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Factors that influence good end of life care in long stay residential care for older people

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PG Dip in Gerontology, MSc (Nursing), Dip. Management, BSC (Hon), RPN, RGN

A thesis submitted to the School of Nursing and Midwifery, National University of Ireland, Galway for the degree of Doctor of Philosophy (Ph.D)

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July 2017
Declaration

I declare that this thesis, submitted to National University of Ireland, Galway for the degree of Doctor in Philosophy (Ph.D.), I hereby certify that this thesis has been composed by me and is based on my own work, unless stated otherwise. No other person’s work has been used without due acknowledgement in this thesis. All references and verbatim extracts have been quoted, and all sources of information, including graphs and tables, have been specifically acknowledged.

Date ________________________________

Signature ________________________________
Abstract

Aim: To generate a grounded theory to understand the factors that influence end of life care in long stay residential care homes.

Background: In this study, the term of ‘end-of-life’ is described as a continuum, rather than a point in time for residents in long stay residential care. Literature has revealed various factors that impact on end of life care, however, little research has examined end of life care for older people in long stay residential care homes from the simultaneous perspectives of residents, their relatives and nursing staff.

Methods: In-depth semi-structured interviews were conducted with a purposive sample of 41 participants selected from 3 publicly managed long stay residential care homes. Interviews were conducted over three times intervals and were analysed using constant comparative analysis, theoretical sampling and memo writing according to the Straussian Grounded theory (Corbin & Strauss 2008)

Findings: The emergent core category was ‘Dying well within a tapestry of relations’. The metaphor ‘tapestry’ is used to describe the way in which all categories within the model weave and relate to one another to focus on end of life in residential care. A model to depict a substantive theory of dying in residential care was used to illustrate four inter-related categories which were: ‘Ethos of Caring’, ‘Organising Care’, ‘Living Environment’ and ‘Resident Centred Relationships’ describes the influencing factors to dying well. Dying well was the chief concern to all participants as were the relationships between residents, care staff and relatives which impacted on residents’ end of life care.

Conclusion: Living well while in care was important to dying well. The relationships that existed between residents, staff and relatives sustained them throughout dying. The triad of relationships were key in having a good death, and this was explained further using the framework of relational ethics (Bergum & Dossetor 2005) which places emphasis on communication and relationship building. The model of compassionate relationship centred care (Dewar and Nolan 2013) was also used to provide an understanding the practices and processes that support compassionate care.

Keywords: end of life care, grounded theory, long stay residential care.
Publications arising from this research

Butler, M (2017) Dying well in a tapestry of relations, factors that influence end of life care for older people in long stay residential care units in Ireland. Oral Conference presentation. 15th World Congress of the European Association for Palliative Care EAPC Madrid, Spain, 18-20 May.
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To Liam and Sarah, for supporting me throughout and on many occasions with enjoyable outdoors pursuits and great music on the way! Thanks.
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<th>All Ireland Institute of Hospice and Palliative Care</th>
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<tbody>
<tr>
<td>CHO</td>
<td>Community Healthcare Organisation</td>
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<tr>
<td>CSO</td>
<td>Central Statistics Office</td>
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<tr>
<td>DH</td>
<td>Department of Health in England and Wales</td>
</tr>
<tr>
<td>DoH</td>
<td>Department of Health, Ireland</td>
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<tr>
<td>DML</td>
<td>Dublin Mid-Leinster</td>
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<tr>
<td>EAPC</td>
<td>European Association of Palliative Care</td>
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<tr>
<td>FETAC</td>
<td>Further Education and Training Awards Council</td>
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<tr>
<td>HIQA</td>
<td>Health Information and Quality Authority</td>
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<tr>
<td>HFH</td>
<td>Hospice Friendly Foundation</td>
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<td>HSE</td>
<td>Health Service Executive</td>
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<tr>
<td>IAPC</td>
<td>Irish Association for Palliative Care</td>
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<td>IHF</td>
<td>Irish Hospice Foundation</td>
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<td>IPMCA</td>
<td>Irish Palliative Medicine Consultants Association</td>
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<td>MMSE</td>
<td>Mini Mental State Examination</td>
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<tr>
<td>NCAOP</td>
<td>National Council on Ageing and Older People</td>
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<td>NMBI</td>
<td>Nursing and Midwifery Board of Ireland</td>
</tr>
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<td>NMPDU</td>
<td>Nursing &amp; Midwifery Planning and Development Unit</td>
</tr>
<tr>
<td>PACE</td>
<td>PAlliative Care for Elderly people</td>
</tr>
<tr>
<td>RCPI</td>
<td>Royal College of Physicians</td>
</tr>
<tr>
<td>SPC</td>
<td>Specialist Palliative Care</td>
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Long Stay Residential Care Homes- terms used.

Long Stay Residential Care Home: In this study, the term long stay residential care home is the umbrella term to reflect permanent dwelling for an older person. In long stay residential care units, nursing care is continuous for older people towards the end of their lives. Similar terms used are HSE Extended Care Unit or Community Nursing Unit which are facilities run by the Health Service Executive. These institutions generally provide accommodation for older people who are in need of care for medical reasons (DOH 2014). The term Residential care is used in regulation documents such as the Health Act of 2007, Health Information and Quality Authority.

Nursing Home: Nursing home is a similar term used and is sometimes used interchangeably with residential care units, especially if it has been used in referenced material. A nursing home is a place for older people who do not need to be in a hospital but who require more assistance or treatment than is available at home. A Private Nursing Home is a long stay residential care home which is run as a private business for the care and maintenance of dependent persons. As the term implies, these are nursing homes established by private individuals or by companies in the private sector, which are run on a profit-making basis (Longs Stay Activities DOH 2013). Nursing home is a term that is frequently used by organisations such as Nursing Homes Ireland and Age Action.

HSE Welfare Home: A home run by the Health Service Executive. These institutions generally provide accommodation for older people who are in need of long or short-term care for medical or other reasons.

Voluntary Home/Hospital for Older People: A home run by a charitable non-profit making organisation in which patients are not maintained for the personal profit of the proprietors. This includes all nursing homes run by religious orders as well as homes run by lay charitable organisations.

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accommodation for older people who are in need of long or short-term care for medical or other reasons.

In this study, residential care units/long stay care homes will be referred to as “Care Home A” or “Care Home B” or “Care Home C”.

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Chapter 1    Introduction

1.1 Introduction and thesis layout

The following chapter will include an introduction to the thesis and provides an overview of ageing populations, and admission to long stay residential care and residential care in Ireland. This will be followed by a description of the various perspectives of end of life care and the policies that guide practices. The rationale, along with aims and objectives for the study will also be described, the initial literature review undertaken prior to data collection, methodology, methods used to obtain data for analysis, data analysis, findings, discussion, conclusions, limitations, and implications for practice.

Following Chapter 1, the thesis layout includes Chapter 2 which provides an overview of the literature on end of life care, a rationale for the study, and the study’s aims.

Chapter 3 will describe the study’s methodology and the background, description and rationale for choosing Grounded Theory.

Chapter 4 describes the methods adopted to collect data and describes approaches taken for ethical approval. This chapter includes the process of data collection, analysis, theoretical sampling and the role of literature in data analysis. Data management using NVivo is also described.

Chapter 5 presents the study’s findings and includes the storyline which is presented in a grounded theory format. The core category is described and detailed description of categories, supported by participant vignettes and related literature is provided.

Chapter 6 discusses how the substantive theory fits with the wider literature on end of life care and how it impacts on dying well in long stay residential care.

Chapter 7 concludes the study with its contribution to knowledge, recommendations to practice, research and education.

1.2 Background

Declining health, increased dependency and the approach of death are often difficult subjects to broach in our society. The author’s motivation to undertake this study
originated from her role as senior manager in a long stay residential care, where older people are admitted to long stay care and where they live and ultimately die there. This study took place in three long stay residential care homes, all similar in terms of practice patterns, resident population, social care, resident dependency levels, policies, procedures, rosters, and management styles. However, each unit had contrasted from each other in several aspects, for example; size, capacity, geographical location, urban and rural setting, and structural layout. This is further explained in Chapter 4. Section 4.4.1. ‘Outline of participating long stay residential care homes’. Each care home had full occupancy of residents and had staff ratios of nurses and health care attendants of 4:6. This enabled a good skill mix of nurse to health care attendant. Shift patterns were organised in teams of nurses and health care attendant. A ward manager or person in charge, oversaw the care routines and daily activities of residents and staff.

Providing end of life care for residents involves a number of professional dimensions from general nursing, psychiatric nursing, and palliative care, and requires many diverse aspects of care, including physical, psychological, and social support. Nurses are pivotal in their role in planning and delivering care that is appropriate to the needs of residents in long stay care, and their families.

Prior to the report on end of life care in acute and residential settings (O’Shea et al. 2008), little work was undertaken on death and dying in residential care homes in Ireland. O’Shea et al.’s report highlighted a number of good practices around death and dying in Ireland’s hospitals and residential care homes. However, the study also uncovered deficits in aspects of care such as, continuity of care, the organisation of care, education and training, culture awareness and staffing levels and physical resources, spiritual and psychological support and communication. This study, in some way, continues the work of O Shea et al. (2008), in its exploration of the factors that facilitate end of life care for residents, and does so from the different perspectives of residents, staff and families. However, this study does more, as it reveals the views from residents, their relatives and care staff, who were receiving or providing care in long stay residential care.
This chapter describes the rationale for the study, its aims and purpose. It will provide background information on older people in Ireland, end of life care in residential care homes and the policies that frame end of life care.

1.3 Ageing populations
An increasing ageing population world-wide is as a result of significant improvements in people’s survival, combined with a general decline in mortality rates. The issue of an ageing population is a major social factor across Europe, and one which is likely to have major economic impacts (European Commission 2011). The number of deaths has decreased, which is mostly attributable to improved living conditions, public health initiatives adopted both globally and nationally and the control of infectious diseases, especially in early childhood (Preston 1977). In Western countries, more people are living longer, and the process of an ageing population, how it happens, and the consequences this has on society is a significant issue concerning older peoples’ end of life care needs (Kinsella 2009). In Europe, men and women are expected to live to 80 and 84 years respectively (Kinsella 2009). A European study on public health found that an average 50 year old man could expect to live to 67 years and a woman to her 68th year in good health, which suggests that there could be 23-29 years of illness and or disability expected before death (Kinsella 2009).

In Ireland, the population of older people aged 65 or over increased by 14.4% during the 5 year period 2007-2012 to 11.6% of the total population (Central Statistics Office [CSO] 2013). According to the census of 2016, the population of older people over 65 has increased by 19.1 per cent since the Census of 2011 to 637,567 (CSO 2016).

The number of people in this age group is predicted to increase from 58,200 in 2011 to approximately 262,900 in 2046, (CSO Projected Older Population, 2016-2046). Consequently, both health and social care services need to anticipate and have prepared programmes to support older people to live well in their homes and communities (Jagger et al. 2008).

Despite the increasing ageing populations, there are fewer supports to help older people in their ageing years. Families have become smaller, blended, and dispersed, affected by immigration, family break up and work commitments (International
Labour Office 2006). The size of families is decreasing, the role of extended families is diminishing and perceptions in respect of intergenerational support and caring for older people is rapidly changing (United Nations 2007). More female family members, traditionally involved in caring and supporting roles within the family and community, are working outside this environment (International Labour Office 2006). These demographic and social changes have major implications for planning and the provision of support for older people. The demand to support older people’s care needs in local communities is anticipated to increase as the older population become more dependent.

1.4 Admission to residential care

Older people admitted to long stay residential care are frequently admitted from acute hospitals and community care services such as residential care homes or from private residences. A survey carried out by the Intelligence Unit in the Department of Health (DoH 2013) analysed data from nursing homes regarding the source of resident admissions. Data showed that more than half of admissions (53.9%) to HSE Residential Care Units came from acute care settings and 34.9% of older people from the community went to private nursing homes. Twenty-six per cent of older people admitted to HSE residential care units were directly admitted from their homes and 18.7% from other long stay care homes (DoH 2013). In 2011, 4.1% of men and 6.7% of women aged 65 and over were in receipt of long term residential care, with over two thirds (68.9%) aged 80 or above (Department of Health 2012). The following figure describes the number and type of long stay residential care homes in Ireland (Table 1.1).

<table>
<thead>
<tr>
<th>Table 1.1: Number of Long Stay Units by Category (Information Unit, Department of Health 2013, p.7)</th>
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<tr>
<td>HSE Extended Care Units</td>
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<td>-------------------------</td>
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<tr>
<td>Total</td>
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There are many reasons for admission which have been described as chronic physical illness (50%) followed by dementia (38%) (Department of Health and Children 2006). Other reasons are where further care is needed following an acute
episode, where a caregiver can no longer support an older person in their own home due to chronic illness combined with reduced functional ability and or cognitive ability, and thirdly to provide end of life care (Spilsbury et al. 2011).

The DoH report (2013) also revealed that residents spent relatively long periods in residential care. Most residents (62.2%) had a length of stay for over one year. Just under one-fifth (18.7%) of all long stay residential care home admissions stayed less than three months. There were 3.3% of people living in residential care for ten years or more. More specifically, of this number, 9.3% of older people lived for ten years or more in HSE managed care homes. The largest proportion of residents in long stay units have a diagnosis of a chronic illness or dementia (32.1%), however these figures are possibly underestimated and that it is believed that probably 83% of all residents in long stay care have dementia (Cahill et al. 2012). Consequently, these figures further support that end of life care is a very important dimension for the lives of older people who are admitted there.

1.5 Residential care in Ireland

The majority of people die in institutional settings, with approximately one in four older people dying in long stay residential care facilities (McKeown et al. 2010). Providing care for older people in long term care for older people in residential care presents many challenges, the most significant of which is the provision of good end of life care.

A literature review carried out by Wowchuck et al. (2007) identified many challenges in providing good end of life care, which included; lack of provider knowledge about the principles and practices of palliative care, care provider attitudes about death and dying, the changing profile and disease trajectories of older people in residential care. Staffing levels and available time for dying residents, lack of physician support, families’ expectations of dying residents, lack of privacy for residents and families and hospitalization of dying residents were also challenges identified (Wowchuck et al. 2007). Many of these concerns have been expressed elsewhere (Ellershaw and Murphy 2005, O’Shea et al. 2008, Payne et al. 2009, Casey et al. 2011, Österlind et al. 2011, Gorlen et al. 2013, Nielsen and Gladsam 2013; Hov et al. 2013 Handley et al. 2014), and will be discussed in more detail in subsequent chapters.
1.6 End of life care: different perspectives

There are differences between younger people and older people when reaching the end of life. More people die in older age groups, and the causes of death for older people are often different to that of younger people (Hall 2011). Older people frequently die from cardiovascular diseases, some cancers, neurological diseases such as Parkinson’s and some dementias (Hall 2011). However, many of these conditions have very different trajectories for older and younger people. When an older person becomes ill, there are often likelihoods of improvements and relapses over time, as opposed a gradual progressive decline often seen in younger age groups (Hall 2011, Davies 2004).

In addition, older people have a very distinct set of needs because their problems are often more complex than those of younger people. They frequently are more commonly affected by multiple health problems of varying severity, and the cumulative effect of these can be greater and lead to significant impairment, such as, impaired immobility and cognitive decline. Medications can also have deleterious consequences with the potential of drug reactions and iatrogenic illness. Furthermore, older people can often face problems of acute illnesses which can be superimposed on mental or physical impairment, economic hardship, and can negatively impair socialisation (Hall 2011, Davies 2004). Consequently, residential care can provide appropriate support for older people at the final phases of their lives.

Many older people die in hospital and as age increases more are dying in care homes. Although many would prefer to die at home, often this is difficult to achieve because of clinical and social circumstances (Gott et al. 2004). An audit conducted in 2008/2009 reported that 43% of Irish people died in busy acute hospitals (McKeown et al. 2010). The audit also reported that one in four of these deaths could have taken place in the community if the necessary supports were in place. Information from the Long-Stay Activity Statistics Information Unit (Department of Health 2013) reported that although many people express a preference to die in their own homes, only 26% of Irish people actually achieve that preference. More significantly, up to 22% of deaths of all older people take place in nursing homes or other long-stay facilities in Ireland (Irish Hospice Foundation 2013). This is a
relatively high proportion of all deaths, which places an onus on nursing homes and long stay care facilities to support people who are in receipt of end of life care.

Older people are cared for in a mixture of public, private and voluntary care facilities with an average 92 percent occupancy rate (Department of Health 2011). In recent years, there has been a reduction of public nursing homes beds from 40% in 2001 to 28% in 2010, while the private sector has risen from 45 % to 63% in the same period (Department of Health 2011). Current government strategy proposes that investment in the supply of more and better care for older people in the community and in residential care is a priority, so that older people have the choice to stay at home in their homes if desired, but also that the supply of formal long term residential care for older persons, including residential care is expanded (Government of Ireland 2011).

1.6.1 Older people and end of life care

The term ‘end of life care’ has evolved in recent years. The Irish Hospice Foundation (2017) explains the term end of life care as, “all aspects of the care relating to dying, death and bereavement which is provided towards the end of life. In this context, 'end of life' can be from the point of receiving a life-limiting diagnosis through the months before death, up to and including the final hours - a continuum rather than a point in time”.

They further explain that the term 'end-of-life care' also refers to the care of people with advanced life-limiting conditions, for whom death within 1-2 years is likely, as well as those in the terminal phase of illness. It also encompasses care of the bodily remains of the deceased person (Irish Hospice Foundation 2017).

Prior to this, a report by the Irish Hospice Foundation and HSE (2008) indicated that end-of-life care is relevant in two scenarios: (1) where there is the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death (HSE and IHF 2008).

Earlier studies from the perspective of older people in residential care were concerned with the issues that older people prioritise at this time (Catt et al. 2005,
Clarke & Seymour 2010) and what interventions are effective in providing support to frail older people and their carers (Jones, O’Connell & Grey 2003). Some researchers focused on what older people’s particular experiences are with end-of-life care, especially in relation to matters of communication and decision making (Aldred, Gott & Gariballa 2005, Seymour, Ingleton, Payne & Beddow 2003, Tetley, Grant & Davies 2009) and others have involved older people in the last phases of their lives to assess understanding of their experiences and views about care provision or key care concepts (Katz, Sidell & Komaromy 2000, Lloyd-Williams, Kennedy, Sixsmith & Sixsmith 2007). Although these findings are reporting on studies predominantly in international locations, these studies have relevance to older people in Irish settings.

1.6.2 Nurses and end of life care

A recent study conducted by the Phelan & McCormack (2013) in collaboration with the All Ireland Gerontological Nurses Association defined what the role of the nurse is in residential care and how it should be developed in the future. The study highlighted the importance of recognising the expertise of gerontological nurses in residential care settings and the evolvement of their role.

Gerontological nursing in residential care is acknowledged as a nursing specialty, requiring specific knowledge and involving different roles such as leadership, nurse prescribing, administration of medications, coordinating multi-disciplinary teams, nutrition and wound care specialists. Furthermore, it is argued that gerontological nurses should be facilitated to develop additional roles such as clinical nurse specialists, advanced nurse practitioners and be involved in palliative and end of life care (Phelan & McCormack 2013), and that this expansion in nursing roles should be based on improvement of quality of care for older people (Mezzy 2005). The need for ongoing palliative care education for nursing staff in providing palliative care for older residents nearing of end-of-life care is also called for (Waldron et al. 2008, Ronaldson 2008, Ellershaw & Murphy 2005, Froggatt and Hoult 2002). Palliative care education for older residential aged care nurses is widely recognised as an essential requirement in the delivery of skilled palliative care to older residents (Froggat 2000, Cohen et al. 2002, Cheek et al. 2003, Hanson & Ersek 2006, Phillips et al. 2006).
The nurse’s intervention contributes to team work and collaboration between medical staff, families and the wider multi-disciplinary team with the ultimate objective to deliver comfortable care to the resident and their families (Lopez 2009, Morrison 2009). Therefore, throughout the uncertain trajectory towards death, it is important to understand nurses’ contribution to delivering quality outcomes and good end of life care for residents and their families.

1.6.3 Families and end of life care

Families, in their role as carers, experience of end of life care in residential care differently to that of nurses and residents. It is acknowledged that families’ experiences and their perception of death and end of life care forms a significant part of quality end of life care, however there is very little research conducted on the views of family members’ perspectives of end of life care (Kendall et al. 2007). Family members often bear significant emotional and physical stress at levels that can adversely affect their own health, especially if they are old and vulnerable themselves (Bern-Klug 2008). It is therefore important to address their concerns. Research on the perspectives of patients, care providers and families has found that quality of life at end of life care was a dynamic process that was negotiated and renegotiated among each participant and was a process moderated by individual values, knowledge and preferences of care (Steinhauser et al. 2000).

1.7 Rationale for study

The themes emerging from this introduction highlight the health and social support needs of our increasing ageing population into the future. As older people are admitted to residential care, there is a demand to provide care that meets their end of life care needs. Some of the challenges facing residential care homes have been identified previously. These include care provider attitudes about death and dying, the changing profile and disease trajectories of older people in nursing homes, staffing levels and available time for dying residents, families’ expectations of dying residents, lack of privacy for residents and families and hospitalisation of dying residents (Wowchuck et al. 2007). While there are many good practices around death and dying in nursing homes, deficits remain, such as continuity of care, the organisation of care, education and training, cultural awareness, staffing levels and physical resources, spiritual and psychological support and communication (O’Shea
et al. 2008). Casey et al. (2011) found that end of life care in residential care homes in Ireland was influenced by three factors; philosophy, culture and organisation of care, knowing the person and physical environment and resources. However, their study did not include the perspectives of residents or their families, which could have uncovered different findings. This is an important omission, as end of life care not only affects staff, but also residents and their families.

This study addresses this gap and focuses on end of life care from the perspective of residents, staff and family. Furthermore, multiple perspectives from residents, staff and families allow for triangulation of sources and lend authenticity to the data (Padgett 1998). What is unique about this study therefore is that end of life care is explored from three perspectives; residents, families and nurses, views that have not been previously explored in older people’s residential care in Ireland. Therefore, a qualitative approach focusing specifically on long term residential care and conducted with multiple perspectives was appropriate to establish a knowledge base to understand the end of life care experience in long stay residential care in Ireland.

1.8 Study aims

The aims of this study were to identify the factors which facilitate or hinder end-of-life care for older residents in public service long stay residential care. In doing this, the study has uncovered residents’, relatives’ and nurses’ perceptions of the factors involved in providing good end-of-life care for those receiving care at life’s end in long stay residential care. The study’s objectives were to examine how the structure and process of care influences end of life care, and explore how the environment influences the outcome of end-of-life care.

1.9 Chapter summary

This chapter has provided background information on end of life care in long stay residential care homes in Ireland. The characteristics of older people, the experiences and perspective of those in residential care settings have been highlighted. Regulation and policy on end of life care in long stay residential care units has also been highlighted. In addition, the study’s aims, objectives and contribution to nursing in older people’s residential care were presented. The
following chapter will provide a focused overview of the literature pertaining to end of life care addressing its meaning and attributes.
Chapter 2 Literature Review

2.1 Introduction
In this chapter, the literature on end of life care of older people living in long stay residential care will be explored. This is relevant because a brief review of the associated concepts of a topic is considered appropriate when undertaking a grounded theory study (Strauss and Corbin 2008, Strauss and Corbin 1998). The appropriateness of reviewing literature in a grounded theory study will also be discussed later in this chapter.

The term ‘end of life care’ was originally coined in North America by Lynn & Adamson (2003) and the term has been used increasingly in discussions on the care of dying and terminal disease (McCallin 2012) and in relation to practice and policy development internationally (Weafer et al. 2009).

In older people’s care settings, end of life care is a complex multi-dimensional and subjective concept relating to the experiences of residents, their families, and staff, and is concerned with process and outcome. It has been defined as care provided at any time in the final period of a life, where there are issues such as physical, social, emotional and spiritual, arising from a person’s death and mortality and needs to be addressed (Froggatt & Payne 2006). More specifically, the Department of Health (UK) defined end of life care as care which ‘helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support’ (Department of Health 2007, p.11).

However, variations exist on end of life care provision. The National Council on Ageing and Older People (NCAOP) and the Irish Hospice Foundation (IHF) reported on End of Life Care for Older People in Acute and Long-Stay Care Settings in Ireland (O’Shea et al. 2008) and found that the quality of life and quality of care at the end of life for older people is varied across care settings including acute hospitals, public extended care units, private nursing homes, voluntary nursing homes and welfare homes. (O’Shea et al. 2008). In Ireland therefore, the current
concern is for equity for older people around end of life which is recognised as an important issue in Irish residential care home regulations (Health Information and Quality Authority 2008). Consequently, much emphasis is being placed on residents’ autonomy, independence, choice, physical and care environment and a person centred approach to care of the dying in residential care.

2.2 The use of literature in grounded theory

There are conflicting viewpoints on the role of literature in grounded theory research. If a literature review is performed at the beginning of a study it may constrain theory development rather than develop it. An initial literature review may contaminate the data and has been considered unnecessary as it may lead to irrelevant ideas and pre-judgments, which may result in premature closure of ideas (Glaser 1992, Stern 1985). Furthermore, it has been suggested that literature should not be consulted because prior studies might influence the researcher’s conceptualisation of the phenomenon under study, and therefore, the classic review of the literature is inappropriate (Stern 1980, Lincoln & Guba 1985, Patton 1990). Glaser (1992, 1998, 2005) also emphasised the importance of avoiding an in depth literature review in the early stages of research. Literature is used to explain the theory; the theory is not derived from it.

However, despite the arguments against undertaking a literature review prior to data collection, there is no consensus as to when it should be carried out (Schreiber 2001, Heath 2006, McGhee et al. 2007). Indeed, researchers are often advised to have some knowledge of a subject prior to undertaking research, rather than a tabula rasa, or blank slate, when entering a field of inquiry (Clarke 2005).

Some authors are critical of researchers who delay in undertaking the literature review, arguing that they are apt to be steeped in specific literature for reasons such as being active scholars and familiar with a wide range of literature (Charmaz & Mitchell 2001). Furthermore, several authors have pointed out that there are sources of a priori knowledge other than the literature: for example, researchers carry into analysis accumulated experiences or preconceptions arising from their discipline or profession (Holton 2007, Charmaz 2006).

Contrary to this, Gilovich (1991) suggests that there is a natural tendency, when examining evidence relevant to a particular phenomenon, to see what is expected.
Sometimes, people readily accept evidence that validates pre-existing ideas and are found to be less responsive to the implications of new information. However, to counteract this occurring, there are many other analysis strategies that can be adopted in conjunction with open coding to protect the principles of inductive validity, such as early in-vivo coding and reflection. Such a strategy was adopted in this study and coding of the data commenced after the first three preliminary interviews.

Familiarisation of the literature on this research topic was necessary for several reasons. Firstly, a review of the existing literature can provide a rationale for the study including justification for the research approach (Coyne & Cowley 2006, Creswell 1998). Grounded theory studies often take a new perspective on an old issue, it is important therefore to be familiar with previous knowledge in order to outline the research phenomenon (Backman & Kyngas 1999). The phenomenon of ‘end of life care’ has many viewpoints. A preliminary literature review can ensure that a study has not already been undertaken (Chiovitti & Piran 2003) and highlight important areas and gaps in existing literature (Creswell 1998, Hutchinson 1993). In addition, a literature review is usually necessary to help the researcher achieve conceptual clarity on the topic and is often essential to satisfy the requirements of local research ethics committees who frequently insist on a well-defined research question so that they can make informed decisions regarding ethical approval (Cutliffe 2005).

Strauss & Corbin (1998) advocate reviewing the literature early in a study for several reasons. It stimulates theoretical sensitivity, provides a secondary source of data, helps the researcher to ask questions, it directs theoretical sampling, and finally, it provides supplementary validity ( Strauss & Corbin, 1998). However, they warn against complete immersion in the literature as it may compromise the researcher’s sense of ‘discovery’ of a theory. With an awareness of this, a preliminary review of literature was undertaken in this study. This was broad and general in scope, thus providing a range of possibilities.

### 2.3 A pre-study literature review

Strauss recommends that researchers using grounded theory methodology read descriptive studies to help make them aware of what to look for in data and what to
ask questions on (Strauss 1998). Literature on end of life care and dying in residential care homes was reviewed three years prior to data collection to ascertain the depth and breadth of work undertaken on the topic to date. This reading developed an increased understanding of the concept of end of life care in the context of older people’s residential care. The outcomes for the pre-study literature review were threefold; it provided a background for the study, it supported the development of a research proposal, and it supported an ethics application. Furthermore, it aided clarification on end of life care in the context of a residential care home. The concepts of older people, residential care, death and dying, end of life care were the focus of the inquiry, helped guide the interview schedule, and developed researcher theoretical sensitivity to the data as concepts emerged. This approach is consistent with the recommendations by Strauss & Corbin (1998). This pre-study literature preceded a more in-depth reading which was undertaken as interviews were carried out, and integrated with analysis of the data as themes emerged.

2.4 Search strategy
The three criteria used for including papers were that they: (1) older people living in long stay residential care; (2) dying and end of life care, (3) were published in the English language; and (4) were peer-reviewed. The two exclusion criteria were studies: (1) carried out in intellectual disability settings/mental health; (2) were an opinion article.

Four notable databases were used for the literature search; CINAHL, PubMed, Embase, PsychInfo, Scopus. Rich Site Summary (RSS) feeds were requested to ensure that the researcher was alerted to new research in the area.

Papers were reviewed by their titles initially to assess their suitability to the substantive area. Following this, if the title was considered relevant, key words. If the title of a research article was deemed relevant to the keywords, the abstracts were then read to assess the study’s suitability according to the inclusion criteria. The reference lists of significant papers were further searched and retrieved and added to the literature search. Seminal paper(s) that spanned 30 years were also included. Search terms in this literature review included the terms similar to “end of life care”
“older people”, and “long stay residential homes”. Figure 2.1 outlines the terms used in the preliminary literature review.

**Figure 2.1 TERMS USED FOR PRELIMINARY LITERATURE REVIEW**

<table>
<thead>
<tr>
<th>Terms used for end of life care</th>
<th>Terms used for older people in residential care homes</th>
<th>Terms used for long stay residential care home for older people</th>
</tr>
</thead>
<tbody>
<tr>
<td>“End of life care”</td>
<td>“Older people”</td>
<td>“Residential care home”</td>
</tr>
<tr>
<td>“Palliative care”</td>
<td>“Aged”</td>
<td>“Care home”</td>
</tr>
<tr>
<td>“Terminal care”</td>
<td>“Elderly”</td>
<td>“Nursing home”</td>
</tr>
<tr>
<td>“Hospice care”</td>
<td>“Geriatric”</td>
<td>“Aged care facility”</td>
</tr>
<tr>
<td>“Death”</td>
<td>“Over 65 years”</td>
<td>“Skilled care facility”</td>
</tr>
<tr>
<td>“Dying”</td>
<td>“Gerontology”</td>
<td></td>
</tr>
</tbody>
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Research articles, reports, and books were initially retrieved, although other literature such as and internet material were used for background information. The process of identifying selected papers for this review is depicted in Table 2.2 (below). The majority of papers found originated from North America, United Kingdom, Western Europe, Ireland, Australia and New Zealand.
The review highlighted that there were differences in the meaning of ‘end-of-life care’ and the term was frequently linked with other similar terms such as ‘dying’, ‘terminal care’ and ‘palliative care’. Using a modified concept analysis of ‘end-of-life care’ further explained its meaning which aided the researcher to refine and focus the term in the specific area of investigation of this study, i.e. older people’s residential care homes. Such a review is useful and helps provide conceptual clarity about the term under study (Chen & Boore 2009). The examination of relevant literature also helped the researcher differentiate between similar and related concepts. The following section will clarify the term long stay care home and older peoples’ residential care in Ireland.

### 2.5 Preliminary review of end of life care literature

The preliminary literature review was based on a purposive sample of seminal literature on end of life care and palliative care. The sample included the writings of Saunders and Baines (1983) on the hospice care movement, the stages of dying by Kübler-Ross (1975), an Irish report on end of life care in Irish settings (O’Shea, Murphy & Larkin 2008) and more recently, an Irish study which identified the
factors that influence dying in residential care homes in Ireland from the perspectives of staff (Casey, Murphy, Larkin, Ni Leime, Payne, Froggatt & O’Shea 2011). As this was a preliminary literature overview, it was used as an analytic tool to stimulate thinking about the dimensions of the research question by promoting self-reflection about conceptual issues. A review of literature can stimulate initial ideas and can be used later in the research process for theoretical sampling (Strauss & Corbin 1998). The following section is focused on various conceptualisations of end of life care.

2.6 Conceptualisations of end of life care

The following section will outline of various conceptualisations of end of life care and its related terms. It is a relatively new term in Irish healthcare and its understanding is quite diverse. There has been a lack of clarity and overall agreement on the understanding of end of life care (Munn 2008, Lorenz et al. 2005 & Seymour et al. 2005). The researcher undertook a modified concept analysis on the term end of life care a number of years previous to data collection and analysis to provide a basis for this research. Using Rogers’ (2000) framework, related terms on end of life care in residential care were identified. Based on the idea that a concept exists as part of a network of similar concepts, understanding those concepts provides a background and helps impart significance to the concept examined (Rogers 2000). This is relevant in clarifying the term end of life in the context of residential care, a term which is frequently used interchangeably with ‘palliative care’, ‘dying’ and ‘terminal care’.

2.7 Terminal care, palliative care, end of life care and related terms

Several terms have been used to address death and dying and the following section will outline many related terms linked with end of life care.

2.7.1 Terminal Care

Terminal care is described as a continuum of palliative care and is used to describe the care that is offered during the period when death is eminent, and life expectancy is limited to a short number of days, hours or less (Department of Health and Children, 2001). This term is often associated with palliative care, which has a different meaning.
2.7.2 Palliative care

One of the earliest explanations of palliative care was described as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses 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 (WHO 2004). This definition evolved from previous definitions offered by the World Health Organisation. Prior to this, the first time the World Health Organisation (1990) defined palliative care as a care specialty that required ‘the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount’ (WHO 1990, p. 24). The goal of palliative care is the achievement of the best quality of life for patients and their families (WHO 1990).

A more recent definition from the World Health Organisation described palliative care as an approach that improved the quality of life of both patients and their families facing the problems linked with life-threatening illnesses, by preventing and relieving suffering by early assessment, identification and intervention and treatment of pain and related symptoms such as physical, psychosocial and spiritual (WHO 1998). The contrast between definitions in the terms ‘specialty’ and ‘approach’ suggests that a specialty requires the close focus of specialist intervention at a specific time period, and the latter, an approach, suggests a broader interaction between members of a multidisciplinary team over a longer period of time. This indicates that greater collaboration between health and social professionals is deemed necessary to comply with the WHO’s recommendations. Furthermore, it suggests that a palliative approach is introduced to care when other curative therapies are no longer used or appropriate, and indicates that palliative care is synonymous with end of life care (WHO 1990).

In a more recent update on the definition of palliative care, the World Health Organisation (2017), explained that palliative care improves the quality of life of both patients and their families who are facing problems associated with life-threatening illness. A palliative care approach addresses suffering of patients by taking care of issues beyond physical symptoms and uses a team approach to support
patients and their caregivers. This approach includes addressing the practical needs of patients providing bereavement counselling for their caregivers. This recent review of palliative care includes the welfare of patients and their caregivers, which can include close family or friends. This adds to previous explanations on palliative care, as it acknowledges the experiences and needs of patients’ caregivers, which can include not only family and close friends, but that of professionals involved in providing care for patients with life limiting illness.

In Ireland, the National Council of Ageing and Older People (2008) explain that palliative care is offered in an integrated multidisciplinary way and when death can be predicted and cure no longer possible, palliative care seeks to optimise comfort and quality of life and to living life to the full and to the end-of-life (National Council of Ageing and Older People 2008). This predates the National Clinical Programme for Palliative Care programme which was established in 2010 as a joint initiative of the HSE Clinical Strategy and Programmes Division and the Royal College of Physicians, Ireland (RCPI). The programme aims to ensure that people with life-limiting conditions and their families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or diagnosis. The function of the governance of the National Clinical Programme for Palliative Care is to report to the National Director Clinical Strategy and Programmes, HSE. The National Clinical Programme for Palliative Care programme promotes collaboration with Clinical Lead, Nursing Lead and Programme Manager to ensure the delivery of the objectives of the programme along with the programme manager who reports to the HSE and RCPI. This Programme encourages collaboration with other programmes works closely with external strategic partners in palliative care including the All Ireland Institute of Hospice and Palliative Care (AIHPC), the Irish Association for Palliative Care (IAPC), the Irish Hospice Foundation (IHF) and Irish Palliative Medicine Consultants Association (IPMCA). The Programme has developed several guidance documents and initiatives: including Rapid discharge for People who wish to die at home, Referring to Specialist Palliative care, Competence Framework, Palliative Care Needs Assessment Guidance, Clinical Guidance and Role Delineation Framework.
2.7.3 Supportive care

Another frequently used term is supportive care. This term refers to the help given to patients and their family to deal with their condition and treatment of it, from a stage of pre-diagnosis, and through the process of diagnosis and treatment. It extends to the phase of cure, continuing illness and or death and into bereavement. It assists patients get the best from their treatment and to live as well as possible with the symptoms and effects of the disease and is placed on equal priority alongside diagnosis and treatment (UK National Council for Palliative Care 2002).

2.7.4 Hospice care

Hospice care is described as the total, active care of a patient and family at that stage of serious illness when the focus has shifted from providing treatment aimed at cure to ensuring the best possible quality of life (Irish Hospice Foundation 2010). Hospices care for the person and their families and carers. They aim to meet their needs, including physical, emotional social and spiritual. Hospice care can be delivered at home, in day care and in a dedicated building in a hospice (All Ireland Institute for Hospice and Palliative Care 2007).

2.7.5 End of life care

The term ‘end of life care’ has evolved in recent years. One of the more current explanations comes from The Irish Hospice Foundation (2017) which describes the term end of life care as “all aspects of the care relating to dying, death and bereavement which is provided towards the end of life. In this context, 'end of life' can be from the point of a receiving a life-limiting diagnosis through the months before death, up to and including the final hours - a continuum rather than a point in time”. The term 'end-of-life care' also refers to the care of people with advanced life-limiting conditions, for whom death within 1-2 years is likely, as well as those in the terminal phase of illness. It also encompasses care of the bodily remains of the deceased person (Irish Hospice Foundation 2017).

In 2014, the HSE National Clinical Programme for Palliative Care developed a set of standards for specialist palliative care (SPC) services in hospice in-patient, outpatient, assessment and community units. The standards were similar to the National Standards for Safer Better Healthcare (HIQA) and were the first of its kind
for SPC services. They were been developed following an extensive engagement process with SPC stakeholders across Ireland. The standards set out key principles of quality and safety with suggestions for supporting evidence of implementation (HSE 2014). The framework document comprises of 12 health and social care disciplines included in the framework, all working with the same core competencies. The guidance document aimed to support all disciplines who provide palliative care at level 1 and 2 (non-specialist palliative care).

End of life care can be the period of time when death is recognised as imminent and/or it can be used in a hospice setting where prognosis is characterised by some definite time period (Watson 2005). Such boundaries are frequently blurred between end of life care and palliative care, with end of life care being increasingly used as a term to encompass aspects of palliative care to address the concerns and issues relating to older people with diseases other than cancer, particularly in residential care settings (Watson 2005). End of life care can vary from a very short period of a few hours or days before an individual dies, and is much easier to define retrospectively than prospectively (Lloyd 2004). However, in residential care, end of life care is described more accurately as; living and losses, experienced in the care home, the actual dying and death, and the bereavement that follows a person’s death (Froggatt 2004).

In contrast, palliative care is described as alleviating symptoms of pain and other physiological and psychological symptoms. However, Watson (2006) considers end-of-life care as an important part of palliative care and can refer to the care of a person during the last part of their lives, from the point at which it has become clear that the person is in a progressive state of decline (Watson 2005). Thus, suggesting that it is considered immediate rather than a longer period of time before death, where the person in residential care may not be aware of an impending death.

The most significant difference between the terms end of life care and palliative care, is that, care for end of life can occur at a time in a resident’s life far away from death depending on residents’ knowledge, feelings and physical ability, and, that it is not predicated on knowing when someone is going to die (Froggatt & Payne 2006). In contrast to this, palliative care supports individuals and families facing problems
associated with life threatening illness, implying that, the individual and family know dying and death is imminent.

It is important to explain some of the associated terms relating to end of life care such as terminal care, palliative care, hospice care and supportive care. They represent a process of care delivered at life’s end and each term has its own emphasis for the care team on care for the person. The interrelationship between these definitions such as palliative care and end of life care serves to further clarify end-of-life care for older people in residential care settings as it incorporates many of these dimensions including a palliative care approach to end of life care.

2.8 Attributes of End of life care

This section will explore the attributes of end of life care identified in the literature relating to older people living in long stay care homes. Several authors have attempted to define end of life care in long stay care and the analysis of the reviewed literature points to several attributes of end-of-life care which are: person centred care for the older person at life’s end, support for family and close friends, effective communication for advance care planning and organisational and environmental support which will be discussed in the following sections.

2.8.1 Person centred care for the older person at life’s end

Care centred on the person originates from a philosophy of personhood which has theological, ethical and social-psychological foundations. These philosophical foundations acknowledge the uniqueness of a person and place an onus on human beings to treat each person with respect and not as a means to an alternative goal (Kitwood 1997, McCormack 2004). The recent development of person-centred care originated from the works of Carl Rogers (1951). Rogers proposed a humanistic psychological approach to psychotherapy, whose central tenet places patients as expert in their own care which means that care teams need to adopt a facilitative role in supporting individuals (Brownie & Horstmanshof 2012, McCormack 2004).

Person centred care is a term used throughout health and social care literature and can be frequently seen in policy development at governmental levels (Brownie & Nanacarrow 2013). Although the term ‘person-centred’ care remains a multi-dimensional and a subjective concept, it has several facets which include; promoting
autonomy, maintaining an individual’s identity, continuing a relationship with, and having a responsive and appropriate care based on residents’ needs and preferences in a patient conducive social environment (Edvardson, Featherstonhaugh, & Nay 2010; Hill, Kolanawaski, Milone-Nuzzo, & Yevchak, 2011). This has particular resonance when applied to end of life care in residential care homes.

Person centred care is a central attribute to the concept of end of life care and means that the complete focus of staff attention to care is directed towards each resident in the context of their residential care home environment. In nursing care, person centred care includes informed flexibility, mutuality, negotiation, transparency, and involvement (McCormack 2004). These are described as part of a developed framework of authenticity and its meaning in a caring relationship between the nurse and resident (McCormack, 2004). This approach recognises the uniqueness of the individual and acknowledges that persons do not exist in a solitary way and live as part of a social context (Kitwood 1997).

The nurse’s role caring for an older resident who is approaching end of life care combines knowledge of gerontology and palliative care. It is a role that has many diverse elements including managing physical, psychological and social aspects of residents’ lives. The physical components and symptom management of a resident’s chronic illness such as lung disease, heart failure, renal disease, pain and dyspnoea are part of the nurse’s role at end of life care (Caprio & Hanson et al. 2008). Their presence with the dying resident refers to the capacity to be with a resident and with a quality of attention and authenticity that informs relationships and actions (Rushton 2009). This is a skilled role of the gerontology nurse and palliative nurse combined and is required within a residential care setting.

Person centred care in residential care homes at end of life indicates that palliative care competencies are required by care staff to effectively manage residents’ end-of-life symptoms (Avis, Greening Jackson, Cox, Miskella 1999) and total patient care implies attending to patients’ total pain and suffering-physical, emotional, social and spiritual and relational being (Carney and Meier 2000). Consequently, end-of-life care in an older persons’ residential care setting requires that nurses need a discrete set of skills (Philips et al. 2006) and knowledge of and about older people in their care in residential care (Froggatt & Payne 2006). Thus, high quality residential care
homes are noted for their compassion of care, communication and sense of community (Kayser-Jones, Chan & Kris 2005).

In summary, person centred care in relation to older people at end of life in residential care relies on the care staff knowing residents, being responsive to their fluctuating care needs, and adapting care appropriately. It requires that care staff have both palliative skills and a gerontological specialism to deliver care that is focused entirely on end of life care to residents, however long that trajectory may indicate. The next section highlights the attribute of support for family, close friends and teams within the residential care home, because residents do not exist in isolation, but within the context of family, friends and team of carers.

2.8.2 Families and end of life care

The experiences of family members of a resident who is nearing death in residential care are different to that of nurses. It is acknowledged that families’ experiences and their perception of death and end of life care forms a significant part of quality end of life care, however, there has been little research conducted on the views of family members’ perspectives of end of life care (Kendall et al. 2007). Family involvement becomes crucial as residents’ progress along the continuum of end-of-life towards death. Families often encounter a range of feelings when caring for an older person with long-term progressive illness. These can include sadness at the potential loss of losing a loved one, fatigue, anxiety, fear associated with leaving people unattended, altered personal and work schedules and an associated emotional burden (Lynn 2001). For many family carers, a good death has been idealised as occurring at a time which is peaceful, dignified, happens in the privacy of a home environment and the company of family and is timely, both in terms of the life-cycle and the normative concept of a long life and dying not being prolonged (Payne et al. 1996a, Clark 2002, Hopkinson & Hallett 2002, Rietjens et al. 2006) This portrayal of a good death is familiar to many nurses and is the ideal to be achieved for the family carers.

A systematic literature review completed by Hennings, Froggatt & Keady (2010) synthesised and evaluated current knowledge about family carers experiences and needs regarding end of life and care at death in homes for people with dementia (Hennings et al 2010). They uncovered three themes from their synthesis which
included; unfamiliar territory, making decisions, and the grieving care giver. The theme of unfamiliar territory depicted family members having a lack of knowledge and experience, poor communication with professionals and opting for adequate interventions in an effort to do the best for the dying relative (Hennings, et al 2010). The second theme found in their study was decision making, and they found that the role of the family member in making decisions for a person with dementia remains unclear for the family member (Hennings et al 2010). Many family carers wished to remain involved in care at the end of life, and those who did not want to be involved wanted their values to be reflected in the decisions made by professionals on their behalf (Carron, Griffith & Arcand 2005 a, Carron Griffith & Arcand 2005b, Lopez 2009). The grieving carer was the third theme found in Hennings et al. (2010) study and this reflected the family member who was in the dual role of both grieving for their relative and being required to make decisions for them with regard to treatments towards the end of life. This role has been described as problematic for carers when entering the palliative phase, due to unresolved grief (Carron, Griffith and Arcand 2005 a). In this group, family carers had strong personal needs and wanted to make contact with staff, sought empathy, reassurance, understanding, guidance and communication (Forbes, Bern-Klug, Gessert 2000, Carron 2005a, Lopez 2009). Family carers felt validated when values and beliefs were shared by professionals (Moyle, Edwards and Clinton 2002, Lopez 2009). Hennings et al. (2010) findings indicate that there are various levels of unmet need for family carers. These findings contribute to understanding the different perspectives of family carers who are involved in the lives of older residents in long stay care. Many of these themes could resonate with lives of family carers for residents in long stay care because a proportion of residents there also have dementia and various levels of cognitive decline.

