.

How Long Will it Take?

This is really up to you but it should take no more than one hour or thereabouts.

What Happens if I Change My Mind?

Taking part in the study is completely up to you. You can change your mind at any stage without having to explain why.

Are There Any Benefits to Taking Part in the Study?

There are no personal rewards for being involved in the study except that it will give you a chance to have your say about your experience. However, we hope that the findings of this study will help to develop and improve practices that could benefit other families in situations like yours in the future.

Are There Any Costs From Being Involved?

The only cost of being involved in the study is the time it takes to talk to us about your experience.

What If I Don't Want to Be Involved?

If you do not want to be involved in the study we will not contact you again.

What Will Happen to the Information Collected From Me?

Confidentiality

We will treat all the information you give us in the strictest confidence.

We will use a false name during the interview and when we type it we will include no information that would allow anyone except the researchers to identify you. Once your interview is typed we will destroy the original recording.

Only the researchers will have access to typed interviews. These will be stored on a secure computer that is protected by a password. We will not publish or share your name with anyone else.

Where can I get more information?

If you have any questions about the study please contact either of the following

Dr. Eileen Courtney

Dr. Mel Duffy

School of Nursing & Human Sciences

School of Nursing & Human Sciences

Dublin City University

Dublin City University

Telephone (01) 700 8525

Telephone (01) 700 8533

Email Eileen.Courtney@dcu.ie

Email Mel.Duffy@dcu.ie

What do I do next?

What do I need to do next?

If you think you might like to part of the study please return the Consent Form (yellow form) in the Freepost envelope provided. We will then contact you to discuss the study and answer any questions

you might have. If you agree to be part of the study we will make arrangements to meet with you (with other family members if you wish) to talk about your experience.

If you do not want to be involved in the study you do not have to do anything.

Thank you for taking the time to read this letter and information leaflet.

We hope that you will agree to be part of our study.

Please return this page in the stamped envelope provided if you are willing to discuss being part of our study.

You are agreeing to be contacted by a member of the research team to talk about being part of the study and have your questions answered. You are free to refuse or change your mind at any time.

I am willing to be contacted by a member of the research team to discuss being part of a study exploring my experience of helping to plan care for my relative at the end of their life.

NAME: ----- please print

Address: -----

Phone Number:-----

The best time to call me is:-----

Thank You.

Appendix 3 – Interview Prompts

- How did you choose the nursing home?
- How long was your mother/father/brother/sister in the nursing home?
- Did you find that whole period of trying to choose a nursing home difficult?
- How would you what would you like to see happen to make that easy for you for other people?
- What would help in that transition?
- Can I ask how did you come to the decision to bring him to the nursing home?
- And you were happy with how they managed his death?
- And how did you feel that was manifested like in your sister's case?
- Do you mind me asking if there was a plan put in place with regard to care for your sister with the nursing home? Did they kind of liaise with you about it?
- I was just wondering when you were talking about male nurses looking after female patients was there any question marks at any stage over the behaviour of the nurses?
- Because you were doing this second time around you knew this time what exactly you wanted did you?
- May I ask you what age was she?
- Did you actually feel that there was a lack of knowledge for Irish traditions or understanding of Irish culture, was that where you are coming from?
- And you were happy with the care plan that was?
- Would you have much consultation with say with the doctors regarding your father's care?
- You know you said your dad changed his mind on a number of occasions about the care would he have approached the nursing home?
- Do you think going into the nursing home extended her life?
- What were his wishes at the time?
- Near the end stages how did that work out for you?
- And how did you feel the nursing home handled kind of the terminal phase the last kind of few hours or days?
- Is there any suggestions that would make a difference to the care. That would make the care better that would make, would have made you as a family feel better?
- May I ask you that when it came to her death and prior to that were ye consulted? Did you feel that you were part and parcel of her care?
- Can I bring you back X to what you said about if you like other European carers. Do you think it was age in relation to knowledge and experience of working with older people or do you think it is cultural from your perspective?
- And you mentioned at the start about vascular degeneration you know how that kind of lead to him entering the nursing home. Would you like to talk about it?
- And after your mum died the aftercare were you happy with that?
- Is there anything would you suggest any improvements or something or anything that would have helped you better?
- Finally, is there anything else that you would like to add?

Appendix 4 – Written Consent for Participation in the Study

Families Experiences of End of Life Care in Nursing Homes

Investigators

Dr Mel Duffy, School of Nursing & Human Sciences, Dublin City University.

Dr Eileen Courtney, School of Nursing & Human Sciences, Dublin City University.

Mr Barry Kestell, School of Nursing & Human Sciences, Dublin City University.

Please indicate that you have agreed to be interviewed for this study by completing this form.

Please circle yes or no for each question -

I have read the Information Leaflet and understand what this study is about YES / NO

I had a chance to ask questions about the study YES / NO

My questions have all been answered YES / NO

I know that this interview will be tape-recorded YES / NO

I know that if I want I can stop the interview at any time, or I can withdraw from the study at any stage without having to explain why YES /NO

I understand that, in order to minimise the chance of being identified, my name will not appear on any interview transcripts, and that the researcher will not attribute any comments to me personally
YES / NO

I have read and understood the information in this form. My questions and concerns have been answered by the researchers. Therefore, I consent to take part in this study

Participants Signature:

Name in Block Capitals:

Researcher's Signature:

Date:

Further contact:

Dr Mel Duffy, School of Nursing & Human Sciences, Dublin City University, Ireland
mel.duffy@dcu.ie

01-7005833

Dr Eileen Courtney, School of Nursing & Human Sciences, Dublin City University, Ireland
eileen.courtney@dcu.ie

01-7008525

Rita Gallagher, Nursing Homes Nursing Projects [NHNP], 193 New Cabra Road
Dublin 7, Ireland