Sanders et al. (2009) describes a group of family members who were described by as having four caregiver portraits, these were described as questioning, all-consumed, reconciled and disengaged. While features of the three portraits, questioning, all-consumed and reconciled are addressed in Hennings’ et al. (2010) study the disengaged carer is not. The disengaged family carer was described as being emotionally disconnected from their family member and were more involved in their own families, lives and work. This portrait of disengaged was described as having
conflict with person with dementia, being focuses on self and career, being minimally involved in care, and being prepared for the death of their relative. Sanders et al. (2009) describes this group as being adult children with a mean age of fifty years. This is relevant in this literature review as it offers a description of the portraits of family members and their level of involvement in the community of a residential care home and the roles they play in residents’ lives when they live and die in long stay residential care.

In summary, family members often bear significant emotional and physical stress at levels that can adversely affect their own health, and especially if they are old and vulnerable themselves (Bern-Klug 2008). It is important to address family members’ concerns when they are involved in caring for residents in residential care. Steinhauser et al. (2000) explored the perspectives of patients, care providers and families and concluded that quality of life at end of life care was a dynamic process that was negotiated and renegotiated among each the people involved and was a process moderated by individual values, knowledge and preferences of care. In this study, the perspectives of families is considered important to contribute to our understanding of the factors the influence good end of life care. Their views and values are relevant to building knowledge on this subject area.

2.8.3 Communication at end of life and care planning

In this literature review, the third attribute; communication at end of life and care planning was identified to support end of life care in residential care homes. Communication is an essential attribute in end of life care, but how communication takes place is often complicated and unpredictable. Residential care homes are similar to other healthcare facilities and require that staff, residents and multidisciplinary teams have excellent communications skills to achieve good outcomes for all involved. Several authors have recognised that good communication is not just a natural occurrence in an organisation, rather, it can be a learned skill (Bajnok et al. 2012, McCaffrey Hayes et al. 2011). When staff practiced effective and empathic communication with patients and families who had been in cancer care, there were positive outcomes noted, such as, patient quality of life, satisfaction with care and medical outcomes (Baile & Aaron 2005)
In particular, staff in residential care homes are often faced with difficult conversations concerning residents’ and families’ end of life care expectations. Several authors have highlighted difficulties in initiating an end of life care conversation and there is a general reluctance to anticipate or discuss death and related issues (Lambert et al. 2005, Phillips et al. 2006). Consequently, being unable to have a conversation about death or end of life care preferences has led to difficulties in informing nursing practice to provide a resident’s preference of care at end of life. Lambert et al. (2005) identified factors which contribute to the decision-making process of competent older people in residential long stay care homes during the process of formulating advance directives. She noted that older people based their choices primarily on information acquired from personal past experiences with death and illness. Residents reported that they obtained very little information from professionals or the media. In her study, the main factors older people considered when they evaluated the information on end of life care were spiritual, emotional, and social considerations (Lambert et al. 2005). This suggests that nurses should have adequate communication skills to be able to understand older people’s views and how they inform their decision making regarding end of life.

In a study conducted in oncology settings by Lufty & Maynard (1998), conversations around end of life care were two-directional. In their study, patients were influenced by the way staff talked about end of life care, and staff talked about end of life care based on how patients reacted and their responses or behaviour when the subject was broached. Thus, if patients appeared disinterested or distressed, staff no longer continued the conversation, and alternatively if patients wanted to engage in the conversation, staff were forthcoming with facilitating the discussion around end of life planning and advance directives. However, in many situations, paternalistic and informative models of communication tended to dominate interactions in hospitals and care homes (Lufty & Maynard 1998). This is apparent in residential care homes, as many residents do not openly talk about dying or their own end of life care needs or preferences (Seymour et al. 2004).

Phillips et al. (2006) also noted that residents’ frailty at admission placed a sense of urgency on nurses to determine as soon as possible residents’ desires about goals of care and advance care planning. This prompted staff to have a skilful conversation around end of life care at an early point in residents’ transition and settling in phase
to residential care. End of life care, when it was assessed, was recorded in residents’ personal careplan and updated as a resident’s status changed (Phillips et al. 2006).

2.8.4 Planning care

In residential care, planning care around residents’ needs has adopted a gerontological emphasis as opposed to an acute or medical approach. In gerontological nursing in residential care involves using a biographical approach which draws on residents’ life histories to understand residents’ needs and hopes (Philips, Ajdrouch & Hillcoat-Nalletamby 2010). Using a biographical approach has assisted nurses in achieving a better understand of an older person in residential care, this approach helps nurses to look beyond a residents’ medical diagnosis and see a person within the context of the relationships within their community (Gallagher 2010). The biographical approach also improved communication methods and relationships between residents’ families and care staff (Gallagher 2010).

A biographical approach has similarities to a resident’s biography or ‘life story’. Life story work involves compiling a person’s life story and giving them opportunities to talk about their lives experiences with which they are comfortable with, is also a dynamic and responsive to residents’ changing life (McKeown, Clarke & Repper 2006). It usually takes the format of a written work, and complements residents’ own careplan, and further underpins the context and framework for person centred care (McKeown, Clarke, Ingleton, Ryuan, & Repper 2010, Thompson 2011). The information obtained in life story work contributes to clinical care, which recommends that the care plan for the person should be based on an assessment of residents’ lives (Cass, Robbins & Richardson 2009).

Adapting a biographical approach and using life story work to understand residents’ care preferences contributes to staff nurses understanding of residents preferred choices when commencing life in residential care and achieve a greater understand their final days. This information contributes to a process of integrated care planning for older residents.

Providing of care for people who are nearing life’s end requires an integrated model of end of life care and requires a plan of care that reflects an inter-disciplinary team approach for the older resident in residential care (Ditillo 2002). An integrated plan
involves broad and diverse aspects of a multi-disciplinary healthcare team, including social care professionals, psychological, and nursing, medical dimensions, and their input is recorded and transferable between the agencies. Communication between these teams is an essential component of care for residents, their families and care staff (Aspinal, Addington Hall, Hughes & Higginson 2003, Shield Wetle, Teno, Miller, & Welch 2010, Thompson, McClement, Menec & Chochinov 2012). Fundamental to residents and staff relationships is open and honest communication (Munn et al. 2008) and these interactions and communications are recorded in residents’ life story and in their careplan. Recording a resident’s life story and their relationships is necessary in any organisation to promote understanding of care delivered to each resident. Maintaining residents’ care-plans which are based on residents’ life story should reflect residents’ preferences at end of life and this is a goal of gerontological nursing which relies on the contribution of all team members.

2.8.5 Advanced Care Planning

Although similar to care planning, the phenomenon of Advanced Care Planning (ACP) in residential care has gained ground in recent years. Lambert et al. (2005). Describe an Advanced Care Plan as the process of preparing for the likely scenario near the death of a person’s life. It is considered important for people who lack cognitive capacity and have not made plans for their own final days of life, as they may receive either unwanted costly medical interventions or the withdrawal of wanted treatments. This would inform health care staff of a residents preferred care near their time of death.

An Advance Care Plan facilitates the communication and understanding of care preferences between a person deemed to have diminished decision-making capacity and their primary health care provider, family members or surrogate decision maker (Chan & Pang 2010, Karel, Moye, Bank & Azar 2007). The process of Advanced Care Planning involves three components: the consideration of health care options, and expression of the person’s values; communicating their wishes, and subsequent documentation (Cantor & Pearlman 2003). This is significant in the light of the recent legislation of the Capacity act (2015) in Ireland which was designed to protect people who can’t make decisions for themselves or lack the mental capacity to do so, and provides a statutory framework where Advanced Care Planning can be used and
not relegated to a practice option. A framework document called ‘Think Ahead’ was introduced in in many residential care homes in Ireland. This document aimed to formalise the process of providing end of life care with the use of residents’ individualised care plans in conjunction with using advanced care planning in the format ‘Think Ahead Form’ (The Irish Hospice Foundation 2010) in residential care. Where this document is used, it provides residents with a mechanism for discussing and recording their choices about healthcare in an advance care plan. It encourages people to appoint someone to record in the form of a written instruction, their future medical care in the event that they become unable to communicate (The Irish Hospice Foundation 2010). However, this document has not been fully implemented across all sectors, possibly due to the complex nature of end of life care planning care and that it may not easily be recorded in one document. This was shown in Fernandes (2008) study who found that although advanced directives appeared to increase the likelihood that a person’s end of life plans were respected, she suggested that sometimes compliance in completing the relevant documentation was low. Fernandes (2008) also suggested that a low compliance rate was possibly due to negative attitudes towards advanced care planning, unclear and vague terminology, disorganisation of recording paper formats. Sometimes it is difficult for people to make their wishes known when coming close to death, and when staff have an understanding that, residents’ end of life plans will be respected, which can take that fear away when dying (Fernandes 2008). Whether the ‘Think Ahead’ format is used as form of advance directive, it is important that care staff remain cognisant of residents’ preferences at end of life care, this should ensure that residents’ expectations are upheld.

Alternative formats have been used to record residents’ preferred end of life care in several UK organisations, for example, the Liverpool Care Pathway (Ellershaw 2003) and Gold Standards Framework (Thomas 2003). In 2002, the Liverpool Care Pathway (LCP) was introduced as a clinical tool to improve care for dying patients and was indicated as a best practice initiative in the National End of life Care Strategy (DH 2008). The Liverpool Care Pathway aimed to incorporate the best hospice practice into hospitals and other care settings. Its main principles were to promote good communication with patient and family; anticipatory planning around meeting spiritual/psychosocial needs and symptom management; and provide care
for family bereavement and after death. They offered structure in the uncertainty that accompanies dying (Ellershaw & Wilkinson, 2003). It addressed care for residents in the last few hours or days and The Gold Standards Framework (Thomas 2003) supported end-of-life care delivery over the last few weeks or months of a person’s life. However, following a period after their implementation they were found to be inadequate in addressing some of the needs and expectations of either residents or their carers.

Ramasamy et al. (2015) found in their qualitative study, that some critical care nurses delivering end of life care, felt this document, the Liverpool Care Pathway, depersonalised the dying person and that it was like a tick-box exercise that nurses felt lacked family involvement (Ramasamy Venkatasalu, Whiting & Carirnduff 2015). Although there were criticisms of the use of the Liverpool Care Pathway in the United Kingdom (Department of Health, 2013), it was suggested that these criticisms of the pathway may not apply if it was used internationally (Knights, Wood & Barclay 2013).

However, both these frameworks were identified as organisational wide processes of communicating across disciplines at residents’ end of life (Froggatt 2005). Unfortunately, their successful implementation was dependent on achieving effective dialogue between staff and individual residents and their families. As a form of communication, dialogue involved a commitment of participation between nurse and resident and the involvement of family members. Successful implementation was mostly reliant on adequate staffing levels, and staffs’ level of knowledge about the pathways and frameworks. Furthermore, both the Liverpool Care Pathway and the Gold Standards Framework were criticised because it was perceived that there was inadequate attention given to the experience of the person at the centre of nurses’ care (Froggatt 2005). The consequence of this could have a deleterious effect on achieving well planned end of life care for older people, based on good communication and involvement of the wider multidisciplinary team.

Since the NHS England’s first strategy for end of life care was published in 2008, there has been a revision of this work for care of the dying person in acute hospitals across the United Kingdom. Many people from long stay residential care need to spend a proportion of their last years, months, and weeks of life in hospital because
of care and treatment that they need, and prefer to receive. This revised and updated version of the ‘Transforming end of life care in acute hospitals: The route to success ‘how to’ guide’, (NHS 2015), aims to improve the quality and experience of care at end of life for patients and their families. This publication offers practical advice and support for clinical staff and hospital leaders for communication and planning required to deliver good end of life care for all in acute hospitals. Within the guide are six practical steps for nurses to address the care preferences of patients admitted to acute care, which include; (1) Each person is seen as an individual (2) Each person gets fair access to care (3) Maximising comfort and wellbeing (4) Care is coordinated (5) All staff are prepared to care (6) Each community/discipline is prepared to help. This is a useful framework for nurses to assess and provide care that the older person preferences and support their families also.

2.8.6 Summary

This section on communication and care planning at end of life explained that an essential attribute of end of life care in residential care settings is effective communication between experienced nurses working in care of the elderly, team members, families and residents on matters concerning end of life care. The following section will discuss the third attribute identified for end of life care, that of the organisation and environmental support within.

2.9 Environmental support and organisational structures

The third attribute identified for end life care in residential settings for older people was organisational structures and environmental support. The physical environment of an organisation supporting end of life care is an important attribute to end of life care. There is a relationship between the physical and sensory environment and healthcare outcomes (Ulrich & Zimring 2008). Evidence based design is a process–based approach that uses current best evidence from practice and research to create care environments that improve staff performance and operational performance. Evidence based design has gained increasing recognition as a progressive way to design comfortable living spaces where health care delivery can be at it optimum (Joint Commission International Patient Safety 2004).
The structure of the environment contributes to an organisation’s culture which is a commonly used expression by managers to describe the way members of an organisation value roles and carry out tasks within it. An organisation’s culture is something that workers consider important, and is valued and accepted. It can be observed as the ‘way things are done around here’ (Office of the Ombudsman 2014). This is relevant because how staff regard the dying process, death, and time after death demonstrates an organisation’s culture. Koren (2010) observed that in long stay residential care homes that many organisational culture changes have occurred and the change of focus of care has moved from an institutionalised care to an alternative new model of care to promote positive living experiences for its residents (Koren 2010).

Long term residential care homes require appropriate organisational structures and environmental supports in place to facilitate the end-of-life trajectory for residents (Kayser-Jones et al. 2003). Appropriate care facilities such as space, ease of access, and privacy, are essential components in delivering good end of life care for all involved. Inadequate staffing, poor supervision, noise, over-crowding, and lack of privacy, have been identified to be the most significant organisational factors that can negatively influence care of terminally ill residents (Kayser-Jones et al. 2003).

Organisations have many functional roles such as nurses, health care attendant staff and management. Management and staff in supervisory managerial positions have a significant role in the provision of end of life care. Managers are people who ensure that the working environment is coordinated through manipulation, delegation and direction to achieve the organisation’s goals and working with and through others by organising specific activities to accomplish particular tasks (Robins & Coulter 1999). An organisation’s staff and management structure can have a major impact on residents’ successful adjustment to residential care. The role of director of nursing, ward manager and staff nurses have key responsibilities in establishing the right environment for older people to die in. However, in a study conducted by Froggatt & Payne (2006), it was found that managers had various understandings of end of life care, and some thought it was the immediate period leading up to the point of death. Some managers spent most of the time managing disparate issues regarding the day-to-day events of a ward, and not always specifically focused on dying residents. Although this study was carried out in a region in England where 261 care
homes and community hospitals were identified, there was a low response rate from private providers and nursing homes, and this may not be representative of residential care homes in other regions. However, from the responses obtained, managers did address the needs of dying residents, manage ward resources accordingly and knew when to liaise with specialist services in regard to dying residents. Some of the concerns for managers is knowing when end of life arises and the various meanings and understandings of the terminology around end of life care, consequently, this can be seen as an opportunity to develop definitions which examine what kind of care constitutes end of life care (Froggatt and Payne 2006).

Going into long stay care is a significant move for many older people (Reed, Cook & Burridge 2002). For many, admission to residential care will mean that older people will die there. It is an important move to go from home to long stay care, and as people get older, their need for regularity and continuity becomes stronger, as they try to maintain habits, environments, relationships and values. Moving from a familiar home and community to residential care can cause stress and discontinuity for residents (Atchley 1989). Discontinuity reduces an individual’s sense of their identity and their capacity for coherence (Atchley 1989) and residents going into long stay care endeavour to achieve some links and familiarity to their previous life. Managers and staff have a responsibility within their organisation to provide structures to support residents maintain their links to their previous lives while in care. Recognising the importance of maintaining links between a resident’s present and previous life helps to keep one’s identity and is an attribute to end of life care. Maintaining connections between the organisation and residents’ home life before admission to care helps to maintain a resident’s identity through their social engagements and home routines (Cooney, Murphy & O’Shea 2009; Tester, Hubbard Downs, MacDonald Murphy 2004). Maintaining residents’ connections promotes older people’s identity which requires staff to support residents’ sense of autonomy which is linked to residents’ having choices. When people exercise choice, it means being involved in decision-making and an interdependency with people connected within and outside the organisation. (McCormack & McCance 2010, Welford, 2012).

Many older people going in to residential care homes hold the view that they will have a good life there and that their interests will be supported while there.
Furthermore, older people in residential care may continue to have purposeful activities which gives meaning to their lives (Bowers, Clark, Crosby, Easterbrook, Macadam, MacDonald, & Smith 2009). The responsibility lies with staff in organisations to promoting residents’ well-being and sense of autonomy within a residential care home.

The following section will explain organisational structures to support staff education and training which are required to support end of life care.

2.10 Policy, regulation and legislation,

In recent years, legislation and policies have aimed to address the end of life care needs older people in residential care. Currently, all residential care homes for older people are regulated under the Health Act (2007)\(^1\). A key element of the act was the identification of quality control measures through compulsory registration, stricter enforcement of dimensions of standards, such as nursing care, nutrition, environment, and governance, increased accountability of proprietors, and information and complaints procedures for consumers. This Act legislated that written policies should support appropriate care and comfort for a resident when they are approaching the end of their lives. Implementation of this Act, and regulation of residential care provision has been monitored by the Health and Information Health Authority (HIQA). This regulatory authority was established under the Health Act

\(^1\) Health Act (2007)
Health Act 2007 (Registration of Designated Centres for Older People) Regulations 2009
Health Act 2007 (Registration of Designated Centres for Older People) (Amendment) Regulations 2010
Health Act (2007) (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009
Health Act (2007) (Care and Welfare of Residents in Designated Centres for Older People) (Amendment) Regulations 2010.
Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) (Amendment) Regulations 2012
Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) (Amendment) Regulations 2013
(2007), and has a role to register and inspect all nursing homes to ensure that they are compliant with 32 national standards (HIQA 2009). Registration is based on the assessment of seven areas of resident care including; rights, protection, health and social care needs, quality of life, staffing, the care environment, governance and management. Inspection reports are available to the public and HIQA can apply to the courts to de-register any nursing home that fails to comply with the national standards.

To further improve standards on end of life care in older people’s residential care homes, the Health Information and Quality Authority implemented a national program of thematic inspections on end-of-life care in all residential care homes (HIQA 2014). The key objective of their thematic inspections was to focus on a specific theme such as, end of life care, and encourage a quality improvement approach across residential care facilities to promote improved outcomes for residents. The thematic inspection on end of life care was based on the legislation and standards of the Health Act (2007/Regulations 2009), and National Quality Standards for Residential Care Settings for Older People in Ireland (2008). It is outlined in regulation 14 and standard 16 of the standard regulations on end of life care that each resident receives care at the end of their lives which meets their physical, emotional, social and spiritual needs and respects their dignity and autonomy (HIQA 2008). Examining care home practices against HIQA regulations and the legislative framework of the Health Act (2007) were therefore very positive developments.

Several agencies have supported end of life care in residential care homes. In 2008, the Irish Hospice Foundation (IHF), Hospice Friendly Hospitals Programme, commissioned the National Audit of End-of-Life Care in Hospitals in Ireland. This resulted in the development of its quality standards for end of life care (Irish Hospice Foundation 2013) as part of its Hospice Friendly Hospitals Program. This programme aimed to implement their standards in all hospitals on a voluntary basis since 2013. The Irish Hospice Foundation (IHF), which was established in the mid-1990’s, aimed to implement hospice principles in hospitals and other care centres in Ireland. Currently, the IHF in partnership with the Health Service Executive (HSE) has established a multi-centre intervention programme, which aims to develop end of
life care capacity, advocate for patients and families and create systems of change in the delivery of hospital care at the end of life in Ireland.

The combined approach between the Health Services Executive and the Irish Hospice Foundation (2008) has resulted in providing palliative care for all with a view of integrating palliative care into disease management frameworks (HSE & IHF 2008). Their goal was to develop hospice and palliative care principles throughout hospitals and promote a comprehensive system of integrated care planning, ethics, communication and strategies for patient autonomy. Another goal was to improve service planning, building design and improve dignity at end of life for all. This report (HSE & IHF 2008) highlighted the focus of palliative care support towards diseases directly linked to age and longevity, chronic obstructive disease, dementia and heart failure (Hegarty & Currow 2007). This has improved end of life care for older people in particular, as the emphasis of a palliative care approach has changed from treating people primarily with a cancer diagnosis, to treating older people with non-cancer diseases. As increasing numbers of older people now die in hospitals or residential care homes, this important shift in emphasis would indicate better outcomes for older people with non-cancer diagnosis at the end of life.

The position of the Nursing and Midwifery Board of Ireland regarding the nursing care of older people (NMBI 2009) requires that nurses should provide care in the spirit of caring, dignity, quality and respect. Regarding end of life care, they point out that the older person should receive comprehensive, compassionate end of life care, which is person-centred and responds to the older person’s unique needs and respects his/her wishes (NMBI 2009 p.13). In their role, nurses can make a difference to the dying person and their families by creating and facilitating a therapeutic milieu that takes care of their physical, psychological, social, cultural and spiritual needs. The nurse’s role focuses on ensuring a comfortable death, relieved of distress and a death that is remembered with peace and comfort by family and friends. Nurses therefore are pivotal in providing good end of life care for older people and are skilled in creating a therapeutic milieu for death that is free from distress, peaceful and comfortable.
In 2014, an European Union (EU) funded project commenced to compare the effectiveness of an intervention to improve PAAlliative Care for Elderly (PACE) people in long term care facilities in Europe. This project was coordinated by the End-of-life care research group Free University Brussels (VUB). The 6.6 million Euro, five-year study, which was funded by the European Commission Framework 7 programme, brought together leading academic researchers from six European countries (Belgium, United Kingdom, Italy, Finland, Poland and Netherlands). Researchers in Belgium lead the project, working with researchers and clinicians from each of the participating countries. The main project included a three-year trial of a previously developed UK palliative care model. Research (including economic, staff and process elements) aimed to determine if a new way to deliver care actually made a difference to outcomes and practices (Aarendonk 2014).

The goals of the PACE project were threefold: (1) to better integrate palliative care into mainstream care, so as to improve the quality of life of not only terminally ill cancer patients, but also older people living with a range of potentially incapacitating diseases. (2) Improve the quality of life for people living in long-term care facilities from not only a physical perspective, but also psychosocially and spiritually. (3) to create a more unified European approach in respect of attitudes and responses to palliative care needs (den Block et al. 2017).

Some European countries have well developed policies and programmes in place such as the UK, followed by Australia and New Zealand, (Quality of Death Index, 2015). Other European countries in the top 10 are Ireland, Belgium, Germany, the Netherlands and France. However, East European countries, are generally lower on that list. While some European countries are leading the way, there is still more to be achieved across Europe with standardising palliative care (The Economist Intelligence Unit 2015).

Each country has a responsibility for different elements of this large and complex study, and although the ultimate goal of PACE is to have an impact on patients in long-term care facilities, the interventions that PACE are developing are specifically aimed at changing the attitudes, knowledge and skills of the staff that care for these patients. One part of the work in PACE is to map the differences between the types of long term care facilities across countries in Europe, that have different (inter)
national and regional regulations, and try and influence the priorities and practices and understand the key drivers for change (Aarendonk 2014, den Block et al. 2017). The PACE project has relevance to this study as it situates dying in older persons long stay residential care in Ireland within the context of European wide palliative care research and policy development.

2.11 Staff education and training

Healthcare staff need to have adequate training and knowledge relating to residents’ palliative care and end-of-life needs and preferences, and this should be assessed, documented and regularly reviewed (Nursing and Midwifery Board Ireland 2009, HIQA 2008). Information obtained from these assessments should be explained to residents, and options discussed at regular intervals with the resident and his/her family or representative, in accordance with the resident’s wishes and regulatory guidelines. Getting to know residents’ intentions and understanding resources available to residents is essential. However, this is dependent on relationships founded on skilled communication based on knowledge and expertise between the resident and care staff and management (Olive 2003).

Education and training also needs to be addressed in long stay care homes. Several studies have noted a lack of palliative care education needs of nursing home staff (Ersek, Kraybill, Hansberry 2000, Froggatt 2000, Brazil and Vohra 2005; Whittaker et al. 2007; O’Shea et al. 2008).

Nurses working in long stay residential care units also need greater palliative care competencies to effectively manage residents’ end of life symptoms (Avis et al. 2009). Special skills are required when delivering specialist gerontological care and palliative care to older people with complex care needs at end of life (Philips 2006). Not knowing when someone was dying or understanding the dying process has been reported as an inhibiting factor in end of life care for nurses (Watson, Hockley & Dewar 2006). In addition, diagnosing death was regarded as another concern that nurses had in relation to end of life care and the challenges that exist around the ‘diagnosis of dying’. If clinicians are not confident in performing such a diagnosis patients may not benefit from end-of-life pathways (Gibbons et al. 2009). However, dying is a dynamic process and residents’ end of life may fluctuate from being stable to actively dying. If staff were to follow a discrete set of steps along an organised
process such as care pathway, this approach may seem restrictive and unresponsive to the cues that dying residents often emit to nurses who have a long-standing connection with someone. Therefore, is essential that adequate training is available for the requirements needed for end of life care for nurses. Organisational structures need to have these in place for practitioners who are delivering care at residents’ life end. It is in these situations nurses depend on their knowledge of each resident’s care preferences and understanding local policy and guidelines and can use them to guide their practice.

2.12 Chapter summary
At the outset, this chapter explained the rationale to support using literature in a grounded theory study, justifying that it is important to have some knowledge of a subject before going into an area of research rather than having a *tabula rasa*, or blank slate, when entering a field of inquiry (Clarke 2005). Using a pre-study literature helps to guide and frame the research question.

Consequently, the literature revealed several associated terms and phrases used to describe end of life care which included terminal care, palliative care, dying, supportive care, hospice care and end of life care. Several essential attributes were highlighted following preliminary review of literature on end of life care in long stay residential care for older people, and the following four were revealed; focusing on the person at the end of their lives, support for their families and team work, communicating at end of life and care planning, and environmental support and organisational structure. Each attribute is interdependent to end of life care and all are necessary for positive outcomes for both family carers and residents. Care at life’s end is intricately connected to the organisation’s ethos in which death occurs and involves the relationships of the people involved with the resident. This chapter also outlined how policies have shaped death and dying care in residential care and the importance of staff training and education.

The following chapter will discuss Grounded Theory, the methodology chosen for this study.
Chapter 3 Methodology

3.1 Introduction
Before embarking on a research study, it is important to recognise one’s philosophical position. This helps to underpin the study and further develop knowledge in nursing and health sciences (Punch 1998). Identifying a research paradigm, and choosing an appropriate methodology and research strategy is a significant undertaking and essential before going into the field of data collection and analysis. Creswell (2003, 2009) recommends that researchers consider three important elements when designing a study; (1) its philosophical assumptions about what constitutes knowledge or paradigm, (2) the strategy taken for the inquiry, and (3) which methods of data collection and analysis are being used. This chapter will provide a philosophical overview, to include positivism, post-positivism, and interpretivism and explain in detail the research strategy adopted.

3.2 Philosophical underpinnings
There are many philosophical terms used in discussions of qualitative studies such as, research paradigm, ontology, epistemology and methodology. The following section will clarify these concepts because they are relevant for researchers to understand so that they can position their inquiry, and the process of data collection and analysis.

Denzin and Lincoln (2015) explain that ‘ontology’ asks what is the real world and what can be known about it and that ‘epistemology’ questions the relationship between the knower and what can be known. ‘Methodology’ questions how researchers go about finding out what they believe can be known. Guba and Lincoln (1994) further explains a paradigm as a basic set of beliefs that guide a persons’ action. Therefore, a researcher’s ontological position (belief about reality) underpins their epistemology (relationship between the researcher and what can be known) and their chosen methodology for a study. Paradigms are necessary for ensuring the philosophical and ontological congruity of the research. Researcher’s needs to ensure that their aims, paradigms, and methods are also epistemologically integrated (Houghton et al. 2012).
3.3 Research paradigms

A research paradigm is a basic set of beliefs that explains how a person sees reality, the nature of the world and their place in it (Guba & Lincoln 1994). The term was first used by Kuhn (1970) to describe the theoretical and methodological basis guiding research. It is explained as a way of looking at natural phenomena that uses a set of philosophical assumptions and guides a researcher’s approach to an inquiry (Polit & Hungler 1995). This is further explained by Guba & Lincoln (2008) who describe paradigms as having three key parts; ontology (understating the nature of reality), epistemology (how knowledge is developed and the relationship between the researcher and knowledge), and methodology (how research is undertaken relative to the inquiry and the situation). The chosen paradigm therefore influences the researcher’s worldview and subsequent actions, with the choice of research paradigm, in part dependent upon research strategy (Denzin & Lincoln 2011).

While there are many research paradigm choices available, there are many variations of strategies and similar approaches to be taken, and are explained in a terminology which can overlap at times (Coffey & Atkinson 1996). It is important that their methodological approaches aim to capture the perceptions of the actors inside, and recognise the way in which people in particular settings come to understand and manage their day-to-day situations.

There are several paradigm approaches to approach research, and Denzin & Lincoln (1994) explain several paradigms including; constructionism, interpretivism, feminism, positivism, post-positivism and critical theory, each of these are approaches taken to understand and explain knowledge further. Creswell (1998) also proposed qualitative approaches such as, biography, grounded theory, ethnography and case studies. These are examples of qualitative approaches and consequently there are recurring actions across the multiple approaches of inquiry. Understanding their differences and similarities where they exist is important for researchers to know, especially when they are justifying their approach to a given research problem (Weaver & Olson 2006).

The following paradigms; positivism, post-positivism, interpretivism and pragmatism are frequently referred to in nursing literature and will be discussed with regard to their epistemological, ontological and methodological approaches.
3.3.1 Positivism

The term positivism is derived from an emphasis on the positive sciences, that is, what can be tested and systematically reviewed rather than an unstructured and speculative experience (Kaplan 1968). The positivist approach uses scientific methods to develop general and abstract laws aimed at describing and predicting patterns in the physical world (Suppe & Jacox 1985). Developments in the natural sciences, such as physics has led early sociologists to believe that these methods could be applied to the study of human behaviour, and as such all research should be compared to this approach (Denzin & Lincoln 2011). Positivists also believe in a cause and effect scenario, which is known as ‘determinism’ and seeks to find out explanations in data.

Epistemologically, the positivists approach regards ‘human beings as if they were objects’ (Parahoo 1998 p.41). This is a criticism of the positivist approach, because it does not consider humans in their contexts and environments and limits its application to practice (Shumaker & Gortner 1992). The aim of positivism is to achieve objective generalizability, and this is achieved with stringent control of contextual variables.

Ontologically, the researcher believes that ‘truth’ can be achieved objectively ‘value free’ and that this enhances credibility, and the researcher’s role is detached from the research (Guba & Lincoln 1994, Clark 1998). However, as Chinn (1985) points out, absolute truth is rarely if ever established. This is known as dualism, which can view the mind as separate from the body; the knower (subject) is separate from the known (object).

Methodologically, positivism aims to reduce concepts to numerical data to allow measurement and observation. It also relies on verification and replication of findings to discover ‘truth’ (Guba & Lincoln, 2008). This involves manipulation of variables, and structured and objective observation of the results (Denzin & Lincoln 2011).

3.3.2 Post-positivism

Post-positivism further develops the positivist approach and has similar aspects such as controlling variables and empirical testing. Research in the post- positivist
paradigm continues its emphasis on well-defined concepts and variables, controlled conditions, precise instrumentation and empirical testing (Guba & Lincoln 1994). Ontologically, it accepts that findings can only ever be approximations of the truth due to unobservable influences, and acknowledges the weakness of all measurement (Lincoln & Guba 2011). Positivism and post-positivism have similarities, in so far as they both subscribe to verification of hypothesis/theory, reductionism and observation and measurement of research objects (Creswell 2009).

Post positivists believe that reality is not a certainty and while they accept the existence of reality, they believe it cannot be found without objective means to achieve it (Philips and Burbules 2000). Objective knowledge is sought through replication of study techniques and approaches. The post-positivist paradigm is judged appropriate for the study of nursing questions requiring systematically gathered and analysed data from representative samples (Bunkers Petardi, Pilkington & Walls, 1996), and technical clinical knowledge about specific interventions (Horsfall 1995) and predictive theories for at-risk individuals and populations (Norbeck 1987).

Post positivism accepts that the outcome of an investigation is an estimation of the truth rather than the truth itself (Popper 1992). Epistemologically, it claims probabilities about human phenomena rather than universal truths (Letourneau & Allen 1999). Post-positivists aim to improve our ability to perceive reality acknowledging the contextually bound nature of research findings and that research findings are not universally generalisable. Researchers relate to subjects from a modified dualist objectivist stance acknowledging that they cannot be entirely objective (Creswell 2009). The post positivist approach attempts to address this difference with positivism, and that it is aims to get an approximation of the truth (Clark 1998) and that by encouraging ongoing scrutiny of research it will achieve the goal of objectivity (Guba & Lincoln 2005).

Methodologically, post positivists use similar techniques as positivist inquirers such as using an experimental approach (Parahoo, 2006). They also believe that there can be influences on research that may not be measured or controlled, such as contextual dimensions, and by using a range of methods including qualitative methods, this helps to achieve strength in the research approach (Parahoo 2006, Denzin & Lincoln, 2011). To achieve this, a variety of methods known as ‘triangulation of methods’
can be used which facilitates researchers to use a combination of two or more theories, methods, or data sources or investigators in the study of a single phenomenon in an effort to enrich, explain, analyse data and reduce bias (Houghton et al. 2012).

### 3.3.3 Interpretivism

Interpretivism originated in the traditions of hermeneutics and phenomenology (Blakie 1993), and its understanding is embedded in the social interaction and our interpretation of the world (Blakie 1993, Holloway & Todres 2006). Interpretive research acknowledges that the participant is the expert and that there is no single ultimate or correct interpretation of reality (Morse 1995). Rather than finding the truth, interpretation is about opening up possibilities from data (Blakie 1993), its meaning is unique and interpretation of data is essential if movement is to be made beyond the data (Nandhakumar & Jones 1997, Rapport 2006).

Interpretivism is located in a relativist ontology, because more than one truth exists and reality is socially and experientially based (Guba 1990), and consequently, reality is different for everyone. The goal of interpretive research is to understand and find meaning in an experience or social situation from many perspectives (Weaver 2006), and following this, the theory emerges inductively. In this paradigm, intersubjectivity (mutual recognition) between researcher and research participants is fostered and valued (Dzurec 1989, Horsfall 1995). Phenomena are studied through the eyes of people in their lived situations and the unitary nature of person-with-environment is congruent with the individualized, holistic practice espoused by the nursing discipline (Drew & Dahlberg 1995). An interpretivist approach aims to uncover the realities of research participant, to be all encompassing, local and specific to each individual in research (Ford-Gilboe 1995).

Epistemologically, interpretivism acknowledges the subjectivist view and researchers need to acknowledge their perceptions and the impact that this can have on research. Researchers using this approach need to balance subjectivity with reflexivity, which acknowledges that the researcher’s values and beliefs can affect the philosophical and methodological approach taken for a study (Lathlean 2010).
Methodologically, data is collected using semi-structured interviews, non-participant observation and documentary analysis. These methods are in keeping with interpretivism which is concerned with achieving an empathetic understanding, rather than testing laws of human behaviour (Neuman 2003).

A review of different phenomenological approaches was conducted by Dowling (2007), and explained that is both a research approach and a philosophy which is used widely in nursing research. There are many perspectives of phenomenology, either as a philosophy or research method. There are predominantly two descriptions of phenomenology; descriptive phenomenology and interpretivist phenomenology. Brentano (1838-1917) used the term descriptive phenomenology which provided Husserl’s development of phenomenology (Moran 2001). Husserl adopted Brentano’s account of intentionality, which is the principle that every mental act is related to some object (Moran 2001) and suggested that all perceptions have meanings (Owen, 1996). For Husserl, the aim of phenomenology was a rigorous and unbiased study of things as they appear in order to come to an essential understanding of human consciousness and experience (Valle et al. 1989). van Manen, a contemporary philosopher, positioned phenomenology in what is called the ‘Dutch school’, and indicated that it is a combination of descriptive and interpretive phenomenology (Cohen and Omery 1994). Heideger emphasised the importance of understanding which was preferable to Husserl’s view of description (Racher and Robinson 2003). Crotty (1996) suggested that nurse researchers should not claim Husserlian (descriptive phenomenology) or Heideggerian (1889-1976) (interpretive-hermeneutic phenomenology) and suggests that researchers use ‘new phenomenological’ methods. This has originated from the US (Crotty 1996) and is considered a way of combining description and interpretive phenomenology (van Manen 1990). An interpretive phenomenological approach is suitable for research that aims to understand and interpret participants' experiences and to determine the meaning of the experiences (Tuohy 2013).

Grounded theory is just one of the interpretive methods that share the common philosophy of phenomenology, which means it is a method to describe the world of the person or people under study. Phenomenology is unlike grounded theory, in that it does not seek to generate a theory or a model. The individual is placed at the centre
of the study and the subjective experience of the individuals’ reality becomes the focus of the research. Meaning is constructed through a shared (common sense) general knowledge and that reality is expressed through the use of detailed language. It has been used to explore meaning, to define and conceptualise nursing an example of which is seen in the works of Watson (1979) where the meaning of nursing and being nursed were explained and in study of caring in nursing (Benner & Wrubel 1989).

3.3.4 Pragmatism

‘Pragmatism’ is derived from the Greek word pragma which means action, from which the words ‘practice’ and ‘practical’ come (James, 2000; Pansiri, 2005b). Pragmatism is a distinctive American philosophy (Aune, 1970; Blosch, 2001) which was developed as a method of inquiry in the early twentieth century by Wendell Holmes, Jr., William James, Charles Sanders Peirce, Chauncey Wright, and George Herbert Mead (Laughlin, 1995; Purcell and Erlanger, 2002). More recently pragmatist theorists include Rorty 1991, Davidson 1990, Tashakkori and Teddlie, 1998; Creswell, 2003).

Their ideas are based on the premise of the reflections of the Kantean/Fichte/Dilthy philosophical thought on the ‘projection of our minds’ (Laughlin, 1995, p. 72). Rorty defines pragmatism as ‘the claim that the function of inquiry is, in Bacon’s words, to “relieve and benefit the condition of man” – to make us happier by enabling us to cope more successfully with the physical environment and with each other’, and that the desired outcome is the result rather than the process (Rorty 1991, p. 27). Mead (1936) considered pragmatism a ‘practical sort of philosophy’ (p.352), emanating from rationalistic philosophies and a philosophical approach to establish ‘the process of knowing- inside the process of conduct (p. 351-351). Pragmatism was considered the precursor to symbolic interactionism (Stryker, 1972; Plummer, 1996; Reynolds, 2003; Musolf, 2009).

Epistemologically, it is concerned with the unification of knowledge and theory to practice which distinguishes pragmatist philosophy from other philosophical positions (Dewey 1992). It is a humanistic movement in philosophy which
emphasises the role and influence of the researcher in the creation of objective and meaningful reality and all findings or theory must be considered in light of this context (Rorty 1991, Shalin 1992). Methodologically pragmatism is frequently used in mixed methods research where inductive, deductive, quantitative and qualitative methods are likely to be applied to address the question. This is because the researcher will select the correct approach for knowledge development which is in keeping with what Denzin & Lincoln (2008) call ‘bricolage’, which is the result of research that has brought together a range of multidisciplinary theories and approaches to a complex research question (Warne & McAndrew, 2008).

Pragmatism is different from traditional views of research, in which a hierarchy of approaches produces 'truths' that are given weight by methodology. It has moved away from positivism and post-positivist traditions and favours a mixed methods approach in its research conditions (Creswell, 2003).

Ontologically, the process of social inquiry is on the outside world, which is based on experiences, thoughts and feelings on the world and this is open to interpretations of experiences. Pragmatists do not preference a single belief or range of beliefs about reality.

Some pragmatists believe that embracing pragmatism is the paramount philosophical foundation for using different paradigms in research and that researchers need to explain each paradigm and to be explicit about when each is used (Caracelli & Greene 1997).

It is an alternative epistemological paradigm where knowledge consists of assertions that result in taking action and experiencing the outcomes. It asserts that choices can be made about the process of inquiry on a given theme (Morgan 2014). Proponents of pragmatism contend that there is no incompatibility between quantitative and qualitative methods, either epistemologically or at practice level, and are encouraged to use whatever works for them with their research inquiry (Howe 1992).

Methodologically, it allows the researcher to emphasise the area of interest to them and identify what works for them in finding out about it, using whatever epistemological and methodological approaches that suit the context of the research (Boham 1999, Gibson 2008, Leigh-Star 2011).
3.4 Research strategy

After identifying the various research paradigms, the next step for a researcher is to explain what research strategy is adopted for the proposed study (Creswell 2009). There are two approaches to a research strategy, quantitative and qualitative (Polit & Hungler 1995, Creswell 2009).

This section will explain why a qualitative approach was undertaken in this study. Research using quantitative approaches tend to identify outcomes, declare facts, test theories and demonstrate relationships (Parahoo 2006). This approach was not considered appropriate by the researcher, because the dynamic between participants involved and the study topic was not deemed to be suitable for a quantitative framework of inquiry.

A quantitative approach is the least appropriate to explore the phenomenon of residents’ final days in residential care. A quantitative approach is favoured for looking at a situation objectively, cause and effect relationships, identifying findings deductively and to generalising them to broader populations (Bowling 2009). Quantitative data deals predominantly with numbers, defining quantities and the relationship between defined attributes. Bowling (2009) suggests that it is more suitable when there is pre-existing knowledge around the area, which can allow data collection to be standardized and controlled.

Many studies have used various approaches to exploring end of life care for residents and their carers. However, evidence has shown that many studies in this area are of a qualitative design and a systematic review on end of life care identified research designs which were classified into three areas and most (sixty-six per-cent) were in the descriptive/ explorative classification as opposed to experimental and survey designs (Andershed 2006).

This research study aimed to provide a greater understanding and further contribute to the development of an appropriate means of supportive care at life’s end in residential care in the future. A quantitative approach could replicate any previous studies and fail to produce an in-depth understanding of the substantive area of end of life care in residential care (Dewing 2002). Furthermore, the emphasis of
qualitative research is to explore the quality and gain a deeper meaning of experiences (Creswell 2009), especially with diverse participant groups, and therefore this study aimed to understand the factors that influence good end of life care for older people in long stay residential care.

### 3.5 Rationale for qualitative research

Qualitative research aims to describe and understand participants’ experiences, including their attitudes, opinions and social experiences (Denzin & Lincoln 2008). It aims to study phenomena in their natural (usual) setting using a variety of approaches. The goal for a researcher is to achieve an understanding of the participant in their social context. There are several qualitative research strategies that researchers can use to achieve this, including ethnography, phenomenology and grounded theory (Denzin & Lincoln 2008).

Ethnography is a type of research that asks questions about the social and cultural practices of groups of people (Buch & Staller 2007), it produces rich, local descriptions and an insider (emic) view and understanding of participants’ views and behaviours (Denzin & Lincoln, 2011). While it focuses on cultural contexts and an understanding participants’ views, in a particular cultural setting, it is not appropriate for this research. This study required more than description or an interpretation of a culture. This study aimed to understand the participants’ views over time and during a time at end of life care.

Phenomenological studies contribute knowledge in the form of ‘deeper understanding of the nature or meaning of our everyday... existence’ (van Manen 1999, p. 9). While Heideggerian interpretive phenomenological study can assist in gaining a deeper understanding of a particular phenomenon, it does not offer adequate in-depth personal, cultural and organisational influences at work. Furthermore it does not offer a level of theoretical understanding of the actions and interventions adopted in long stay residential care where residents are nearing end of life, which is the aim of this research.

Grounded theory has its emphasis on discovering meaning and generating theories from data (Glaser & Strauss 1967). Grounded theory studies concentrate on the interactions between people, how they socially construct meanings, their conditions
and contexts, and consequences and the symbolic meaning of artefacts (Strauss & Corbin, 2008, Bluff 2005, Strauss & Corbin, 1998). This is especially appropriate for this research study.

In line with symbolic interactionism, grounded theorists assume that people sharing common circumstances and experiences, and thus, their common meanings and behaviours constitute the essence of grounded theory (Hutchinson and Wilson 2001). The aim of a grounded theory approach for this study was to develop a conceptual or theoretical model that endeavours to explain the end of life care in residential care homes. As it is predominantly an inductive approach, it is more appropriate where the aim is explore factors that influence for people involved with the end of life care for older people in residential care.

This research study intended to develop a theory on end of life care in residential care settings which transcends the substantive area of interest, producing a theoretical understanding that is applicable to a range of contexts where residents in long stay residential care homes are receiving end of life care.

### 3.6 Symbolic interactionism and grounded theory

In order to provide meaningful evidenced based care to residents living in residential care nearing the end of their lives, it is important to understand their health related illnesses and how they gain meaning and insight to their situation. Symbolic interactionism is a useful to guide to illustrate how nurses, residents and their relatives interpret their social context of death and dying in residential care, how they construct meaning from symbols, and determine their course of action especially at a time when faced with end of life care.

Specifically, this study aims to illuminate what residents see, and understand how they view life and death in residential care. To understand what they think is important and how they define their situation. Similarly, residents are viewed in the context of other residents, nurses, care staff and their relatives who have been involved in their life story and future plans. In using symbolic interactionism, Ritzer (1992) indicated that there should be three criteria; that there is a focus on the interaction between the actor and their world; a view that the actor and the world is a dynamic process, and, the importance of the actor’s ability to interpret the social
world. Interpretive research methods based on symbolic interactionism focuses on aspects omitted by other methods of inquiry, through its exploration of people’s experiences, their actions and variations of these across time and context.

What people do is based upon the meaning they ascribe to the action of others (Blumer 1962). The process is mediated by symbols. These are the stimuli which have an ascribed value and an individual’s response is a reaction to the meaning ascribed, not the stimulus itself (Stern, 2007). Symbolic interactionist research seeks to explain a process by which meaning is arrived at by people in their social context. Hunter (2014) highlighted that although there is an understanding that symbolic interactionist research is the default theoretical perspective for grounded theory research, several writers have refuted this (Glaser, 2005, Bryant and Charmaz 2007, Sterns 2007), suggesting that there is a clear applicability of symbolic interactionism to grounded theory. The interpretations and actions made by individuals can only be understood within the context of social setting and interaction. Stern (2007) described it as a useful backdrop for grounded theory “An assumption that people act and react based on their relationships” (p.121). Hunter (2014) further highlighted the relationship between symbolic interactionism and grounded theory in clarifying that individuals ascribe meaning to the action of others and respond to symbols and stimuli rather than clear direction. This understanding can be useful in guiding our understanding of relationships between emergent categories (selective coding) rather than being the paradigm upon which the entire research rests (Hunter 2014).

Consequently, grounded theory methods help to translate people’s private experiences and understanding of their experiences to a common language and processes which can be easily understood by residents, care staff and relatives in long stay residential care.

Symbolic interactionism is an empirical social science based on the study of human group life and human conduct (Blumer, 1969). Although Herbert Mead (1934) is credited with developing symbolic interactionism, the term was not initially used, and it was Blumer who unexpectedly, coined the phrase symbolic interactionism in a chapter he wrote in *Man and Society* (Blumer, 1939) and that it ‘caught on and came into general use’ (Blumer, 1969, p.1).
The theory and conceptualisation of symbolic interactionism developed in the late 19th and early 20th centuries in the Chicago School (Deegan, 2001; Muslof 2003). Symbolic interactionists distinguish themselves from other social scientists by their shared claim to Mead’s symbolic interactionism understanding, and his original idea that “human biological organism possess a mind and a self” (Herman-Kinney & Verschaeve, 2003, p. 214). More significantly, meaning and the concepts of self, action, and interaction are key interweaving themes that feature in various interpretations of symbolic interactionism. This means, that an individual’s perspective on a situation and how they interpret the world, and event or a situation, influences how they act (Blumer 1969). The phenomenon being examined is about the process of end of life care in in residential care homes. Participants in the study are older people, nurses and relatives who are involved in the process of providing care in the context of community nursing.

In selecting grounded theory, the researcher-participant relationship becomes the interactive context within which the researcher comes to understand the perspectives of residents, their carers and relatives’ ways of knowing and find meaning in the process of dying in residential care.

The concept of meaning is key to symbolic interactionism. It assumes that people act on shared meanings. A psychological view of the origin of meaning contends that meaning is an expression of sensations, feelings, memories, ideas, attitudes, and motives that are brought into play in connection with a person’s perception of a thing (Blumer, 1969). Meaning arises in the process of interaction. The meaning of something is not fixed or rigid; it is fluid, changeable, and open to reappraisal (Blumer, 1969; Charon, 2007; Mead, 1934; Plummer, 1996). In grounded theory, establishing meaning from the data, involves an initial coding and intermediate coding phases, the researcher ascribes meanings to data through the use of codes.

The following section will explain the origins of grounded theory and clarify why this methodology was the most appropriate for this study.

3.6.1 Grounded Theory

The way in which phenomena are understood are important in symbolic interactionism and grounded theory. Knowledge is both subjective and re-
constructed and this is key to identifying new knowledge on the processes involved in dying in residential care. Although each participant's world view is created uniquely, there are commonalities between participants. These commonalities are the meanings and interpretations participants give to the phenomenon of dying and end of life care in residential care.

The philosophical assumptions underpinning grounded theory are derived from a symbolic interactionist sociology and pragmatist philosophy, which have been outlined in the previous section (Strauss 1987, Morse 1994, Milliken & Schreiber, 2001, Charmaz 2003, Clarke 2003, Bryant 2009, Nathaniel 2011, Stern & Porr 2011).

Grounded theory emerged in the 1960’s when Glaser and Strauss titled their original book ‘The Discovery of Grounded Theory’ (1967) and simultaneously explained an important epistemological standpoint about creating scientific knowledge. This publication of The Discovery of Grounded Theory: Strategies for Qualitative Research (Glaser & Strauss 1967) was a milestone in social research. At this time, there was a widespread tendency to regard sociological research as a way of verifying and refining ‘grand theories’. Glaser & Strauss challenged this by arguing a need to develop new theory that was relevant and carefully derived from data, rather than furthering what they perceived as largely deductive and speculative theory (Glaser & Strauss 1967 p. 29).

The book, _Discovery of Grounded Theory_ was published to provide an alternative type of research that supported the production of systematically developed novel theory in a substantive area. Grounded theory methodology is the discovery of theory from data systematically gathered from social research (Glaser & Strauss 1967 p2). In a broader context, grounded theory was developed in response to two significant social and research stimuli at the time. Firstly, the development of grounded theory was a direct challenge to the dominating quantitative research approach during the 1960’s. Secondly, researchers who had preference towards qualitative inquiry, recognised there was lack of systematic guidelines available at the time to improve the quality of qualitative research and stand up to critical appraisal.

The process of data collection and rigorous analysis of data helped position grounded theory as an accepted methodology for social research. By combining the depth and
richness of qualitative research traditions with the logic, rigour and systematic analysis associated with quantitative research, grounded theory espoused an innovative research methodology for social and health care sciences (Walker and Myerick 2006).

Glaser’s background consisted of training in quantitative methods and middle range theories in Columbia University. Strauss’s background was very opposite to Glaser’s, and his background was in symbolic interaction which came from his studies in the Chicago school and its emphasis on pragmatist philosophy, symbolic interactionism, and ethnographic traditions at Chicago. The Chicago School was particularly associated with qualitative methodologies, especially those using a naturalistic observational approach to the study of human group life and human conduct, such as symbolic interactionism (Blumer, 1969).

Glaser and Strauss, both aware of their different styles and perspectives on grounded theory, argued against their disciplinary trends. They worked together at the University of California until the early 1970’s where grounded theory methodology emerged, however, their subsequent separate paths contributed to their methodological difference from then on. Grounded theory methodology proposed by Glaser and Strauss in 1967 were the first guiding principles and represented a framework of good practices. In different research contexts, researchers were encouraged to tune and apply the methodology flexibly.

Following Glaser and Strauss’s development of grounded theory as a qualitative design in 1967, they later elaborated their ideas in the many subsequent texts (Glaser 1967, Glaser and Strauss 1967, Strauss 1987, Strauss & Corbin 1990, 1998). Despite Glaser and Strauss’ initial collaboration which produced such works as Awareness of Dying (Glaser and Strauss 1965) and Time for Dying (Glaser & Strauss 1968), the two authors disagreed on the approach of grounded theory. Glaser criticised Strauss’s approach to grounded theory as being too structured and prescribed (Glaser 1992).

3.6.2 Divergence of grounded theory methods

Since its introduction, grounded theory methodology has diverged into three discernible versions: the earliest being classic grounded theory which is associated
with Barney Glaser, following this was an evolved grounded theory which is mostly associated with Anslem Strauss, Juliette Corbin, and Adele Clarke; and more recently, constructivist grounded theory which is associated with the work of Kathy Charmaz (Chamberlain, Mills and Usher 2013). Deciding which methodological version to use was the next step taken in this study. Understanding grounded theories’ origins guided the process of decision making which is outlined in the next section.

Grounded theory explains and describes the systems and behaviours, which are being studied and is also a methodology for theory development which is grounded in data systematically gathered and analysed (Strauss & Corbin 1994). Consequently, each grounded theorist’s approach aims to search for social processes present in human interaction and aims to discover patterns and processes and understand how a group of people define their reality via their social interactions (Stern 1982, Cutliffe 2000). As a result of the emergence of differences in methodology used in grounded theory, researchers should identify which methodology they wish to use for their enquiry (Dey 2004).

In grounded theory, researchers seek to identify the main concern of individuals on a specific subject and within a particular area and to account for how this is resolved. Through a systematic approach to data collection and analysis, patterns within data from this area are identified and conceptualised. As well as exploring how the conceptualised patterns may vary and what may account for the variation, through this a theory of resolving the core concern is developed, and a theory emerges from data (Glaser & Strauss 1967).

Mills et al (2006) describes the work of Glaser as traditional and the work of Strauss and Corbin as evolved. Philosophically, Strauss and Corbin (1990, 1998) address the paradigm that underpins their method. They discovered the relationship between reality and truth. This positions them as relativist pragmatists by stating that “theories are embedded in ‘history’, historical epochs, eras and moments, are to be taken into account in the creation, judgment, revision and re-formulation of theories” (Strauss & Corbin 1994, p.280).

Grounded theory is grounded in social interaction; it is fluid in the way it evolves and unfolds, has its goal in the ‘non-mathematical process of interpretation’ (Strauss
Corbin & Corbin (1998: 8-14) and arrives at a meaningful understanding of events, particularly of human action and human experience. It aims to explore social processes found in interaction between people. It aims to demonstrate how groups of people such as residents, their carers and nurses define their reality (Cutliffe 2000) and its goal is to construct theories in order to understand phenomena (Haig 1995). More recently, Charmaz (2006) has advocated a ‘constructivist’ approach to grounded theory, thus introducing another perspective about procedures for grounded theory. However, it is because of the more systematic procedures of Strauss & Corbin (1990, 1998) that this study uses the Strauss & Corbin (1998) approach. Strauss & Corbin (1998) indicate that ‘because grounded theories are drawn from data, are likely to offer insight, enhance understanding, and provide a meaningful guide to action’ (p 12). This type of methodological inquiry requires a degree of rigour and grounding analysis in data. However, debates over which type of grounded theory to use continue, whether it is simply as a method of analysis rather than a methodological approach that influences the overall design and conduct of the study (Glaser 1999, Murphy et al. 1998, Willig 2001, Barbour 2003). Willig (2001) attributes this to the lack of detail in Glaser and Strauss’s (1967) description of grounded theory, whereas Glaser (1999) suggests that students’ training, widespread use of grounded theory and cultural diversity have affected how grounded theory is used.

Glaser’s approach is viewed as the more, original, traditional or orthodox approach to data analysis, while Strauss (and Corbin’s approach) is viewed as having re-modelled the original version (Heath & Crowley 2004, Melia 1996, Glaser 1992). In the original text, data analysis is loosely described (Glaser & Strauss 1967). Consequently Strauss & Corbin published two texts to attempt to clarify the steps involved in the process of data analysis (Strauss & Corbin 1998a, 1990, Corbin & Strauss 2008).

Corbin and Strauss (2008) and Strauss & Corbin (1998a) indicated that researchers should trust their judgement on which approach to use and avoid worrying about which method to select. The following quotation emphasises this clearly; “Sometimes 2 Strauss died in 1996 and his book was completed by Corbin

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one has to use common sense and not to get caught up in worrying about the right or wrong way. The important thing is to trust oneself ... use the procedures and techniques flexibility and according to their abilities and the realities of their study” (Strauss & Corbin, 1998a p. 295).

Although Corbin published a third edition of grounded theory, she has acknowledged that her thinking has evolved and her text represents a modernization of the methods, however, it is balanced with her awareness of her aim to combine the good elements of Strauss’s work and making it more contemporary. This was criticised by many, such as Melia (1996) who indicated that it was similar to a programme and very formulaic.

Glaser was also critical of this and found it untrue to the original method arguing that it was “forced, full. Conceptual description” Glaser, 1992 p.5). The third edition of Basics of Qualitative Research (2008) is less prescriptive and more flexible in its approach. Strauss & Corbin (1998) indicate that ‘because grounded theories are drawn from data, are likely to offer insight, enhance understanding, and provide a meaningful guide to action’ (p 12). This type of methodological inquiry requires a degree of rigour and grounding analysis in data.

The following (Figure 3.1), demonstrates the comparisons and summary of the analytical processes between the dominant grounded theorists Glaser (1978, 1982), Strauss & Corbin (1990, 1998) and Charmaz (1983, 1990) adapted from Chen and Boore (2009).
3.6.3 **Application Grounded theory in end of life care studies**

Grounded theory has been the chosen methodology for a variety research inquiries ranging from psychology, nursing, health care management, education, teaching, information technology application and social care. These examples illustrate the diverse areas and approaches to grounded theory. In different professional contexts, its aim is to develop theory that has applicability and appropriateness in the context of the user. Many examples appear in counselling and psychology are from Kinnier *et al.* (2001), Morrow and Smith (1995), and (Rennie 1994), however, there are several authors who have explored dying and end of life and have used different approaches of grounded theory for their inquiries; Long-Sutehall (2011) used Charmas’ methodology, Munn (2008) used Strauss & Corbin (1998) and Gallagher (2015) used Glaser’s classic methodology.
These will be discussed in the following section to illustrate the context where grounded theory was used and the outcomes of these studies. Long-Stutehall’s (2011) grounded theory methodology study is used to illustrate how differing dying trajectories impact on nurses’ decision-making underpinning withdrawal of treatment processes, and what nurses do to shape withdrawal of treatment in critical care environments. Using Charmaz’s grounded theory method, single audio-recorded qualitative interviews with thirteen critical care nurses from four intensive care specialities were carried out. Interviews were facilitated by an end-of-life vignette developed with clinical collaborators. Long-Stutehall’s (2011) findings showed that nurses provided end of life care (including collaborative and action-oriented skills) to shape the dying trajectory of patients so as to satisfy the wishes of patients and family, and their own professional aims. Long-Stutehalls’ (2011) approach to data analysis was carried out in three phases, the first analysis of data involved coding, grouping of codes and memoing. The second phase of analysis involved more data and focused coding and expanding of coding list, free writing, and memo sorting. The final round involved theoretical coding, making active decisions about where to look for data, clarifying properties, and agreement of key category as a basic social psychological process.

Another example of a study using grounded theory methodology was carried out by Munn et al. (2008), who examined the end of life experience in long term care from the perspectives of key stakeholders. This study was based in North America and used Strauss & Corbin’s grounded theory techniques to elicit manifest and latent themes. Five overarching themes emerged which included components of a good death in long term care, normalcy of dying, the role of relationships in the provision and receipt of care, and hospice contributions to care in long stay care, and stakeholder recommendations for enhancing end of life care in these settings. Underlying these themes was one central category, closeness, based on physical proximity and frequency of contact. The central category that is related to all categories, appears frequently in the data, is abstract, and grows in depth and power upon further examination (Strauss & Corbin 1998). This study followed Strauss & Corbin’s (1998) open coding, selective coding, and axial coding of their data, which is true to the Strauss & Corbin grounded theory approach.
The third example of a study to use grounded theory methodology (Glaser) was Gallagher et al. (2015) who aimed to understand nurses’ end of life decision-making practices in ICUs in different cultural contexts. Interviews were conducted with experienced ICU nurses in university or hospital premises in five countries: Brazil, England, Germany, Ireland, and Palestine. Their study used grounded theory to inform data collection and analysis. Interviews were facilitated by using key questions. The comparative analysis of the data within and across data generated by the different research teams enabled researchers to develop a deeper understanding of end of life decision-making practices in the ICU. Their results showed the core category that emerged was ‘negotiated reorienting’. Whilst nurses do not make the ‘ultimate’ end of life decisions, they engage in two core practices: consensus seeking (involving coaxing, information cuing and voice enabling); and emotional holding (creating time-space and comfort giving).

There was consensus regarding the core concept and core practices employed by nurses in the ICUs in the five participating countries. However, there were some discernible differences regarding the power dynamics in nurse–doctor relationships, particularly in relation to the cultural perspectives on death and dying and in the development of palliative care. The research suggests the need for culturally sensitive ethics education and bereavement support in different cultural contexts.

These examples of end of life care studies that used grounded theory methodologies and further illustrate the types of studies and they are used in and the appropriateness for choosing grounded theory for the proposed research which aided the researcher’s decision-making process.

3.6.4 Issues considered when choosing a grounded theory for this study

When using grounded theory, the interaction between the researcher and the data results in ‘discovering’, or creating, categories. In short, the ‘discovery’ process consists of the researcher creating new insights about the data and constructing the analysis. How the researcher uses the method and which questions the researcher brings to the data shape the results. Having a background embedded in nursing
concepts prompted the researcher to look for constructions around status, relationships, ritual, and self-concept. In addition, the researcher’s perspective leads to asking certain kinds of questions. In this study some of the questions included; how do older people, their families, and nurses construct definitions of end-of-life care, for themselves and their situation? Who is involved in their definitions? How do their definitions compare with larger cultural themes and social values? What do older people see in their situations; of what are they aware; unaware of at end of life? How do they feel about others, themselves, their plans, hopes and prospects? What are the processes involved that influence end of life care? Under which conditions do older people and nurses have relative autonomy and control? Under which do they not? These questions help the researcher analyse data and discover categories from the data.

The aim of this research was to explore the many factors which influence good end-of-life care for residents in long stay care homes. The perceptions of residents and their families, and staff of end-of life care is less well known. The aim was to illuminate a deeper understanding of a specific phenomenon, that of end-of-life care for older people and the perspectives of the residents’ families and staff involved in their care. This fits the aim of qualitative research, which is to gain an understanding of the nature and form of a phenomenon, to unpack meanings, develop explanations and to help develop ideas concepts or theories (Ritchie et al. 2003 p. 82).

Grounded theory methodology (Strauss & Corbin 1998) was chosen because it outlines its processes clearly and offers specific guidelines for data analysis, which, for the novice researcher with little research experience is useful as it is prescriptive and structured. The guidelines offered by Strauss & Corbin provide concrete direction and fitted well with my research question. Charmaz’s methodology was also considered as suitable for the study. However, following discussions with two experienced grounded theory researchers and extensive reading, Strauss & Corbin’s approach to grounded theory was considered the most appropriate for this study.

The process in deciding which methodology to choose from is explained in the following memo (Figure 3.2), which represents the researcher’s reflexivity in making that decision. Reflexivity refers to the ability of the researcher to reflect upon, explore and examine social processes and contextual factors influencing the research
relationship as well as participants’ lives (Fonow & Cook 1991). The following, outlines a reflexive memo to illustrate choosing which methodology to use.

**Figure 3.2 Reflexive memo on choosing which methodology**

Memo 11/10/2010

“Of the three approaches, I am least comfortable with Charmaz, as it is an approach which addresses both aspects of Glaser and Strauss & Corbin and is a new and unchartered for me. Charmaz (2003, 2006, 2008a) argues for acknowledgement of the researcher as co-constructer of both the research outcome and the research process. I feel as if this will undermine my objectivity in my analysis and compromise potential trustworthiness of the findings. I am left now with either Glaser or Strauss approach. The Glaserian School stresses the interpretive, contextual and emergent nature of theory development. Glaser (1992) states “The research question in a Grounded Theory study is not a statement that identifies the phenomenon to be studied. The problem emerges and questions regarding the problem emerge by which to guide theoretical sampling. Out of open-coding, collection by theoretical sampling, and analyzing by constant comparison emerge a focus for the research” (p. 25). Therefore, this approach suggests very strongly not to undertake a literature review in the substantive area or related areas where the research is to be done. Only when the study is nearly completed, to transcribe interviews and analyse using coding techniques, and incorporate literature search in the substantive area so that it can be woven into the theory as more data for constant comparison (Glaser, 1998). Given that my research was led by a research question, the Glaserian Grounded Theory approach is inappropriate. Furthermore, my prior knowledge in the area (from professional experience, education and training) would make the demand of the Glaserian approach (going into the field without any idea of what to look for) unrealistic.

In comparison, the Straussian School, emphasises a highly complex and systematic coding technique and permits a preliminary literature study to identify research problems and the areas in which to look for data. According to Straussian guidelines, “…the researcher does not begin a project with a preconceived theory in mind” but rather “he/she begins with an area of study and allows the theory to emerge from the data” (Strauss & Corbin, 1998, p. 12). Therefore, I considered Straussian Grounded Theory to be more appropriate than the Glaserian one for my research study. In this project, I have to take special care to “…avoid imposing concepts that reflect his/her (my) own epistemological predilections other than those emerging from interaction with the study site, its participants and subsequent data” (Douglas, 2004, p. 60). Using memos throughout data collection and analysis and reflexivity along with close supervision and monitoring with my supervisor I hope to maintain objectivity and rigour in data collection and analysis. Cooney (2011) addressed
rigour and grounded theory and asserted several strategies to be adopted, such as; cross checking emerging concepts with participants meanings, asking experts if the theory fits their experiences, recording all detailed memos outlining all sampling and analytical decisions throughout the research process were some of the ways to maintain rigour in her Straussian grounded theory study. She concluded, that process and product should be considered when judging the credibility of grounded theory study (Cooney 2011). Reflexivity allows the researcher to include our ‘selves’ in the research by making transparent our values and beliefs that influence the research process (Etherington 2007). A critical approach to reflexivity brings a particular focus on the researcher’s own power and privilege, a position that can contribute to tension when critiquing the power struggles of participants (Soyini-Madison 2005).

3.6.5 Summary

Understanding the philosophical, epistemological, and ontological approach of a research study is paramount prior to entering a field of study. This is based on three reasons; it is important to know about its philosophical assumptions about what constitutes knowledge or paradigm; secondly, this supports the strategy taken for the inquiry, and thirdly, which methods of data collection and analysis to use (Creswell 2009, 2003).

There were several reasons for choosing Strauss & Corbin’s (1990, 1998) version of grounded theory. The factors that influenced the decision to use Grounded Theory methodology has been offered, as it is an appropriate methodology because it places an importance on identifying the structural and the contextual, symbolic interaction, and influences on the phenomenon being examined, i.e. exploring factors that influence end of life care in residential care homes. This dual approach highlights the need to examine the micro and macro influences on a phenomenon, the strategies that participants adopt to live and work in long stay care homes.

Strauss & Corbin (1998) describe two basic operations of grounded theory; the first is asking questions of the data and the second is making comparisons. Questioning a problematic situation in the data can lead the researcher to a new level of understanding. Questioning can also lead the researcher to different types of methodological technologies. Some questions can be directed at substantive matters for example, ‘what are the most common factors that affect care at end of life’. And
other questions can be directed at more theoretical issues, for example ‘How do these factors affect end-of-life care?’ Identifying concepts and how they relate can lead to the development of theory. A good question is one that leads the researcher to answers that serve the developing theoretical formulation (Strauss & Corbin 1998).

Another reason for choosing Strauss & Corbin’s (1990, 1998) approach is based on a contemporary move towards constructivist ontology and post-structuralist paradigm. This ontological approach was considered more appropriate than the critical realist ontology and post-positivist paradigm of grounded theory, as it fits with the researchers own position as a practitioner researcher who sees the life in long stay residential care homes and people involved in them. This section justifies the methodological approaches taken to examine the phenomenon in question. The following will explain some of the processes used in Strauss & Corbin’s (1990, 1998) methodology.

### 3.6.6 Theoretical Sensitivity

Theoretical sensitivity means that the researcher is aware of what the data means throughout the process of data collection and analysis. It ensures that the researcher undertakes an in-depth analysis of data to support an emerging theory. Strauss & Corbin’s (1998) revised grounded theory acknowledges the value of the researcher agency in data collection and analysis and describe it as “…having insight into, and being able to give meaning to the events and happenings in the data” (Strauss & Corbin 1998a, p.46).

Objectivity enables the researcher to have confidence that the research findings are a reasonable and impartial representation of the problem under investigation, and, sensitivity allows creativity and the discovery of new theory from the data. Schreiber (2001 p.60) clarifies the process further by explaining that it is the “…ability of the researcher to think inductively and move from the particular (data) to the general or abstract, that is to build theory from observation of the specifics”. By developing sensitivity to the data, it means being able to see beneath the obvious in the text of an interview transcription or other media and see new data, making comparisons, asking questions, and gathering more data from other sources.
The researcher maintains a balance between objectivity and sensitivity. Nurses practicing in residential care for older people are familiar with the clinical context, for example, life in residential care, death and dying, administrative and staff issues, and have an awareness and insightfulness of the situation which heightens their level of sensitivity. Nurses and managers in this area would be familiar with relevant literature on their area of practice. A researcher in the area would demonstrate their research expertise by being able to conceptualise, understand, visualise, make abstract connection, and separate out what is important (Strauss & Corbin, 2008; Glaser 2004; Schreiber 2001, Strauss & Corbin 1998; Strauss & Corbin 1990). In order to achieve this the researcher needs to be able to challenge their preconceptions about the data (Schreiber, 2001).

Literature can also be used as an analytic tool if used in theoretical terms. If used in this way literature can provide a rich source of events to stimulate thinking about properties for asking conceptual questions. It can stimulate initial ideas to be used for theoretical sampling (Strauss & Corbin 1998 p.47). The following figure (3.3) aims to demonstrate examples of using literature to develop theoretical sensitivity to data.

**Figure 3.3: Developing theoretical sensitivity using literature**

<table>
<thead>
<tr>
<th>Concern</th>
<th>Illustration (using memo)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compare properties, dimensions and meaning of a code such as ‘facing death’.</td>
<td>Compared understandings ‘end of life care’ to dying, terminal, palliative, nearing death, a good death, (e.g. RCN, 2008; HIQA, 2009; O’Shea, 2008; Murphy, 2006, Murray, 2005, Gott, Seymour Bellamey, Clark, Ahmedzai 2004) 2004) and community care (e.g. Froggat, 2002, 2005, 2006, McCormack; van der Heide 2006)</td>
</tr>
<tr>
<td>Identify significant concepts that are found repeatedly in the data and which appear in the literature.</td>
<td>The literature helped name codes from initial terms used where resident would use the phrase ‘not mind about end of life care’ to ‘normalcy’ of dying’ (Johnson 2015)</td>
</tr>
<tr>
<td>Find clues as to what to look for in the data and generate questions to ask respondents</td>
<td>Repetition of what nurses replied during interview, ‘helping the family’ and residents wish to ‘keep family connections’ alerted me to examining the view of family participants, therefore, I had to dig further into analysis around the concept of ‘family’/ ‘community’/ ‘connections’ to find out if they were the same or different from the literature.</td>
</tr>
<tr>
<td>Look for how properties and dimensions of documented concepts and relationships vary under different sets of</td>
<td>For example, I examined the meaning of ‘Dignity’, looked at the literature and found that it was linked with ‘Meaning of life’, ‘body’, ‘and privacy’ which was frequently used throughout the interviews with nurses</td>
</tr>
</tbody>
</table>
conditions (e.g. Johnson 2015; Lebech 2012, Casey 2011; Manthorpe 2010, Cass, 2009; Dwyer 2008; RCN 2008,). Other literature related to was found in nursing homes as frequently linked to environment and space afforded to older people and residents (Hall, Longhurst & Higginson 2009, Pleschberger 2007, HIQA, HfH, Weafer, McCarthy 2008).

Check quoted materials from interviews and field notes as well as descriptive materials concerning events, actions, setting and actors’ perspectives.

Nurses wanted to provide ‘Good end of life care’ and maintain a sense of ‘Autonomy’ (e.g. ten Hav 2001, Welford 2011, Weafer 2009).

Formulate questions that act as a stepping-off point before and after interviews

Literature on residential care for older people (O’Shea, Murphy, Cooney, Gannon 2013) outlined areas of concern for older people, areas such as: living well, enjoying life within the home; acknowledging their past lives as part of their identity. Thus, it helped focus questions relevant to the topic area.

Stimulate questions during the analysis process

I saw differences between participants, residents, and family members and nurse. This prompted to form new propositions (what are the differences between participants, why, what common goal connects them) which led to a new cycle of data collection. This action consequently increased participant numbers.

Provide insights into where to theoretically sample

The literature on families’ level of involvement provided useful insights into where to investigate, for example to interview relatives who have residents who are living in residential care homes, or relatives who recently lost a relative.

Confirm findings and/or illustrate where the literature is over simplistic and/or only partially explains phenomena

I constantly compared findings to existing theories on end of life care such as, (Dobrina 2014, Wright 2012, Desbiens et al. 2012; Kolcaba 2011, O’Shea 2008, McGrath and Holewa 2007; Murray 2007; Wagner 2005; Watson 2005; Larson 2000) and found where aspects of these theories do not fit completely with long stay residential care, and how my theory can correct this (my theory explains that what is unique in the community of long stay resident with staff and family involvement) using Dewar & Nolan 2014, Bergum & Dossetor theory of relational ethics.

Strauss & Corbin lists various sources of theoretical sensitivity; the literature, professional experience, and personal experience. Literature is important because it provides a background of information which informs (sensitises) the researcher as to what is happening in the data (Corbin & Strauss 2008, Strauss & Corbin 1998, Strauss & Corbin 1990). However, the researcher needs to be able to discriminate between sensitizing concepts which can help focus the data collection and the use of

Professional experience and personal experience are acknowledged as a potential source of sensitivity as it can enable the researcher to move into an area more quickly because she/he does not have to spend time getting to know an area or an event. This reflects my own position as a nurse researcher and manager of a care home in daily contact with residents and their carers throughout their end of life care trajectory. The factors that influence good end of life care for residents and their carers’ perceptions is central to this study. This ‘bottom up’ method is used for discovering relationships in raw data and then organising them into a theoretical explanatory scheme (Strauss & Corbin, 1998, p.11).

For example, professional experience working in the field under study, provides insight on how things work in residential care and helps the researcher to understand what is seen and heard (Strauss & Corbin1998, 1990). However, some professional experience can block a researcher from seeing things that may have become routine or ‘obvious’ to them. Strauss & Corbin (1998, p.47) suggests that the researcher compare what ‘one thinks one sees to what one sees at the property or dimensional level’ to prevent the researcher from inadvertently imposing their own personal experience on the data.

Life experience is another source of theoretical sensitivity, such as experiencing loss and deaths over a period of time. Strauss & Corbin advise that personal experience may limit insight, if the researcher assumes that their experience is the same as participants. It is very important that the researcher is fully aware of their own biases. Schreiber (2001) stresses the importance of memo writing about personal beliefs, biases and ‘personal’ theories, which should be set aside and compared to the data at a later stage. This approach helps to ensure that theory emerges from the actual data rather than the experiences of the researcher.

3.7 Data Analysis

Data analysis is concerned with synthesis and analysis of the data collected by the researcher to produce something that is universally understood. It brings order and structure to a mass of collected data (Marshall 1989). As the data is collected, it
should be analysed simultaneously by looking at all the possible interpretations. This involves using particular coding procedures which begins with open coding.

During open coding the researcher is concerned with data being collected by the generating categories and their properties and then seeks to determine how categories vary dimensionally. It is not until major categories are finally integrated to form a larger theoretical scheme that the research findings take the form of a theory. Practically, coding allows the researcher to condense large quantities of raw data such as interview transcripts into manageable units to facilitate further analysis. It aids organisation, retrieval, analysis, and interpretation of data. It also involves going beyond the data, thinking creatively, and generating new theories and frameworks.

Analysing data is a process that brings order and structure to a mass of collected data. Coding makes resilient links between data and ideas, links that can be traced back to where particular ideas originated from and what data was coded there to justify and account for the researcher’s interpretation of the ideas (Morse et al. 2002).

In order to define a theory, the researcher must first ask questions of the data and then make comparisons. Questioning a problematic situation in the data can lead the researcher to a new level of understanding. Questioning can also lead the researcher to different types of methodological technologies. A sensitizing question which will help tune the researcher into what the data might be indicating objectively rather than naming them or classifying them without a thorough examination of the object at the property and dimensional levels (Strauss & Corbin 1998, p. 80). There are times when the researcher needs to stand back and ask what is going on with the data. In doing this, the researcher begins to draw on properties from what previous knowledge s/he has to make comparisons.

3.7.1 Coding

Coding makes resilient links between data and ideas, links that can be traced back to where particular ideas originated from and what data was coded there to justify and account for the researcher’s interpretation of the ideas (Morse 2002). Strauss & Corbin (1998) identify different types of coding termed ‘Open Coding’ and ‘Axial Coding’. Charmaz (2006) points out that there are three phases to coding regardless
of which type of grounded theory is used; (i) Initial coding (ii) Focused coding and (iii) Theoretical coding. Initial coding is referred as ‘open coding’ and is the first phase, during which the researcher engages intimately with the raw data, assigning labels, codes to segments of the data. The coding process allows researchers to generate categories and identity links between them (Hunter et al., 2010) Data analysis directs researchers to move from open coding to axial coding and to selective coding. Concepts, categories and sub-categories are continuously questioned and compared, with the aim of identifying the core category and its links with the others (Hunter et al 2010).

3.7.2. Open coding

Open coding, as explained by Strauss & Corbin (1998) is the analytic process through which concepts are identified and their properties and dimensions are discovered in the data (p.101). There are two types of open or substantive coding, in-vivo codes, and sociological constructs. In-vivo codes are directly related to the language of the data and can be seen as having imagery because they give sufficient meaning to the data (Strauss, 1987). Using in-vivo coding helps to avoid situations where researchers might otherwise impose their preconceived opinions on the codes (Hutchinson, 1993). Sociological constructs are derived from a combination of substantive data from the field and the researcher’s scholarly knowledge and expertise.

As part of initial coding, in vivo codes may be generated. These are the codes of participants’ special terms, and are particularly useful because they preserve participants’ views and actions in the coding itself. In vivo codes may be general terms familiar to most people, an innovative term which concisely encapsulates meanings or experiences, or ‘insider’ terms specific to a certain group of people. Unpacking these codes can reveal hidden assumptions and direct data collection and analysis.

Coding and categorising data is the process of associating labels with sections of the data to depict what the data is about. Coding distils data, sorts them, and gives a handle for making comparisons with other segments of data (Charmaz 2006). These labels are called ‘codes’ and can be attached to words, phrases, sentences or entire
paragraphs (Miles & Huberman 1994). By linking raw data with theory development, coding represents the ‘analytic scaffolding’ by bridging the data and conclusions (Charmaz 2005, p. 517). Practically, coding allows the researcher to condense large quantities of raw data such as interview transcripts into manageable units to facilitate further analysis. It aids organisation, retrieval, analysis, and interpretation of data. It also involves going beyond the data, thinking creatively, and generating new theories and frameworks.

3.7.3 Axial Coding

Axial coding is the appreciation of concepts in terms of their dynamic interrelationships. These should form the basis of the construction of the theory (Goulding 1999). Abstract concepts encompass a number of terms found in the data. “The theoretical significance of a concept springs from its relationship to other concepts of its connection to a broader gestalt on an individual’s experience” (Spiggle 1994, p. 497). Therefore, when a concept is identified, its attributes may be further explored in greater depth, and its characteristics and dimension examined in terms of their weaknesses or intensity (Goulding 1999).

Following on from coding, axial coding emerges, where the researcher identifies one or more of the predominant categories (called the core phenomenon) and re-examines the data or collects new data to build a model around this core phenomenon. The model generated can be similar to the axel of a wheel representing the core phenomenon and the spokes representing new data. This often represented by a visual model in the form of a figure or diagram which consists of causal conditions, (what factors caused the core phenomenon), contextual an intervening conditions (broad and specific factors which influence strategies) and consequences (the outcomes from using the strategies) (Creswell 2007). A core category pulls together all the strands in order to offer an explanation of the behaviour under study. It has theoretical significance and its development should be traceable back through the data (Goulding 1999).
Selective Coding

Selective coding is the process of integrating and refining the theory (Strauss & Corbin 1998 p.143). Watching theory develop is a process that evolves over time, which begins with the first aspect of analysis and ends at the final writing. As with all phases of analysis, integration is an interaction between the analyst and the data. Strauss & Corbin (1998 p.144) describe it as the ‘analytic gestalt’ which includes not only the researcher as analyst, but also the evolution of thinking that occurs during the process through the immersion in the data and the cumulative body of information that has been documented through memos. Although the data describes how the concepts were developed, it is not until the relationships are recognised as such by the analyst that they emerge (Strauss & Corbin p.144).

Strauss & Corbin (1998) outlined several techniques to facilitate integration of the concepts analysed in a study. If theory building is a goal of the research project then the findings should be presented as a set of interrelated concepts not just a listing of themes. Relational statements, like concepts, are abstracted from the data. However, because they are interpreted abstractions and not descriptive detail of each case (raw data) they (like concepts) are ‘constructed’ out of the data by the analyst. Strauss & Corbin (1998) explain that by using the term ‘constructed’, they mean that the researcher reduces the data from many cases into concepts and sets of relational statements that can be used to explain, broadly, what is going on (Strauss & Corbin 1998 p.145).

With integration, categories are organised around a single explanatory concept. Integration occurs over time, beginning with the first steps of analysis and finishing with the final writing. When a central idea is decided upon, major categories are related to it through explanatory statements of relationships. Various techniques can be used for this, including writing a storyline, sorting, or using memos, using computer programs, or using diagrams. Once a theoretical scheme is organised, the researcher is ready to refine the theory, taking off excess and filling in poorly developed categories. Poorly developed categories are further developed. The theory is validated by comparing it to raw data and by presenting it to respondents for their reaction. A theory that is grounded in the data is recognisable to participants, although it might not fit every aspect of their cases, the larger concepts should apply.
In selective coding the researcher then takes the model and develops prepositions or hypothesis that interrelate the categories in the model. Strauss & Corbin (1998) take this further suggesting to locate it within both macro and micro conditions and consequences. They advance the conditional/consequential matrix as a coding device to help the researcher make these conditions, this matrix is represented as a set of concentric circles with labels that build outward from the individual, group, community organisation (Creswell 2007).

A matrix is an extension of the coding paradigm, which focuses solely on the conditions and consequences related to the phenomenon under study. Strauss & Corbin (1998), has advanced the conditional matrix as another analytical aid that sensitises the researcher to the variety of conditions and consequences that surrounds the actions and interactions of people. This process aids the researcher’s view of the process and influences in the study.

The researcher can explore the conditions or consequences that exist in the individual, group, or family context using a micro-lens, or explore the community or national context using the faraway macro lens (Walker 2006). This is used as an extension of the coding paradigm, and as a matrix it has the potential to force the data further in preconceived ways. Used as a tool, based on emergence, the matrix and the tracing of conditions and consequences can enrich theory (Walker 2006). Strauss & Corbin (1990) asserted that it is only one tool of many that should help the researcher look beyond the obvious, linking the process to structure to develop theory.

3.7.5 Memoing and Diagramming

Memos are the researcher’s record of analysis, thoughts, interpretations questions and directions for further data collection (Strauss & Corbin 1998 p.110). Memos are ‘informal and analytical notes’ which the researcher produces during the research process (Charmaz 2006 p72). An important activity during coding is the writing of memos. Corbin and Strauss (1990 p,10) maintain that, writing theoretical memos is an integral part of doing grounded theory. Since the analyst cannot readily keep track of all the categories, properties, hypotheses, and generative questions that evolve
from the analytical process, there must be a system for doing so. The use of memos constitutes such a system. Memos are not just ideas; they are involved in the formulation and revision of theory during the research process.

There are least three types of memo that are described: code memos, theoretical memos and operational memos. Code memos relate to open coding and thus focus on conceptual labelling. Theoretical memos relate to axial and selective coding and thus focus on paradigm features and indications of process. Finally, operational memos contain directions relating to the evolving research design.

Diagrams and memos are used as part of the analytical process. Diagrams visually represent the conceptual relationship that develops among categories (Strauss 1990, Strauss 1999). They assist the researcher to identify the consistency of these relationships. Memos are notes that the researcher makes throughout the research in order to record and explicate the theory as it develops. They are the essential tools for capturing the ideas of the researcher, for abstraction and theory development, which continues throughout the research (Stern 1985, Glaser 1978, Charmaz 2000). They reflect the researcher’s internal dialogue with the data at a point in time.

Memoing is both inductive and deductive. It is inductive during the process of conceptualizing the data and deductive when the researcher assesses how the conceptual labels, categories and subcategories link together (Hutchinson, 1993). Memo writing provides the researcher with a way of analysing and questioning taken for granted aspects of the research process and preconceptions about the data (Charmaz, 1990). Memos reflect the researcher’s ideas about codes in every way that occurs to the researcher at a point in time (McCann and Clark 2003a). Beck (1993) argues that memos raise the data to a conceptual level, develop properties of each category and generate hypotheses about connections between each category. Memos can also help develop ideas which occur and document the origin of a concept (Orona 2002). Charmaz (2006) differentiates between early memos and late memos and explains how systematic memoing can raise focused codes to abstract categories by helping the researcher to define categories and explicate their properties, specify conditions, reveal relationships reveal consequences within the data. Memos need not be textual and can also take the form of diagrams.
3.7.6 Uncovering the core category.

Deciding a central category represents the main theme of the research. Although the central category evolves from research, it is also an abstraction. It consists of all the products of analysis condensed into a core category which with the story line explains what the research is all about.

The core category subsumes the major categories and explains much of the variation in the data. It possesses analytical power, and that gives it ability to pull the other categories together to form an exploratory whole.

In the Strauss & Corbin’s approach, this is achieved through their exploration of the centrality of the story, a narrative rendering of the analysis, to the eventual development of the core or central category (Strauss & Corbin 1998).

In writing a story about the analysis, Strauss & Corbin (1998) advocated that researchers describe their “gut sense” about the subject matter of the research (Strauss & Corbin 1998 p. 150). The story line becomes the final conceptualization of the core category, and as such, this conceptual label must fit the stories/data it represents (Strauss & Corbin 1990, p. 121). It is a process that acknowledges the reconstruction of the participants’ stories by the researcher and the fulfilment of their obligation to “give voice—albeit in the context of their own inevitable interpretations” (Strauss & Corbin 1994, p. 281).

Strauss (1987) outlines six criteria for choosing a central category; it must be a central theme, it must appear frequently in the data, the explanation that evolves is logical and there is no forcing of the data. The name or phrase used to describe the central theme should be sufficiently abstract that it can be used to undertake research in other substantive areas, leading to the development of a more general theory. The concept is defined analytically through integration with other concepts, and it is able to explain variation as well as the main point relayed by that data. That is when conditions vary the explanation still holds, although the way in which a phenomenon is expressed might look somewhat different.
3.7.7. **Theoretical sampling**

Before the study starts it is important to consider the issues about recruitment of participants and the location of the study sites. This is known as purposive sampling, which is sampling using some pre-determined criteria, for example, age group, medical condition, place of work and professional experience (Paton 1990). Theoretical sampling is about gathering data driven by concepts derived from the evolving theory and based on the concept of ‘making comparisons’ whose purpose is to go to places, people, or events that will maximise opportunities to discover variations among concepts and to develop categories in terms of their properties and dimensions (Strauss & Corbin 1998, p. 201).

Some of the questions posed by Strauss & Corbin (1998) are; Why does one use theoretical sampling rather than another type of sampling; How does the researcher proceed? How much sampling should be done? At what times and how long for? The sample used in this research was drawn from three residential care settings governed by the Health Service Executive. In qualitative research, this is considered relevant and an appropriate population sample for this type of study as it places more emphasis on data worthiness and the quality of the information generated rather than generalisability if its findings. The three selected Health Service Executive managed nursing homes of contrasting size but with similar management structures. This is described as a purposive theoretical sampling (Silverman 1997). By choosing a relatively homogenous and similar group of nursing care units provides consistency to the interview data (Silverman 1997).

As initial data are collected and analysed, more decisions are made about the participants, sample size, the settings, and the type of data to be collected are based on the emerging theory (Glaser 1978). Glaser and Strauss (1967 p.45) define theoretical sampling as a process of collecting data for generating theory, where the analyst jointly collects, codes and analyses data and then decides on what data to collect next and where to find this, in order to develop theory as it emerges. Theoretical sampling directs the researcher to build upon concepts and possible hypotheses which are emerging from the collected data, and becomes increasingly important as analysis progresses (Charmaz 2006, Jeon 2004). This leads to purposive sampling.
The researcher collects new data and compares emerging categories and establishes emerging boundaries that are related to the evolving theory (Strauss 1990, Strauss 1998, Charmaz 2000). Sampling continues to a stage, in the process of analysis, called theoretical saturation, and this is reached when no new data emerges relevant to the particular categories and sub-categories. The emerged categories have a conceptual density and all variations in categories can be explained. It is important to clearly explain and validate the links between the categories (Strauss 1990, Strauss, 1998). The quality of the data is more important in theoretical saturation than in the frequency with which it reoccurs. The opportunity for theoretical saturation to occur is enhanced when the sample is clearly defined and the research question explicit (Morse 1995). While the research question is focused, it should also be open-ended enough to enable the theory to be developed (Smith 1997).

3.7.8. The role of literature in grounded theory

Using literature in grounded theory has been discussed earlier and is re-visited again in this chapter in conjunction with with the role of the researcher’s memos. There are conflicting discussions about the role of the literature in grounded theory research. If a literature review is performed at the beginning of the study it may constrain theory development rather than develop it. Several authors suggested that literature should not be consulted because prior studies might influence the researcher’s conceptualization of the phenomenon under study, and therefore, the classic review of the literature is inappropriate (Stern 1980, Lincoln & Guba 1985, Patton 1990).

Glaser (1992, 1998, 2005) emphasised the importance of avoiding a literature review in the early stages of research. When undertaking grounded theory, the researcher should collect the data in the field first and then start coding, constantly and re-coding as appropriate until an emerging integration of categories and properties emerge. They may then begin to review the literature in a substantive field and relate it to their own work in many ways. Glaser (1992) and Stern (1985) believe that an initial literature review may contaminate the data and is not needed as it may lead to irrelevant ideas and pre-judgements which may result in premature closure of ideas. Literature is used to explain the theory, the theory is not derived from it. Moreover, Charmaz (2006: 165) suggests that delaying the review of the literature can avoid
having pre-conceived ideas and imposing them on the work. Delaying the literature review also allows the researcher to articulate her ideas from the data.

However, despite the argument against undertaking a literature review prior to data collection, there is no consensus as to when it should be carried out. (Schreiber 2001, Heath 2006, McGhee et al. 2007). Charmaz and Mitchell (2001) were critical of researchers who delayed in doing the literature review, arguing that they are apt to be steeped in specific literature for a variety of reasons beyond a specific research project since they are active scholars. Furthermore, there are sources of a priori knowledge other than the literature: for example, researchers carry into analysis accumulated experiences or preconceptions arising from their discipline or profession (Holton 2007, Charmaz 2006).

However, contrary to this, Gilovich (1991), suggests that there is a natural tendency in human reasoning, when examining evidence relevant to a particular phenomenon, an inclination to see what is expected. Sometimes, people readily accept evidence that validates pre-existing ideas and are found to be less responsive to the implications of new information. However, there are many other analysis strategies to be adopted in conjunction with open coding and protect the principles of inductive validity, such as early in-vivo coding.

Although there are debates regarding the timing of the literature review, funding and research governance agencies demand a high degree of transparency so the majority of research cannot avoid some level of preliminary literature review.

As a novice researcher, familiarisation of the literature on this research topic was necessary and several views for advocating this are offered here. Firstly, a review of the existing literature can provide a rationale for the study including justification for the research approach (Coyne & Cowley 2006, Creswell 1998). Grounded theory studies often take a new perspective on an old issue, therefore it is important to be familiar with previous knowledge so as to outline the research phenomenon (Backman & Kyngas 1999). Secondly, it can ensure that the study has not already been done (Chiovitti & Piran 2003) and also highlight important areas and voids in existing literature (Creswell 1998, Hutchinson 1993).
Cutliffe (2005) pointed out that a comprehensive literature review is typically necessary to satisfy the requirements of local research ethics committees who insist on a well-defined research question so that they can make informed decisions regarding ethical approval. This requires researchers to make a strong argument to be supported by relevant literature to establish the need for research. In addition, Strauss & Corbin (1998) advocated reviewing the literature early in a study for several reasons, as follows: it stimulates theoretical sensitivity, provides a secondary source of data and stimulates questions for further inquiry. At later stages in research it directs theoretical sampling and can provide supplementary validity a study’s findings. Thirdly, McCann and Clark (2003a) explain how a literature review of a topic can contextualize the study, and reveal how the topic has been studied (or not) to date (McMenemin 2006, Denzin 2002). Fourthly, it can help a researcher develop sensitizing concepts and gain theoretical sensitivity, (McCann and Clark 2003a).

The use of memos in conjunction with relevant literature, supports data analysis and the researcher’s theoretical sensitivity to the data. This directs data to conceptual categories and the emergency of substantive theory development.

3.7.9 Summary

This section has outlined the possible philosophical approaches and research design that could have been for this research. An overview of the historical development of the grounded theory Strauss & Corbin (1990, 1998) and rationale for the research was provided. Various approaches were not deemed appropriate for this study, and finally an interpretivist approach of Strauss and Corbin’s grounded theory was chosen because it is considered to be the most appropriate paradigm position and research design for identifying the factors that influence end of life care for older people in residential care. An outline of data collection and analysis has been explained with rationale offered for the choices made by the researcher. The following chapter will describe the research methods used in this research.
Chapter 4  Research Methods

4.1 Introduction
The following chapter will describe the methods adopted in this study to ascertain the factors that facilitate or hinder good end of life care for older people in long stay residential care homes. This chapter will consist of an overview of the ethical considerations such as consent, the phases of data collection, inclusion criteria, sample recruitment and recruitment procedure. It will describe data collection, analysis, and theoretical sensitivity. This chapter will describe the approach taken for engagement with the literature throughout the research process, and how it relates to the findings. The chapter will provide a description of data management, a coding framework and will conclude with the criteria for establishing trustworthiness and summary of the chapter.

4.2 Ethical Considerations
The study received ethical approval from the Research Ethics Committee of the National University of Ireland and University of Galway (University Ethics Reference Number: 11/Aug10). (Ethics approval letter in Appendix 1). Ethical approval permitted recruitment of participants from nursing homes within the Health Service Executive (HSE) western area in 2010 and remained valid until the study’s completion in 2016. This study was guided by five ethical principles; respect for human dignity, respect for free and informed consent, respect for privacy and confidentiality, respect for justice and inclusiveness, and balancing harms and benefits (Canadian Institutes of Health Research 2010). These principles were addressed through the ethics application process because older people living in residential care can at times be considered vulnerable and as such require careful attention to their needs. The following section outlines issues of consent

4.3 Consent
There are issues to acknowledge when looking for informed consent from participants such as older people when conducting in research in residential care units. Consent is a social activity where researchers meet participants in an effort to
gain and maintain consent for their study (Dewing 2007). This means that the researcher gets to know the participant and ascertain their well-being and their wish to take part in a study. Competent decision-making involves the ability of a potential participant to understand and appreciate the context and implications of the decision, and it also involves the capacity to translate the decision into action (National Consent Policy 2014). It is important to understand how the capacity of potential participants is assessed prior to consenting to the research study (Fisk et al. 2007, Innes 2002, 2009, Slaughter et al. 2007). This was achieved by asking the directors of nursing of the participating residential care units as to which residents had functional capacity and were willing to consent to participate in the study. The following section will provide an overview of aspects of consent such as; autonomy, inclusion, dependent or unequal relationships and process consent, maintaining confidentiality and anonymity, balancing harm and benefit and what to do with incidental findings, gate-keeping which were relevant to this study. (Consent Form Appendix 2).

4.3.1 Autonomy

In this study consent was described as a process of consent, which permitted participants to change their minds at any time of the research study (Dewing 2007). Process consent values participant’s autonomy as well as their assumed ability to participate in research as well as their right to withdraw from research. It is an ongoing process of informed consent which ensured that prospective participants were given adequate opportunities to discuss and contemplate their participation, and renew or remove consent. In this study, the standard set out by HIQA (2009) which states that residents were presumed capable of making informed decisions in the absence of evidence to the contrary was followed (HIQA 2009, p. 11). The researcher provided information sheets to inform participants about the study (Appendix 3). This was followed by a verbal explanation to further clarify any aspects of the interview process. This is recommended as it is important to provide adequate information for residents, nurses and their families about the nature of the interview before agreeing to take part (Banister, Burman, Parker, Taylor, & Tindall, 1994).
4.3.2 Inclusion

Understanding what issues are important to older people is an important goal of research. Including residents to participate in research is important because researching sensitive issues, such as end-of-life care, can give a voice to a group of residents who could otherwise be forgotten (Goldsmith 1996, Mak et al. 2003). Under the European Communities (Clinical Trials on Medicinal Products for Human Use Regulations 2004), consent for clinical trials research participation, on behalf of an adult lacking in decision making capacity, must be obtained by the persons’ legal representative. This has been the more traditional competency view of obtaining consent. A unilateral process of consent can lead to the exclusion of some people who lack a required minimum level of competence, and it also promotes proxy consent. This can be provided by a person who is not connected to the research and who may be a family member or legal representative. In this study, proxies by managers were not accepted as consent. All participants including residents with cognitive impairment gave their consent to participate. This supported inclusion of participants to become involved in the study. In contrast, there were also actions taken by the researcher to reduce potential control in dependent or unequal relationships.

4.3.3 Dependent or unequal relationships

Process consent is discussed in the National Consent Policy (2014) which provides information for obtaining consent from people in dependent or unequal relationships. This occurs when one person has or has had a position of influence or authority over the other, for example, in health and social care or in residential care. Being in a dependent or unequal relationship can influence a person’s decision to participate in research, as these relationships can compromise the voluntary character of participants’ decisions. While the decision to agree does not necessarily invalidate the consent, it necessitates that the process in which the consent was obtained. People in dependent or unequal relationships might be vulnerable to being over-researched because of the relative ease of access to them as research populations (National Consent Policy 2014). This was counteracted in this study by establishing if any resident was in a previous study, and if they were, they were offered the choice to participate or abstain.
4.3.4 Process Consent

A once off informed consent form is not suitable for older people who can be vulnerable and have possible cognitive impairment. In qualitative research, knowledge is generated by theory emergence; this can pose certain challenges with getting consent from participants. Data collection can follow various directions, such as interviews or observation methods in qualitative research (Houghton 2010), therefore, a once off consent may not be appropriate as the researcher may have to re-visit participants at various stages of data collection (McDonnell 2000, Holloway & Wheeler 2002). Achieving ethical consent with vulnerable adults in an ongoing process and needs to be constantly negotiated (Berg 1985, Holloway & Wheeler 2002) and is referred to as informed process consent (Munhall 1988, Behi & Nolan, Ensign 2003, Dewing 2007). In this study using process consent facilitated participants to be more involved with the research process, and made it possible to negotiate and update the participant’s position in regard to consent, throughout the research process (Polit & Tatano Beck 2006). Furthermore, participants in this study, who had dementia could remove consent, through process consent, and leave the study (Black et al. 2010). Throughout the data collection period of this study, participants were consulted at each meeting with the researcher to ascertain if they still agreed to be involved in the study. The researcher provided an information leaflet about the study which included information of when and how the interview would be conducted. The researcher spoke to family members and care staff for advice, knowledge about the participants and for an introduction before engaging with either a resident or relatives. Understanding residents or families’ preferences for meetings, their ability to engage/communicate, their cognitive ability or their demeanour on any day was essential for the success of the research interviews. Knowing how to lead into and pace an interview was crucial to developing a rapport with participants to get research data. The researcher applied her clinical background skills, and communication ability to each meeting and interview situation and successfully achieved many interviews from residents, staff and relatives.

4.3.5 Maintaining confidentiality and anonymity

Conducting research in institutions such as residential care homes can pose challenges in maintaining confidentiality as they are shared living and workplaces
for residents and staff. Interviews were conducted in a private room or area of the participants’ choosing. Several steps were taken to maintain confidentiality and autonomy of participants. Each research site was given a code. Any identifying data, the names of participating residents, staff and relatives were stored in a separate location from their study codes. The names of research participants were excluded on transcriptions, consent forms and demographic information. All of the site and participant data was stored separately from their study codes. Written informed consent was obtained from all study participants prior to interview. Each participant was given a copy of their signed consent form and information leaflet, and the researcher kept a copy for filing. All of the site and participant data was securely filed away and locked away and will be stored for five years (2017) according to the university guidelines, and at which point they will be destroyed. In accordance to the Data Protection (Amendment) Act 2003 (Government of Ireland, 2003), the interview transcriptions, interview recordings, researcher memos and Nvivo® 10 codes for each participant were electronically secured with passwords.

4.3.6 Balancing harm and benefit

The concepts of beneficence and non-maleficence are frequently interlinked and refer to a researchers’ ethical obligation to maximise benefits and minimise harm to research participants (Israel & Hay 2009). To attempt to balance the risk of harm against the potential benefits that may accrue from participation, researchers need to consider several factors. These include; the particular kinds of harm that may occur; how likely these are to occur; the ways in which these harms can be minimized; and the ways of maximizing both short and long term benefits (World Medical Association, 1964). It is generally accepted that risks and benefits should be balanced and shown to be in a favourable ratio (Beauchamp & Childress 2001, Strohm Kitchener & Kitchener, 2009). While some scientific research can have the potential to cause physical harm to participants, in social science research the concept of harm is considered most likely to involve psychological distress, discomfort, social disadvantage, or invasion of privacy (Israel & Hay, 2009). This particular study dealt with a sensitive topic which was considered private to participants and had the potential to be emotionally charged. Consequently, the study could potentially pose a psychological or intrusive threat to participants. In this
respect, a plan for the support and protection of participants was developed at the outset of the study. This included that in the event that a participant got upset during interview, the interview would be ceased immediately, the line manager informed, and the care team involved in helping the distresses participant. Where a staff member could become upset, the line manager would also be informed and counselling would be offered to the participant if needed. Arrangements were also made with directors of nursing of the care units to withdraw from the study if desired.

4.3.7 Consent and incidental findings

When interviewing residents and staff, researchers may come across some information that may be relevant to their medical care. The term “incidental findings” refers to findings which were not anticipated by the researcher or were outside the scope of the research (HSE National Consent Policy 2013). If prospective participants did not want to be given medically relevant information, this was recorded and respected. There may be incidental findings which are considered to be essential for the care of a patient, for example, if a resident/relative had information which could directly affect their care and have an immediate clinical significance, then the researcher would have a duty of care to the participant to share this with the care team. It would be necessary then to mention this to the participant during the consent process and explain that information would be shared with professional staff if it was deemed necessary. In this study, information on end of life care was discussed with participants and she did not find any information throughout her interviews which could constitute incidental findings.

4.3.8 Gate-keeper

The term ‘gate keeper’ refers to people who use their position to influence or mediate access between researchers and participants. Gate-keeping is a process of allowing or denying a researcher access to someone or something (Holloway and Wheeler 2002). It can occur in any health care, social care and education context and access to this varies with regard to the process of gate keeping (Mander 1992). It is a deliberate process to ensure that vulnerable patients or their families are protected. Furthermore, healthcare professionals can also be considered vulnerable,
if they are asked to participate in research and they too must be protected. Within healthcare, the gatekeeper is a person of power, control and a responsibility and can be available to protect potentially vulnerable people (Holloway and Wheeler, 2002). However, the alternative can also exist as enthusiastic recruits can potentially coerce residents and carers into agreeing to participate (Hopkinson 2005). Fundamentally, gate keeping serves to prevent harm to residents and other participants and protect them from undue distress.

In this study, recruitment of residents was facilitated by the Clinical Nurse Manager 2 or the Assistant Director of Nursing of each participating care home. These people acted as gate-keeper, and assisted in identifying residents, staff and families, who in their opinion were able and willing to take part in the interview. This worked as a protective mechanism for residents who were considered vulnerable by the person in charge. This process also facilitated access between staff, residents and the researcher, because the Clinical Nurse Manager 2 or the Assistant Director of Nursing could identify the most suitable staff or residents to participate in the study. An example of ‘gate-keeping’ in action was when a resident was recently bereaved, the Clinical Nurse Manager 2 felt that it was insensitive to ask them to participate in an interview and the researcher agreed to exclude the resident from participating in the study. The following Figure 4.1, depicts the process of consent obtained in this study and highlights the process of interview used in obtaining consent from all participants.
**Figure 4.1: Process of Consent**

- **Access to Residents**
  - Eligibility - living in long stay care for >6 months

  - Person-in-charge, Clinical Nurse Manager (CNM) acted as gate-keeper, identified resident, outlined study to residents, and gave/explained to information sheet/letter

  - If resident was interested, a suitable date to meet was negotiated/agreed with CNM to visit care home. On arrival and meeting CNM/resident, the aims of study were discussed, information sheet explained again and consent was obtained (either at the first meeting or just before the proposed interview)

  - If resident was not interested - no further contact was made

  - Resident was given time to think about participation, at least a week.

  - If resident was interested and had fully understood and was satisfied with the information sheet, informed written consent was taken and the resident interview commenced

  - If family member or spouse wished to be present, with the residents' consent a separate written consent was also obtained for them

  - Final Step: Processual consent - consent during/after the interview if there was a need to re-interview participant
4.4 Phases of Data Collection and Analysis

The following section will describe the research phases and the process of data collection and analysis. The participating care homes were chosen because they were representative of publicly managed long stay care homes which were located adjacent to urban areas. The researcher was not familiar with staff working in these homes, nor residents or their families which further minimised bias potential. Data collection methods for this study included; researcher participant interviews, observation and sampling of extant literature. Data collection and analysis took place over two years, and over three time phases. This allowed sufficient time for recruitment of participants outlined in Figure 4.2.

**Figure 4.2: Overview of Phases of Data Collection and Analysis**

4.4.1 Phase 1

This was the first phase of data collection and involved two visits to the participating Care Home A and interviewing five participants. The five participants included three residents and two staff nurses. Unfortunately, the audio recorder did not work for the staff interviews, however, when this was recognised, contemporaneous notes were made on the conversation and used as part of the data analysis. This mishap
was beneficial in reminding the researcher to ensure that recording equipment was in good working order prior to subsequent interviews.

There were over 150 open codes at the initial analysis. This phase of data analysis involved line-by-line coding and some of the open codes included ‘don’t mind’, ‘other people’s deaths’, ‘making plans’, ‘making arrangements’, ‘family, (son, wife, cousin, nephew)’. Memos and reflections on this analysis were made simultaneously. Memos recorded included queries about staff assessing residents’ end of life care plans, and raising concerns about residents’ care preferences about care treatments when they became unwell. Care staff were concerned with recording care, involving families in discussions and getting help from care professionals. The analysis of this phase also revealed that nurses and residents spoke about ‘planning’ in different ways; residents spoke about planning to come into residential care and having discussions with their families, and staff talked about planning with references to care plans and arrangements for further medical care when a resident’s health condition deteriorated. The emergence of these codes guided the researcher to direct the inquiry to the families of residents and find out their perspective on planning for end of life care and dying. This iterative process directed theoretical sampling to interview relatives. Relatives’ perspectives was missing and this data could be compared to the perspectives of residents and nurses. A memo recorded at the time reflected that the emergent codes prompted further questioning and comparison. This meant that an interview schedule for relatives was drafted for phase two analysis.

### 4.4.2 Phase 2

Phase two involved visiting a second care home. The focus of these interviews was to reveal relatives’ views on dying in residential care. There were six researcher visits and twenty-two interviews undertaken, four of which were with relatives. During this phase of analysis the emergent themes were compared with the literature to provide guidance with further analysis, to corroborate categories, and further explain codes. This phase of coding helped to stimulate conceptual ideas. The iterative process of coding, comparing categories, sorting out memos and checking with literature was constant, until such time as the categories became richer and denser. New codes
emerged and new categories were formed when analysis of relative interview were coded and analysed. For example, relatives talked about having a ‘nice place to visit’ in open coding, this re-occurred in several phases of analysis. This open code represented the reality of families visiting the care home. A category emerged conceptually called ‘creating a caring environment’ which represented ‘the local area’, the ‘decorations inside’ and the ‘friendliness of staff’. This term changed as further comparisons with literature and the author’s own preference with naming categories. The category of ‘caring environment’ comprised of ‘micro-environment’ and ‘macro-environment’, which represented the researcher’s theoretical sensitivity on the topic. Many codes overlapped, as new codes and categories emerged. This phase of data collection and analysis involved referring to literature to challenge some emerging themes. Selective coding involved the selection of categories that best represented participant views of end of life care in residential care. Some codes were discarded while others were linked with categories and sub-categories, which strengthened their properties.

The second phase of analysis included interviewing staff other than nurses, which included health care assistants and a speech and language therapist, and managers. Codes that emerged from care staff were compared to the views of nurses, residents and relatives. This phase also relied on my theoretical sensitivity to recognise relevant themes, and challenge prior assumptions. Many memos were recorded and analysed throughout this phase. This phase involved being able to distinguish my previous knowledge and experience to what was emerging from data, and use this knowledge to further explain and clarify categories and their properties.

4.4.2 Phase 3

The third and final phase of data collection and analysis focused on establishing if any more collected data could reveal new codes or categories. This phase involved two visits to a third care home, where fifteen interviews were conducted with resident, relatives and staff participants. Similar to previous phases, comparisons were made between categories, memos, participants’ interview transcripts and literature. This is also known as theoretical saturation of data. This phase of analysis focused on the conceptualisation of major categories and the emergence of a core
category to represent the major categories from data. Throughout analysis during this phase, newly analysed data reinforced previous codes and categories. Divergent codes were analysed and compared to categories and sub-categories for their properties and dimensions. For example, the code ‘enabling’ was chiefly concerned with residents’ moving to care, engaging in activities and finding friends, praying, and many similar codes. This code was later integrated with the category ‘ethos of caring’. Theoretical saturation occurred when new data collected revealed any further information on the emergent categories.

Theory development arises from the analysis of data and constant comparison of incidents. For example, staff derived meaning from the way they created a caring environment when someone was dying and this was compared to how a caring environment was created when residents were living in residential care. This comparison of incidents was compared and contrasted to literature about residential care home building environments, working environments, and organisational culture.

4.4.3 Participating Long Stay Residential Care Homes

Three long stay care units of similar character and all located in the West of Ireland, were selected because they provided residential care for older people (Table 4.1). Each residential care home had similar characteristics but were not identical as they were located a considerable distance apart and located close to medium sized regional towns. It was important to maintain consistency between the settings as this helps in the development a substantive theory on a particular area of inquiry (Strauss & Corbin, 1998). The three units were registered with Health Information and Quality Authority (HIQA) and Health Service Executive (HSE) managed and registered. They were similar to one another, in contrast to this, if they were very diverse, i.e. contrasted extremely to each other, it may not have been possible to get a single emerging theory.

Using three residential care units in the study also facilitated sample recruitment. There were some similarities between the units in terms of practice patterns, resident population, social care, resident dependency levels, policies, procedures, rosters, and management styles. However, each unit had contrasted from each other in several
aspects, for example; size, capacity, geographical location, urban and rural setting, and structural layout.

Residential Care Unit (A) was a purpose-built, single-storey building and operational since 1973. The home had a capacity of accommodating up to 41 residents. The centre provided care to dependent older residents who required long stay and respite care. Many of the current residents had maximum dependency needs. A physiotherapy department was located within the building and it was close the town which enabled easy access for residents to go to local amenities such as the post office, shops bank and church.

There were good levels of staffing in this care home and staff turnover was low which contributed to continuity of care. Staff were knowledgeable of residents’ preferred routines.

The second residential care unit (B) was a relatively new (2006) purpose-built two – storey 100 bed building situated locally to a town. The building overlooked secure landscaped gardens and had clear views across the rural landscape. There was a day-care facility, multidisciplinary room, treatment room, physiotherapy, and occupational therapy rooms and the laundry, hair dressing room, prayer room, smoking room and staff facilities were also located within the building. This unit was clean, attractively furnished and well maintained. Social activities such as art classes, Sonas, an activity based programme for residents, and reflexology were available to residents along with card playing, knitting and board games. Staff were actively involved with residents when the researcher visited the unit.

The third long stay residential care unit (C) was located on the outskirts of coastal town in the Western region. It was a two-storey building and had 24 places providing residential care to older people many of whom had dementia. It was built in 1875 and in 1970 it was opened as a residential care facility for older persons. Residents had access to an enclosed secure garden area which was furnished with outdoor seating. The residential care unit used its own bus to take residents to clinic appointments, on shopping trips and during the summer months, on outings and sight-seeing trips.
Staff were involved with residents and interacted with them warmly. Some staff were observed spending one-to-one time with residents. Residents were encouraged to be involved in the wide range of recreational events taking place. Staff and residents were predominantly from the local area and involvement in the local community was considered important to all. Staff ensured that residents were kept up-to-date with all local news and assisted residents to be involved in local annual events.

**TABLE 4.1 PROFILE OF PARTICIPATING LONG STAY RESIDENTIAL CARE HOMES**

<table>
<thead>
<tr>
<th>Unit</th>
<th>Year Built</th>
<th>Capacity</th>
<th>Single room</th>
<th>Twin room</th>
<th>3 bedded room</th>
<th>4 bedded room</th>
<th>5 bedded room</th>
<th>Lounge</th>
<th>Dining</th>
<th>Values room</th>
<th>Oratory</th>
</tr>
</thead>
<tbody>
<tr>
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<td>41</td>
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<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>B</td>
<td>2006</td>
<td>100</td>
<td>100</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>C</td>
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<td>6</td>
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<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

**4.4.4 Resident participants**

Fifteen residents took part in the study from three residential care homes (Table 4.3 Resident participant profile). The youngest resident was 73 years and oldest was 92 years. Seven residents had shared accommodation and lived with one or more other residents.

The Waterlow score (Waterlow 2005) was used to ascertain a resident’s level of dependency. The Waterlow score is widely used in residential care homes to establish a level of dependency and potential risk to skin integrity. Assessment is carried out based on an assessment score of the following domains; continence, mobility, nutrition, body mass index, gender and age. A score of greater than “10 +” indicated that a resident was at risk of potential malnutrition or neurological deficit. A score of greater than 15+ indicated a “high risk”, and at 20+ score indicated that a resident was at a very high risk (Waterlow 2005). A score of 15 or less was noted in 12 resident participants, this indicated that there were at ‘risk or at high risk of possible tissue malnutrition, however some of these residents were observed as independent, mobile and engaged in life in the care home. However, 3 residents were at risk and had a score of between 15-20 Waterlow score. On perusal of their
nursing careplan, these residents had evidence and a record of two or more illnesses, comorbidity, such as renal disease with cardiac disease, Chronic Obstructive Pulmonary Disease (COPD) (Resident 6); skin cancer with mild cerebral vascular accident (CVA) (Resident 11).

Each resident’s cognitive capacity was also recorded using the Mini-Mental Score Examination (MMSE) (Folstein 1975). The rationale for this was that residents can participate in a study and articulate their feelings even when they have a low mini-mental score. Although it is a numerical value, it can indicate the cognitive capacity of residents. The MMSE is a tool that is used by clinicians such as GPs or neuropsychologists to help diagnose and assess dementia. It is only one part of these processes and clinicians will often consider a person’s MMSE score alongside the results of other tests.

In general, scores of 0-17 indicates severe cognitive impairment, 18-23 mild cognitive impairment and 24 to 30 indicates a decreased possibility of dementia. However, getting a score below this does not always mean that a person has dementia - their mental abilities might be impaired for another reason or they may have a physical problem such as difficulty hearing, which makes it harder for them to take the test. For people with learning disabilities, difficulty speaking, or for those who are not fluent enough in a language in which the MMSE can be given, a different method can be used to assess dementia severity when treatment is being considered. The MMSE score is one of the things a staff nurse in long stay care considers when deciding if drugs will help a person with dementia. It can also be used as a guide to assess someone’s capacity to understand and retain information with a view to providing consent to participate in research.

The residents lived in care homes for many years, with 12 residents having lived in resident care homes for five years or less (Table 4.2). Years in residence was calculated to the nearest full year, for example if a resident was in residence for 2 years and 2 months, this was documented as 2 years, and like if a resident was in resident for 18 years and 9 months, this was recorded as 19 years. Three residents lived for greater than 7 years, the longest length of time was 19 years.
<table>
<thead>
<tr>
<th>No</th>
<th>Resident Participant</th>
<th>Age</th>
<th>Single or shared room</th>
<th>Waterlow</th>
<th>MMSE ≤ 23</th>
<th>Years ≤ residence</th>
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</thead>
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<td>16</td>
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<td>2</td>
</tr>
<tr>
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<td>15</td>
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<td>Resident</td>
<td>80</td>
<td>shared</td>
<td>8</td>
<td>27</td>
<td>5</td>
</tr>
<tr>
<td>15</td>
<td>Resident</td>
<td>92</td>
<td>shared</td>
<td>12</td>
<td>27</td>
<td>5</td>
</tr>
</tbody>
</table>

### 4.4.5 Staff participants

There were 18 staff research participants, 4 managers, 9 nurses, 2 Health Care Attendants (HCAs) and 2 Speech and Language Therapists (SLTs), and 1 Activity Therapist. Staffs’ work experience in older people’s care settings varied from 5 to nineteen years. There were 9 staff who had 6 years or less experience in long stay residential care, and 7 staff had greater than 10 years, with one manager having 20 years’ experience. There were 6 nurses who had a post graduate diploma in Gerontology nursing, four managers had management certificates, and 1 nurse had a palliative care certificate. Health care attendants and speech and language staff had certificates relevant to their posts, (FETAC carers course Level 5, and Speech and Language qualifications.) See Table 4.4 depicting staff training, experience and information profile.

Table 4.3 Staff participant profiles
4.4.6 Relative participants

Seven relatives took part in the study (Table 4.5 outlines the profile of relative participants). Their involvement came after the second round of interviews. Three relatives participated following the deaths of their relatives in care. Four relatives participated while their relative was still in care, one of whom was caring for her husband while he was in a terminal phase of life.

Table 4.4: Profile of relative participants
<table>
<thead>
<tr>
<th>No</th>
<th>Relative (Male/Female)</th>
<th>Relationship with resident</th>
<th>Current status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Relative (M)</td>
<td>Brother</td>
<td>Deceased within past year</td>
</tr>
<tr>
<td>2</td>
<td>Relative (F)</td>
<td>Husband</td>
<td>Currently living in long stay care</td>
</tr>
<tr>
<td>3</td>
<td>Relative (F)</td>
<td>Husband dying</td>
<td>Receiving palliative care</td>
</tr>
<tr>
<td>4</td>
<td>Relative (F)</td>
<td>Husband</td>
<td>Deceased within the past year</td>
</tr>
<tr>
<td>5</td>
<td>Relative (F)</td>
<td>Husband</td>
<td>Currently living in long stay care</td>
</tr>
<tr>
<td>6</td>
<td>Relative (F)</td>
<td>Two relatives</td>
<td>One deceased within two years. One alive in long term care</td>
</tr>
<tr>
<td>7</td>
<td>Relative (M)</td>
<td>Wife</td>
<td>Currently living in long stay care, receiving treatment for cancer</td>
</tr>
</tbody>
</table>

### 4.5 Sample Recruitment

Purposive sampling was used in the early phases of data collection. Purposive sampling is a sampling strategy where participants are chosen by the researcher because they are typically involved in the phenomenon of interest or because they are knowledgeable about the issues under investigation (Polit & Hungler 1995). As analysis progressed, theoretical sampling was used.

Participants were recruited from three long stay care homes in the West of Ireland. The researcher provided the managers of each participating care home an information pack which included an A4 Poster outlining the study, information leaflets with the researcher’s contact details, and consent forms for residents, staff and relatives (Appendix 3 and 4). Following this, notices were placed in staff rooms, reception and ward notice boards within each of the care homes. This is usual practice in conducting field research. Initially researchers write to key people or ward managers to explain the purpose of their research, this is considered practice to offer to meet managers to explain the research in more detail (Benton and McCormack 2000).

Subsequent visits to the care homes helped develop a warm relationship between participants and the researcher to facilitate future access to staff residents and relatives. These meetings offered good opportunities to develop trust between the managers and researcher who demonstrated an interest in the research site (Polit & Beck, 2004).
4.6 Recruitment procedure

Following the process of consent and negotiating with the Director of Nursing and Clinical Nurse manager as gate-keeper, residents, staff and relatives were asked to participate in the study. Each participant had time to ask questions about the study, and to decide to participate or decline. Participants who met the inclusion criteria agreed to sign a consent form to participate in an interview. Those interested in participating in the study were asked to sign a consent form. In Care Home A, the interviewer made two visits and interviewed five participants. Coding and analysis commenced with the first interview and continued and themes continued to emerge following the interviewed in Care Home B and C. In care home B, the interviewer made six visits and interviewed twenty-two participants. The final interviews were beneficial to the research process as they further developed certain themes that were emerging in previous data and they facilitated reaching theoretical saturation in the study. There were 3 visits to Care Home C where fifteen interviews were carried out. The researcher interviewed between one and four participants on each visit. There were 11 visits altogether (Table 4.5 Recruitment procedure)

Table 4.5: Recruitment procedure

<table>
<thead>
<tr>
<th>Care Home</th>
<th>Interviews</th>
<th>Participant</th>
<th>Researcher visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>5</td>
<td>Residents/staff</td>
<td>2</td>
</tr>
<tr>
<td>B</td>
<td>22</td>
<td>Residents/Staff/Relatives</td>
<td>6</td>
</tr>
<tr>
<td>C</td>
<td>15</td>
<td>Residents/Staff/Relatives</td>
<td>2</td>
</tr>
</tbody>
</table>

Interviews took place over an eighteen-month period from the years 2010-2011. Forty interviews were recorded. Interviews took place at various times throughout the day from 10 am until 9 pm in the evening. On two occasions interviews took place in the evening after residents’ tea was finished because staff felt they had more time to spend talking to the researcher. The following table (Table 4.6) illustrates the numbers of participants and frequency of Care Home visits taken by the researcher.
Table 4.6 Care home visits and Participant interview process

<table>
<thead>
<tr>
<th>Care Home</th>
<th>No</th>
<th>Participant Type</th>
<th>Date</th>
<th>Researcher Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Home A</td>
<td>1</td>
<td>Resident</td>
<td>Oct-2011</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Resident</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Resident</td>
<td>Nov-2011</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Nurse</td>
<td>Oct-2011</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>Nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>Manager</td>
<td>Mar-2012</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>Manager</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>Resident</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>Resident</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>Resident</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>Resident</td>
<td>May-2012</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>12</td>
<td>Resident</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>13</td>
<td>Resident</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>14</td>
<td>Manager</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>15</td>
<td>Nurse</td>
<td>Jul-2012</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>16</td>
<td>Nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>17</td>
<td>Nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>18</td>
<td>Nurse</td>
<td>Sep-2012</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>19</td>
<td>S and L</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>20</td>
<td>Nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>21</td>
<td>HCA</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>22</td>
<td>Resident</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>23</td>
<td>Relative</td>
<td>Oct-2012</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>24</td>
<td>Relative</td>
<td>Dec-2012</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>25</td>
<td>Relative</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>26</td>
<td>Nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>27</td>
<td>Relative</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care Home B</td>
<td>28</td>
<td>Relative</td>
<td>Jan-2013</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>29</td>
<td>Resident</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>30</td>
<td>Staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>31</td>
<td>Staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>32</td>
<td>Manager</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>33</td>
<td>Resident</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>34</td>
<td>Resident</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>35</td>
<td>Resident</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Interviews were chosen as a means of collecting data from patient, staff and relative participants as they provide a method of eliciting the perceptions and experiences of participants. Interviews are a suitable method for collecting data for grounded theory analysis (Payne 2007) and are consistent with an epistemological perspective that considers talking to and listening to people as a meaningful way of constructing data (Mason 2005). Furthermore, interviews provide an opportunity for people who are unable to respond to questionnaires, to share their views and experiences (Sullivan 1998). Through the use of interviews, residents and participants can contribute to the future care of others by providing important perspectives which may help to inform policy makers to deliver improved care for future residents. The interview process allows participants to discuss and reflect on their experiences and the meaning that their experiences have for them (Warren 2001).

4.7 Developing the Interview Schedule

Interview schedules were drafted by the researcher which were piloted in one site. Reflective notes were made on how the interview went and what feelings were participants experiencing in the process of the interview and the appropriateness of the questions. These reflective notes, recorded as memos, were discussed with the researcher’s supervisory team. Feedback from the researcher’s supervisory team suggested to use alternative words/phrases in the interview guide, which would help in future interviews to help participants talk about their experiences and feelings on end of life care. The introduction of an interview was a time used to find out the participant’s readiness to begin the interview and an opportunity for the researcher to pay attention to the emotional state of participants to prevent harm (Murray et al. 2009). Being able to listen keenly to all interviewees, the researcher was able to see
any participants’ discomfort and make alternative supportive arrangements, which included stopping the interview, making contact with supportive services for participants. In this study there was no evidence of distress from any of the participants.

### 4.7.2 Residents Interview guide

The semi-structured interview guide for residents focused on residents’ current lives in residential care, and on their feelings around their own end of life care. Conversations between interviewer and participant were initially about residents’ earlier lives and their life prior to residential care. This was important to help establish trust, build rapport and put participants at ease (Booth & Booth, 1994, Smith et al. 1995). This was a gentler approach to lead into to what is sometimes a difficult subject of death and dying. This approach was subtle and helped elicit residents’ views on death and dying. Interviews took place at a place of the participants’ choosing and lasted from 15 minutes to 45 minutes. Following each interview, time was allowed for personal reflections, note taking and short summary of the interview. (Residents interview guide Appendix 5).

### 4.7.2 Staff Interview guide

The semi-structured interview guide for staff included questions about their experience working with older people in residential care (Staff interview guide Appendix 6). The following are examples of some of the questions used; Tell me of a time recently when you were supported in giving care to someone who was at or near end of life? Have you ever witnessed someone at end of life? What structures are needed to support good end of life care? An example of a probing question included: Please describe as completely as you can what things you needed to help with supporting someone who was nearing the end of life? (for example; customs and rituals, symptom management), What’s important (useful, necessary, essential) at end of life for an older person here? What is good end of life care about?
4.7.3 Relatives Interview guide

Many relative participants had been involved with their resident relative’s care for a long period of time and were happy to participate in the study (Relatives interview guide Appendix 7).

Interviewing relatives took place mostly in the care home while they were visiting the resident. Relatives in this study included both the relatives of residents who were currently alive and living in the residential care home and relatives whose resident relative was recently deceased. One relative participant whose sister died within the previous month was keen to meet and talk about her sister’s death and what the dying experience was like for the relative. Most relatives were happy about talking about their connection with their relative, the staff and life within the care home. Two relatives had partners in the care home and who were in the final stages of dying. Another relative agreed to be interviewed but did not turn up on the agreed time.

4.7.4 Pilot interviews

The first two pilot interviews were a useful experience because it highlighted issues with the recording device. The purpose of the pilot interview is to evaluate the feasibility, clarity and appropriateness of the semi-structured interview guide (Parahoo 1997). The initial interview questions were broadly based on an earlier literature review conducted at the outset of the study and in consultation with the study’s supervisors. The interviews helped the researcher attune to the participants’ linguistic styles. Buckledee (1994) noted that researcher’s interviewing skills improve over time as interviewers undertake more interviews in the same study (Buckledee 1994). The nurse participants of the first two interviews agreed that the questions were appropriate. Good interview questions should contribute to the development of themes and to the aims of the study and there should be good interview interaction between the interviewer and the participant (Kvale 1996). The interview questions should encourage a positive interaction between the researcher and participant to maintain the flow of the conversation so that participants can talk about their feelings and experiences (Kvale 1996). Most interviews between researcher and participants were both thematically relevant and dynamically positive.
In some interviews, it took a longer time to get participants to have free flowing conversations; however, most participants achieved a good conversation and developed a dynamic interview. The exception was with one resident who was unable to articulate his feelings clearly or talk about his experiences. Most interviews were conducted in private in room adjacent to the work area, one interview was conducted in a café close to a residential care home. Nurse interviews were conducted during their breaks or at a time that was quieter on the ward. Where residents had shared bedroom accommodation, the interview took place in a private room adjacent to the communal areas in the residential care unit. In one long stay residential care home, the residents had their own single room and this facilitated privacy for the interview.

4.8 Data Collection

Data collection and analysis were systematic and sequential (Corbin & Strauss, 1990) starting with data collection, followed by analysis, followed by more data collection and further analysis, until categories reached saturation, (Strauss & Corbin 1998). Data was collected with individual face-to-face interviews using a semi-structured interview schedule as previously outlined. Resident participant nursing careplans were reviewed, and notes were taken of the environment of each participating residential care home. This occurred from October 2011 until March 2013 (See Table 4.7 care home visits and participant interview process). Data collection proceeded on the basis of theoretical sampling. Theoretical sampling involves selecting research participants on the basis of themes emerging from current data and analysis, in order to develop and elaborate categories and examine provisional hypothesis (Glaser and Strauss 1967). With each additional interview, questions were more focused on relevant concepts as categories were refined (Strauss and Corbin 1998). In this way, theoretical sampling was systematic and cumulative (Strauss and Corbin 1998). The first tentative themes were of space, environment, relationships, family and staff. This changed the direction of data collection to explore more on relationships, family and staff and consequently to interview relatives of residents to ascertain their views and experiences of death and dying. It was important to explore the views of families of residents about end of life care (Appendix 8b, figure of memo following interviewing).
These steps were recorded as five phases in the data analysis software (Appendix 8, NVivo data analysis). Theoretical sampling involved reviewing existing transcript data, collecting new data on concepts with subsequent interviews, and collecting data through alternative sources, for example, care notes and observation of the environment.

4.9 Data Analysis

Grounded Theory (Glaser and Strauss, 1967; Glaser, 1992; Strauss and Corbin, 1990) is a research methodology in which theory and models are inductively extracted from the analysis of contextual data. Analysis involves the iterative discovery of concepts and tentative explanations of phenomena, as theory emerges from data. Grounded theory uses constant comparative method of analysis. Furthermore, analysis is based on asking questions and making theoretical comparisons, two essential actions for theory development (Strauss and Corbin 1998). The coding processes followed Strauss and Corbin’s (1998) techniques of open coding to discover categories, axial coding to further develop and relate the categories, and selective coding to integrate and refine the theory. These coding techniques are not necessarily sequential analytic steps, but facilitated the progress of analysis to a higher and more abstract theorising, which aimed to move away from a theoretical description to a conceptual ordering and then to an explanatory scheme (Strauss and Corbin 1998).

Axial coding is termed axial, because coding occurs around the axis of a category, which was achieved by relating categories to subcategories. Alternating to data collection with analysis provided a sense of direction, and promoted a greater sensitivity to data and enabled me to redirect and revise interview questions as the analysis proceeded. As data collection following the first eight participants, (six residents, two staff), the basis of a theory began to emerge, it became important to theoretically sample relatives as tentative findings seemed to indicate a strong reference to the families involvement in end of life care. Theoretical sampling involves selecting research participants on the basis of themes emerging from current data and analysis, in order to develop elaborate categories and examine provisional hypothesis (Glaser 1967). Relatives’ experiences and feelings were not being
represented at the early stages of data collection, even though they were being referred to throughout the conversations with staff and resident participants.

Following a meeting with the supervisory team, a need to interview more residents’ relatives was recognised to get a richer sense of the processes involved in end of life care for their relative. It enabled the researcher to follow up on, validate, and develop concepts (Corbin & Strauss 1998). The following sections describes how three coding techniques (open coding, axial coding, and selective coding) were used in the study, as well as other tools to support analysis for example, memo writing, diagramming, and coding paradigm, as outlined by Strauss and Corbin (1998).

4.9.1 Open Coding

Each interview was listened to in its entirety before it was transcribed and read several times, this helped to gain an overall understanding of the content. The first phase of analysis was open coding, this is when data is looked at line-by-line and a word is written to describe it on the page margin. The aim of open coding is to identify codes in the data and begin to discover categories and their properties and dimensions. Each line was coded to one word or phrase. Then the interview was summarised outlining the storyline and to get a sense of the participants view of the subject. This was done to understand the context of each participant’s end of life care and to maintain a chronological order of events and sequence of actions, which is necessary for a coding process. A process is a sequence of actions and interactions pertaining to a phenomenon as they evolve over time (Strauss and Corbin 1998).

Following the first eight interviews there were 34 codes identified and there were 36 memos written about the codes identifies, participants, setting, interview schedule and the context (Appendix 8c: open coding and data analysis).

For example, ‘the room that a resident lived in’ and ‘curtains’ generated from earlier interviews was more fully investigated by the next participant about this concept. These open codes became part of a broader category called ‘environment’. Other open codes such as ‘don’t mind talking about end of life care’ and ‘not talking directly about end of life care’ became part of a broader category called ‘An awareness of end of life care’. Another example was the expression ‘Divine
Mercies’, and ‘crucifix’ was merged with a category of ‘prayer and ritual’ also
generated in early interviews was investigated further by various participant types.

Codes (labels) of key words, short phrases or expression that the researcher
considered interesting were noted in the margins of the transcripts. Sentences and
paragraphs were analysed to establish certain themes (patterns in the data) and
asking ‘What was going on?’ in the data (Strauss and Corbin 1998). Questions were
asked of the data to facilitate constant comparison of the data, for example, “What
makes the space where the resident lives in similar or different to another resident”.
Or “Is the space important to another type of participant?”, Has “space” the same
meaning as “environment” or “atmosphere”? Who creates the “space”? For
instance, with the in-vivo code “room living in,” the researcher asked ‘why was this
important to the resident?’. Was the descriptions of the room the resident was living
connected to other aspects of space, environment or atmosphere? How were they
linked, similar or different? Who considered them important, and how were they
involved? Codes identified through line-by-line analysis of the first interview
transcript led to the development of early categories and themes.

4.9.2 Codes, Concepts, Categories and Themes, terminology.

At this stage of describing the method used for this study, it is important to clarify
some frequently used terms in this chapter. Codes, concepts, categories, sub
categories and themes are often used interchangeably. In grounded theory (Strauss &
Corbin 1998) use the term concept for lower level coding, and the term category for
a combination of several concepts. Categories represent a higher level of
abstraction than codes. Categories are concepts that stand for a phenomenon and sub
categories are concepts that pertain to a category, giving it further clarification and
specification (Strauss and Corbin 1998). However, when using NVivo software the
term category is often used for a descriptive level of coding and the term concept is
used for a more abstract level of coding (Bazeley 2007, 2009).

The term theme is often used as an integrating and relational word used between
categories (Richards 2005). Codes identify a feature of the data that is interesting for
the researcher and relates to the most basic segment or part of the raw data that can
be assessed in connection with the research question (Boyatzis 1998). The process
of coding forms part of research analysis (Myles & Huberman, 1994) as codes are later organised into meaningful groups (Tuckett 2005). A theme captures something important about the data in relation to categories and broader concepts. Themes within the data were identified in an inductive way ‘bottom up’ approach rather than a deductive or ‘top down’ approach (Boyatzis 1998). Themes that start to develop are where the interpretative analysis of the data occurs (Myles & Huberman, 1994). In summary, codes become categories that are connected by common themes between them, and emerge in to broader concepts.

4.9.3 Axial Coding- Relating Categories

The aim of axial coding is to further develop and relate categories to their sub categories to allow a more complete explanation about the phenomenon (Strauss and Corbin 1998). Axial coding was used as an analytic tool to organise the data conceptually and to identify relations between, and among categories and their sub categories (Strauss and Corbin 1998). The following figure depicts the process of open coding and category development (Figure 4.3).

![Diagram](https://example.com/diagram.png)

**FIGURE 4.3: OPEN CODING AND CATEGORY DEVELOPMENT**

A coding paradigm focuses on three aspects of the phenomenon; the conditions and the actions and interactions of the people in response to what is happening in the situations (See Table 4.8 coding paradigm). The focus of the analysis became one of purposefully looking at action and interaction and noting sequences and changes and how these evolved in response to changes in conditions.
For example, when talking about planning and care plans on end of life care, the researcher asked questions about if planning was important, and then why it was, what were the consequences of having a plan for a resident at end of life care. What does the nurse do to promote a good care planning at end of life care?

The coding paradigm stimulated thinking about how participants conceptualised relationships, the conditions and context that surrounded the residents’ relationships with staff and family carers, the strategies that nurses engaged in, and the consequences of how the different types of relationships were managed.

**TABLE 4.7: CODING PARADIGM**

<table>
<thead>
<tr>
<th>Example of coding paradigm on ‘Planning’</th>
<th>Resident</th>
<th>Staff</th>
<th>Relative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purposeful preparing</td>
<td>13</td>
<td>82</td>
<td>25</td>
</tr>
<tr>
<td>Using careplans</td>
<td>1</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>Not making decisions</td>
<td>3</td>
<td>22</td>
<td>9</td>
</tr>
<tr>
<td>Panning or Preparing</td>
<td>3</td>
<td>35</td>
<td>14</td>
</tr>
<tr>
<td>Planning end of life care</td>
<td>10</td>
<td>28</td>
<td>3</td>
</tr>
<tr>
<td>Policy on EOLC</td>
<td>0</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

In this illustration, staff, residents and relatives placed planning as an important aspect of end of life care. Residents did not consider careplans, not being able to make decisions on end of life care, or the organisation’s policy as an important factor to their end of life care. The coding paradigm was further used as a guide to integrate structure (conditional context of the phenomenon) with process (sequences of action over time). This is key to developing theory (Strauss and Corbin 1998). “What conditions combine to create the context in which the action and interaction is located?” (Strauss and Corbin 1998 p. 168).

To illustrate this further, there were several categories following the axial coding phase of analysis. These codes were grouped into categories with their properties. As analysis progressed there were 44 codes finally defined.

Following the interviews with residents there were repetitions of many codes, such as ‘planning’, ‘relationships’, ‘feeling ill’, and ‘environment’. Atkinson (1983)
outlined the analytical importance of participant driven categories, that the actual words can be of particular analytical importance. These words suggested that I ask residents about their relationships within and outside the organisation, their relationships between their carers and families.

Constant comparisons led to the discovery of variations, such as diversity and ranges of properties, and general patterns in the data (Strauss and Corbin 1998). Coding progressed to an increased level of abstraction from identifying codes and naming categories. Constant comparisons between interview transcripts helped group several codes into categories. Writing memos on themes emerging from data and reflecting on how codes are being combined into categories advanced my analytical thinking as I began to ask theoretical questions of the data. Throughout analysis, the techniques of constant comparison analysis and asking questions were used. Creating categories involved considering meanings in context and coding and reflecting on all the data related to them. New data from interviews was constantly being compared to previous interviews and modifications or additions were made to categories based on these comparisons. Codes of events, incidents, or actions and interactions found to be conceptually related (i.e. they had related meanings or relating to a similar phenomenon) were grouped into categories.

The example of a coding paradigm on ‘planning’ (Table 4.9) highlights an early analysis that showed who was or was not ‘making decisions’ with issues around end of life care. The researcher asked of the data, who did ‘not make decisions?’ which pushed the researcher to look more deeply at the data to explain what was going on. In this category, some staff did not make or record decisions, or plans, around end of life care, justifying that it was something that could ‘take care of itself’. When the researcher ‘peeled away’ the layers of this category, there were many uncovered meanings from different participant perspectives on the process of ‘making decisions’ that contributed to this category.

Category names were based on what represented the event or what was happening when examining data comparatively in context and from in vivo codes (the participants’ own words). Themes evolved into several different categories by coding text segments relevant to the category, while other themes pertaining to the
category became subcategories. Categories remained provisional until further verified with the data. As analysis progressed, each interview became more focused and specific as data were theoretically sampled for properties and dimensions of emerging categories.

4.9.4 Engagement with literature throughout the research process

Grounded theory is not linear, but is concurrent, iterative and integrative, and engaging with literature is an essential part of data analysis and recognising the emergence of codes (McGhee et al 2007). Strauss and Corbin (1998) advocate conducting a literature review early in a study and focused on the advantages of the extant literature in a grounded theory study. An early review of literature is important in framing the research proposal, for submission to ethics committees and examining seminal texts for guidance in defining the scope of research (McCallin 2003, Cutliffe 2005). However, becoming too acquainted the extant ideas may result in testing hypothesis, whether carried out overtly or subconsciously (Sudaby 2006). Strauss and Corbin (1998) advocate that the researcher should engage with the literature throughout data analysis as a secondary source of data and also use literature for comparisons with the data. The literature can direct theoretical sampling, help with concept development and defining properties and dimensions. This study used the literature and voices of participants to guide theoretical sampling. Literature was reviewed in an interactive between with codes and data. As data was collected analysed, it was compared to extant literature, which aided concept development. Paying attention to respondents’ concerns was key in directing the focus of this study, and this guided data collection analysis and concept development.

4.9.5 Paying attention to residents’ and relatives’ language

Residents used their own type of language when talking about end of life care. This was a valuable analytic tool used during open and axial coding to develop categories. Special attention was given to the symbolic meanings and metaphors that participants used in their language to interpret and describe their experience of end of life care. Examining aspects of language is used to show how individuals
organise, convey meaning, and express their differences through language and expression (Coffey & Atkinson, 1996). For example, one resident (R2) spoke about having ‘her affairs in order’ as part of her preparation for end of life, this meant having her personal business and relationships managed with her son and daughter. This further illustrates that there were different levels (dimensions) of preparing for end of life care. Particular attention was given to words and expression around end of life and the terms given to it. One example is when one relative described when his brother died was, ‘it was like the candle went out’. Another resident described having an ‘outer body experience’ during her time in intensive care when she was received life-saving treatment for her lung disease.

Another relative described meeting staff one particular day and saying that they were unfriendly and had ‘faces like thunder’. She was angry with some of the staff and said that staff should be ‘hand-picked’ and that this should be from the top down. I initially coded this to relationships and then as the organisation’s culture (Relative 22). As the researcher probed more the relative explained that she was trying to get some treatment from nurses for her husband’s mouth care and this was difficult.

4.9.6 Selective Coding- Integrating and Refining the Theory

Selective coding is described as a process of integrating and refining a theory by interrelating categories in to larger theoretical scheme (Strauss & Corbin, 1998). During the concurrent process of data collection, data analysis and memo writing and developing a storyline, five major categories were developed, as follows: comfort, dignity, life before death, peaceful death and support for carers. Each category was developed, refined and interrelated by systematically connecting concepts through statements of relationships in the form of journaling and using memos and annotations.

As the process of data refinement and data reduction is ongoing, the researcher wrote several memos to reduce five categories to three; enabling transition to long stay care, organising care, planning residents care, preparing the environment, supporting staff, and maintaining connections. These categories were still too many, as they did not capture the central essence of the study. One of the steps in integrating categories is to recognise a central concept. Through a lengthy process of
memoing and reflection, five further categories emerged; leaving the community, increasing frailty, and, communicating as partners in care, preparing for dying, and relating to one another.

The central concept that encapsulated these categories finally emerged and was defined as ‘Living well and dying well within a tapestry of relations’. This was a conceptualization that fit the data, (all the categories combined) and offered a clear explanation of what the data was about. It has analytical power in its ability to capture the data completely, under which all other categories could be subsumed to from an explanatory whole (Strauss & Corbin, 1998).

Labelling the core category facilitated integration as it enabled the researcher to explore the process used throughout the analysis. I used several techniques of diagramming, memoing and writing the storyline. For instance, diagramming was useful in considering the logic of relationships. Refining the theory involved reviewing the scheme for internal consistency and gaps in logic and validating the scheme against incoming data (Strauss & Corbin, 1998).

The coding paradigm of conditions, actions, interactions and consequences outlined by Strauss and Corbin (1998) facilitated integrating the emerging theory and defining relationships between categories. The five main categories of antecedents, actions/interactions, and consequences were interrelated through temporal and causal statements of relationship. Nurse, resident and relative and contextual factors were linked through patterns of conditions and intervening relational statements.

4.10 Theoretical Sensitivity

Theoretical sensitivity is the ability to recognise what is important in the data and give it a meaning. It means having insight in the data which is achieved by what the researcher brings to the study as well as through the immersion in the data during the data collection and analysis phases (Strauss & Corbin 1998). Sensitivity to theoretically relevant concepts is central to recognising the properties of the concepts in the data (Strauss & Corbin 1998). Becoming theoretically sensitive during data analysis was a process that occurred while the researcher worked in a long stay care home. Being in regular contact with staff, residents and relatives, enabled the researcher to develop an awareness of residents’, and their carers’ broad concerns as
they were nearing end of life care. It was simultaneously developed through prolonged engagement with the data and with regular feedback from academic supervisors.

Regular feedback and questions concerning the data from my supervisors challenged me to re-think the data and consider alternative interpretations of the data. For example, earlier in the process of engagement with analysis I considered ‘Faith’ as a central concept, however when it was explored further through memo writing and in a storyline, I became concerned that I could not incorporate the many strands of data which had been collected to the term. Finally, from the researcher epistemological standpoint, I felt that as a central concept, ‘faith’ was not an appropriate central concept to adequately articulate the core category of the study.

4.10.1 Reaching Theoretical Saturation

Theoretical saturation is a point in the process of category development where no new properties, dimensions, or relationships emerge during data analysis. This is a point for deciding when to stop sampling. It is a critical concept in grounded theory and is a subjective decision (Hallberg 2006). Saturation is a function of theoretical completeness (Barker et al. 1992). Theoretical saturation happens when “no new information seems to emerge during coding, that is, when no new properties, dimensions, conditions, actions/interactions, or consequences are seen in the data” (Strauss and Corbin 1998 p. 136). It is based on the researcher’s ability to use personal and professional experience as well as methodological knowledge and think abstractly about new ways to see the data in the process of developing a theory. It also can be seen as the researcher’s ability of manipulating data in such a way that best reflect reality (Hallberg 2006, p.143). Hall and Callery (2001) suggest that theoretical sensitivity should be reached in conjunction with reflexivity through memo writing about how, for example, the researcher-participant interaction and the researcher’s perspective affect the analysis and the results.

Consequently, the researcher decided that theoretical saturation had been reached following an extensive reflexive process, from the beginning to the study until the final round of interviews and coding. This was also guided by the criteria outlined by Strauss and Corbin (1998), i.e. that categories are well developed in terms of their
properties and dimensions demonstrating variation, and relationships among categories are well established and validated (through a process of inter-rater reliability with my supervisor) with the data. The author had developed several similar categories, and through a process of reflexivity and memo writing decided that many were the same and required more conceptual thinking of the categories. Little new data could be added to any category by further interviews. More interviews would have meant further repetition of the same categories, a point of diminishing return. The researcher consulted with her supervisors and agreed that this was the point where theoretical saturation of the concepts had been reached.

4.11 Data Management

Data management was supported by NVivo 10 ® software which was used to store, organise, indexing and search data and help record analytical insights in the form of memos (Cresswell 2007). Several studies have used similar software in qualitative studies to organise data and support analysis (DeWitt, Ploeg & Black 2012, Phelan & McCormack 2010). In this study, the types of document stored in the software included participant transcripts, interview schedules, literature documents in PDF format, interview summaries and memos. This software supported a process of constant comparative analysis of transcripts through features including ‘free nodes’, ‘tree nodes’, ‘annotations’, ‘memos’ and ‘see also’ links, terms which are used with NVivo software. These terms are used in the software so that users can understand the phases of analysis and demonstrate auditability of the research analysis. Higher levels of interpretation and analysis occur with the researcher.

Much of the research data was obtained through interviews with participants. Interviews were recorded and transcribed by the researcher. This data was stored in a locked filing cabinet in a secure room. Participants’ information was anonymised as described in the previous methods chapter. As data was transcribed from the audio recorder it was transferred to a software package which supported data management and retrieval throughout the study. The earlier ‘Methods’ chapter describes how this research used NVivo 10 software to manage the study’s data. Grounded theorists are advised not to use such software to manage data in order to avoid the potential that use of computer assisted data analysis software will interfere with constant comparison. Glaser (2003) argues that doing so will diminish the researcher’s own
inductive processes which should arise from non-linear sorting of memos and concepts. The researcher used Nvivo as a tool to aid analysis, and transcribed each interview, uploaded it to the software and coded each line. Each code was grouped into ‘tree’ and ‘parent’ nodes, which formed a hierarchy of themes. The researcher developed a good working knowledge of NVivo 10 concurrently with her developing knowledge of Strauß and Corbin grounded theory methodology. This enhanced the researcher’s understanding that the software NVivo 10 is a tool which helps with the requirements of the methodology and was not used as a tool of analysis. During the constant comparative process, analysis was not dictated by the structure of the NVivo 10 software. Rather, the researcher developed codes and concepts only from her own interpretation and analysis and in response to connections and patterns that emerged from the data. Pre-programmed codes, or automatic coding, which is a function of the software, was not used. NVivo 10 allowed the researcher to store and organise all of the data, memos, codes and categories in an accessible manner. The software also helped by creating separate overlapping NVivo projects throughout the research phases which allowed transparency of the process of data analysis. The process of coding and conceptualisation was easily illustrated and accessible. The use of NVivo 10 facilitated organised storage of participant data, researcher memos, literature, tables and models depicting connections between concepts and categories. This thesis shows that using NVivo 10 illustrated the phases of analysis in a clear, organised and transparent way (Appendix 8d Coding tree-selective coding).

4.11.1 Creating Free Nodes, Tree Nodes, and Annotations

Demographic details were also imported. Data was organised into a folder hierarchy by data type (for example, interviews with participants, or interview schedule).

NVivo 10 stored data in ‘nodes’ which are repositories for themes and categories and one such node type is a ‘case node’ which is a single file that stores each participant’s contribution from their interview.

These case nodes, once populated, are then physically linked to the demographics tables which facilitate integration between the qualitative and demographic aspects of the data. Thus, intangibles such as attitude and beliefs (for example, data coded in a node which hosts all references to ‘life before care’) can be intersected with aspects
such as age, gender, education, length of stay and for detailed analyses in order to help the researcher understand the phenomena under scrutiny.

4.11.2 Linking

NVivo is a type of database known as a ‘relational database’. This type of database facilitates linking all relevant data generated during the data gathering and importation process. The following data types were formally linked in the database:

- Sources
- Field Notes and Observations
- Memos
- Digital Data
- Literature Review
- Library and Journal Articles
- Field Notes and Observations

The researcher maintained a diary of her observations from each participating care home. These observations included the demeanour of staff, residents, and relatives towards one another. Field notes included the documentation relating to resident care assessments and care planning and in particular around end of life care. The researcher documented her observations and sometimes they included nuances relating to the conversations during interview, for example if a resident laughed, or relative participant’s facial expression changed and became worried or excited during the conversation, this was noted in the researcher’s field note diary. This was important to maintain field notes because it was linked to point of the transcript and the audio tape which provided a richer interpretation of the interview, and demonstrated that the analysis of data was not conducted solely on the text from the transcript.

4.11.3 Memos

From the earliest stages of this study to its completion, the researcher maintained a diary to record her reflections, which are otherwise known as memos in grounded theory.
My thoughts and opinions were recorded, in a diary, as new concepts, categories and the central category emerged. There were many questions posed over time and theory development prompted many reflective notes to be recorded questions between the researcher and her supervisors. The contents of the diary were transcribed to the software package which held all data pertaining to the research, and were subsequently known as ‘memos/project journal’.

Many self-reflective memos led to questions which helped analyse and interrogate interview transcripts further.

Memos served three purposes for analysis which were;

1) Giving context to sources of information, interviews, and observational data.

2) Generating proposition statements

3) Defining Nodes

Memos made on thoughts and ideas from early interviews gave a context to the sources of information. Giving context to an entire source of information in the form of an interview, for example; one relative participant displayed considerable knowledge of the area on end of life care and later revealed that her daughter was a doctor, which meant that she was familiar with the popular expressions used at the bed side. (My reflection on this was that it provided the participant with a sense of equality [power of knowledge] with health care professions delivering care for her partner). Another nurse participant explained that she was caring for her parent who was at end of life and receiving palliative care. She also asked if she should express her professional or private views, clearly distinguishing between herself as a person who provided care and as a person who received care and this phenomenon was pervasive throughout the interview. A memo, setting out these details attached to the document served to remind the researcher of this broad context later in the data analysis process.

Memos were written frequently after interviews and at various points of the analysis process and recorded to the software which was used as methodological (operational), theoretical and analytical ways (Strauss & Corbin 1998). For example, an analytical memo is a note about what the researcher thought about what she was seeing in the data, and what decisions were being made regarding themes and
categories as they emerged and evolved from data analysis. The researcher arranged her ‘Memos’ file in groups, such as ‘early themes’, which reflected the initial themes that emerged from the pilot interviews and early round of interviews. Another example of a memo was called the ‘project journal’ and this was where the author wrote her reflective thoughts following meetings, Graduate Research Committee (GRC) outcomes, actions to take, and results to follow up of research decisions. A second group of analytical memos was on how and why she altered the interview schedule. There were more memos written on residents’, staff and relatives’ interviews. Towards the end of the interview and analysis process the researcher has a memo folder on theoretical saturation and the process of concept development. Memos formed part of a reflexive journal and contained thoughts and feelings about the research process, analysis, how I might be interpreting data and what influences were on the authors’ analysis.

Memos link coding and theory development and the researcher can raise the conceptual level of those ideas towards the developing theory, they develop the researcher to work with concepts instead of line-by-line codes taken from transcripts.

4.11.4 Including Literature

Using literature relevant to the study was imported and linked to the transcripts as a means of setting the primary data in dialogue with the theories and theorists under review. The literature was used to guide the researcher’s questioning and interview guide, and at stage three of the data collection process. Published data from key theorists was imported into the database and segments from these publications were coded against the central conceptual themes of the study.

4.11.5 Coding Framework

In data analysis, nodes hold data which has been coded from sources. All nodes created in the study were defined by the researcher to add clarity to data analysis and show how analysis was completed.

There were five types of nodes used to show how data was analysed;

- Free Nodes which are stand-alone repository used for broad, thematic, participant driven coding known as categories.
• Tree Nodes, which are similar to free nodes with two exceptions:
  They can have relationships with other nodes and thus may be grouped into
  themes
  They can have ‘children’ and thereby have a hierarchy imposed on them.
  (Figure 1)
• Case Nodes, which were used to generate a case file which held all data
  related to a participant and which was physically linked to their demographic
  details which provided contextual information about participants.
• Relationship Nodes: were used to formally log relationships across and
  between themes and categories.
• Matrix Nodes: These were used to intersect disparate nodes with cases and
  demographics. They were also used to analyse qualitative coding. For
  example, how often something was raised unprompted (number of coding
  references) or how animated a person was about something (number of words
  coded). For example; several transcripts were coded manually, where one
  word was written on the margin of the sheet of paper. Creating free nodes
  allowed sections of the interview text to be coded and also showed
  frequencies with which these codes appeared in the participants’ interview.
  For example, a free node like ‘ritual’ showed three different sources, from
  resident, relative and nurse referred to ‘ritual’ and represented a matrix note
  as it was coded to three participant groups (See appendix 8 for table of
  coding framework).

4.11.6 Criteria for Establishing Trustworthiness

Trustworthiness is establishing whether the findings are of any value to the reader
and the process of the research journey was rigorous enough. Lincoln and Guba
(1985) described four criteria that can be used to establish trustworthiness of
naturalistic inquiry: credibility, transferability, dependability, and confirmability.
They also proposed several techniques within each criterion. Strauss and Corbin
(1998) advanced criteria that serve to judge the adequacy of the research process and
to evaluate the analytic logic used by the researcher in theory-building research.
McCann and Clark (2003) identified the following criteria to establish
trustworthiness: concept generation, relationship of concepts, concept and category linkage and density, theory variation, conditions for theory variation, account for process, and significance of theoretical findings. This is used to demonstrate trustworthiness in this study. In this study, the researcher generated such concepts such as ethos of caring, organising care, caring environment and resident centred relationships. The researcher highlighted that each concept was related through a process of actions. This was illustrated by using a metaphor of a tapestry to help illustrate the interconnectedness of the concepts. The theory of ‘dying well in a tapestry of relations’ was identified as the core category in this study, which was the main concern for all participants. Within the core category were concepts that were used to further explain how participants address their main concern, which is, dying well in residential care homes. In essence, the core category was the central concern of the study participants and this emerged from the data as a concept and category linkage. This will be further discussed in Chapter 5, Findings.

4.12 Literature

In keeping with grounded theory procedures (Strauss and Corbin, 1990, 1998) the researcher made every effort to avoid incorporating her preconceived ideas to the emergent theoretical framework. The researcher did a preliminary overview of literature to inform her research proposal. Then as data was collected it was compared to literature. Strauss and Corbin (1990, 1998) acknowledge that remaining open is an ongoing effort and the researcher cannot be expected to approach the research entirely free from beliefs and theoretical understandings gained from the literature or from professional experience. The researcher tried to minimise the impact of previous experience by constantly asking, ‘what category does this data indicate and what is this participant’s main concern’? As noted in previous chapters, accessing the literature in the substantive area was undertaken in a phased manner, the first phase to initially inform the researcher of preliminary literature to familiarise herself with substantive concerns, (conducted five years previously) and to inform her research proposal. The second phase was at the time of comparing categories to extant literature which provided context and general understanding of the emerging categories. Constant comparison and memoing
processes ensured that any data derived from pre-existing knowledge earned its place in the research along with other data (Strauss and Corbin 1990, 1998).

Though Strauss and Corbin (1998) indicated that these criteria are meant as guidelines, they are useful for evaluating the credibility and quality of the theory. In addition, these questions assisted in developing analytic, theoretical, and methodological memos throughout data collection and analysis, comprising the study’s audit trail.

4.13 Chapter Summary

This chapter presented the methods adopted to find out the factors that influence end of life care in residential care homes. It discussed the relevance of consent and participation in research, selection and recruitment of participants, inclusion criteria, and interview development. Data collection and data analysis was conducted by the researcher using interviews, memos and using software to support her data analysis and theoretical sensitivity on the data. This chapter describes the process of reaching theoretical saturation, data management and establishing trustworthiness of the analysis. The following chapter will describe the emergence of concepts and core category from the data.
Chapter 5 Findings

5.1 Storyline

The following section describes the study's storyline. The storyline is developed when the researcher has ‘sense of what the study is all about’ (Strauss & Corbin, 1998 p.148) and provides the reader with an overview of the study. The following chapter will describe the the emergent categories and sub-categories. Sections written in text boxes represent how the categories and sub-categories integrate with extant literature, and this is used to further develop a substantive theory.

The core category in this study was identified as ‘dying well in a tapestry of relations’. The data in this study revealed that to ‘die well’, residents firstly had to ‘live well’. This process of ‘living well’ occurred within a community of people in residential care who became increasingly frail and eventually died. The core category of ‘dying well in a tapestry of relations’ is the central concern for all participants of this study. Nurse and relative participants were concerned that residents would be well cared for and die well in residential care. Resident participants also wanted to live well in residential care and experience a good death.

The core category of living and dying well in a tapestry of relations represents the views and meaning each participant gave to end of life care in residential care. Residents initially described that they ‘didn’t mind’ living in residential care or talking about dying, but preferred to talk about other people’s death, either in their lives prior to admission to residential care or deaths they had seen while in care. For nurses, their wish was to be able to enable residents have a good life and that end of life care was about living well. When death came, it was important to acknowledge the resident’s preferred way to die. For relatives, they wanted their resident relative to be comfortable and to live a fulfilled life in the care home. They also wanted to be able to enjoy visits and in a friendly care home.

In this study there were 19 staff participant interviews, 14 of whom were qualified nurses and the remainder were health care attendants (two), speech and language therapist, and one activity therapist. Occasionally the term staff is used however the term ‘Nurse participant’ refers to the staff group as a whole (as outlined previous chapter- Methods)
A conceptual model of the factors that facilitate or hinder dying well in residential care has been developed (Figure 5.1). Within this conceptual model are the concepts of ethos of caring, organising care, caring environment, and resident centred relationships; these are the concepts that facilitate or hinder dying well in residential care. The metaphor ‘tapestry’ is used to describe the way in which all concepts within the model weave and relate to one another to focus on end of life in residential care. Resident centred relationships are crafted through the concepts of, ethos of caring, organising care, and caring environment. The relationships between residents, nurses and relatives, like strands in a fabric, create resident centred relationships which help residents live well and then die well in residential care.

**Figure 5.1: Conceptual model of the factors that impact on dying well. Outer circle depicts the core category**
5.1.1 Using a metaphor

The metaphor *tapestry* is used in the core category to help explain the concept of dying well in residential care. In this study, *the tapestry of relations in dying well* in residential care is woven by multiple complex and complicated threads. The threads of the tapestry represent residents, their relatives and care staff relating to each other in the residential community.

*Dying well* in residential care is created, like a tapestry. Together, the people involved create good end of life care for residents against the background of an ethos of caring, organising care and caring environment, which is similar to a fabric. If the fabric is to be woven and become aesthetically pleasing, each piece of material must connect and crisscross with the other. The pattern of the tapestry represents the concepts of *ethos of caring, organising care* and *the caring environment* in residential care communities which ultimately influences *resident centred relationships* in end of life care.

5.1.2 Conceptual description

In explaining the storyline, the core category is the main concern for study participants, i.e. residents, nursing staff and relatives. Within the core category are concepts that are used to further explain how participants address their main concern, which is, dying well in residential care homes. In essence, the core category is the central concern of the study participants and this emerged from the data as concepts *ethos of caring, organising care, caring environment* and *resident centred relationships*.

The conceptual framework is built from the concepts within the data. Concepts are used to explain the study’s conceptual framework of dying well in residential care. The analysis of data has revealed that *ethos of caring, organising care* and the *caring environment* are the concepts that shape the extent to which a person can die well or not in residential care homes. These concepts will be described and explained along with the essential inter-play between residents, staff and relatives in residential care settings which represent the fourth concept of *resident centred relationships*. Each concept is developed from the data, and is interconnected with the other. This is a fluid process where each concept co-exists with the other.
Each of the four concepts that comprise the conceptual model (Figure 1) are described below.

5.1.3 Ethos of caring

An ethos of caring within the residential unit influenced dying well in residential care and refers to how death and dying were regarded by all staff. Staff participants described how their values and other’s values shaped how they cared for residents and each other.

Staff and relative participants described an ethos of caring as one which promoted excellence in its service to older people in residential care which had a positive impact on dying well. Dying well was facilitated where the care team demonstrated an ethos of caring which promoted resident choice, enabled residents to live well, and helped residents’ express spirituality while living and dying. Staff participants described having confidence in their everyday practice. They also felt supported and encouraged by colleagues and facilitating residents to die well gave them a sense of well-being. Resident participants described the organisation’s ethos as being inclusive of relatives, enabling residents’ choice and allowing expression of their spirituality. An ethos of caring that enabled residents to ‘live well’ promoted resident centred relationships. Relative participants placed importance on residents’ living well in residential care and this meant having good relationships with the people around them.

When the ethos of care was described as controlling and disempowering, residents and relative participants described this as having a negative effect on the experience of dying in residential care. They felt they had little choice or control in their way of living, and had to accept their new lives in the community of residential care. Where the ethos of caring was not based on resident centred relationship, living well and ‘dying well’ was not facilitated.

5.1.4 Organising Care

Organising care was an essential concept to dying well in residential care. This reflected how work was organised and carried out by all staff in the residential care homes. The dimensions associated with organising care were planning care
around residents’ care needs, and recording care which was concerned with documenting the discussions and plans around end of life care and dying. How care was organised impacted on relationships between nurses, relatives and residents. The way care was organised also determined work allocation and skill mix and therefore impacted on the expertise available to residents and how their daily care evolved. Care was planned based on the social and nursing care needs of residents, which meant that different grades of staff were involved in many aspects of residents’ care, for example, helping with personal care, managing symptoms, planning social events, and helping with relatives’ needs, all of which was focused on resident centred relationships.

*Resident centred relationships* could only take place when structures, such as management teams, training and educational opportunities, and appropriate equipment were in place. Nurse participants felt that this facilitated them in the provision of good care. However, when any of these were absent it constrained their practice. When care was well organised, nurses described this as having residents’ care plans in place, adequate skill mix of staff on the ward and having access to other supportive professionals, such as palliative care specialists which facilitated dying well. Nurse participants described unplanned care when they were unsure of a resident’s end of life preference plan. They described care as disorganised when they had difficulties in accessing equipment or the expertise of the multi-disciplinary team, which contributed to uncertainty for staff and hindered *resident centred relationships* at a resident’s end of life. Some staff had not received training on end of life care, and felt they relied on their own prior experiences of death and dying to guide and support dying residents and their relatives.

Nurse and relative participants in this study found that to die well, residents needed to have lived well in residential care. They needed to develop the relationships around them that would sustain them through the dying process. Nurse participants focused on residents living as well as possible when their health was good, and to foster relationships between themselves, staff and relatives within the community of the care home.
Resident participants’ care was organised to include various social activities, days out, and excursions which enriched their lives further by developing their relationships while in residential care. Nurse participants equated living well in residential care with a good quality of life, and good end of life care.

Resident centred relationships were only possible when resources were allocated in particular ways, such as when training and education, skilled staff, equipment, care-plans, and specialist skills were in place in the residential care home. If any of these elements were absent, participants described care that was not organised, not resident centred and not contributing to dying well.

When care was well organised, nurse participants described having access to appropriate equipment for end of life care, such as specialist beds, adequate analgesia, single rooms for a dying person, and having a quiet environment available for relatives. Nurse participants described organised care as having resident centred social activities arranged for residents who were well enough to participate in and enjoy. Residents reported that they felt that their care was good when activities and social events were organised around their interests and abilities. Some residents reported feeling at ease with nurses and reported that they felt comfortable in their company because they were not rushing around and had time to spend with them in an unhurried manner. Resident participants were unhappy with how their care was organised when they were unable to make choices about the way they spent their day, or when they could not spend the time with people they wanted to be with.

Relatives reported that care was organised when they could talk to staff members easily and the person they spoke with knew about their relative. They reported that it was important to have someone that could understand their concerns and talk about their relative’s health status and care needs. They valued having access to their relative around visiting times and having friendly relationships with staff when they visited the care home. Relatives felt that when care was disorganised it had a negative effect on them and it contributed to misunderstandings and confusion. Disorganised care compromised resident centred relationships, because residents could not live their chosen way of life, and staff could not carry out their roles completely when a resident was dying.
5.1.5 **A caring environment**

In this study the concept of *a caring environment* describes *macro and micro environmental* factors that shaped the living and dying environments for residents, staff and relatives. For residents, having a *caring environment* was the space where they could socialise together with their relatives and staff.

The *macro-environment* was the structure and design of the building, inside and outside the residential care home and included the spaces residents lived in and the surrounding outside areas. The *macro environment* focused on the community where the resident came from. It also included outside community involvement who interacted with residents, relatives and staff.

The *micro environment* revealed residents’ living space and how they shared their time and space with other residents, relatives and staff. It reflected the design of the rooms or ward that residents lived and died in. Residents, staff and relatives described this as the space where residents socialised and related to one another. This space was described as their bed area, where their personal items were kept and the ward and corridor where their room was located. The environment impacted on the community of people and their relationships with one another.

The *micro environment* was also the place where dying took place, a place shared by residents and their relatives. Nurse participants reported that a comfortable peaceful environment was essential when a resident was dying. This was described as an environment that had low background noise, soft furnishing in the interior design, and adjustable lighting, which helped nurses provide a comfortable death. Nurse participants reported that a *caring environment* nearer to the time of a resident’s death was important and this meant there was adequate space for residents and their families. Nurses strived to create a *caring environment* for the death of a resident in either shared or single room accommodation. Some nurses reported that sometimes they preferred a shared room accommodation for residents, however, when a resident was approaching death, it was more important to have a private room for their relatives to be with the dying person.

Many resident participants reported that they preferred single room accommodation and their own space. They liked where their bed was located and
having adequate space for their personal items near them. They also reported that they enjoyed the companionship of meeting other residents and their relatives in either their own personal space or in homely designed communal areas. Others did not like that they had to share their space with other residents and their relatives.

In summary, the concept of *caring environment* in this study was a contributing factor to dying well. Nurse participants tried to ensure that the environment was arranged in such a way that it contributed to a good death. Resident participants described preferring to living in single rooms although some described enjoying the companionship of others in shared room accommodation. Nurse participants appeared to prefer shared accommodation for residents, however, when death was imminent, they described preferring a single room to accommodate residents and family preferences.

### 5.1.6 Resident Centred Relationships

The concept of *resident centred relationships* represents the relationships between staff and relatives involved with residents in the process of living well and *dying well* in residential care. The concept of *resident centred relationships* between staff, relatives and residents reflects the inter-connectedness between the study participants. Deliberate strategies were in place for nurse participants to get to know residents. This took place through staff involvement in activities such as assisting with personal care, life story work, and participating in some of the organisations’ social events. This meant that participants exchanged information, chose treatments, discussed plans of care, and allocated resources collaboratively. Communication between nurse participants and residents and their relatives was essential to resident centred relationships and developed over time. When nurse participants had knowledge of residents, it provided the basis of their goals of care and was central to building relationships. *Knowing the resident* helped staff communicate their goals to other team members. When staff knew the individual personhood of each resident, they could involve their relatives in aspects of residents’ care if they wished. Nurse participants were also readily available to residents and relatives, and this enhanced communication.
Communication was most effective where there was acknowledgement and understanding of each other’s roles, between residents, relatives and nurse participants. Relatives’ needs were acknowledged by care staff when their resident-relative was approaching death. Some relatives wanted to be involved in the day-to-day care of their resident relatives’ lives and others wanted less involvement, however, each study participant appreciated the importance of relationships in the care homes. Care staff brought aspects of their personhood, such as culture, faith, traditions, into their relationships with residents and relatives, and understood relatives’ emotions and empathised with them which helped develop deeper understandings of both relatives’ and residents’ needs.

Some relatives wanted to help with meal times, personal care, preparing clothing and participating in excursions with residents when possible, while others did not want this level of involvement. Relatives expressed their willingness to continue in their caring role with their resident-relative while in residential care. The strength of relationships between nurses, residents and relatives underpinned how care was delivered. Relatives described their experiences of getting on well with staff as an important factor to contributing to good end of life care. When relatives or staff described tensions in their relationships within the care homes, this was described as hindering dying well.

*Resident centred relationships* were essential to both living well and dying well and were highly interrelated in this study. Residents, relatives and staff spoke about living well in residential care, and this impacted on residents dying well. Staff, residents and relatives arrived from diverse backgrounds and converged together to occupy the community of residential care. The residential care unit was the world where the complex social worlds of staff, residents, and relatives overlapped and were interdependent. The following figure depicts the findings using grounded theory terminology (Figure 5.2).
5.1.7 Section summary of the storyline

This storyline has described the study’s model of living well and dying well in residential care. This study found that end of life care in residential care settings is based on the core category of ‘dying well in a tapestry of relations’. To ‘die well’, all participants were focused on the concept of Resident Centred Relationships. The framework to support this is dependent upon the concepts of ethos of care, organisation of care, and a caring environment. These concepts are woven together, as in a tapestry, and result in good end of life in residential care. The following section will present each of these concepts in relation to relevant literature.

5.2 Category-Ethos of Caring

This category describes staff and managements’ view of caring which consequently influenced resident centred relationships and dying well in residential care. The organisation’s ethos of caring shaped the way in which people lived and impacted on the extent that resident participants were able to die well. The category of ethos of caring in residential care refers to how death and dying were valued by all staff. This category influenced how care was organised,
the environment and the relationships between study participants. Ethos of caring highlighted the values held by staff and was concerned with knowing residents and their relatives. This knowing enabled residents to live in a way that was based on their choices and care preferences. This formed the basis for an ethos of caring that enabled living well, which was essential for dying well.

The category of ethos of caring has strong resonance with Bergum and Dossetor’s relational ethics approach (Bergum and Dossetor 2005). A relational ethical approach illuminates the reality of personal human experiences, the importance of relationships, and helps us understand how ethical healthcare is practiced. A relational ethics approach to clinical practice is one that places emphasis on communication and relationship building. It is founded on the assumption that ethical practice is situated in relationship (Austin, Bergum and Dossetor 2003). This approach seems more meaningful when seeking to understand the significance of relationships when older people die in residential care. A relational ethical understanding of dying in long stay residential care shines a spotlight on the relationships that matter between residents, their relatives and staff to facilitate a good death for residents. When nurses give their care to older people at the end of their lives and orient themselves towards a relational ethical understanding of dying, they may become more sensitive to the ways that dying effects the well-being of staff and their families, as well as the ways to provide good death for their residents.

Relational ethics has four conceptual components; engagement, mutual respect, embodiment and environment (Bergum & Dossetor 2005).

- Engagement urges the cultivation of a sensitivity that promotes authentic connection between carer and recipient. It expects that there is a true presence of individuals in caring, personal responsiveness, and a person having empathy are key components of engagement.

- Mutual respect is identified as the central theme of a relational ethic. Respect is described as interactive and reciprocal, with an emphasis on respect for a person and acceptance of difference. Mutual respect asks carers to begin by respecting themselves in order to respect others. It asks each person to respect their own individual power and see the equality in
what individuals do together (Larkin 2015).

- Embodiment means that the feeling body is integrated with the thinking mind. Scientific knowledge and human compassion are given equal status and the importance of emotion and feeling in ethical action is valued. Embodiment refers to the knowledge that people live within a specific historical and social context which shapes their understanding and response to the world around them (Larkin 2015). To understand illness from a resident’s view point, factual knowledge is not enough, a subjective awareness of that illness – the feelings this illness brings to the patient, is also required (Larkin 2015). Relational ethics argues that this understanding is achieved through a narrative where personal stories enable care staff to better understand the aspects of illness that are hard to express and not easily known.

- Environment expands the concept of the relational space beyond the individual level and explores the web of relations that connect the individual to the health care system, the community.

The category of ethos of caring and sub categories of enabling residents to live well, promoting choice and expressing spirituality resonate strongly with mutual respect described by Bergum and Dossetor (2005).

The first, mutual respect will be compared to ethos of caring for its similarities and differences. Mutual respect has been identified as the central theme of a relational ethic. It is described as interactive and reciprocal process, with an emphasis on respect for and acceptance of difference. In coming to mutual respect, there is a need to be both respectful of others and also respectful of oneself. Mutual respect means that people take others into themselves and give to others in reciprocity. In doing this they understand each other in the social context of how they live together. Instead of thinking “I think therefore I am”, a suggested alternative way of thinking is “I am because of you”, or “I am because we are” (Bergum & Dossetor 2005 p 53). This view demonstrates that a person exists in the context of relationships with others.

Mutual respect has strong resonance with the concept of ethos of caring. When comparing mutual respect to the concept of ethos of caring, mutual respect was
evident where staff, managers, residents and relatives, lived in a community
where opportunity and choice to grow and develop were available. Managers
enabled staff to support one another when a resident was dying, they listened to
their concerns and helped carry out tasks concerned with a dying resident. Staff
supported one another when caring for a resident who was dying.

The concept of an ethos of caring compares well to mutual respect where care
staff helped residents choose their preferred way to live and to die. ‘Promoting
choice’ and helping residents ‘express their spirituality’ contributed to an ethos of
caring when someone was dying. Many participant nurses had spent years with
residents over the course of their lives in residential care, enabling residents to
choose their preferred way of living, respecting resident routines, choices and how
they lived their lives. Staff paid attention to the detail of a residents’ life through
knowing their life story, and had understanding what was important to them at the
end of their lives. For example, when a nurse tactfully tried to establish from a
resident how they would like their final days, they would approach the resident
sensitively, knowing the most appropriate time to broach the subject, revisit it, or
defer the conversation about end of life care to another time. Mutual respect is
about knowing when to talk about end of life care choices and how to sensitively
address it. Where nurses are being attentive to ‘the other’, the resident, it creates a
relational space for unconditional regard between two people which consequently
forms a connection between the other and the self (Bergum and Dossetor 2005).

Mutual respect was evident where staff supported residents to live well during
their lives in residential care, enabling them to choose to live their preferred way
of life. Staff supported relatives and residents during the time of a residents’
death by paying attention to the details, for example having religious item left
nearby, encouraging families to be present or having prayers said if preferred.

The concept of ethos of caring is similar to mutual respect in with the way nurses
looked after residents when they were dying, showing support to relatives through
caring conversations and caring actions to guide them during the death of a
resident. The concept of ethos of caring in the ToDWTR highlights that
relationships specific to each resident was based on an approach underpinned by
mutual respect between residents their relatives and healthcare personnel. Staff
communicated with residents and their families in friendly ways to encourage relationships that would enable residents to live well, and sustain them at the time of their death.

Where managers and staff could not support one another, there was an absence of mutual respect. For example, the concept of enabling resident to live well happened when there were adequate numbers of skilled staff to carry out care duties to facilitate this. Staff felt disempowered when they felt had not adequate numbers of staff to deliver care they perceived to enable residents to live well, and die well in residential care.

Mutual respect was absent when relationships were perceived as ‘controlling’ by staff and this did not depict an ethos of caring. Staff described a previous management style as controlling, and this had a negative effect on relationships between staff, managers and residents and consequently, dying well. Relatives felt uncomfortable and unsure of how to engage with their resident relative if staff were distant and not communicating well with them. Resident participants described taking time to get to know staff, to be able to feel comfortable with visiting their resident relative. Relatives wanted to be able to engage with the community of residential care home and see their resident relative engage in the community of residential care. Where there was an absence of mutual respect, residents felt they had little choice or control in their way of living, and felt they had to reluctantly accept their new lives in the community of residential care. Where the ethos of caring was not based mutual respect, ‘dying well’ was hindered. Mutual respect extends our understanding of what is important in identifying the elements that contribute to dying well. If participants felt that they were not respected, they had a negative experience of relationships within the care home and this impacted negatively on dying. Participants who experienced mutual respect, engaged well in the community of residential care, and consequently, were sustained by their relationship and could experience a good death.
Several sub-categories impacted on the category of the ethos of caring (Figure 5.3), which were as follows; enabling residents to live well, promoting choice, and expressing spirituality.

![Figure 5.3: Category of Ethos of Caring and sub categories of enabling residents to live well, promoting choice and expressing spirituality](image)

The sub-category of *enabling residents to live well* describes how managers and staff participants helped residents live meaningful lives in residential care. Manager participants described how they hoped that residents could continue living in a community where residents’ interests were maintained by care staff, and that their families and friends could visit them when they wanted.

Manager participants promoted an open-awareness for staff participants about death and dying. One manager describes below how practice had changed over time, from an ethos of a closed awareness of death to an open awareness and involvement. This open awareness is described as having a positive impact on dying well.

*Manager:* “But they [the residents] came in the front door and they leave by the front door. And "death" is an extension of life, and we, staff, and some of the relatives, stopped hiding it, you know, one time, we used to pull the curtains around the resident
who was dying and we didn’t talk about it, and they [deceased resident] left the back door. Whereas now, you know, others [residents and their relatives] are popping in and out to see if someone is dying, yeah, and it’s nice, you see, because, other residents and sometimes staff, well they say a prayer, and chat and shake the Holy Water. We had a nice death, now last week in X Ward, now a lovely death of a lady who has been here for many years had died. And now like that, her friends, which were mainly the other residents that shared a big room with the others, they held her hand, and said their prayers and shook holy water and all of that”.

(Manager 12-Care Home B)

Relative participants described a caring ethos when staff spent time with them while their relative was dying. Nurse participants showed an ethos of caring by spending time with families, having caring conversations and bringing tea to relative participants. Relative participants valued having friendly staff to talk to. The following describes one of the ways this occurred.

Relative: “The next thing the tea arrived for us, and the staff stayed there with us for a while. Talking to us and just spending time with us, they were so nice. We knew all the staff, and on the final night, my nephew was there, his mother, the nurse and the assistant. One of the nurses came in and we were having a good chat. There are a few staff there you can have talk to, and even the care staff, not just the nurses”.

(Relative 23 Care Home B)

An open-awareness of death also involved staff caring for one another. Care staff participants demonstrated an ethos of caring when they showed kindness towards one another at the death of a resident. Staff participants tried to be aware of other staffs’ feelings when caring for a resident who was dying. Staff participants described that they could feel attached to residents as some residents lived in the participating care homes for periods of up to five or ten years. A nurse participant
reported that if a colleague had a personal bereavement, it was important to be
cognisant of their feelings around the time of a resident’s death. A caring ethos
meant that nurse participants coordinated work to support a colleague cope with
her personal loss. Nurse participants were mindful of the feelings of other staff,
relatives, and residents at a time when a resident was dying. The following
describes a nurse’s view on caring for staff when a resident was approaching
death.

Nurse: “You need to be mindful of other staff, everybody’s attitude
towards death is different, and it depends on how the staff are as
well on the day when someone is dying. Like, I mean you could be
working with staff who has lost somebody to them recently, you
know, and it depends, you just have to coordinate [the duty] and
facilitate the whole thing differently, taking into account their
feelings at the time. And you’ve got to be mindful of other staff
members as well that they may be very attached to that resident as
well; they might have looked after him for 5 or 10 years. And
equally somebody of the team may have lost someone quiet close to
them. It’s very important to take into consideration how other
people are feeling around the time of someone dying, staff,
relatives as well as the resident themselves. And that needs to be
facilitated and coordinated in the right way. There is a right way
and a not so right way, meaning, you can ignore it [death] and
upset people if it [death] is ignored”.

(Staff 36-Care Home C)

A manager participant described an-uncaring ethos as controlling and
disempowering and as having a ‘power over’ staff and residents within in the care
home. This had a negative impact on residents and one nurse participant used the
metaphor of ‘they’d kick the dog and the dog would kick the cat’ to emphasise the
effect of a cruel management style. She described the relief she felt when that kind
of era died out and a new manager valued an ethos of caring and unkind
behaviour was not tolerated.
Manager: “There was a time, I don't know, there was a certain amount of oppression or something or that kind of a negative tone...maybe an oppression, maybe that’s a very strong word too. It would be a ‘power-over’, that kind of a word a ‘power over’, authoritative, and I think the [some people] had it in their day, a definite power-over, power language, and then they’ kicked the cat or they’d [managers] kick the dog and the dog would kick the cat’, and the lower down you were, the next down the hierarchy ladder, they earned from that, and there were given the authority to use the ‘power-over’ the next and it was always used. It used to bother me terribly, but then kind of that era died out and that a lovely, lovely director XX came in, and couldn’t bear anyone to say anything wrong to any patient, the person would love to bring them all home with them! [laughs]. He was a lovely, lovely person. If you said anything wrong now, [the new manager] she’d 'sack' you! [the new manager]. We couldn’t tolerate that sort of thing at all now”.

(Manager 8-Care Home B)

Another nurse participant felt there was an un-caring ethos when her manager did not enquire how her team felt were after the recent death of a resident.

Interviewer: “Would your manager ask you if you were OK after a resident died”?

Staff: “Ah, no, not really, she’s not here usually, no, she wouldn’t be here, she wouldn’t really ask, you see with nights...She wouldn’t come around that much anyway.

(Staff 38-Care Home C)

Nurse participants valued a caring ethos, which they reported facilitated resident centred relationships between staff, relatives and residents. Staff valued promoting choice and expressing spirituality. These sub-concepts underpinned a caring ethos and helped residents live and die well in residential care.
The term ethos means the character or disposition of a community, and is the dominant assumption of a person, people or period. It is considered the underlying sentiment that informs the beliefs, customs, or practices of a group or society (Collins online dictionary (www.collinsdictionary.com)). The current use and meaning of the word in many organisations represents the fundamental character or spirit of a culture of an organisation which in this study can be described as caring and inclusive, or, in contrast, controlling and unfriendly.

In nursing, ethos is a set of values perceived to exist within the nursing profession that develops in individuals over time. Nurse managers have been reported to be central to the quality of life of older adults, as they shaped the ethos of care within the facilities (Murphy, 2007, Murphy et al. 2006). For example, delivering holistic care, has been reported by patients and professionals alike as being important to the ‘ethos of nursing’ which involved putting patients at the centre of care, and focusing as much on patient need as on tasks (Rapport et al. 2013). A caring ethos is regarded as central to the nursing profession and to the individual nurse’s role (Kitson 1987, Leininger 1988, Kyle, 1995, Bradshaw 1996, McCance et al. 1997, Mackintosh 2000, Rapport et al. 2013).

An organisation’s ethos of care can have a positive or a negative impact on the care given to dying residents. The ethos of care in an organisation is key to enhancing quality of life in residential care (Cooney et al. 2009). In a grounded study of 101 older people in 12 nursing home sites in Ireland, Cooney et al. (2009) identified factors such as ethos of care, a sense of self and identity, connectedness, social relationships and networks, and the availability of activities and therapies; all of which had an impact on quality of life for older people. These factors were further mediated by the older person’s ability to adapt, their previous life experiences and health status as well as environmental factors such as the physical and social environment.

Similarly, other researchers have also found that the ethos of an organisation can influence the delivery of quality care. This ethos may be influenced positively by several approaches such as, having a philosophy of care which
guides practice (Redfern & Norman 1999) and good ward leadership (Kitson 1991, Nazarro 1998, Bravo et al.1999). Several researchers have shown that residents’ autonomy was enhanced when they were involved in decision making, and where the residential unit operated a culture and atmosphere of flexibility within an ethos of maintaining resident dignity (McCormack & McCance 2006, Davies, Ellis & Laker 2000, Welford 2010). Kitson (1991) found that a lack of caring ethos was likely to impact negatively on quality care. Moreover, abusive or neglecting acts of care reflect an ethos that ignores the dignity of the individual (Rehnsfeldt 2014).

This study’s findings reveal that the organisations’ ethos of care emphasised resident centred relationships, and valued that residents should live well and die well in residential care. The ethos of care also extended to staff in their care for residents and each other. Where this was absent staff sought support. The findings in this study revealed that staffs’ ethos of caring towards residents and their relatives was evident had an impact on dying well.

The sub-category of enabling residents to live well describes the way that staff were involved with relatives to help residents live well and die well in residential care. This will be described in the following section.

5.2.1 Enabling residents to live well

The sub-category of enabling residents to live well is described in the way that staff were involved with residents to live well in residential care, which contributed to dying well. Enabling residents to live well allowed staff to engage with residents and their relatives, plan and discuss death with residents and relatives, and helped create an open awareness of death in residential care. In this study enabling residents to live well was a foundation for dying well, and several sub-categories needed to be in place for this.

The sub-categories of choosing a resident’s care home, knowing the person, involving the family, engaging the person, and developing relationships were essential to enabling residents to live well in the participating care homes.
Enabling residents to live well involved the first step of being able to choose their own residential care home when possible. Choosing the resident’s care home involved resident and family participants reaching the reality that it was time for the older person to go into residential care. In most facilities, residents were aware that admission to residential care was the final phase of their lives. Living well commenced from the time of the resident’s admission, and at the beginning of the relationship between the nurse and relative who helped them choose and settle into a nursing home. The following describes a relative’s account of what it was like to get her aunt and uncle into the same nursing home.

Relative: “So they [the older couple-prospective residents] found it difficult ... so I asked ‘Please, please, could you get them in here? [Care Home B]’ ... They could accept one of the couple first, but eventually they accepted the two. Thank God, the Manager [of Nursing Home B] here said ‘Yes, if you don’t mind putting them into a small room’. And I said, as long as they are here as a couple, because they are here now. And they [the manager and staff] helped to get them [residents] in here”.

(Relative 34- Care Home C).

Some residents described the inevitability of going into a nursing home, realising that they were unable to look after themselves in their own homes and understood that they would probably die in residential care. Resident participants did not talk about their own dying or death, instead, they referred to increased helplessness and frailty. They described choosing to go into a care home for many reasons, for example in the following vignette it is because the resident participant felt more helpless and frail.

Resident: “At my age, that makes it easy [to go into a nursing home], when you to choose to go there [to a nursing home]. It’s down the line, when you’re helpless and frail or careless. A helpless life, when you cannot manage or look after yourself.

(Resident 33-Care Home C)
Nurse participants felt that it was important to know the resident well, which enabled residents to live well and die well in residential care. Nurse participants also believed that involving relatives in care needs assessment at admission helped residents settle into care. Entering into residential care involved staff and relatives talking with one another to assess and establish residents’ preferred choices for living in residential care and care needs.

Relative participants felt it was important that their relative resident lived well in residential care and readily shared their knowledge of the resident with nurses during the admission process. Relative participants enjoyed visiting their resident relative. Relatives valued being able to visit and having friendly relationships with staff when they visited the care home. Nurses were concerned with the assessment of each resident which helped them to know the resident. With the help of relatives, nurses attained holistic knowledge about each resident which helped residents choose the way they wanted to live in residential care.

*Nurse:* “The fact that we know them [residents] very well, from when they came in first, we’d have years really where we would know the resident initially, and I suppose their family as well. I suppose when a resident comes into us, they might not be able to express themselves, then, we would have to depend on their family for more information”.

(Nurse 13 Care Home B)

Involving the family in care was important in enabling residents to live well, and it meant that relatives were often knowledgeable about residents’ interests and their social lives, which they shared with nurses. The constancy of nurses’ engagement with residents and relatives over a prolonged time enhanced nurses’ understanding of residents’ needs and fostered relationships with their relatives. Nurse participants drew their knowledge of residents over time and tried to help them live well, even though residents often had declining health. The following describes how nurses got to know and understand residents in residential care.

*Nurse:* “Well, I suppose over a long time, you know, we’re getting to know them, it’s when we are caring for them, we are constantly
engaging with residents, or whoever is in their family. And when their illness is getting worse, we are there to a certain degree, recovering them, rehabilitating them to a certain level of independence. I’m not saying we are able to get them fully independent, but we can help them overcome some of their problems, I would like to think that residents here could have good fun when they settle in a bit”.

(Nurse 13- Care Home B)

One nurse participant described that living well in residential care commenced at admission and it developed from good relationships between residents, relatives and staff:

_Nurse: “I think from the very beginning, [admission] you know, relationships are very important between residents and nurses, because, right from the start, when you know their first names, they can get to know yours and you can talk to them. When we understand them from their families, about them more, and if they [resident] are in a state of confusion, you can help them to understand what’s going on.”_

(Nurse 2-Care Home A)

These vignettes highlight the complex but subtle interactions between residents. It is necessary to develop this type of knowledge and understanding to ensure that all parties experience compassionate relationship-centred care (Dewar & Nolan 2013). End of life care, especially in residential care, is about living fully in close relationships with other residents until death and consequently, nurses have a responsibility to focus on relationships with residents, their relative within their practice and philosophy. This is similar to the ethos of caring where staff and relatives, through their relationships with each other, enabled residents to live well in residential care, promote choice and facilitate them to express their spirituality.

Nurses and relative participants communicated with residents at different levels, through conversations, and by getting to know residents’ personal care
preferences and social interests. Nurses were often the first person the resident and relative got to know in residential care. Nurses got to know residents and their families from the time of admission until residents’ deaths, and they were the constant person throughout the resident’s living and dying trajectory in residential care. Resident participants described how important it was for them to maintain strong connections to their families and outside communities, and that families were made welcome by staff when they visited. It was important to them that relatives were free to come and go freely as if it was the residents’ home. One relative participant explained that he could walk straight into their relative’s room as opposed to seeking access through staff.

Relative: “It was grand, his own room. Well yes it did make a difference being in his own room, but he was in the same room for the past three years. We knew his room and we walked straight into it, whenever we visited. He like that and liked us to come in and see what was going one and tell our news”.

(Relative 23 – Care Home B)

Engaging with the person was important to enable residents to live well in residential care. There was strong evidence of staff engaging with residents from the frequent site visits conducted by the researcher. These visits provided an opportunity to observe how staff engaged with residents. Staff and resident participants were friendly to one another and the atmosphere in the care homes was warm and welcoming. In various places within the care homes, staff participated with residents with a variety of social activities, including music, reading newspapers or listening to residents’ conversations. Resident participants appeared to enjoy relaxed and friendly relationships with staff. Some residents were involved in purposeful tasks such as folding napkins, setting the dining table, watering flowers, wiping down tables or looking after a pet dog. Other residents looked forward to regular visits from the local priest, the care home manager or other visitors from the local town. Some residents enjoyed going to Mass, while others did not want to go. Several residents did not like group activities, however, they still enjoyed being in the same room as the activity. Other residents enjoyed group activities and looked forward to events like arts and crafts and traditional
music sessions, Mass and Day-Care, which provided them an opportunity to meet former neighbours and friends.

When residents were no longer able to engage in group activities, staff participants were sensitive to this and adjusted the activity appropriately to a resident’s interest or ability. In one nursing home, the activity therapist could see residents becoming weaker and noticed their declining interests in scheduled activities.

*Therapist:* “This lady [resident] had a lot of knowledge about everything; she travelled and loved to talk. And now she has gone downhill mentally and physically as well as that she has stopped eating, more or less, and that’s a sign that she doesn’t want to get involved anymore and I needed to change my activity with her and when she is able to be interested in something.. I am doing something more sensory with her now and she seems to enjoy that a bit better”.

(Staff 36-Care Home C)

Many older people in residential care settings have several chronic conditions such as diabetes, heart disease or musculoskeletal and psychological diseases. In these cases it is often difficult to ascertain if they are approaching death (Lynn and Adamson 2003, Murray *et al.* 2005). In residential care, residents are more frequently concerned with living rather than dying, and most of their concerns with living are described as wanting to be recognised as a person, to have a choice and be in control, to be connected to their families and the outside world, and be spiritually connected and physically comforted (Strohbuecker *et al.* 2011). When residents discuss death and dying, they prefer to have a comfortable death and to be made aware of another person’s death in the nursing home so that they could pray for them (Strohbuecker *et al.* 2011). In this study (Strohbuecker *et al.* 2011), residents were chiefly concerned with living well day-to-day and engaging with their relatives being present with them in their environment which is similar to the findings of this study.
Residents’ care plans were examined as documentary evidence of the social activities that residents participated in. There was sufficient evidence gathered in residents’ care plans to provide detailed information about the person to enable a personalised activity record for all residents. There were adequate activity assessment records that showed that there were planned activities to match residents’ interests and abilities. Residents’ care plans described a variety of interests that residents enjoyed. On a daily basis, there were a variety of activities planned in the participating residential care homes. Social activity relevant to residents was key in enabling residents to live well in residential care.

*Enabling residents to live well* acknowledges the strong relationships between staff and relative participants and they strove to be involved with residents to help them to live well and die well while in residential care. One nurse participant explained that she wanted to keep residents as interactive in their community as long as possible and that her knowledge of a resident developed from residents and relatives and being with them.

*Nurse*: “I suppose really... you get to know the family and then and we try and keep the person [resident] as interactive as possible, for as long as possible, and, as independent as possible too. And as mobile as possible, and really as the condition progresses, ahm, you still have a knowing of what they are all about as a person from their careplan and their families, and from being with them”

(Nurse 15-Care Home B).
engaging in socially productive activities is one of the important determinants of successful ageing (Rowe & Kahn 1997) and productive ageing (Morrow-Howell et al. 2001, Burr et al. 2002). Older persons involvement in stimulating activities and interactions with others create a sense of community among them. There are six types of social engagement activities levels (Levasseur et al. 2010) ranging from proximal to distal involvement with others: (i) doing an activity in preparation for connecting with others, (ii) being with others, (iii) interacting with others without doing a specific activity, (iv) doing an activity with others, (v) helping others, and (vi) contributing to society. Many of these were evident in this study, such as, being involved, or choosing not to be involved in group activities like arts and crafts, music and going to Mass and Day Care. Therefore, maintaining socially active involvement between the older person’s outside community and residential care community helps an older person contribute to others and society. The social activities refer to staying connected (Richard et al. 2008, Register & Herman 2010), civic engagement (Burr et al. 2002), and being involved in religious activities (Cnaan et al. 2008, Taylor et al. 2009). Productive engagement provides the opportunities for an enhanced feeling of usefulness, better health and well-being, successful ageing, and ultimately improved quality of life (Thanakwang & Isaramalai 2013). In this study, this was evident when residents participated in activities like folding napkins and watering indoor plants.

Going into long stay residential care is a major life event for many older people. The choice of going into long stay care is often precipitated by older peoples’ anxieties for their health status and for some, the potential for accidental serious injury or the event of their own death if they continue to remain at home (Lee et al. 2002). Older age has been conceptualised as a social construction, labelled a ‘third age’ (Laslett 1989), and described as a time of extended consumerism, opportunity and activity in later life. Rowe and Kahn (1989) further explain this as successful older adults who demonstrate a low probability of disease or disease-related disability and who possess high cognitive and physical functional capacity and continue active engagement with life (Rowe and Kahn, 1998, p. 433). In contrast to this, Baltes & Smith (2002) refer to a ‘fourth age’, with contrasting and different characteristics, at approximately aged 85 and older and as a phase of life where there is a loss of agency and bodily self-control and is
often linked to frailty. Furthermore, Jones & Higgs, (2010) mention that the ‘fourth age’ is a terminal place from which there is no escape, nowhere to go other than death (Jones & Higgs, 2010). This is a social construction, and it appears to be a major risk factor for human dignity (Baltes & Smith, 2002, p.3). Maintaining the dignity of older people is key to person centred care, who are vulnerable to loss of personhood due to cognitive decline and or institutionalisation. This is a key element of person centred care and it is suggested that by adopting this approach, the life and the value of the older person becomes central (Dewing 2004). Promoting dignity, respect and autonomy is central to person centred care (Epp 2003, Welford 2010), along with incorporating knowledge of the values of the individual who is the centre of the care process (McCormack & McCance 2010).

In residential care, frailty has been synonymous with the dwindling slow dying trajectory of many older people (Markel, Reed and Browne 2003, Lynn & Adamson 2003). This trajectory is described as gradual and unpredictable and encompasses multiple health problems which have accumulated over time. At some undefined stage, the person enters the dying phase, which can be described as a fluid process. This social construction of identities, such as the dying phase and late old age are conceptualised as liminal (Hockey and James 2003). Liminality is a transitional point between social structures, which allows for the potential of redefinition of self -identity (Turner 1974). This is reflected in the findings of this study, where residents were reflective of their movement from home to residential care and acknowledged that while they would live there for a time, their health declined and they would eventually die there.

Section summary

This section highlighted the sub-category of enabling residents to live well. Enabling residents to live well in residential care included the sub-categories of choosing the residents’ care home, knowing the person, involving families in care, engaging with the person, and developing relationships. These sub-categories inter-link with each other to enable residents live well.
Living well was a foundation to dying well and residents needed to be able to choose to live in residential care. Resident participants needed to be involved in the social life of the community in the residential care home. Living well had a strong emphasis on understanding the person. Enabling residents to live well was based on strong relationships which allowed staff to engage with residents and their relatives, to plan and discuss death with residents and relatives, and further develop an open awareness of death that was likely to occur in residential care. The following section will discuss the sub-category of *promoting choice* for residents in residential care.

### 5.2.2 Promoting Choice

The sub-category of '*promoting choice*' focused on the extent to which participants were able to choose their care preferences. It describes how resident participants could choose how they liked to spend their lives in residential care home.

Staff were key in promoting residents’ choice which helped residents to live the type of lives they wanted to. *Promoting choice* enabled residents to *live well* and consequently *die well*. By focusing on what the person choose in residential care, set the platform for the implementation of their choices around end of life. In order to promote choice, staff needed to assess residents to understand their interests and their end of life preferences.

In promoting residents’ choices, staff participants asked residents what their care preferences were, what they would like to do and actively helped residents to choose and live their choices.

Managers considered *promoting residents' choice* as an important concern which underpinned a *caring ethos*. Residents who exercised personal choices felt that they were at the centre of care and reported that management staff listened to them and had a strong interest in their well-being, and this was valued by residents. The following account from a resident depicts this.

*Resident*: “You know I am getting on the finest here. And I do go out and in and out. And I’m getting the best of care and the best of
attention from everyone and the best of everything. And if I want anything all I have to do is shout anything... like that’s what I’m saying like. You wouldn’t meet friendlier, or nicer, nicer staff you know. And even the Matron herself, that’s Marie, she comes in there herself fairly often you know and ask ‘how’re you getting on? and ‘how are you keeping?’ and go off again’.

(Resident 08 - Care Home B)

Resident participant care preference was demonstrated when nurse participants helped residents pursue their interests to get involved in the activities and community life in the care home. Staff participants explained that although long stay care was associated with end of life care, residents could also choose to do things to help them enjoy life and pursue ongoing interests while in care. Where residents were able to choose and implement their care preferences, this gave them a sense of well-being which was an important for dying well. The following vignette emphasises a manager’s perspective about residents choosing to participate in the community life and activities of the care home.

Manager: “For an older person here, I don’t think end of life care begins when they come here...they [residents] realise the great life they can have here, and they stop thinking about ‘I’m dying’ bit. You know, and they are quite happy to stay and they start choosing to going on outings and doing different activity things here, and they like, ‘park’ the dying bit”

(Manager 12- Care Home B)

Another resident made it clear where he preferred to spend the last days of his life, and chose the residential care home he had settled into rather than be in his previous home:

Resident: “There’s no way I’d go back to the way I was living, I wouldn’t even have a new house. If there was a new house in the town there for you, I wouldn’t have it. No, I’ll choose here, I’ll stay here, thank you very much, everything’s’ grand here”.

(Resident 8-Care Home B)
In one care home a resident described that he could choose what time he liked to get up at and what he choose for breakfast.

*Resident: I don’t get up until 9 or 9.30 AM. Some of them [residents] are up earlier, but I don’t stir until about 9.30. Then I go for a bit of breakfast. I only like porridge, you can have anything you like, I don’t like anything heavy, just the porridge, it keeps me going. I don’t do much then after that, sit in my usual spot, look at them [staff] working, I might have a chat with one or two of them, I don’t do much after that.*

Resident 01- Care Home A

Residents’ care preferences included a variety of activities which appealed to them. Promoting choice involved staff assessing what residents liked. The following describes when an activity therapist chose certain activities to suit residents’ preferences which encouraged conversations around their interests.

*Activity Therapist: “With them, the residents, depending on what I’m doing, but talking to them, and getting them to talk about what they might have done. If say, I was knitting, I would say, “Did you used to knit?” and they might say, “Oh yeah, I used to knit hats or cardigans”, or whatever, and that sort of thing. And that applies to any creative thing I might be doing. I remember once, I was making potato prints, [laughs] there were 2 sisters, one was 96 and the other one was 98 and she was absolutely disgusted because I was using potato, because it was food. They talked so much about it because they were horrified that I was using potato and they would have been born in what 1911 and seen the food rationing”.*

(Activity Therapist - Care Home C).

Another resident liked to join in some activities, but preferred to have the company of another resident.

*Resident: “I don’t like being on my own too much, and, you see, some days I might decide to join in the things going on in the*
sitting room, painting and all that. There could be music, or just a
general chat or something; I usually go in if Monica [resident] is
in there. Sometimes I just fold up the table napkins for the staff.
You know it just passes the time nicely”.

(Resident 20-Care Home B)

Being able to choose what to do and who to spend time with was essential to
helping residents live well and die well in participating care homes. When
residents’ relatives could not choose for their resident, they felt that choice was
restrictive which did not help residents to live well or die well in residential care.
In the following vignette, a relative describes feeling frustrated by regulations
which she felt was preventing her from exercising her or her dying husband’s
choice.

Relative: “Well you see that’s just it, all these the regulations!
[angry]. Well, I came back in again and I brought in diced
chicken from home. You see, he has lost a lot of weight and his
haemoglobin is very low. But, you see, I wasn’t allowed to bring
him in food, you see it is a stupid, vicious circle of nonsense [the
regulations] As far as I’m concerned [laughs and shakes her
head] you see its very important to me. People say you can’t do
this, you don’t do that, and you can’t go into the kitchen, Hello!
that’s bullshit. You know, that’s the stuff I’m talking about, that’s
the stuff that needs to be addressed”.

(Relative 28-Care Home C)

Staff participants needed to understand relatives’ frustrations to be sensitive to
relatives’ worries. The conditions for promoting choice occurred when staff
helped relatives participate with residents’ care. This meant that relatives and
residents felt that they were at the centre of care and that management listened to
them, and supported them in their choices and care preferences.

In the literature, promoting choice is closely connected to quality of life in
residential care homes. Cooney et al. (2009) emphasised that where residents
could exercise their choice regarding how they spent their day, their quality of life
was enhanced. When residents felt they had a choice, they felt that this helped them feel at home and they could live their lives as usual.

The concept of quality of life has both subjective and objective elements (Bowling et al. 2003). The subjective elements of QOL include a sense of well-being, perceived happiness, and life satisfaction (Haas 1999, Smith 2000). Objective elements include independence, social activity and perceived choice and control over life (Bowling et al. 2003). Several researchers have found that autonomy, choice and control, the social and physical environment, and meaningful activities are important determinants of residents’ quality of life, (Ball et al. 2000, Edwards et al. 2003, Murphy et al. 2007). Several features of quality of life have been identified as important, namely, autonomy, individuality, dignity, privacy, enjoyment, meaningful activity, relationships, security, comfort, spiritual well being, and functional competence (Keane 2003b, Keane et al.2003). Although literature on quality of life is described as complex and is frequently difficult to define and measure, it links in with the organisation’s ethos of quality of care (Hopkinson et al. 2003, Clarke & Ross 2006, Murphy et al. 2007). The interactions of nursing home staff with residents powerfully determines residents’ perceptions of quality of life (Saliba and Schenelle 2002). This resonates strongly with the findings of this present study, and relationships between residents, staff and relatives were observed by the researcher to be professional yet friendly and relaxed.

Being able exercise choice nearer to the time of death was important for residents. For residents to die well they wanted to have a choice over aspects of their care prior to death and after death. For example, nurse participants helped residents in choosing what to wear at the time of death. This was important in helping residents die well. One manager described how a resident wanted to wear a special outfit when she died;

Manager: “There was a lady that was in the Legion of Mary for years and she had her habit [shroud] and it came in her with her and she had it, oh I’d say 15 years here. You know, we would air it and take it out and think, it’s lovely and admire it. ...Oh we’d have
great chats about it, and what she’d wear when the time [death] came. We had it washed and cleaned, we were afraid it could get dilapidated or disintegrated after 20 years and being in that organisation [Legion of Mary]. To get this habit and be laid out in it was important to her [with the image of Our Lady on the front] in preparation of their deaths, so when it [death] comes, they want to wear it, so they have to establish, so that we’d know when they’d say ‘when I die, I want this on’, and you know we would adhere to that”.

(Manager 5- Care Home B).

Staff spoke to residents about what they would like to choose nearer their time of death. One relative explained how he spoke to a manager about having to make a decision about his mothers’ living will in her final months

Interviewer: kind of planning was involved, like, was there a living will?

Relative: Well no not really, we had spoken to Marie before she became forgetful, and you see, she never wanted any operations or anything big like that when she got old. She is really in the later stages of dementia now, and can’t make up her own mind, well really, she doesn’t understand anything now or what the outcome is of any course of action.

Interviewer: So how do you get around that?

Relative: Well we didn't do much about it really, the discussion came up with one of the nurses when he was first admitted to [Care Home C] about what would we like about resuscitation. Marie [Resident] didn’t understand, well I said, she, or we wanted that [resuscitation], because if anything happened, I just couldn’t let her go. But it didn’t work like that, so, when she got worse and went into the acute hospital, while she was for cardiac resuscitation, she went for surgery, she didn’t want a big operation. So, it was a dilemma really, should she have a big
operation or should he not. I didn’t know really. I was confused really, not knowing which course of action to take, to go between the care home and hospitals for long term treatments or to keep her as comfortable as possible. So finally, after a lot of soul searching, the comfort route seemed the most comfortable, or most honourable to my mothers’ life. It wasn’t easy you know, it was the worst time of my life.

Relative 34 Care Home C

Relative participants also enabled residents choose where they wanted to die;

I must say when he was moved in here, to this home, before, he was in the Acute hospital, when he was very bad, but he didn’t want to stay there, too busy you see, when they discharged him out, it was just like coming home, [going to the nursing home].

(Relative 34 Care Home C)

Nurse: In order to put that (end of life care) in place there does need to be planning, and I think planning involves if anyways at all being able to put into somebody’s care plan when they are able to tell you how they would like things to go. And then if they are not able or it hasn’t been discussed with them, then there needs to be a meeting between the resident if they are able, the GP, between the nursing team, the resident of course being the most important and what they want and then the family of the resident. And from there formulate a plan moving forward, that everybody is happy with and that everybody can move on with. To ensure their comfort and dignity is maintained.

(Nurse 35-Care Home B)

In summary, promoting choice is concerned with enabling residents live well and choose their care preferences in residential care. Care staff enabled residents to live well by first assessing their care needs and preferences and facilitating them to live as independently as they could while in care. Relative participants also helped residents make choices with regard to where they wanted to die. The
following section describes the sub-category of expressing spirituality and how residents did this.

### 5.2.3 Expressing spirituality

The sub-category, ‘expressing spirituality’, was an important aspect of *living well* and *dying well* in residential care. For residents, expressing spirituality was an awareness of their spirituality and the meaning they placed on their religious beliefs and the role played in the use of prayers. For nurse participants, expressing spirituality was revealed in their participation in prayers at the time of a resident’s death and their acknowledgment of the importance of rituals to residents and relatives at the time of death.

Residents expressed values such as *living right*, and attending mass, which they believed to be important before death. Residents and relatives spoke about their faith providing spiritual support to them.

*Resident:* “You wouldn’t want to be in sin, you mightn’t want to meet Him [God] in sin. It is very important, you know, there’s a lot who are the author of their own misfortune...I do think so. If you’re fairly right with the Man up above [God], you’ll be alright when you meet Him, because, you want to live right and be right living, you have to be fairly right. Well that’s the truth now”

(Resident 9- Care Home B).

*Resident:* “I’ll tell you, I go to mass every morning, not every morning, just 3 mornings a week. I told her [the nurse] that I’d pray for her, say a decade of the Rosary for her seeing as she was so kind and nice. She was all about me”

(Resident 7- Care Home B)

Nurses were acutely aware of residents’ need for spiritual care.

*Nurse:* “One of the most important things to an elderly person is when they are here is to see the priest, or the person of their denomination, you know what I mean, and to see that their spirituality needs are met is really important”
Prayer played an important role in expressing spirituality for residents. This was revealed both in the actual reciting of prayers and the meaning residents attached to the prayers.

Resident: “This is more important to me than anything, [pointing to her table and book shelf of prayer leaflets and prayer books]. This is more important. Sometimes there is a priest who comes in, but this is more important...there is a hymn, and the last line is, 'He leadeth me, He leadeth me beside the waters that run'...And look what I’ve ended up with [pointing out the window at the view outside her window]. And this is part of it, look at the view outside the window, the symbol of water, the symbol of peace, and there is peace”

(Resident 06 - Care Home 2).

The importance of prayer for residents is further revealed below in a resident’s recounting of her confrontation with death on a previous occasion and how she had prayed for a ‘happy death’.

Resident: “I say prayers to the Lord for a happy death, and I was in ICU twice, and twice I was on, a, oh, what do they call it when they give you the paddles [defibrillator used in Cardio-Pulmonary Resuscitation] Oh Yeah, oh Yeah, there were doing thing on me, the paddles. Yeah, and the second time I was up there I had an out of body experience, it was wonderful... Yeah, yeah, I was at such peace, peace... I wasn’t feeling everything around me”.

(Resident 4 - Care Home B)

Prayers were also important to relatives and nurses. When a resident was nearing death, nurses and relatives would join together in prayers.

Relative: The nurse stayed with us, after Bill [resident] died. We said the rosary ourselves, I’d say the nurses said it too before we arrived. It took us an hour to get there after we got the call...Yes it
was very peaceful, [the death of their resident relative] yes, and that is important.

(Relative 23- Care Home B)

Nurses also placed emphasis on the importance of being ‘available’ to join in prayers at the time of a resident’s death, even if they were ‘not a very religious person’.

Manager: “The Night sister would make herself available particularly if someone was dying, for two reasons, first to help out the ward for things to be done other residents and for the nurse on duty, and secondly to say a few prayers with them, the families of a resident who was dying. You see, they mightn’t be able to do it themselves. She’d always make sure there would be a cup of tea available for them and just really making them at home”.

(Manager 2- Care Home B)

Relative: “Yes they are all very good here, even though the lady [manager] who was on wouldn’t have been a very religious person, I think she still said a few prayers with us and I thought that was nice”.

(Relative 34 – Care Home C)

One nurse participant was not Roman Catholic, however she too joined in the praying at the time of a resident’s death (praying in her own faith and language).

Interviewer: When everyone was in the room together, did someone say the prayers for the dying? Who did this?

Nurse: The Health Care Attendant, they weren’t saying them too loud, they were doing it, but, I didn’t do it. I dint do it, because, because, I’m not Catholic and I don’t say these prayers, so I just said prayers in my own language, in my mind.

(Nurse 28-Care Home C)
The nurse participants clearly acknowledged the importance of religion to residents’ living well and dying well.

*Nurse:* “Most of our community here are Catholic, they were brought up in that era where religion was foremost and it was expected of you to go to the masses, ceremony, it was very much to the fore...But I think understanding what your faith holds for yourself, and to the other person, that you [the staff nurse] wouldn’t be lording it over everyone, because you know if a resident has fallen away from religion or not, and religion may not be as important to them now as it was, and to respect that”.

(Nurse 15 –Care Home B).

*Manager:* “They are very mindful of people’s religions here, residents are a spiritual people. One time we had all Catholics, but now we have many different religious persuasions here. You know, we have Church of Ireland, Church of England, and we have reverend who support their faith. We are very spiritual here because we used to have Mass every single day, now we have it four days a week. And every three months we have it on the residents’ wards. And all the residents get the Sacrament of the Sick every three months”.

(Manager 12-Care Home B)

A complex relationship exists between spirituality and religion, where spirituality is individual, and religion is perceived as an organised faith system, beliefs, worship, religious rituals and a relationship with a divine being (Rumbold 2003, Sinclair 2006, Reid 2014). Reid (2014) explored theories related to the development of spirituality and its relationship to end of life circumstances with older people. She found that religion was strongly connected with some established tradition of common beliefs and practices concerning the sacred, and more significantly, beliefs about life after death. Religion could be practiced alone or privately, but it was more frequently organised and practiced within a community (Reid 2014). In contrast, spirituality was considered more an
individual concept. Spirituality was not usually associated with rules associated with religion and it was a very personal, and typically something that people defined for themselves. It is related to transcendence, trying to connect with something intangible (Reid 2014).

Chochinov (2006) describes spirituality as a dynamic process which evolves over time, often triggered in the context of serious illness, a challenge, or by confrontation with death which challenges one’s belief system (Vachon et al. 2009).

In the context of these findings spirituality and religion often overlap. The UK’s National Health Service (NHS) recognises that spiritual care is care that people look for when faced with major life upheaval such as, trauma, ill health or sadness. Spirituality can include the need for meaning, for self-worth, to be able to express oneself, and for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging a human connection in compassionate relationships, and can support the needs of the person in whatever direction required” (NHS Education for Scotland, 2009). The findings presented in this current study support this definition. The use of prayer and sacrament were particularly evident in the care homes. In addition, nursing activities in the field of spiritual expression aims to focus on the resident to find meaning in their lives and to support religious and cultural needs (Tornoe, Danolt, Kvigne and Sorlie 2014).

Puchalski, (2006) acknowledged how spiritual values can help people build resilience to their situation, handle adversity and cope with illness and suffering. This was evident in the findings of this study. Levin (2002) also explained that spirituality was an invisible factor in health and indicated that people who had spiritual and/or religious affiliations and participation, demonstrated the highest levels of psychological well-being (over all other factors such as health or financial wealth), and had lower levels of depression or chronic anxiety, irrespective of their state of health. Furthermore, Davey (2009), who based her studies with older people in New Zealand noted that spirituality was understood and expressed in different ways. In her study, several participants saw it in the natural world and others looked inwards to themselves, their ethics, values and
behaviour, for their source. Social relationships with their friends, immediate and extended families was also found to represent spirituality (Davey 2009). She also noted that older respondents were more likely to place importance on spirituality in their lives than younger ones, and women more so than men. The present study’s findings correspond with the literature, in that spirituality and religion are often factors that positively affects the older person’s adjustment to later life (Koenig, Smiley & Gonzales 1988).

Religion and expressing spirituality are often regarded as a central focus of life for an older person as they serve as a source of emotional strength, comfort and inspiration during difficult times. Prayer was used more frequently among older adults than in other age groups (Levin & Taylor, 1997). Several studies have reported a significant association between participation in religious activities and morale, happiness, usefulness and quality of life (Blazer & Palmore 1976, Ellison & Gay 1990, Gallagher 2008).

Many studies attempted to examine the effects of religion on older people’s physical and mental health. Attendance at religious services has been positively correlated with older peoples’ health status and functional capacity (Mull, Cox & Sullivan 1987, Gallagher 2008). At end of life, Holstein & Minkler, (2003) suggest that spirituality is a core human concern at the time of death, and at such a time it as is important to meet the spiritual needs as meeting physical needs. The traditional emphasis on the physical needs, or physical state, of elderly or terminally ill people, has at times denied people the dignity of continuing to struggle to accept a situation, such as dying (Holstein & Minkler 2003). Furthermore, to address this, Sulmasy (2002) points out that holistic care should consider and meet the needs of patients as whole persons acknowledging their spiritual needs as well as their more obvious physical, psychological and social needs (Sulmasy, 2002). Spirituality can include the tradition and ritual of religion but frequently transcends religiosity (Reid 2014). Spirituality is a pattern of feelings, responses, and behaviour, usually with strong cultural roots, that gives life meaning and purpose (Jernigan, 2001). Koenig (2002) noted the importance of addressing the spiritual needs of people during the final days of their lives and noted that religious beliefs and practices could be an important resource for
coping with illness especially with terminal illness. He found that people with faith allowed people to “give up their need to control and instead to trust that God will control their circumstances, based on God’s love and wisdom and unique knowledge of their circumstances (Koenig 2002, p. 20). Older people’s resilience to the effects of a devastating events in their personal lives and the ability to return to coping after such adversity is strongly related to levels of meaningfulness in older people lives especially of meaningfulness comes from high levels of religious or spiritual beliefs (Felten & Hall 2001, Reid 2014). Resilience was noted in older frail people where there was faith or spiritual beliefs and where people had social connectedness and personal resources such as a previous spiritual grounding in their lives (Felten and Hall 2001, Kinsel 2005)

This study’s findings show that death and dying is not solely about physical death demonstrating that there is strong spiritual component. Abbas and Panjwani (2008) explain that while death may be physical, it is also an holistic event with a spiritual dimension at its core. This finding in this study highlighted that spirituality or religion played an important part in the lives on residents and living in residential care and to their dying. Many residents lived a spiritual life which sustained them throughout their lives and deaths in residential care.

The subcategory ‘expressing spirituality’ has been shown in several diverse ways from the way residents live and how they chose to live their lives, how they pray and how they participate in rituals in the care homes. Prayer was important to resident, relatives and nurse participants, especially in the end of life care rituals nearing the time of death.

**Section summary**

The category of ethos of caring consisted of the sub categories of enabling residents to live well, promoting choice, and expressing spirituality. This theoretical concept emerged from participants’ data and is compared to the literature and contributes to the emergence of a core category which aids the development of a substantive theory.
5.3 Category-Organsing Care

The category of *organising care* describes how work was organised around residents’ lives and their deaths in residential care. *Organising care* was an essential category in facilitating resident relationships and *dying well* in the participating residential care homes. Organising care around living well and dying well involved planning and managing residents’ personal and social care needs. Staff ensured that residents had their own personal items around them, that their room was comfortable, and that their health symptoms were treated and managed. In organising care, staff also administered medications and related therapeutic programmes of treatment.

For nurse participants *organising care* shaped how work was carried out by all staff and impacted on dying well. The category of organising care affected how staff assessed and planned their care around residents’ care needs and preferences. For resident participants, they described *organising care* as having their needs met and being able to enjoy the things they liked to do. The following figure illustrates the category of organising care and sub categories of planning and coordinating care (Figure 5.4).

**Figure 5.4: Category of Organising Care and Sub Categories of Planning and Recording Care**
For manager participants, the sub category of planning care for a dying resident meant, liaising with the multidisciplinary team, specialists in palliative care, and organising the availability of single room accommodation with comfortable furniture to support the family and the dying relative.

Manager: “When the end is near, we have to organise that things are right, you know, staff levels, skilled people, and to have a palliative care room upstairs and it is a beautiful suite, and there is a family room just attached to it with beautiful reclining chairs and the family can just stay there. The mattresses... the new mattress, so now, we now have a mattress that turns the person, nice things like that which have made such a difference in their quality of life at their [residents] end, so that you’re not hurting them. We have the palliative care specialists that come, in. We have that lovely room which gives us time, and the families like it too, it means so much to them”.

(Manager 3-Care Home B)

Nurse participants felt that organising the wider team in managing the symptoms of dying residents was important. Sometimes this meant that residents could stay on residential care for their final days rather than be moved to an acute hospital for further care.

Nurse: “We try to keep them as pain free and as comfortable as possible...we would just really have the doctor here, as such, ahm, the Occupational Therapist and the physio really if they were chesty, or something like that but, and the specialist palliative care support.

(Nurse 13- Care Home B)

5.3.1 Planning Care

Planning care was a sub-category of organising care. It involved nurse participants planning care around residents’ needs during the dying phase. It also
involved discussions with families of residents. For resident participants, planning occurred with families and nurses from the time they were admitted.

_Nurse_: “I suppose really, when some [residents] come in, they’re really at the end of the dementia stage...so, you get to know the family and then and you kind of keep them as interactive as possible, plan things with them for as long as possible. And really as the condition progresses, they become less able to make any decisions about dying, but, ahm, you still have a kind of a knowing of what they are all about as a person from their careplan and their families, from being with them”.

(Nurse 15-Care Home B).

Some nurse participants expressed difficulties with assessing residents’ end of life preferences. Therefore, planning and recording dying care preferences were difficult to achieve. Consequently, implementing a plan was difficult if there was none in place.

_Manager_: “A lot of the nurses have difficulty with the concept themselves [end of life] so they find it hard to ask questions that they don’t want to be asked themselves, so they won’t ask it to the residents either. So what I have been saying to the nurse is, some of the non-controversial or non-laden questions in the Careplan [Document] on that sheet of ‘end of life care’ could be asked and you could show the page without having to say anything. And leave it at that, and if people are volunteering more information well and good”.

(Manager 12- Care Home A)

Manager participants realised the difficulty staff experienced in discussing residents’ end of life care.

_Manager_: “It’s not an easy question, you know. It’s not a direct question you ask, you know, like, “what are your plans.”? It just doesn’t work like that”
Some relative participants also preferred not talking about planning end of life care. However, making after death choices was important for relative participants and residents, for example, burial arrangements, and this contributed to dying well. One relative described that although she and her husband had nothing arranged about the funeral, she remarked that there was an awareness of which graveyard the resident would be buried in.

(Int): “Have you any arrangements or plans made for Mark?
Relative: “No, there’s nothing arranged [with the funeral director]
No, or written, no, nothing.
(Int): Is that the way you want it, like it?
Relative: Mark will stay here until the Lord takes him, and, then he’ll go to our local graveyard. After that, I’ll probably be gone. That’s the way I like it. And after, that I be taken out home (to the local graveyard), and that’s it”.

While residential care homes are places where dying and end-of-life care is provided, providing good end of life care involves overcoming various challenges for residents and staff such as advance care planning (ACP). This is a process with discussion between an individual and carers (relative, nurse, and physician) to ensure that the individual’s wishes and preferences are known (Heide 2014, Mullick, Martin & Sallnow 2013). The practice and legal framework of advanced care planning varies between countries and is interpreted differently, but often includes repeated discussions with relatives, nurses and physicians; appointment of a substitute decision maker; and use of written advance directives. Advanced care directive is a document that describes one’s future preferences for medical treatment in anticipation of a time when one is unable to express these preferences because of illness or injury (Roth 2014). However, in the context of this present study care planning was centred on residents’ preferences for living day to day with an awareness of dying and death.
Several definitions of advanced care planning have been offered, as follows: In Ireland, advanced care planning is referred to as a process of discussion and reflection about goals, values and preferences for future treatment in the context of an anticipated deterioration in the patient’s condition with loss of capacity to make decisions and communicate these to others (RCPI. 2014). This process may lead to the formulation of an advance healthcare directive, an advance decision to refuse treatment or to the appointment of a decision-making assistant to help interpret a person’s advance preferences (McCarthy et al. 2011).

Advanced care planning has been explained as a process of discussion between an individual and their care provider, whatever their discipline and if the individual requests, it can be their family and friends that may be included.” (Holman & Hockley 2010). Mullick et al. (2013) describes advance care planning (ACP) as something which aims to help patients establish decisions about their future care that may occur when they lose capacity. It is a process of discussion between an individual and their care provider, may also include family and friends (Thomas & Lobo 2011), and is a voluntary process of discussions and reviews to help an individual who has capacity to anticipate how their condition may affect them in the future. If they wish, they can set on record choices or decisions about their care and treatment so that these can then be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses. Advanced care planning has three possible outcomes: a verbal or written advance statement of wishes and feelings, beliefs and values; a verbal or written advance decision to refuse treatment, (must be written with specific requirements if refusing life-sustaining treatment); an enduring power of attorney (NHS England Your Life-Your Choice). In Ireland, the Power of attorney is a legal device that can be set up by a person (the donor) during his/her life when he/she is in good mental health. It allows another specially appointed person (the attorney) to take actions on the donor’s behalf if he/she is absent, abroad or incapacitated through illness. (Government of Ireland, Powers of Attorney Act 1996 A)

Advance care planning is the process of discussions between the resident and their carers about future medical, social, emotional and spiritual preferences, in the
event that the person cannot speak for him/herself due to serious illness or emergency (Irish Hospice Foundation 2010).

The use of advanced care planning has a positive influence on the quality of end-of-life care (Brinkman-Stoppelenburg, Rietjens and van der Heide, 2014).

Unfortunately, advanced care planning is not yet widely used in nursing homes, and decision-making in end-of-life care may therefore lead to conflicts between the staff and relatives (Dreyer, Førde and Nortvedt 2012). In this present study participants did not use advanced care directives. However, in residents’ care plans, there were records of residents’ future preferences for medical/hospital care in anticipation of a time when a resident is unable to express these preferences because of deteriorating health, illness or injury. In addition, end of life care preferences were recorded in residents’ care plans which is a nursing document used to record individual plans of care for each resident.

Nurse participants described how residents were not always ready to talk about death or the end of their lives. There was dissonance between what nurses believed should be in a resident’s care plan and what residents could talk about with nurses. Although there was an open awareness of death there was tension with some nurses, residents and relatives, who still found the topic of dying difficult to discuss and were unsure of how or when to broach the subject with a resident or relative. Some nurses denied that relatives talked about their care preferences at the end of their lives.

*Interviewer: “Do they [residents] ever talk about their own death, or what they want at the end?*

*Nurse: No not really, not too many. I suppose there are a few that possibly would, but not so many have done so that I’m aware of”.*

(Nurse 29-Care Home C)

Nursing staff are often reluctant to discuss death with older people in residential care settings (Wadensten Condén, Wahlund, Murray 2007, Fрогgart, Vaughan, Bernard, Wild 2009). Some people do not feel comfortable discussing issues associated with end-of-life care which may be explained by the traditional taboo
surrounding death and dying. When older people living in physical decline were asked what gave them hope, comfort and strength during their illnesses, they responded, that they appreciated being asked about what sustained theme during a challenging time (Koenig 2001). Ternstedt & Franklin (2006) noted in their study on the views of older people in nursing homes, that resident participants were uncomfortable with discussing dying, however, many spoke about their deaths as being inevitable and sometimes welcome, if not to end their suffering but to cease being a burden to their families and spouses, (Ternstedt & Franklin 2006). However, Holloway (2007) points out that death is no longer a taboo subject and as a society, there is an increased acceptance of discussions death and dying. Regardless of whether there is a taboo about death, dying is an important societal event and the death of a resident is an important event as everybody’s death matters to somebody.

End of life conversations are based on death and dying, and several researchers have described that their study participants had clear ideas of having a good or bad death, (Broom and Cavenaught 2010, Seymour 2010, Gott, Small, Barnes et al. 2008, Steinhauser 2000). These conversations included aspects such as the palliation of symptoms, decisions regarding care planning and preferred place of death to achieve a good death. All of the aforementioned studies took into account individual care preferences, values, cultural and religious practices and beliefs which are becoming more important to people as they are faced with advancing age and physical decline (HIQA 2008). Evidence of this is contained in many national initiatives (HIQA 2008, Irish Hospice Foundation 2010).

In this study, residents preferred to talk about living rather than their death alone. Residents described having witnessed the deaths of others, experiencing their own physical decline, their reduced independence, and that they were aware that their decline was likely to worsen. These findings are consistent with Clarke Korocheno and Bundon (2012) who noted in their study on the way older people with chronic conditions talk and prepare for death and dying, found that older people did not describe an awareness of a good or bad death but that they wished that their deaths be quick and free from prolonged suffering. Expressing a desire not to suffer, some participants in this study, such as residents, or residents
relatives, attempted to exercise a measure of control in the form of planning their deaths through discussion, arranging their wills, and recording plans in their care-plans. This contrasts to Kelner’s (1995) study whose participants articulated a strong will to be in charge of their end of life health care decisions, and have the power and means to hasten their deaths.

In the National Quality Standards for Residential Care Settings for Older People in Ireland-End of Life care requirements, HIQA (2008) point out that residents should be given opportunities to engage in advanced planning but should not be placed under undue pressure if they choose not to engage. Furthermore, each resident should have appropriate information to make informed decisions and supported by someone who understands the complexities of the process as well as the clinical implications of the decisions. Discussions around death and dying should be proactive to provide timely access to safe and efficient care to meet the individualised needs and preferences of residents approaching end of life.

Advance care planning offers several benefits, which include facilitating the coordination of multidisciplinary teams working across acute, secondary and primary care services. The second advantage to having residents’ end of life care plans recorded is that the emotional distress and other pressures inherent in situations where a resident is approaching death can sometimes lead to misunderstandings. However, this can usually be avoided through early, sensitive discussion and planning about how best to manage the resident’s care (HIQA 2008, General Medical Council 2010, HSE National Consent Policy (2015)) These regulatory guidance indicators are at odds with the present study’s findings. Staff were trying to achieve good end of life care, however, they lacked formal training on care plan recording and conversations around dying and end of life care.

5.3.2 Recording care

The sub category of recording care provided to residents was important to nurse participants. Relative participants were also aware of the necessary discussion and documentation required for end of life care. Staff participants described the importance of documenting dying care preferences in a resident’s care plan.
Speech and Language Therapist: “I think here, definitely, their needs are listened to and acted on, if they are verbal and cognitively able, definitely the nursing staff will be listening regularly and it’s all documented in their careplan, usually. When it comes to a person with severe cognitive difficulties like end stage dementia, the families will be heavily involved in the discussions and decision making”

(Speech and language Therapist – Care Home B)

Nursing documentation and care planning dates back to the 1970’s and involves nurses documenting a resident’s assessment, plan of care, implementation and an evaluation of the nurse’s plan (Mason 1999). In the 1970’s nursing careplans were documents that emphasised the promise of the written care plan as a means of promoting continuity of care and sharing of information about patient needs with all clinical team members (Kelly 1966). Care plans are designed to provide an organised framework for planning, delivering and evaluating nursing care (Karshmer 1991). They provide a medium of communication between teams and a record of care given (Griffith-Kennedy & Christensen 1986). One study found that care plans have little influence on patient outcomes, (Henry et al. 1994) but are probably more influential on care processes (Norris et al. 1990). More recently, Taunton et al. (2004) examined how the Resident Assessment Instrument was used in the assessment and planning documentation for residents in three nursing homes and described the care planning process used. They found that the care-planning process and residential care home approach to the resident assessment instruments process were linked. Residential care homes differed in how much they involved direct caregivers in the care-planning process. The researchers reported that some staff believed that they knew what to do in providing care to residents without looking residents’ plan of care. This theme of the working staff’s lack of belief in the instrumental value of the care plan is reminiscent of the descriptive writing of nurses in the 1970s. Dellefield (2006) asserts there is a need to find ways to integrate the care-planning process and the written plan of care into the daily operations of residential care units and to
involve nursing and health care staff. Completion of the care-plan document has become the unique responsibility of nurses, and the interdisciplinary team, with usually apparently little physician involvement (Hawes et al. 1997; Institute of Medicine, 1986). The integration of an interdisciplinary care plan into the daily activity of a residential care home, or implementing the written care plan, is difficult work, and nurses require sufficient time to accomplish this work (Dellefield, 2006). This challenge was evident in this present study’s findings. Nurses explained that they were familiarising themselves to the new care plan format and simultaneously expressed competing time demands with direct resident care. In this study, the care plans recorded assessments which addressed residents’ care preferences and choices. This facilitated both living well and dying well with care preferences for further treatment in the event of them becoming unwell recorded. Nursing documentation is a mandatory and essential part of nursing care which contributes to better communication and continuity of care among health care professionals (NMBI 2002, Nursing and Midwifery Council 2010). A more recent study carried out in residential care settings in Ireland, noted that the care plan represented a written record of the individual resident’s nursing plan and that care plans facilitated nurses to review individual residents with a view to planning for emerging needs, anticipatory care and also goals for addressing residents’ needs (Phelan and McCormack 2013). In 2010, the Nursing & Midwifery Planning and Development Unit (NMPDU), in conjunction with HSE, Dublin Mid-Leinster (DML) Services for Older Persons published an evidence based document which outlined a minimum dataset and support documentation and assessment tools for use in residential care settings. The aim of the DML Careplan was to provide nurses working in residential care with a comprehensive range of evidence based tools to support them in all aspects of resident assessment and care planning. This new care plan format was introduced to all residential care homes in this study. Although training was in place for nurses to gain confidence with the layout of the care plan, some remained uncomfortable with talking about death and dying care preferences. This finding is similar to that reported by Travis et al. (2004) who noted that incomplete resident assessments and planning for end of life care have been reported to be
either not attempted or not completed comprehensively in long stay care (Travis et al. (2004).

In conclusion, the category of organising care has described how care was organised with staff participants and other team members. Staff participants worked to plan care around dying residents’ care needs and preferences at the end of their lives. Documenting care was considered important to nurse participants, however death and dying were often difficult subjects to talk about with residents and consequently recording discussions on death and dying was also difficult.

5.4 Category- A caring environment

The category of a caring environment describes the sub categories of the macro and micro environmental factors that shaped the living and dying environments for residents, staff and relatives. For nurse participants, it was important to create a caring environment for residents, living or dying, in shared or single room accommodation. For residents, a caring environment was the space where they could socialise with each other, their relatives and staff.

The macro environment was the structure and design of the residential care home, both inside and outside and included the spaces residents lived in and the surrounding outside areas. It included the involvement of the outside community who interacted with residents, relatives and staff. In this study, the sub-categories of macro environment focused on the community where the resident came from and the community that interacted with the residential home.

The micro environment revealed the space where residents’ lived and how they shared their time and space with other residents, relatives and staff. This space was significant for living well and dying well for resident participants and their families. This space could be their bed area, where their personal items were kept or the ward and corridor where their room was located. The micro environment reflected the design of the rooms and was the space where living and dying took place. The category of a caring environment with the sub categories of macro environment and micro-environment are depicted in Figure 5.5.
The dimensions of the environment can be considered both macro and micro (DoH, UK 2008), and this view applies in particular to this present study. The following components of a macro-environment are considered important; location of a residential care home close to transport or urban area to improve accessibility for families, availability of parking, a pleasant environment to live in, familiarity with staff and the care and kindness to be shown by all care staff (DoH, UK 2008).

5.4.1 Macro environment

The sub-category of the macro-environment describes the outer world context of the residential care unit. It describes how the residential care home fitted in the context of the local community and the relationships between the care home and community. Participating care homes were located in the outer area of towns, which rendered them accessible for residents and relatives. There were strong connections between participating care home residents and the local community. Relatives were aware of a time when a residential care home was not a comfortable environment for its occupants.

*Relative: “It had a work house history, it was not a very comforting thought to come here, you know, we didn’t want to*
come here when we were younger. This place, you know, was not a nice place to go to”.

(Relative 34- Care Home C)

However, buildings purposes changed over time and perceptions changed, and residents enjoyed the buildings proximity to the local town.

Resident: “I can go to town once a week, come and go as I please”

(Resident 8- Care Home B)

Resident: “I used to go to the mart in the town when I was a bit stronger, now some of them come to me to see me”.

(Resident 9- Care Home B)

One relative spoke about living near a participating care home, which meant that she could cycle every day to visit her husband.

Relative: “Well depending on the weather, I can come here on a bicycle, otherwise, if it’s wet I get a taxi”.

(Relative 21- Care Home B)

Participants valued the strong connections with the local community. Staff and residents mentioned the deliberate strategies that were adopted to maintain connections with the outside community.

Manager: “Yes, we have open shows in this nursing home, our residents participate actively in the Local Towns’ annual Arts Show, during arts week. So, we had exhibitions here, and we had a performance of singing and music groups so that people from outside are invited to come in here, and we have a few things like that during the year, depending on the season, or the occasion”.

(Manager 3- Care Home C)

Resident: “She’d [receptionist] bring up the newspaper too. I enjoy the newspaper, reading, I’d read anything, the free newspaper and the daily one. Have to read the sport page on a Monday after all the football or hurling on a Sunday. You know,
the deaths too, the deaths. Hard to believe, so many are gone. If I don’t get to hear them on the radio, I’ll look at them on the paper”.

(Resident 7-Care Home B)

5.4.2 Micro-environment

The sub-category of *micro environment* referred to the areas within the care home where residents lived. Resident participants described that they did not mind living with other residents. Some Residents described liking their bed area whether it was living with other residents or alone in their own room.

*Resident:* “I was on the ground floor [shared area], under the window in the old building, when I went there first, they used to pull a curtain across... We didn’t mind where we were. There were six beds where we were, like three beds here and three beds there. We’re all together here now and we have our own rooms, I do like it here better”.

(Resident 8-Care Home B)

It is well recognised that the environment influences the behaviour and interaction between people. Stimuli such as lighting, colour shades, odours space and furniture can have a positive or negative effect on people. Staff can at times manage the visual and audio environment of residential care homes by adjusting the lighting, background noise, keeping quiet conversations, and arranging seating in relaxed and well lit rooms can encourage conversations (Tolson & McIntosh 1997). Many nursing homes have tried to provide more domestic type settings by building smaller residential units and/or providing single rooms in which the occupants can have their personal belongings around them (Peace *et al.* 1997). The common living rooms and hallways tend to be more colourful and are furnished like residents’ own homes. In some care homes, staff have changed their uniforms from hospital-like outfits to more homely ways of dressing to promote a sense of homeliness (Peace *et al.* 1997). Irish legislation outlines that residents’ rooms should be of a suitable size and layout for the needs of residents (Government of Ireland 2007).
Cook and Clarke (2010) explored strategies that staff could adopt in their daily practice to support social interaction in care homes. They identified the INTERACT framework which would provide a guide to long stay residential care home staff to consider to promote social interactions. The framework comprises of 8 aspects that can be identified and planned to support social interaction. These aspects are: (1) individualise the type and quality of social interaction, (2) notice the quiet withdrawn residents, (3) time to talk, (4) environmental conditions, (5) recognise and support relationships, (6) assess individual problems and action plan, (7) create the care home community, (8) use technologies to support interaction. This framework has relevance to this study as it the potential to enhance the social interaction between those living, working and visiting residential care and can contribute to residents’ sense of well-being (Cook & Clark 2010).

In this study staff attempted to create a home like interior for residents with the aid of furniture and equipment. One participating residential care home had only single room occupancy, while the two other participating homes had mostly shared room occupancy, although they had a single room available to them for when a resident was dying. Living in a single or a shared room in a residential care environment has been associated with privacy as well as being a place where people live together and establish fellowship (Douglas 1991, Gullestad 1992). For older people, living in their own homes represents their ability to maintain the home and is a powerful symbol of independence (Thorsen 1990). Several studies have established the views of old people towards their homes, and all have the following assumptions; that the home is a private space; the resident has the power to control this private space; the home is the predominant space for personal relationships; with people who are close (family and/or friends); the home has a strong symbolic power (Sixsmith 1990, Thorsen 1990, Gurney & Means 1993, Zingmark et al. 1995, Hammer 1999). It is important for managers to achieve a home-like environment in residential care for residents which impacts positively on older people living there (Cooney, Murphy and O’Shea 2008). In their study on quality of life, Cooney, et al (2008) found that the organisation’s ethos of care, sense of self and the importance connectedness and meaningful
activity contributed to residents’ quality of life. It has also been shown that single rooms improve interaction with family members and contribute positively to physician–patient communication (Van de Glind 2008). However, single rooms may also present challenges, such as isolation, additional cost, and fewer opportunities for surveillance of patients leading to greater falls risk (Rigg 2013). Furthermore there remains unclear evidence underpinning the increasing move towards single-bedded rooms for older people (Van de Glind et al. 2008). In this present study, although many participants shared their room with other residents, individual bed areas were private to a resident. The staff and residents were observed respecting residents’ own spaces by seeking permission prior to accessing a resident’s space. In this present study, residents who lived in shared accommodation were confident about their defined space in the multi-occupancy ward, and displayed their personal belongings on the furniture beside them. Their space was their own personal area which was private to them and other people in the room respected it.

Staff participants purposefully helped visiting relatives to feel at home.

* Catering Staff: “We had anything the relatives from England wanted. Tea, a place to sleep over, I showed them where the toilets were. We tried to make them feel at home from home. I mean, the dining room and furniture is all well laid out [like home] and we even have that old sideboard that used to be here in the old days, it’s still very good, that makes the place nice. Visitors often say how nice the side-board is. They don’t realise how old it is really”.

(Catering staff- Care Home C)

The micro environment meant that some residents could live well in either a single room or in a share room. However, sharing a room with other residents was not living well for some.

* Resident: “Oh, absolutely, absolutely, I prefer to sleep on my own. I do, you know, all that carry on last night, coughing, wheezing, and all of that, getting in and out of bed. That sort of thing, the
disturbance, it upsets the other person, in another room where there are more people in it. They might have a curtain around but that’s not enough for noises. The disturbance, the disturbance, they cause. You have to think of other people like”.

(Resident 3-Care Home A)

Nurse participants preferred shared room accommodation and described the camaraderie that existed between residents especially as some held the view that noises in the ward were sometimes comforting and familiar and reassuring to residents. Some relatives and residents enjoyed being in the same room together.

*Nurse: “ I think we got over it, you know, when I think about it, and they [the residents] got used to all those noises, it was probably familiar to them and it was involvement for them too…it had its own advantages. You know it’s lovely to have the relatives in the same room, and they can sit with them [the resident] for as long as they like and drink tea and whatever…. We had twelve beds now in the main ward below, when you think of the other eleven, and if there is one person dying, whether she is conscious or unconscious; she could hear all the noise going on. And they knew our voices, which could be reassuring to an old person; the staff always remain the same”.

(Nurse 13-Care Home B)

Whether residents lived in single rooms or shared rooms, nurses tried to make the micro-environment a pleasant and comfortable living environment for residents and relatives.

*Nurse: “You see, we see the bigger picture of what their wishes are, you see we have made an effort to make their rooms nice, the sitting rooms cozy and put in some country things into them...It might look like a nursing home but inside we try and make it softer and more cozy”

(Nurse 14-Care Home B)

In this study, relative participants preferred the open plan ward where nurses could see a group of residents together in one area.
Relative: “Well, I think this is a lovely nursing home, but I think it’s really wasted, there is so much in it. It was better when the beds were around each other, and they had the nurses’ office in the center and if someone was getting unwell, going to die, they were near the office and could be seen and be looked after”.

Relative 23 Care Home B

Several staff participants also preferred the open plan ward and surmised that residents felt lonely in single rooms.

Care Attendant: “The single rooms are lovely, but it was much better in shared rooms, everyone knew everyone. Everyone would join in like, and when someone was dying, and like, and after, at a funeral, they said the prayers together. This was better for older people, they knew what was going on, and the single rooms are lonely”.

(Care Attendant 19- Care Home B)

Care staff’s views of the environment were both positive and negative in this study. Several staff participants preferred the shared room accommodation. From the residents’ perspective, many preferred single room accommodation as some felt they could have quietness at night. In this study, the environment influenced relationships between residents and relatives and staff, and offered a way to socialise or provide solitude for participants. In a recent survey to establish older patients’ views on staying in a single or shared room (Reid et al. 2014), it was reported that the location of single rooms on the ward affected the level of patient satisfaction and loneliness. They noted that older patients living in single rooms with frequent passers-by and who had a good view onto the main ward corridor did not feel as lonely as patients who were in a room at the end of the ward, with fewer passers-by, and described greater feelings of isolation. Contrary to the perception that patients may feel isolated in single rooms, a field study conducted by Hauge (2008) of residents’ perceptions of daily life in shared living rooms, found that there was a forced relationship between the residents in common living
areas. Consequently, residents with the best health resources withdrew from the common area to control both where and with whom they wished to spend their time. This is relevant in this study because it indicates that residents can prefer their ‘own company’ for personal quiet and solitude rather than being placed in shared accommodation.

The micro-environment was important for dying well. Nurse participants clearly acknowledged the importance of a caring environment for a resident at the time of dying. Staff participants aimed to modify the dying environment by changing the atmosphere in the micro environment. This was achieved by using dimmed lighting, reducing the noise levels on the ward, and facilitating the presence of people with the dying resident.

Nurse: “We try to help the families, usually to understand that an old person has lived their life and they don’t want to see them suffer, and want to see them dying in a peaceful manner like that and want to see them in a nice place, new equipment and nice furniture, surrounded by their families and nurses are involved and ah, it gives everybody comfort and solace”.

(Nurse 15-Care Home B)

The dying environment is often the time that families remember most when confronted with the death of a relative. The environment is especially important to residents and their families when death is imminent. However, much of the existing literature suggests that the environment influences residents’ lives in complex and various ways. There is a potentially supporting effect of an aesthetic sensory environment in hospital surroundings which can contribute to strengthen patients’ experiences of well-being, positive mood, dignity and feeling of safety (Wikström 2000; Martinsen 2001, 2005; Ellingson 2007, Edvardson et al. 2005, 2006). Todres et al. (2009) also noted that patients’ personal experiences of the architecture of space can be conducive to privacy, dignity, homeliness and hopefulness. Martinsen (2001, 2005) suggested that sensory impressions in the hospital rooms with their variations of form, colours and decoration contribute to patients’ experiences of life courage, feeling of safety and being in a positive
mood. In this study nurse participants revealed that a calm environment for a resident nearing the time of dying helped relatives and staff and had a positive effect on residents and their relatives. Waldrop (2009) noted that comfort care is holistic and person-centered focusing on the interrelationship between physical, psychosocial, and spiritual issues. She found that comfort care comprised of the interrelationship between symptom management (e.g., pain, dyspnoea, anorexia, and dry mouth), and family care (e.g. emotional support, death education). It also involved the interpersonal relationships (e.g., with residents, family) and, combined with interdisciplinary teams (Waldrop 2009).

Kayser-Jones (2003) investigated the physical environment and organisational factors that influenced the process of providing care to terminally ill nursing home residents. She found that the physical environment was not conducive to end-of-life care. The rooms were crowded, there was little privacy, and the facilities were noisy. Inadequate staffing and lack of supervision were among the most significant organisational factors that influenced care. Although the study was conducted in only two residential care units, she contended that the physical environment was not conducive to end-of-life care. A lack of supplies may give the impression that residents are not valued, and a noisy environment detracts from the respect and dignity that residents and their families want and deserve. The researcher felt that the televisions were often playing for the entertainment of the staff rather than for the benefit of the residents.

Although there has been limited research undertaken exploring the physical environment in care settings where people are dying, it is a significant factor that must be considered. Some hospitals create a home-like environment on palliative care units (Milbank Memorial Fund, 2000). It is recommended that a separate unit should be available for residents who are terminally ill, where the philosophy of palliative care can be implemented, which could provide the space and quiet atmosphere that residents and families desire (Kayser-Jones 2003).

Within the micro environment of a dying resident, nurse participants placed importance on letting other residents know about the death of resident, especially if the resident was known by a group of other residents in the care home.
Nurse: “Well first of all, I told them [the other residents] because there is only a curtain between them and if it [dying] has been going on for so long, you must remember at this stage, they don’t know if they [the dying resident] are dead or not. And I said to them that “I don’t know if you know, but, such and such passed away last night”.

(Nurse 35- Care Home C)

Nurses used their expertise to make someone comfortable and enable a good death.

Nurse: “You know in my observation, you know the last time somebody died here, she was a good age, ninety-six years when she was passing away. And you know she was very peaceful, very happy, because a lot of the family were there, and they spent the last few days and hours with her. In the last few days, we met the GP and the family, and they didn’t want her moving to the emergency room, no, they knew, that she was fading away. She only needed a little bit of analgesia, in the end. We met a couple of times with the palliative care too and they said she was comfortable, like she hadn’t any distressing symptoms, a little draw on her breath, but we kept her comfortable. She was peaceful, you know not in any pain and comfortable, with her family around her”.

(Nurse 16 care Home B)

Some residents felt that they were not prepared for death or to witness the death of another person.

Resident: “There were four beds in it. I’m there was a good while, am and ah, there was about five, am, there was one man after a week or two, he was there for a long time and he died. I used to put up with it, you know, just put up with it.

Interviewer: “Were you there that time, when he died”?

Resident: “I was, I was, I was in the very same room, you see, you see there was curtains pulled across, screens, pulled across, that’s it, I usen’t be watching him at all, I used to turn the other way in
the bed you know, no passing any heed, so I took no notice of him anyway, much. Later, I’d go out in the evenings when his visitors would come in. Ahm, Ahm, just so that they’d have their time. He wasn’t well for a long time”.

(Resident 1 - Care Home A)

Staff participants felt that dying in a shared room could have a positive effect on other residents.

Manager: “A resident was in a shared room and when another resident died, and she thought to herself, ‘so that is how the staff here regards someone when they die, and I [resident] feel safe that the staff can be so nice’. So, for the alive resident, she learned a lot by looking at it! .... It was very positive for the resident to see how nurses treated the death of another old person it was an eye-opener for her [resident]”

(Manager 30 - Care Home C)

The category of a caring environment was a contributing factor to dying well in this study. Staff were key in providing a caring environment which supported dying and resident centred relationships. One participating residential care homes had single rooms accommodation for its residents and, two residential care homes were predominantly multi-occupancy shared accommodation. These two care homes did not meet the regulatory requirements (HIQA 2008) of providing single room occupancy for its residents. The third residential care home had all single room accommodation. Residents who had single rooms reported that they preferred single rooms than shared rooms. Residents who shared rooms with other residents described that they had to negotiate with other ward residents whether to remain on the ward or leave the room at periods of time throughout the day.

When the death of a resident was approaching, nurses reported that a calm environment, such as low background noise, soft furnishing in the interior design, and adjustable lighting, helped to provide a comfortable death.
Manager: “It was a very calming physical environment, I'm not sure what made it like that, but maybe because her daughter was holding her [dying resident] hand, rubbing her down, I’d say because they were there, and the presence of touch was important. She came in and sat with him for hours, all night, but it was an experience”

(Manager 5-Care Home B)

Staff participants valued the calmness associated with death and dying and felt it contributed to good end of life care:

Manager: “I like the serenity of it all now, you know the calmness, the niceness that comes with dying... And I think if the nurse is there she should stay with them as long as they can, and I think they [residents] like prayer”.

(Manager 12-Care Home B)

Nurses placed value on having a single room available to a resident who was dying which they felt helped the family. They preferred this type of dying environment to a shared room for a dying resident.

Nurse: “It is important to have a room where the family can be on their own with a resident at the end, because it is nice to have it quiet and to have too much noise going on around them. And it’s lovely for their family who can sit with them, and the family don’t feel as if they are interfering with other people, because it’s a very special time for the family”

(Nurse 13 Care Home B)

Privacy and dignity are closely related concepts associated to the environment of care in residential care homes (HIQA 2014, Hospice Friendly Foundation 2010). Several studies on privacy and control in nursing homes show that privacy can be a concern for managers and care givers in institutional care. The achievement of maintaining privacy in everyday contexts is limited (Nystrøm & Segesten 1994, Kane et al. 1997, De Veer & Kerkstra 2001, Boyle 2004, McColgan 2005).
However, single rooms are one approach to providing privacy and dignity (Pennington 2013). The Hospice Friendly Hospitals Programme (2012) (Quality Standards for end of life care in hospitals) outline in Standard 1.5 that the hospital environment should take into account design and dignity guidelines for physical environments supporting end of life care to preserve dignity and privacy. In residential care homes, this is achieved by providing adequate space for each resident. Dignity consists of the two aspects of human dignity and social dignity. Human dignity is an intrinsic and inseparable value of each individual, and cannot be measured or compared and it is an independent concept (Walsh 2002). Social dignity is a part of human dignity, and one of its consequences is the acknowledgment of the individual. Contrary to human dignity, it is situation-dependent, empirical, awardable, comparable and acquirable through social interactions (Walsh 2002). The opposite holds with not having dignity which is expressed as undignified and indignity, which mean insult and dishonour (Allmark 2002). In this present study, staff focused their care on maintaining residents’ privacy and dignity in care and particularly spoke about privacy and dignity when a resident was dying. Managers made arrangements to provide a single room to support the dying resident and their relatives.

This category of environment in this thesis compares to Bergum and Dossetor’s (2005) concept of environment which is the second component to underpin relational ethics and is relevant and similar to the category of a caring environment.

The category of environment in this study influences the macro and micro environment on personal choice. In relational ethics, environment means that the most important life decisions can only be made within a ‘web of relations’ (Bergum & Dossetor 2005:xiii). In other words, our right to make specific choices is not about ‘I’ alone, but about ‘I’ in our community. For example, living in care involves relationships with a community where older people live and staff work. Staff may have concerns about individuals’ decisions on the right to personal self-determination to cease a treatment. This illustrates society’s interest in what we do and therefore, personal autonomy is not so personal after all.
Benetar (2005) asserts that in order to foster social cohesion to benefit and progress the health of all peoples, there is a need to reconsider the relationship between the macro (the world at large in which we live and exist) and the micro (the things that determine who I am, my freedoms and choices).

This is similar to the categories used in the category of environment in this study and the interpretations and interactions the participants drew from living and dying in residential care. The environment is the micro environment of the residents’ living space and the macro environment is the context and location of the residential care home and the community it fits into. Although choice is important to promote, sometimes the environment in the context of the dying that makes choice difficult. Nurses described that the environment was frequently restrictive in delivering care to a resident who was dying in a busy ward. Where relatives and friends wanted to visit, and have their final moment with a resident, they sometimes described feeling uncomfortable with going into a room other residents. Nurses felt that the ward area was small and confined to facilitate increased numbers and frequency of visits by people and this affected other residents in the ward. Nurses balanced this with the dying resident’s preference to remain on the ward amongst the other residents with whom they may have lived and enjoyed a relationship with for a long time. However, they were aware of the impact it may have had on other residents sharing the environment, and other staff trying to carry out their workload. In shared ward areas, dying well, for one resident was negotiated by staff with other residents’ preferences. It was important for nurses to balance the needs of one resident with others.

Relationships and choice were discussed with staff, residents and relative. Sometimes residents were accepting of their environment and frequently did not complain. However, relatives were more vocal and tended to talk to staff about the perceived intrusion of their visiting a dying resident. Therefore, the environment influenced relationships and how a death impacted on the environment of care, the living spaces of residents and access of relatives to visit their resident relative who was dying.

While acute invasive care has opened up many choices for older people in residential care, it is important to consider whether at times, the acute intrusive
care distracts from the lived reality of human suffering. For example, if dying well for a resident means being asked to choose his or her end of life care preferences for active treatment and it results in transfer to and acute care setting for further tests or treatments, they might think that the environment may not make this an easy choice if the acute care centre, and the environment is over-crowded, loud and intrusive and to get there takes a two-hour travel journey by ambulance. Added to this is the possibility of waiting undefined hours in an emergency room for further care. Therefore, if we say to a resident that a decision is ‘your choice or preference’, the subtext is that it is not really. The ‘you’ is not about the individual but the ‘you’ as a part of a network of meaningful relations and that determines how and why decisions are made. The category of a caring environment highlighted that residents made choices based on the environment they were living in and it was contingent on the structures, and relationships they found themselves in.

In conclusion, this section highlighted that the category of a caring environment contributed to living well and dying well in residential care. In this study, a caring environment meant the micro and macro environments of residential care homes contributed to resident centred relationships. It emphasised the links participants maintained to the external community (macro-environment) and the relationship that residents, staff and relative had within the residential care home (micro-environment). Having a homely environment was important for residents. Nurse participants valued having a single room available for dying residents, which was important part of the micro-environment. The category of a caring environment meant that staff deliberately altered the dying environment to help residents and their relatives feel comforted during a resident’s dying phase.

5.5 Category- Resident centred relationships

The category of resident centred relationships describes the ways in which relationships developed between nurses, residents and relatives. The relationships between nurses, residents and relatives shaped the experience of dying in residential care. The category of resident centred relationships is inter-related with the three previous categories, ethos of caring, organising care and caring.
environment. The category of resident centred relationships sustained participants during the time of residents’ dying and death and impacted on dying in residential care homes. Resident centred relationships is described with two sub-categories, knowing the person and facilitating families, this is depicted in Figure 5.6.

![Figure 5.6: Resident centred relationships and sub categories of knowing the person and facilitating families](image)

### 5.5.1 Knowing the person

The sub category of knowing the person was intrinsic to resident centered relationships. Knowing the person was based on a staffs’ assessment of a resident which resulted in knowledge of residents’ care preferences and their social activities and personal interests also. Deliberate strategies were in place to enable resident centered relationships develop. Staff got to know and understand residents through their Life Story. This helped staff to gain a deeper knowledge of residents, which facilitated residents to live well and die well in residential care. Knowing the person began with an assessment of what was important in a resident’s life that would help them live well in residential care. Knowing what was important to residents contributed to developing a plan of care based on residents’ preferences. How care was organised around residents’ preferences facilitated staff to spend time with each resident, which enabled the formation of relationships.
Nurse: “You still have a kind of a knowing of what they are all about as the person, from their careplans, their families, from being with them over the years, you know. And then you just have a kind of knowing, a kind of what they want or what is important to them be it spiritual guidance, or what they would prefer, you know, the fact that they could have worked all their lives, or cared for families, or whatever they did, it’s all taken into account when we are preparing things for them while they’re here”.

Nurse 15 Care Home B

Staff interacted with residents while attending to their activities of daily living, providing personal care, bathing, helping at meal times and engaging with residents at social activities. Staff developed relationships with residents’ families and interacted with them on issues of care and family related issues. These relationships sustained both relatives and staff during the time of death, as conversations were based on their knowledge and understanding of the important aspects of residents’ lives. This affected the dying experience because relationship conversations at the time of death revolved around the awareness of a resident’s life and significant others.

The following vignette illustrates how the nurse got to know someone.

Nurse: “We find out from the families through our chats, over time what they [residents] would like, most families want, to be there with the resident at the end. And they give you their number so that you can contact them when you see a change in the resident’s health. You can ask them to come in night and day, and then, ahm, when the person is dying, once everything is set up, alter, lights, reduce the noise level, and everything set up, the patient is made comfortable. Everything you can do to make them comfortable, physically, is being done, and sometimes if we think it’s suitable, the prayers are started and they are left to be with the dying person, you know, then you leave it, a kind of in Gods’ hands, for the next thing to happen. You never know when the exact hour or minute.
Life story is useful to prevent older people from being viewed as a similar group and can prevent ageist and preconceived views of older people (Bernard 1998). Life story and identity have often been considered interdependent to the other (McAdams, Diamond, de St. Aubin, & Mansfield, 1997). ‘Life story work' is an umbrella term for the literature on biographical accounts of peoples’ lives (McKeown et al. 2006), however defining it is difficult because there are a number of overlapping uses of the term. In their systematic review of Life story literature, McKeown et al. (2006) define Life story work as a term given to biographical approaches in health and social care that provide people the opportunity to talk about their life experiences. There are positive views about the advantages of Life story work. For the individual, it is supposed to help people make sense of their identity and the importance of individuals connecting their past to their present lives through Life story work is emphasised (Coleman et al. 1998). Moreover, Life story work can enrich the life experience of those involved (Bender et al. 1999). Staff in this study gathered information about residents’ lives, their work, families, and the townlands they grew up in. This contributed to dying well because staff could meet residents’ expectations and provide care that was consistent to their values.

In residential care settings, life story work can also be advantageous to carers because it helps them see the person behind the patient (Clarke et al. 2003). It can also be the basis for the formulation of person-centred evaluations and care plans (Gibson 1998) and development of relationships between the individual and the practitioner (Clarke et al. 2003). Moreover, Gibson (1998) suggests there is an indirect therapeutic benefit from the Life Story work process and it can help relatives to connect with the individual with cognitive decline, through sharing memories (Clarke et al. 2003). In addition, the biographical approach of Life Story work can inform nursing assessments, planning and evaluation (Johnson et al. 1998). In the aforementioned study (Johnson et al. 1998) life story work informed nursing assessment, planning and evaluation in community settings by providing information to nurses about the important aspects of residents’ life. It
was used because the authors argued that the needs of their clients were not solely medical and contributed to a greater understanding of the individual in resident centred care.

Biographical stories or life stories provides people (if they desire) opportunities to talk about their life experiences, family, friends, and work, sometimes using photographs or personal belongings as triggers to these memories (Adams et al. 1998, Jarvis 1998). These can be recorded by their carers or families, which can include those who are caring for them to understand their actions, views, needs and hopes more fully. Some people may find recalling the past difficult and painful emotionally (Hunt et al. 1997) and care staff need to be sensitive to this and provide the necessary support in these circumstances.

In this present study staff were sensitive and caring about residents’ personal and were deliberate in their attempts to get to know residents. This occurred through continual contact and conversations with residents through their care routines, and social activities in the residential care units.

5.5.2 Facilitating families
The subcategory of facilitating families describes the nurse-resident-relative relationships, which developed through the care routines with residents that staff and relatives were involved in. Some relatives wanted to help with meal times, and personal care, and felt it was very important to be involved in care because it sustained a connection between relative, resident and staff.

Relative: “For the first year I used to come in here, then, it became two years. I used to come in here every day at half-twelve and I’d give him [husband] his dinner and stay till 3pm. He’s my husband, you know. It’s good, it’s good, that they let me, that it’s fine with them. I could come in for dinner and, we [staff] would chat together ....but that was the way I could cope with him being gone, and console myself with him being in a home. Yeah they [staff] don’t seem to mind”
Some nurses were unsure if relatives wanted to get involved in personal care aspects of a relative.

_Nurse: “I think it would be very difficult for all individuals [relatives] and for individual families to join in [resident care], I don’t think it’s a barrier, I don’t think everybody in the family would want to get involved, join in. So it’s a difficult thing. The nurse has to judge the situation, Yeah, the family mightn’t want to get involved”._

(Nurse 24-Care Home B)

Facilitating families in residential care is an ongoing process and requires nurses’ attention. Where there are many residents it may take more time for nurses to include families when compared to settings with fewer residents. Contact with families can be difficult as for some residents, the distance between the care homes and the residents’ family can limit the frequency of visits. Planning activities and interactions that appeal to residents is important, and interactions with a purpose need, such as involving younger, intergenerational people needs to be according to the residents preference (Cook and Bailey 2013). To counteract this, knowledge of the resident can be obtained from residents’ relatives, which can reveal important information before it becomes apparent to staff members, whose attention may be distracted due to their responsibility for a large number of residents (Rowles & High 1996). Furthermore, in some residential care homes, the family might not have the courage to collaborate with the nursing staff (Astedt-Kurki et al. 1997).

It is important that staff consider a resident’s whole family as the client of nursing in residential care (Rowles & High 1996). In this study, some relatives approached staff tentatively to participate in care routines of their relative and to be a voice for them when their care did not reflect the preferences of the resident. Staff were responsive to relatives’ requests to participate in care routines. In addition, staff facilitated relatives well when
a resident was dying and this provided good end of life care.

When families talked about their relationship with the dying resident to nurses, it strengthened family involvement with the resident’s care. Nurses deliberately spent time with dying residents to help deepen relationships with families. This knowledge helped nurses to build and deepen relationships further. This had a positive impact on dying well. Relationships between staff and residents that were unhurried had a positive effect on dying well. Nurses showed compassion and kindness to relatives as their resident relative was dying.

Manager: “I facilitated the family so carefully... I said to the family, the grandchildren, then "Would you like to leave Mammy [dying resident] with her sister"? her only living sister”. The daughter-in-law was also present. I said, the daughter-in-law was there, as was the only son, and there was a grand-son and a grand-daughter. The daughter took over and she took the chain of mothers neck and gave it to Lucy and said, "now Lucy [the granddaughter] that’s for you", and it was so meaningful, she was so glad to get it and then she said to somebody else, maybe Granny’s watch, because they [family] knew at this stage like that it was she [resident] wasn’t aware that she was taking them off her no more than if they were just giving her a wash for her personal care. I just said a few kind, maybe they were reassuring words and stayed with them as they talked about their mother, or grandmother. But, but it was awfully meaningful for the family, but not for the person in the bed, but for the family, they really connected to the moment, you know, and the grieving process but it was certainly helpful. Now, I don’t think they could have done it without Nurse X, you know. She said to them in the room “now this time is very, very precious, you know that ‘Granny is going to God’ and that made it very easy for them... Am, the woman in the bed that was dying, she was pain free. Now that pain and symptoms had been looked after earlier, because she was a Difene pump and sure she was an old
woman, she wasn’t palliative care, but she was ninety-two I think so that her time had come”.

(Manager 5-Care Home 02)

The following is an example of a situation when a family was not facilitated. A relative describes her relative’s feelings of being excluded when staff spoke in a foreign language.

Relative: “I did feel bad, and they [my family] felt a little bit left out [of the nursing home environment], and it was fine when I was there because I could walk away, but, Bridget and Tom [Aunt and Uncle residents, couple] were sitting there and the TV was on in Irish and the radio was in Irish. They had spent all their time in England; they had no Irish. No more than me! I mean, I may understand a few words but they [aunt and uncle] hadn’t a clue, having spent their lives in England... Well, the staff just assumed they understood, but they hadn’t a clue. The staff would communicate to you in English, but they talked to themselves all the time in Irish. I felt, we felt, like such outsiders. And I found that difficult as a visitor, I know my aunt and uncle hated it, but could do nothing about it... I think they were really lonely you know... We couldn’t wait to get out and get to here, I tell you”.

(Relative 34-Care Home C)

Staff developed their relationships with residents and relatives by being friendly and welcoming relatives to the care home when they visited. This friendship was drawn upon at the time of dying because there was an established rapport between resident, relative and nurse. This was valued by nurse and relative participants at the time of dying.

Family involvement in nursing homes helps provide individualised care, reduce loneliness and provide a continuing link to residents’ life story and personal care preferences (Robinson 1994). Involvement of the family following the admission of a resident to a care home can influence the quality of life for residents (Ekman & Norberg 1988) as well as the quality of visits for families (Linsk et al. 1988, Hertzberg & Ekman 1996). Some family members provide the kind of support
that nursing home staff might have neither the time to provide nor the necessary knowledge of the resident's personality. In addition, families have described how they have contributed to staffs’ knowledge in personalising the care of their relative, through sharing biographical information (Duncan & Morgan 1994). However, Hertzberg et al. (2001) found that some families expressed uncertainty about whether the information they shared was being used by staff.

In this present study relatives described feeling included and being consulted by staff in the care home. When staff report information to families about the resident’s daily behaviour, this demonstrates to families the personal caring the resident received during their day, and this interaction supported meaningful relationships between families and staff (Duncan & Morgan 1994). Furthermore, families have deliberately explained to staff how emotional or psychosocial care should be provided in addition to the more task based aspects of care (Bowers 1988, Duncan & Morgan 1994) and described this as a shared responsibility between relatives and staff (Dempsey & Pruchno 1993).

Weises’ (1973) discussion on relational situations is relevant to the present study. Weiss (1973) classified loneliness in different types of relationships which meet different needs and described six categories of relational situations, where each was associated with a particular type of relationship. ‘Attachment’ is where one person gains a sense of security from another, and absence may result in loneliness of emotional isolation. ‘Social integration’ is provided by a network of relationships where a person shares common interests or concerns. ‘Opportunity of nurturance’, occurs when an individual is the provider of assistance rather than the recipient. ‘Reassurance of worth’ is derived from relationships where the person’s skills and abilities are acknowledged. Absence of a support and a sense of worth may result in low self-regard. Weises’ (1973) categories of relational situations resonate with family involvement when a resident is dying; attachment occurs when relationships develop between nurses and residents and families have a sense of security within the relationship. In addition, at the time of a resident’s death, social integration occurs within the community of the residential care home setting and a reliable reliance occurs when nurses’ therapeutic role intervenes to support relatives at the time of a resident’s death.
This is particularly relevant to this study because staff developed relationships with residents, so that when a resident was dying, staff could be depended upon to implement the resident’s preferred care choices. In addition, staff in this study facilitated family involvement, and were sensitive to the needs of family members. Absence of nurses therapeutic role and family involvement and can result in a sense of vulnerability. Finally, Wieses’ (1989) proposal of ‘guidance’ represents relationships with persons who can usually provide knowledge, advice or expertise and is normally obtained from teachers or leaders. In this present study guidance came from nursing staff who could offered advice, based on their expertise in nursing older people. Weiss’s framework appears appropriate for understanding the relationships and well-being of residents, their families and nursing staff.

At the time of a resident’s death, nurses were aware of the resident’s end of life care preferences and were sensitive to relatives;

Nurse: “I think you need to be mindful of what the resident who is dying wants and their relative too, I think you have to assure residents and relatives at all times that people [staff] are working together, assessing everything, as a team, and that the resident is pain free, happy, not happy, but that they are comfortable and that their privacy and dignity are maintained at all times”.

(Nurse 36-Care Home C)

Good relationships between residents, staff and relatives are considered to be best practice in residential care setting (HIQA 2008, NMBI 2010). It is important to address the needs of residents, their relatives as well as the staff who work in residential care homes (Nolan et al. 2001, 2006, McCormack 2004, National Care Homes Research and Development Forum 2007; Patterson et al. 2011).

Participation in leisure activities is positively associated with psychosocial well-being, health, and survival (Adams, Leibbrandt, & Moon, 2011) and although evidence suggests that both social engagement and participation in
leisure activities are important for health (Wang, Karp, Winblad, & Fratiglioni, 2002), social engagement may matter to older adults more (Litwin & Shiovitz-Ezra, 2006).

Communication with residents, family, friends, and staff has been reported as the most important activity care staff performed in a study on residents’ perceptions and experiences of social interaction and participation in leisure activities in residential aged care homes (Tomas et al. 2013). However, it was also noted that there were insufficient opportunities in residential care for this communication to occur (Thomas, O’Connell, & Gaskin 2013). This finding is similar to those of previous studies (e.g., Tate, Lah, & Cuddy 2003), which highlighted that communication with family and friends are a high priority of many residents. However, one in three elderly residents may not receive a visitor in a given 12-month period (Findlay & Cartwright 2002). Although maintaining relationships with family and friends is of high priority for residents, evidence suggests that their capacities to form new social relationships upon moving into assisted care have a more positive effect on well-being than the continuation of existing relationships (Street et al. 2007).

In Ireland, service users are the people who come in contact with health services and include residents, their relatives and staff (CAG-HSE 2009). Residents and relatives have a broad perception of health care quality which can include their perceptions of interpersonal relations and the environment, as opposed to what health care professionals perceive, which are outcomes of care (CAG-HSE 2009). Furthermore, inclusion of residents and relatives is likely to encourage confidence and support and improve the overall quality of the health service.

Browne-Wilson’s (2009) study examined the contributions of developing personal relationships in care homes, and discovered that there were three important elements identified for residents; being involved with family members and staff; being an individual, being involved, for instance, as in decision making; and being partners, for instance, as in care delivery. In this study, being partners, as described by Browne-Wilson (2009), meant that residents, their relatives and staff shared mutual concerns and participated in
the activities concerning residents’ well-being. Staff and relatives were involved in aspects of residents’ care such as personal and social care activities along a continuum of time in the care home until a resident’s death. In this study, relationships between residents, nurses, and families was fostered over the life-time of the resident in the participating care homes, which helped residents to live well and die well in residential care. Browne-Wilsons’ findings also noted that personal relationships were essential to residents, family members and staff having positive experiences of, and being able to make a valuable contribution to life within a care home. Furthermore, she noted that relationships initially flourished primarily during the delivery of direct resident personal care, which provided a legitimate focus for interaction between care staff and residents. This was also evident in this current study, where family members negotiated their way with care staff to participating in the care of their resident relative.

It has been shown that personal relationships in care homes influence residents’ and family members’ perception of the quality of care (Grau, Chandler and Saunders 1995, Bowers, Fibich and Jacobson 2001, Kellet 1998, Sandberg, Nolan and Lundh 2002), and staff’s feelings of job satisfaction (Moyle et al. 2003). These findings are consistent with this study’s findings because staff got to know residents and their relatives through the care routines of residents. An important finding of this study was the ways in which residents, family members and staff interacted with one another, for example, through care routines and social activities, and this was greatly influenced by the ethos of caring, organisation of caring, and the environment of care in the residential care units. This had a positive impact on living well and dying well in residential care, because relationships were established and communication between residents, families and staff was established. This suggests that understanding and valuing everyday ‘routines’ is a useful starting point in supporting the development of positive relationships between residents, family members and staff. Staff participants were also involved in planning care to suit residents’ preferences and abilities.
The category of resident centred relationships resonates strongly with Dewar and Nolan’s (2013) model on compassionate relationship centred care which provides insights that assist our understanding in the relationships between nurse, resident and families when a resident is in the final days of life. It highlights the interplay between the dimensions that underpin relational knowledge, knowing who I am and knowing how I feel and the overlap with resident centred relationships which involves knowing the residents and facilitating families at the end of life. This is explained and linked to this category below.

Dewar and Nolan’s (2013) model of compassionate relationship centred care focuses on understanding the practices and processes that support compassionate care. Their study emphasised that engaging in appreciative caring conversations promotes compassionate relationship centred care. This resonates with this study’s participants and the way they related to one another. They used appreciative inquiry and an action research approach to clarify compassionate care and identify strategies to promote this in care settings for older people. Their model explains that relational knowledge informs relational practices and these are activities are necessary to develop and sustain interpersonal relationships between patients, their families and carers (Parker 2008). Relational practices are necessary to achieve compassion (Parker 2008; Williams et al, 2009). Relational knowledge informs relational practices and this is achieved in understanding how a person exists within the healthcare system. Dewar and Nolan (2013) explain that there are two forms of person and relational knowledge, (1) ‘knowing who I am and what matters to me’, and (2) ‘understanding how I feel’. These two forms of relational knowledge enable staff, patients and families to work together to shape the way things are done. To achieve relational knowledge and relational practices involves staff engaging in ‘appreciative caring conversations’. At the centre of their model is the articulation of caring conversations that represent an advanced and highly skilful form of relational practice. This resonates with this substantive theory, of dying well in a tapestry of relations, at the centre is the category of resident centred relationships, which is influenced by an ethos of caring. Staff and relatives through their relationships enable residents to live well, express their spirituality and choose their preferred life in residential care through their day-
Dewar & Nolan (2013) identified that in providing compassionate relationship-centred care involved relational process and this requires nurses to engage in what are described as the “7 C’s”; Connecting emotionally, Connecting, Courageous, Compromising, Considerate, Curious, and Collaborative. Consequently, the person and relational knowledge developed by staff, residents, and relatives during their ‘appreciative caring conversations’ informed compassionate relationship-centred care. The model of ‘appreciative caring conversations’ is most similar to the relatedness that occurs between resident, relative and nurse. These concepts are interdependent and resonate with compassionate relationship-centred care (Dewar and Nolan 2013). Nurses who live their working lives with residents in residential care connect with residents and their families. Through their relationships they develop appreciative caring conversations in getting to know residents and their relatives and providing them their care preferences.

The concept of resident-centred relationships is similar to Dewar and Nolan’s model of compassionate relationship-centred care. The similarity lies in the way the Dewar and Nolan’s (2013) describe compassion as having four essential characteristics which are; (1) that relationships are built on built on empathy, emotional support, and efforts to relieve a person’s distress suffering and concerns, (2) effective interactions between participants over time and across settings, (3) staff, patients and families being active participants in decision making and (4) contextualised knowledge of the patient and family both individually and as members of a network of relationships. These characteristics resonate with the concepts of resident-centred relationship in the way the managers and staff valued relationships with residents and their families. Staffs’ focus was on resident-centred relationships throughout his/her life in care and the final days of life. When a resident was approaching death in care, it was staffs’ and relatives focus and chief concern, and their actions and behaviours were directed to activities such as creating a caring environment and managing symptoms.

The concept of resident-centred care emphasises the significance of knowing the resident and facilitating families, and the importance of relationships between
residents, staff and families. This is similar to Dewar and Nolan’s (2013) model, who identified that developing person and relational knowledge was important in creating compassionate relationship-centred care. Dewar and Nolan’s (2013) model stated that creating compassionate relationship was developed by staff, patients and families during their ‘appreciative caring conversations’ which occurred when staff spoke to patients during care. This is particularly relevant to the category of resident centred relationships, because, the seemingly mundane interactions between staff, residents and relatives has meaning and significance, and that the type of knowledge gained in these interactions should be recognised and valued. Where people value this type of knowledge it reflects an organisations ethos of caring, and this plays a pivotal role in the way that everyone works together to shape the experience of dying well in residential care.

According to Dewar and Nolan’s (2013) model, developing person and relational knowledge involved people making connections, engaging emotionally and reflecting on the insights gained to better understand the experience of the ‘other’. These processes caused uncertainties and had the potential to create tensions but also led to opportunities to challenge existing practice and to forge more responsive relationships between all groups. This is relevant in the concept of relationship centred care where nurses took time in getting to know the resident and their end of life care preferences and how they wanted to be cared for in their final days.

In developing person and relational knowledge care, Dewar and Nolan (2013) identified two dimensions, which were; ‘Knowing who I am and what matters to me’ and ‘Understanding how I feel’. The first dimension ‘knowing who I am and what matters to me’ is similar to resident centred relationships, because it involved staff, patients and family members better understanding how people define themselves and what they see as important, including their likes, dislikes, values and beliefs. Such knowledge comprised of three subtypes; ‘making a connection and clicking’, ‘knowing the little things that matter’, and ‘not assuming how people want to be cared for’. In order to know who people are and what matters to them staff sought to ‘click’ with the person as soon as possible. This resonates strongly with the concept resident centred relationships, because,
staff purposefully enabled residents to live well during their stay in residential care. Managers and staff encourage residents to choose their preferred way of life and enabled residents to live a good life in residential care and express their spirituality. Where this was absent, participants felt isolated and alone, and consequently did not participate or enjoy living, working or visiting residential care units.

The second dimension of Dewar and Nolan’s (2013) description of compassionate relationship centred care is ‘understanding how I feel’. This also reflects two concepts of resident centred relationships in the theory of dying well in a tapestry of relations, in so far as this dimension required that staff explore the emotional aspects of care which involved four types of action: ‘recognising emotion and articulating feelings’; ‘connecting with others by asking how they are feeling’; ‘noticing’ how you and others feel about experiences’; and ‘supporting people to hear and respond to feedback’. In the concept of resident centred relationships, the categories of ‘knowing the resident’ and ‘facilitating families’, meant that staff communicated to residents and relatives in ways that showed that they recognised emotions and feelings, and acknowledged how others felt about experiences especially at the time of the death of a resident. By communicating with residents their families through the care routines of daily life, staff got to know resident and were able to respond sensitively and appropriately to any possible changes that may occur during residents’ deaths in care. Similar to Dewar and Nolan’ (2013) model, when staff and patients shared their feelings in a more responsive and connected way, stronger relationship ensued which was valued by staff, residents and families. Resident centred relationships in the substantive theory of dying well in a tapestry of relations, involved staff getting to know residents through their life story, and being contact with their families and their community. This illustrates the interconnectedness of the concepts resident centred relationships and the relationships between nurses, residents and relatives to weave a tapestry of relations.

In conclusion, the category of resident centred relationships is concerned with the way that relationships between study participants were concerned with dying well.
This category outlines the inter-relatedness of categories ethos of caring, organising care, a caring environment and resident centred relationships and their impact on dying well. This category describes how knowing the person involves assessment of care needs, and planning and evaluation of residents’ care needs, which contributed to their dying needs. Nurses deliberately achieved an understanding of residents through gaining knowledge of their life story, which resulted in strong bonds between residents, relatives and care staff. In addition, resident centred relationships were dependent upon facilitating families both in care routines and the community of the residential care home.

5.5.3 Chapter Summary of Findings

This chapter has described the study findings. These findings resulted from a process of constant comparison analysis of the data until the categories and subcategories emerged. All study participants were concerned with dying well in residential care. This was the main concept and emerged as the core category of dying well within a tapestry of relations. The core category of dying well in resident care homes depended on the interplay of the categories of an ethos of caring, organising care, a caring environment, and resident centred relationships. Each of these categories is intertwined with each other as staff, relatives and residents were concerned with both living and dying well in residential care.

Dying well in residential care was contingent upon the ethos of caring, the way in which care was organised, a caring environment and relationships. The category of ethos of caring describes participants’ values of death and dying which shaped the way in which staff delivered care. Several sub-categories impacted on the category of the ethos of caring, these sub-categories were; enabling residents to live well, promoting choice, and expressing spirituality. The category of organising care describes how nurses organised care, how they planned their care to meet residents’ preferred choices to live well and residents’ end of life needs. The category of the caring environment describes a macro and micro environment and how it impacted on dying well in residential care.

Enabling residents to live well describes how managers and staff helped residents live meaningful lives in residential care. This was based on sub categories of
knowing the person, involving the family and developing relationships with residents and their families. This was important because in this study, dying well was contingent on living well in residential care. Staff participants were concerned with promoting choice, which focused on the extent to which resident participants were able to choose their care preferences, choose how to spend their lives in residential care home and what they would like at their time of death.

The subcategory of expressing spirituality was an important aspect of living well and dying well in residential care. For residents, expressing spirituality was an awareness of their spirituality and the meaning they placed on their religious beliefs and the role played in the use of prayers. For nurse participants, expressing spirituality was revealed in their participation in prayers at the time of a resident’s death and their acknowledgment of the importance of rituals to residents and relatives at the time of death.

The category of organising care describes how work was organised around residents’ lives in residential care until their eventual death. Staff participants felt that when care was well organised it impacted on dying well. The way care was organised determined work allocation and skill mix and therefore impacted on the expertise available to residents and how their daily care was shaped. Organising care involved planning residents’ care around their care needs and preferences. Organising care was concerned with nursing skills and managing symptoms of dying, liaising with multi-disciplinary team for further support. Recording care was concerned with documentation of residents’ and relatives’ dying care preferences, and this included dying within the residential care home or moving to an acute hospital and also the after care of the deceased.

Resident centred relationships was described as the relationships that developed as a result of staff knowing the person through residents’ life stories and facilitating relatives at the time of death.

In the following chapter, the core category of this study, ‘dying well in a tapestry of relations’ will be discussed.
Chapter 6 Discussion

6.1 Introduction

The following chapter concludes the thesis with a discussion of the findings and its contribution to knowledge. In this chapter, the Theory of Dying Well in a Tapestry of Relations (ToDWTR) is compared to relevant literature which will offer further enhancement of the theory. The findings from this grounded theory study have informed a substantive theory of end of life care in long stay residential care for older people. A substantive theory is a working theory of action for a specific context and is transferable to similar situations to the current contexts. This substantive theory highlighted the relationships between participants when a resident was dying. This is the first study to uncover the perspectives of residents, relatives and care staff on end of life care in long stay residential care in Ireland. The theory is unique because it also involves relatives’ views of end of life care as well as those of staff and residents. The voices of all study participants, i.e. nurses, relatives and residents were analysed to uncover the four overlapping and interconnected categories. The substantive theory of dying well comprises of four inter-related categories which emerged as core to ‘dying well’ in residential care: ethos of caring, organising care, caring environment and resident centred relationships.

A visual representation of the theory of dying well in residential care is presented in the model depicted in Figure 6.1.
The categories of ethos of caring, organising care, the caring environment and resident centred relationships are the prerequisites of dying well in residential care. These categories are interrelated and concurrent. This study also illuminates what is ‘invisible’ in the relationships that occur in residential care. These findings strengthen the results of similar studies, which have also identified these factors as important.

6.2 Ethos of caring and conversations on end of life.

The ethos of caring was concerned with how staff in the care home viewed death and communicated this to others. In this study, when staff were reluctant to talk about future care of a dying resident, it made things difficult when a resident’s condition deteriorated. When members of the team were uncomfortable with death issues, and did not talk about death, other staff took on the role of supporting the team when death was imminent. If managers did not support staff during a time of death, staff felt that they didn’t care and in turn they could show the same unfeeling and indifferent behaviour towards others. An ethos of caring was concerned with how staff communicated with one another as colleagues and as effective care teams. When staff were busy and gave little time to residents and their relatives it meant that they had not enough time to spend on conversations around end of life care. Residents interpreted staff’s behaviour, conversations and relationships with each other, and found them to be friendly or not friendly. Similarly, relatives interpreted
staffs’ behaviour as being approachable and caring or not. Consequently, it is important that an ethos of caring prevails in residential care homes, where staff feel cherished and nurtured by professional colleagues and this permeates throughout the care home to residents and relatives. This is reflected in the work of Bollig et al. (2017) who suggested a need for ethics work and ethics reflection in residential care. Systematic ethics work is based on the biomedical ethics as proposed by Beauchamp and Childress (2001) where autonomy is the central concept in modern bioethics, as well as palliative care ethics and hospice philosophy, and patients’ and their relatives’ wishes and needs are paramount. In order to respect residents’ autonomy in nursing homes, residents and relatives should be included in discussions about ethical challenges and making decisions on care. Ethical challenges in regard to decision making and end of life care can be discussed and reflected upon by managers and staff in systematic ethics work in residential care. Bollig et al. (2017) also found that where a systematic ethics existed, it was appreciated by all staff in residential care homes and that it helped staff reach a consensus in the majority of case discussions. They concluded that systematic ethics discussion should be implemented in all nursing homes and the participation of relatives and physicians could be improved.

Communication between staff and the multidisciplinary care teams, palliative care and hospital services was evident in this study. This is important as highlighted in a recent similar study (Tremkin-Greener et al. 2016) which examined nursing homes’ excessive reliance on hospitalisations and infrequent use of hospice care at end of life care. The study identified records of 54,526 residents aged over 65 years who died in 2011 and showed that improved communication was statistically significant in explaining variations in measures of end of life transitions in nursing homes. Nursing homes that showed increased communication between nurses and residents showed fewer residents were transferred to hospital for end of life care. There was a negative association with transferring residents to acute care solely for end of life care and an increase of time spent by nursing staff communicating with residents and their families about end of life care facilitated a resident dying in residential care as opposed to acute hospital. When there was a presence of palliative care teams in a nursing home, this seemed to significantly reduce the likelihood of end of life care transfers to acute care units. Furthermore, their findings showed there was a poor
referral to hospice care homes and this may be due to provider and payment structures between nursing homes and hospice care services. Where there was improved communication between nursing home providers and residents/families, fewer in-hospital deaths resulted, thus averting burdensome transitions to hospital. They concluded that further investment in palliative care training for nursing home staff is important to provide better end of life care, but also to reduce unnecessary transition to more expensive care settings (Tremkin-Greener et al. 2016).

My study also showed that some staff had inadequate training and relied on prior experience to help them with end of life care. These findings correlate well with similar studies on end of life care. Bükki et al. (2016), used focus group interviews to explore the attitudes and concerns of nursing homes staff on the processes that influence end of life care at an institutional level. They found that staff experienced various issues with their workload, such as, ethical conflicts, deleterious effects of restorative aims, resources, fear, lack of training, knowledge and skills, lack of attachment, frustration and abuse were some of the attitudes elicited in their study. While they experienced many concerns with delivering end of life care, staff were highly motivated to provide good end of life care for residents and described “living palliative and hospice care” which included performing rituals, building stable teams and addressing staffs’ fear and avoidance. They described that one of the first steps to better end of life care was to have reflective debriefing groups to improve care, support individuals which could build professional resilience and generate a change in culture (Bükki et al. 2016),

When managers supported staff by acknowledging the emotional burden of caring for residents at the end of their lives, staff felt appreciated and valued. This exemplified an ethos of caring for staff, residents and relatives. Kanoh et al. (2018) recognised that adequate practical education programmes for end of life care and end of life care discussions were crucial for quality end of life care in aged care facilities in Japan. Their nationwide cross-sectional survey of the managing directors of 3437 aged care facilities sought to find out if staff conducted end of life care or end of life care discussions. The response rate in the survey was 20%, and over 70% of respondents reported that there end of life care and end of life care discussions took place with residents in aged care facilities. Kanoh et al (2018) reported that end of care discussions usually took place between the physician and family usually after
the residents condition deteriorated. This may reflect the cultural background where good end of life care is conducted mainly with the family. One of the components of a good death in Japan is not being unaware of approaching death and a patient can avoid facing difficult decision by leaving important decisions to their family. Barriers to having end of life care and end of life discussion were identified as inadequate education for staff in aged care facilities. Staff feared having end of life care discussions. They indicated that training on end of life care and end of life care discussion should be made available to staff on a regular basis which could increase their confidence and reduce their fear on having end of life care discussions (Kanoh et al 2018)

Communication between staff and residents to was necessary to understand residents’ end of life care preferences. When some residents were asked about end of life care, they responded that they ‘didn’t mind’, or had ‘no preferences in place’ on end of life, but had spoken about previous deaths that had occurred in their life time, or another residents’ death. This apparent indifference or acceptance was relevant to the theory of dying well in a tapestry of relations because it emphasised that residents were not concerned about dying, but rather, living. This apparent indifference meant that nurses elicited through caring conversations over time, residents’ preferences while respecting their autonomy and wish not to talk about their own end of life care preferences. Other residents were able to talk about their care preferences with staff. Relatives were involved when a resident first came into care and again when a residents’ condition deteriorated. This occurred when a resident’s condition deteriorated and relatives were called to visit their sick or dying resident. If relatives were involved or did not want to participate, nurses consulted with resident, GP., and the multidisciplinary team to provide end of life care to residents. This relied on good communication and resident centred relationships. This resonated with the findings reported by Gjerberg et al. (2015) in a study which aimed to understand patients’ and relatives’ experiences and perspectives on end of life communication and shared decision making. The study uncovered that few patients and relatives had participated in conversations around end of life care. Many relatives wanted to have this conversation, while patients’ opinions on this varied from being reluctant or indifferent. Most patients and relatives wanted to be informed about the patients’ health condition and be involved in decision-making.
process, but leave final decision to health professionals (Gjerberg et al. 2015). Their study concluded that nursing home staff should initiate conversations around end of life care preferences, assisting patients and relatives to talk about these issues care preferences at life’s end. However, they should also be sensitive to the diversity of opinions of patients and relatives on end of life care preferences and the timing for such conversations. They suggested that care professionals should take the responsibility for these conversations based on a resident’s need for information and involving residents’ families according to the resident’s competency to consent thereby preparing for a shared decision making in a trusting relationship (Gjerberg et al. 2015).

6.3 Living and end of life care

The caring environment impacted on the entire milieu of living and dying well in residential care. Living and dying existed together in residential care. Residents enjoyed their relationships with other residents and care staff. The looked forward to talking to staff and being involved in social activities with other residents. If the caring environment was noisy or over-crowded, poorly lit, residents, relatives and staff felt uncomfortable and sometimes this compromised delivering high quality care. If the caring environment lacked opportunities for social encounters for residents and relatives, either in private or in groups, relatives felt restricted. Relatives enjoyed visiting a friendly environment, were staff were cheery and welcoming in their greetings to them. Where this was absent, relatives avoided visiting and sometimes felt they were excluded. Relatives wanted to feel at home when they visited their relatives. Nurses also wanted to ensure that relatives could visit when they wanted. Some residents preferred their own space, while others did not mind having to share sleeping accommodation, and were able to enjoy the companionship of other residents and their relatives when they visited. Residents cared for each other and were concerned when a resident’s condition deteriorated or when they died and wanted to be involved in rituals and traditions around death.

Living was as important as when dying occurred in each care home in this study. Sussman et al. (2107) address the tensions associated with caring for the living and dying within one care community. Their study aimed to explore caring for living and dying in one community and on how palliative care address the needs of residents,
their relatives and care staff. Their findings suggest that eliciting residents’ perceptions of end of life comfort, sharing information about a fellow residents death more personally, and ensuring that residents, families and staff can constructively participate in providing comfort care to dying residents could extend the purview of end of life comfort and support expanded integration of palliative care principles within long stay care facilities. Their findings noted that conditions that comfort the dying also appear to comfort the living and process and practices that engage willing residents in comforting someone who is dying in their care community would ensure that that the human presence is paramount to end of life comfort and provide a sense of comfort to the resident attending to the dying individual (Sussman et al. 2017).

Staff wanted to involve relatives in the community of the residential care home. When residents were interested in caring for the dying resident, they were also facilitated. The views of relatives on end of life care of residents was also explored by Andersson et al. (2016) who found that most family members reported that there was enough help with nursing and personal care of the dying residents in the last 3 days and months of life. Families also reported that they were told by staff that their resident relative was likely to die shortly. Their study revealed that there was a positive picture of personal, nursing care and communication. However there was inadequate management for symptom relief in the last days of life. They suggest that it is important to work in collaboration with other disciplines to improve symptom relief (Andersson et al. 2016).

Sánchez-Garcia et al. (2016) also found that having discussions around end of life care were key in facilitating good end of life care. Using a descriptive qualitative approach, their study aimed to identify facilitating factors or barriers to end of life care as experienced by nursing home staff through three focus group interviews with care staff from several nursing homes. Their results showed several barriers to implementing good end of life care. These included that care staff found it difficult to communicate, described feelings of guilt, had difficulty in understanding the deterioration of the resident, and addressing the issue of death too late. Care staff also acknowledged that they did not encourage the participation of relatives, and although advance care directives were valued, they were not used systematically. Their findings also included that staff had poor communication with other professionals, and did not anticipate residents’ needs. Furthermore, barriers to good
end of life care included a lack of training for care home staff, and a lack of adequate equipment and human resources. They concluded that it was necessary to have good communication between care home staff, families and other health care workers (Sánchez-Garcia et al. 2017).

6.4 Summary

The core category called ‘dying well in a tapestry of relations’, represents the voices of the participants of nurses, relatives and residents to uncover the four overlapping and inter-related concepts; ethos of caring, organising care, caring environment and resident centred relationships. A model depicting this emphasises the relationships between residents, nurses and relatives. This model further clarifies the interconnectedness of the relationships of participants and the emergent themes. The metaphor of a tapestry of relations depicts the interconnectedness of the relationships between residents, nurses and relatives in residential care throughout living and especially the dying phase of care. This study highlighted the good practices that exist in care homes where there was an ethos of caring and conversations on end of life could be had with residents, nurses and relatives. Furthermore, living and end of life care coexist in residential care homes. Essentially, communication between staff resident and relative is essential in delivering good end of life care for older people in residential are settings.

The following chapter describe this theory’s contribution to knowledge, implications for practice and recommendations for future research.
Chapter 7  Contribution to knowledge, recommendations and limitations.

7.1 Introduction
The final chapter outlines the contributions that this substantive theory of dying well has made to knowledge development. This chapter will outline the contribution to practice, recommendations for policy, education, audit, future research and limitations of this research.

7.2 Contribution to Knowledge
This study has developed and increased our knowledge by providing insights into the complexity of dying in older peoples’ long stay residential care homes.

The study findings have situated ‘dying well in a tapestry of relations’ as a critical concept in participants’ experiences of death and dying in long stay residential care and acknowledges the triad relationship between resident, nurses and relatives.

This study developed a substantive theory of dying in residential care and recognises that there is a relationship between the categories of an ethos of caring, organising care, a caring environment and resident centred relationships and an interdependence between the stakeholders in residential care (residents, relatives and care staff).

This substantive theory, ‘dying well in a tapestry of relations’, has uncovered participants’ perceptions of the factors that influence good end-of-life care. These factors were, an ethos of caring, organising care, a caring environment and having a focus on resident centred relationships.

This theory has built a comprehensive account of end of life care in residential care, from the perspective of residents, their relatives and staff delivering their care.

7.3 Recommendations
This theory of dying well in a tapestry of relations explains residents’, relatives’ and staff experiences of living and dying in residential care. It describes ‘dying well’ as central to people’s experiences and whether this was enhanced or diminished by the ways in which residents, relatives and staff interacted with each other in their environment of their residential care home. The theory of dying well in a tapestry of
relations is a unifying and accessible concept for families, staff, and members of the multi-disciplinary team to assist in understanding older people’s experience of dying in long stay residential care. The goal is to develop recommendations to optimise residents’ experiences of a good death in their final days in residential care. In terms of practice, staff can respond appropriately and compassionately to residents’ dying trajectory and care preferences, and enhance the care environment, to facilitate residents to have a good death and families’ experiences of death. The core category of dying well in a tapestry of relations is helpful in generating a shared understanding of the roles and contributions within and across disciplines to enhance quality of experience for older people and their families in residential care.

Practice recommendations relate to three subcategories; ethos of caring, organising care and caring environment.

7.3.1 Practice

The theory of dying well in a tapestry of relations is relevant for practice because much of the current focus of clinical care is on metrics (Patterson et al. 2011) and this often fails to capture the complex nature of relational practices which are necessary to achieve compassion (Parker 2008, Williams et al. 2009). The practice recommendation will relates to the four categories that influence practice; ethos of caring, organising care, caring environment and resident centred relationships.

Ethos of Caring

1. The main focus of caring should be one of compassion and this should inform managers to understand that they have an opportunity to lead and manage the care for residents who are at the end of their lives. This study supports Cook and Browne-Wilson (2010) assertion that the quality of interpersonal relationships between staff and residents can be positive. Exchanges between staff and residents can lead to familiarity with each others’ background. This understanding of residents and staffs’ life circumstances lead to a mutual understanding and this was valued by residents. The incidences of sharing between resident and staff were enjoyable and fulfilling for residents, who actively shared their experiences and tried to create opportunities to interact with staff (Cook and Browne-
Wilson (2010). This study recommends that care staff need to recognise, acknowledge and support residents’ aspirations regarding their future lives and that staff need to be conscious of residents’ goals in long stay residential care. An ethos of caring is demonstrated by the behaviour of staff and managers, behaviour which results in residents, family, friends and staff feeling valued. It requires nurses to be leaders and relate to residents and relatives with commitment in a nurturing and caring way that fosters compassionate care.

2. This study highlighted that living in residential care involved developing relationships in a community of older people and where staff work. This provided residents with the opportunity of companionships and reciprocity which contributed to residents living well in residential care. An ethos of caring should be demonstrated by staff in their relationships and behaviour with residents and their relatives. This would be evidenced by staff conversations with residents and their relatives showing empathy and an understanding of their perspectives. Staff should demonstrate an ethos of caring by behaviour that enables residents to live their preferred life choices, where details about residents’ personalities are known and acknowledged by staff. Therefore, it is recommended that in all long stay residential care homes should have adequate numbers of skilled staff proportionate to the number of residents in the facility, with complimentary roles and responsibilities to facilitate caring relationships between staff and residents. Some examples of complimentary roles are; dedicated staff to carry out meaningful activities that appeal to residents and stimulate residents’ interests; a social worker for older people’s services; a specialist palliative care nurse to provide support pain and symptom management for residents.

Organising care that enables preferences for living and dying

The theory of dying well describes how care is organised around residents’ care preferences throughout their lives in residential care and at the time of their deaths. Care preferences should be planned by staff in collaboration with residents and their relatives and recorded.
1. Organising care around older people’s care needs at the end of life is an essential category of the findings of this study. Specialist palliative care services may be recommended for a small number of older people in residential care, whereas general palliative care is appropriate regardless of diagnosis. When residents die, they have often lived through multiple illnesses and disabling chronic conditions over a long period of time. This study recommends the following to improve the organisation of care around residents end of life care needs; a) include the work of clinical nurse specialists, b) ensure more hospice beds in care homes, and c) ascertain the views of recently bereaved relatives on the care their relative received.

2. Supporting the relatives of a resident who is dying in long stay care is a key part of the findings in this study. Relatives can provide help for residents with personal care, along with emotional, social and financial support. They frequently perform tasks that are usually performed by nurses, such as assessing for pain, managing symptoms and helping with medications. Caregiving can be rewarding to relatives when they feel they have contributed positively to the resident’s quality of life. This study recommends nurses need to actively determine if the burden of care giving from a relative may result in physical and emotional exhaustion. It further recommends that nurses and managers should liaise with educators to provide training for relatives who are providing end of life support. This includes contributing to designing training programmes specifically to enhance relatives’ knowledge of the disease trajectory to improve their confidence in their carer role.

3. Records of residents’ care preferences should be revised and updated to reflect changes that may occur in a resident’s health status or change in preferences. Planning and reaching decisions about care and treatments are central to residents in care, and sometimes residents rely on nurses to advocate for them. The use of paper based care-plans posed a challenge to some participants in this study because of the volume and weight of the documents and folders used to depict a resident’s plan of care. It is recommended from the findings of this study that the use of computerised careplans/digital technology should be introduced as a means of recording residents’ personal careplans and other information regarding their care.
preferences, biographical data and prescribed medications. This data should be managed within each care home and could further permit ease of transfer of a resident from residential care home to acute care setting, or transfer information about prescribed medication, prescriptions and allow for easy retrieval.

A caring environment

1. The links between the style of the residential care setting, ethos of caring and resident centred care are interwoven. Maintaining, promoting and maximising residents’ independence is essential during their lives in residential care, as is providing a physical and social environment that enables residents to achieve this. Nurses are in a position to shape this in a way that helps residents live and die in care and accommodates relatives’ participation in the residential care home’s community. Staff can facilitate changes in residents’ micro environment by making it homely in ways such as accessorising the care home micro-environment with suitable lighting, ventilation, choice of colours, textures, furnishing, access to gardens, space for residents’ personal photos and furniture. Residents’ own rooms should ideally resemble domestic type design and layout with features that help residents connect with their previous lives. Residents should have ease of access to outdoor spaces, and experience the comfort of having families share their room and garden areas.

2. Catering for residents’ dying needs requires attention to the design and layout of the physical environment. Dying residents can have particular needs for the bedroom layout, adjacent communal space and associated need for privacy which can positively influence the dying and death experience for residents and their families. The onus is on nurses and managers to understand residents’ needs when they are nearing death and to ensure the physical environment matches their requirements. This may require moving residents to a private room. This should be arranged by managers and where possible each resident should be facilitated to have his/her own room to die in. Room dimensions and layout options should ensure that there is adequate space on either side of the bed, to enable
access for carers and any necessary equipment. In all new builds and extensions, all single bedrooms are required to have a minimum of 12.5 square meters usable floor-space (excluding en-suite facilities) and 80% of residents should be accommodated in single rooms. Managers of residential care homes need to ensure that they create caring environments by enhancing the milieu nurses’ work areas and residents’ living spaces. Where new buildings are commissioned, managers should be aware that a homelike environment is consistent with residents’ own domestic buildings both inside and outside. New buildings, sometimes two storey, that house concentrated numbers of residents is unlikely to represent the domestic appearance of residents’ own homes of the 1930’s or 1940s’. In future, residential care home managers and care home resident committees should be actively encouraged to be involved in early stages of care home design stages to give voice to residents. Such involvement would give residents and staff of care homes greater prestige and acknowledgement of their experience as people who work and live in these environment. It is recommended that consultation with service users is essential when planning the design off any long stay residential care homes.

Resident centred relationships

1. When relational ethics is applied to decision making it offers an ethical framework for nurses that can help answer ethical questions within complex environments. The basic premise of relational ethics is that ethical decisions and actions evolve within the context of a relationship, in this case, the people involved with a resident and their relatives. Within relational ethics, relationship exists between nurses, residents and relatives, who are interdependent and connected. Nurses strive to do the right thing for residents, to guide them with decision making, activating their choices and preferences. Reflecting on these findings, in discussion with relatives, nurses can determine what is fitting or what is the right thing to do for residents at the end of their lives. This “right thing” is revealed to nurses, residents and relatives, through meaningful dialogue and constant appraisal of care. This is possible when nurses understand residents’ perspectives
through their relationship with them over many years. Nurses also need to appreciate the context in which an ethical issue arises and clinical decisions are agreed. The context is a dynamic and fluid interaction for participants. It is this interaction that inspires (requires) responsibility from nurses (Olthuis 1997). Organising care requires nurses to be responsive and adaptive to the subtle deteriorating changes experienced by residents during life and at the time of death in residential care.

2. In this study, care of the dying resident is the central focus of care staff and relatives. The duality of relatives giving care to residents and receiving care from nurses also requires attentive nursing care. Nurses therefore are required to be flexible in their approach to delivering care and facilitate each resident’s relatives to contribute to care delivery. It is recommended that nursing staff involve residents’ relatives, where possible, and include them in care planning and in some decision making around relatives’ life choice preferences. This is a continually negotiated process and as such needs to be reassessed by nurses, residents and relatives.

3. Pain and other symptom management for residents can be delivered when nurses are confident to deliver such care. Although prognostication of death is impossible, discussions on care preferences, such the right to refuse further medical intervention (e.g. acute admission or cardiac resuscitation) can be useful to inform staff of residents’ preferences.

4. In understanding residents better, care staff should use documentation aides such as residents’ life story books. Furthermore, the contribution of ‘life story’ along with clinical assessments noted in this study and in the literature, provides a comprehensive assessment of residents’ personal and social background. This activity should be encouraged in resident care assessments and in the process of planning care around residents’ care preferences. This would not only inform carers of residents’ social and emotional context but also inform carers of residents’ end of life care preferences.

7.3.2 Education and Training

1. This study identified deficits in some nurses’ understanding of death and dying and many staff may need competence and skills training in the areas of
recognising dying, disease trajectories, and talking about death. Central to providing good end of life care is the need to address nurses’ education and training needs and support the provision of care by adequate staffing levels within residential care homes. Moreover, organisations need to introduce care practices around end of life care that supports palliative care practices. The recommendations from this study are that care staff working in residential care homes need foundation training on end of life care and a planned schedule of training and refresher courses on end of life care should be made mandatory. The theory of dying well in a tapestry of relations should be integrated in nursing curricula (undergraduate and postgraduate) and curricula for multidisciplinary care staff. This theory could underpin training between gerontological, palliative care and dementia care nursing specialisms in long stay residential care. Residents frequently have complex care needs and require combinations of all three and are underserved in terms of all three skill sets.

2. This study revealed that nurses’ own personal life experiences of death and dying informed their delivery of end of life care. Through this type of experiential learning, they were able to nurture an understanding of residents’ humanity and guide their decisions. The findings of this study recommend that there should be peer education for advanced care planning. This training would provide care staff with the knowledge base and skills to understand advance care planning and gain knowledge of residents’ individualised care preferences toward the end of their lives.

7.3.3 Policy

Residential care home policies should improve support for relatives when their resident relative is moving into the end of life phase. This support should also extend into relatives’ bereavement.

Organisational policies and human resources strategies should enhance the welfare of staff working in residential care homes who are frequently dealing with death and dying.


7.4 Audit

Current policy outlines that residential care units are to undergo regular inspection to maintain and improve their standards. In 2014, a HIQA audit of 195 residential care homes found that providers were mostly compliant with key components of the theme end of life care (HIQA 2015). Audit of care practices within care homes should be compared to national standards. This highlights the benefits of regulation, audit and enforcement. Managers should be recognised for improving standards of care and introducing good practices and encouraged to maintain improvements in practice.

7.5 Future Research and Theoretical Development

Further research into the relationship between residents, relatives and staff in residential care and the role of relational ethics is required. This should help in achieving a greater understanding of what motivates staff to actively be involved in the process of residents’ dying and could offer a means of enhancing care.

This theory, dying well in a tapestry of relations, holds the potential to develop a measurement scale to objectively measure the factors that influence end of life care; an ethos of caring, a caring environment, organising care and resident centred relationships. A mixed methods approach using quantifiable measurement tools could provide objective ways to assess influencing factors on end of life care in residential care homes.

No research has yet been identified that examines the long-term, post intervention impact of end of life care education on staff behaviour and application of their skills at end of life care. Further research is required to explore the effect of education on staff behaviour and skills following a schedule of training.

More research should be conducted into the effects of the environment on dying well in residential care. Given that this contributes to the well-being of residents and staff working in residential care, this should be researched further to establish the ideal care environment for older people at the end of their lives.

A triad of relations is depicted in compassionate relationship centred care (Dewar and Nolan 2013) where two main forms of compassionate care are acknowledged, (1) know who I am and, (2) know what is important to me. This theory is represented...
in this study in the caring conversations between staff, residents and relatives in an
endeavour to know the resident through resident centred care, their life story and
relationships with relatives and community. Knowing what is important to residents
towards the end of their lives was gleaned by staff through understanding and
adhering to residents’ care preferences and the way care was organised. Future
research is required to further understanding relatives’ needs during the provision of
end of life care for their relative in care.

7.6 Research Limitations

In this study, the researcher found that theoretical sampling favoured the
accessibility of staff and resident data. The relative lack of family involvement data
could be viewed as a limitation to the overall study. Although there were smaller
numbers of relatives interviewed, more data from relatives could have allowed
further comparison of categories and may have altered the overall conceptualisation.
However, relatives’ data had place in the analysis and showed credibility and
relevance, which allowed it to contribute to the saturation of the emergent concepts
and the resultant theoretical model.

This study was conducted in publicly managed residential care homes. Different
findings may have been shown if the participating sites been privately owned.
Having a broader representation of types of residential care homes could have
influenced the data collected and findings.

7.7 Summary

The theory presented in this study illustrates a new understanding on death and dying
in residential care; that is, to die well residents have to live well. This theory also
explains the significance of the triad of relationships between residents, nurses and
relatives and through their relationships they contribute to the factors that influence
dying well.

How residents live their lives when they are well, impacts on their death. When
residents can choose and participate in their preferred way of life, this contributes to
their final days. Relatives who contributed to the community of the residential care
home and were involved with residents’ lives helped residents to live well and this
consequently helped them to have a good death. When nurses, relatives and residents were focused on relationships with residents, this influenced dying well.

There is a central role played by staff, specifically managers, to positively adjust and influence working conditions. A caring environment is a place where staff can deliver care that enables residents and relatives not only live a good life in care, but also during their final days.

This systematic explication of what influences dying well in residential care represents the views of residents, their relatives and nursing staff and impacts upon the caring environment where change can be implemented. Future policy makers and leaders in health care need to appreciate that the environment where living and dying occurs plays an important part and contributes to the welfare of staff, residents and relatives in residential care homes.

Finally, this research provides a good example of how Strauss and Corbin’s (1998) grounded theory methodology facilitates the emergence of complex theoretical categories. The technique of adding data to codes and categories helped reach theoretical saturation and conceptual development. It offers an example of an approach to analysis of data and literature reviewing in Strauss’s grounded theory which allows the researcher to achieve a balance between being familiar with the literature and permitting conceptualisation of categories to later being guided by literature, thus achieving a greater understanding on the topic of end of life care in residential care settings.

### 7.8 Concluding comments

This study set about identifying the factors that influence good end of life care in long stay care settings. Through a grounded theory methodology, the main concern for all participants was *dying well in a tapestry of relations*, and from the data four categories emerged to inform this substantive theory; an ethos of caring, creating a caring environment, organising care, and having resident centred relationships.

The tapestry of relations reflects residents’ journey through the process of living and dying in residential care. The relationships between resident, nurse and relative fit with the dynamic relationship that exists in residential care homes where residents live and die. This triad of relations is depicted in compassionate relationship centred...
care (Dewar and Nolan 2013) where two main forms of compassionate care are acknowledged, (1) know who I am and (2) know what is important to me. In this study, this theory is represented in the caring conversations between staff, residents and relatives in their endeavor to know the resident through resident centred care, their life story and relationships with relatives and community. Knowing what is important to residents towards the end of their lives was gleaned by staff through the way care was organised and understanding and adhering to residents’ care preferences.

The framework of relational ethics helps to understand the theory of dying well in a tapestry of relations, by further clarifying the relationships between resident, relative and nurse through its four dimensions, of engagement, mutual respect, embodiment and environment. Relational ethics requires carers to see people not as individuals but as ‘interdependent agents’ (Bergum and Dossetor 2005:9), and is an approach which does not diminish personal autonomy but places autonomy and choice in a context of the wider community. Relational ethics is explained as being a focus on communication between staff and their patients, which is known as a ‘relational space’, and is necessary for ‘discovering knowledge about others through dialogue and sensitive interaction’ (Bergum and Dossetor 2005 p.xii). The theory of relational engagement demonstrates the way that nurses, residents, and relatives engage with each other, caring and responding to residents’ needs and ultimately supporting them in their journey towards death.

The implications for practice are that this study places an imperative for managers to influence a positive ethos of caring in residential care. The theory of dying well in a tapestry of relations is an acknowledgement of the process of relational ethics applied to death and dying in residential care. Nurse managers are in a position to influence the way care is provided in practice, and to ensure availability of training and education programmes for staff so that they can support not only residents on their final journey but also their relatives involved in their care.

Finally, the researcher has travelled her own journey of enlightenment through years of endeavour with this chosen research area in finding out, at a moment in time, what are the influencing factors on end of life care in residential care settings.
“The end of a work such as this should signal neither a conclusion nor a final word, but rather a punctuation in time that marks a stop merely to take a breath” (Lincoln and Denzin 2005, p1115)
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Appendices

Appendix 1: Ethics Approval

From: O'Connell, Ethne
Sent: 28 September 2011 17:32
To: Mary Butler; mary.butler@hse.ie Cc: Dowling, Maura; Felmann, Heike
Subject: RE: Ethics Application: 11/AUG/10

Sent on behalf of Dr Heike Felmann, Acting Chair, Research Ethics Committee

Dear Ms Butler

Ethics Application: An exploration of the factors that influence good end-of-life care for older residents in long stay residential care.

I wrote to you regarding the above proposal which was submitted for Ethical review. Having reviewed your response to my letter, I am pleased to inform you that your proposal has been granted APPROVAL.

All NUI Galway Research Ethics Committee approval is given subject to the Principal Investigator submitting an annual report to the Committee. The first report is due on or before 31st August 2012. Please see section 7 of the REC's Standard Operating Procedures for further details which also includes other instances where you are required to report to the REC.

Dr Heike Felmann Research Ethics Committee
(Should you require a hard copy of this letter please contact me – details below)

Ethne O'Connell

Research Office Room
127, Science and Engineering Technology Building
National University of Ireland, Galway

Tel: +353 91 524411 (ext 5312)
+353 91 495312 (direct)
Fax: +353 91 494591 http://www.nuigalway.ie/research/vp_research/location.html
Appendix 2: Consent Form

A study to identify
Factors that influence end-of-life care for older residents in long stay residential care.

Please tick the appropriate answer.
I confirm that I have read and understood the Patient Information Leaflet dated _____/____/____ attached, and that I have had ample opportunity to ask questions all of which have been satisfactorily answered. □Yes  □No

I understand that my participation in this study is entirely voluntary and that I may withdraw at any time, without giving reason, and without this decision affecting my future treatment or care. □Yes  □No

I understand that my nursing records may be viewed by the principle investigator___________________________ □Yes  □No

I understand that my identity will remain confidential at all times. □Yes  □No

I am aware of the potential risks of this research study. □Yes  □No

I have been given a copy of the Information Leaflet and this Consent form for my records. □Yes  □No

Interviewee___________________________ __________________________
Signature and dated                  Name in block capitals

Interviewer___________________________ __________________________
Signature and dated                  Name in block capital
Appendix 3: Information Leaflet

Principal Investigator’s Name: Mary Butler
Principal Investigator’s Title: Assistant Director of Nursing
Telephone No. of Principal Investigator: xxx

You are being invited to take part in a nursing research study carried out in the XXX Nursing Unit. Before you decide whether or not you wish to take part, you should read this information sheet carefully and discuss it with your family and friends if you wish.

Take time to ask questions – do not feel rushed or under any obligation to make a hasty judgment. You should clearly understand the risks and benefits of participating in this study so that you can make a decision that is right for you – this process is known as ‘Informed Consent’.

You are not obliged to take part in this study and choosing not to participate will have no effect on your future care or relationships with between staff.

You may change your mind at any time (before the start of the study or even after you have started the study) for whatever reason without having to justify your decision and without any negative impact on the care you will receive from the care staff.

WHY IS THIS STUDY BEING DONE?
Providing good end-of-life care to older people and their families in long stay settings has become an important concern for many in the past decade (HIQA 2009). There is little information or research on the end-of-life care received by older people in long stay residential care homes exists in Ireland to. It is a broad concept to define and involves the physical, social, psychological and spiritual care of people with advanced disease. End of life care has a poorly developed research base and there is a need to improve this. I aim to identify factors that influence good end-of-life care for older residents in long stay residential care.
WHO IS ORGANISING AND FUNDING THIS STUDY?
I (Mary Butler) am the principal investigator and am a qualified general and psychiatric nurse with a specific interest in older peoples’ nursing (geronotology). I am doing this study as part of a PhD programme in NUI Galway with supervision from Dr Maura Dowling, Professor Kathy Murphy, Dr Philip Larkin, Professor of Nursing in UCD who are supervising this research.

I have many years of experience in acute and chronic nursing and more recently in care of the elderly in the HSE Western Region. This study is part funded by the Mayo-Hospice foundation.

HOW WILL IT BE CARRIED OUT?
I would like to interview people in November 2012. If you are interested you will be given a time and location for the interview. This will normally take place in a private room in XXX Nursing Unit, Town. The interview time will last between 20 minutes and 1 hour. There may be a second, shorter interview within a two week time frame following the first interview.

During the interview time, I will ask you 3 or 4 questions about your time in the nursing home, and ask you what you think matters to someone who was near end-of-life in the home.

You will be asked to answer questions in your own words and this information will be recorded during the interview. Afterwards I will transcribe it and code it so that your identity will remain anonymous. I will be the only person to have access to the code. The recordings will be destroyed following transcription. Your identity will not be made known to others. The content of your interview will be used solely for the purposes of this study and not passed on to any other party. The information will be reviewed only by myself.

Part of the study involves looking at your nursing home notes. This will involve the taking down brief notes about your care specifically about end-of-life care.
I will also look the area you are living (or working) in. This will involve looking at the general environment of the ward, the doors, windows, bathrooms and other physical things in your area.

WHAT WILL HAPPEN TO ME IF I AGREE TO TAKE PART?
Your will be asked to meet the interviewer at an agreed time to be interviewed. The interview will be conducted by asking 3 or 4 open-ended questions. If there is anything you do not wish to talk about you can tell the interviewer not to ask a particular question, or to stop the interview.

There are no known risks from the interview, however, if you would like to get more information about the study I will meet you before the interview and talk to you about any other concerns you may have.

Following the interview you may be asked again to check the information you gave during the interview, this will involve more of your time. You may be invited to be interviewed again some time after the interview. The researcher will let you know what is likely to happen after each interview.

It is not known if there is psychological stress associated with this interview, if you are upset by any of the content of the interview, I will stop the interview immediately and check with you if you wish some support and guide you to a colleague for help. However, research interviews can be a source of support for some people who wish to express their views on a certain issues.

BENEFITS
The information will be collated and presented as part of a study to inform nursing practice regarding the factors that facilitate or hinder good end-of-life care in nursing homes. The results will be used to contribute towards providing an improved service and to deliver a higher standard of care. Some benefits have been noted in practice development areas and respondents voicing their views to interviewers/researchers on a particular subject.
WHAT IF SOMETHING HAPPENS AS A RESULT OF MY PARTICIPATION IN THIS STUDY?

If you are upset or distressed as a result of the interview, I will guide you to supportive services, such as your ward manager or counseling in case of psychological distress, or referral to a specialist (such as palliative care team) if more support is requested. However, I have extensive nursing experience and have developed skills of interviewing and counseling and hope that the interview does not cause distress in any way.

YOUR RESPONSIBILITIES AS A PARTICIPANT
As a participant you will be requested to provide information that is faithful to your experience and knowledge.

OUR RESPONSIBILITIES TO YOU AS INVESTIGATORS
When the study is completed you will be notified of any publication details and a copy will be provided to you if you request.

CONFIDENTIALITY
Your information will be coded and unidentifiable by another person, that means that your name will not appear in any text in the study. I will maintain confidentiality on any the contents of the interview. That means that other people outside of the interview will not know what was talked about during the interview. The original data on the recording will be destroyed by being deleted from the audio tape once it is transcribed. Information will be secured in a locked room at all times and encrypted in a software computer. I will maintain confidentiality about your identity and will not disclose any information you provide through interview.

If there are any issues relating to the subject you would like to discuss outside the interview, I will guide you to an appropriate person who will deal with that issue. The information obtained at interview will only be used for the purposes of this study and will not be passed on to another party.

I will also look at your nursing notes. This will also be coded and unidentifiable. Your name will not be used in collecting data.
The researcher will hold the code and be the only one to break the code. She will hold the data for a period of 6 years and it will be destroyed by deleting, (technology) and by shredding (any paper)

IF YOU REQUIRE FURTHER INFORMATION
If you have any further questions about the study, or if you wish to withdraw from the study you may do so without justifying your decision and your future treatment will not be effected.

For additional information now or any future time please contact:

Name: Mary Butler
Address: --- Phone Number: ---
Appendix 4: Poster

End of life care study in Long Stay Care Homes

Would you like to have your voice heard?

If are a nurse, carer, resident or relative and would like to participate in a research study exploring the factors that influence end of life care in long stay care homes, then contact Mary Butler (PhD Student NUI Galway) who will visit XXX Nursing Unit on

......&....../12/ 2013

Interviews will be confidential and last from 10 minutes to 45 minutes

Mary can be contacted on 0867887854 or mary.butler@hse.ie and maryobrienbutler@gmail.com
### Appendix 5: Interview Guide Residents

<table>
<thead>
<tr>
<th>Focus</th>
<th>Question</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Life before death</em></td>
<td><strong>Question</strong>&lt;br&gt;How have you managed the important things in your life?&lt;br&gt;How did you deal with moving in to this care home/ like getting used to here. What kind of things did you do before you came in? What do you think are the important things to prepare for end of life? Do you keep up with contacts from home / outside the care home?&lt;br&gt;<strong>Prompts</strong>&lt;br&gt;Has your illness/frailty affected your getting used to (transition into) long stay care? Do you see your friends/do you have many visitors now? Have you ever been present at someone’s end of life? Do residents maintain contact with their previous interests and activities including their social groups</td>
<td></td>
</tr>
<tr>
<td><em>Comfort and Dignity</em></td>
<td><strong>Question</strong>&lt;br&gt;What do you think contributes to comfort for your at end of life? Have you any pain or discomfort now? What do you do to alleviate it? How do you cope with discomfort or pain? What do you think of the room/ward you are in? Is it what you would like for yourself (another person) at end of life?&lt;br&gt;<strong>Prompts</strong>&lt;br&gt;Have you ever helped someone achieve comfort (i.e. peace in their lives?) What did you do? What would you like for yourself?</td>
<td></td>
</tr>
<tr>
<td><em>Support</em></td>
<td><strong>Question</strong>&lt;br&gt;What kind of support do you think you need? How do you help yourself? Is there another kind of support/strength or coping you use facing end of life? What does the nurse do to facilitate this?&lt;br&gt;<strong>Prompts</strong>&lt;br&gt;What examples, can you recall incidences? What do you do when there are not any nurse around? Has prayer and your faith a part to play in support for you? What kind of relationship do you have with the nurses?</td>
<td></td>
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</table>
Appendix 6: Interview Guide Staff

<table>
<thead>
<tr>
<th>Focus</th>
<th>Question</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Life before death</strong></td>
<td>What planning occurs in preparation for end of life care for residents?</td>
<td>What do you think are the important things to prepare for end of life? When does planning begin? What dimensions (aspects) of the residents’ life do you incorporate into the residents end of life care?</td>
</tr>
<tr>
<td><strong>Comfort and Dignity</strong></td>
<td>What structures are needed for good end of life care?</td>
<td>Who needs to be involved? What is the role of relatives in end of life care? What makes a good atmosphere at end of life? What kind of space is needed at time of death? How do the skills and expertise of staff contribute to the end of life care? What communication/documentation skills are needed (care planning, discussions with relatives, advance directives, capacity and resuscitation status)? How do personal experiences contribute to end of life care? What equipment/furnishings contribute to a good environment?</td>
</tr>
<tr>
<td><strong>Support</strong></td>
<td>What kind of support do relatives need after the resident’s death?</td>
<td>How do you support relatives immediately at the resident’s death? How do you support relatives immediately after the resident’s death?</td>
</tr>
<tr>
<td></td>
<td>What kind of support is needed for staff need after the resident’s death?</td>
<td></td>
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</table>
## Appendix 7: Interview Guide, Relatives

<table>
<thead>
<tr>
<th>Focus</th>
<th>Question</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Life before death</em></td>
<td>What do you think is important for end of life care for an older person residing here?</td>
<td>Have you ever been present at someone’s death?</td>
</tr>
<tr>
<td></td>
<td>What kind of planning was made in preparation for end of life care for your relative?</td>
<td>What do you think are the important things to prepare for end of life?</td>
</tr>
<tr>
<td><em>Comfort and Dignity</em></td>
<td>Can you tell me about the final days/hours of your relatives life and the care that they received in that time?</td>
<td>What people were involved in providing end of life care?</td>
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<tr>
<td></td>
<td>What was the atmosphere like at end of life care?</td>
<td>What kinds of things are staff doing?</td>
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<tr>
<td></td>
<td>What do staff do to enhance the environment?</td>
<td>What kind of things do staff say?</td>
</tr>
<tr>
<td></td>
<td>What happened at the point of death?</td>
<td>What happened at the point of death?</td>
</tr>
<tr>
<td><em>Support</em></td>
<td>How were you supported at your relatives' point of death?</td>
<td>What did staff say to you immediately after your relative death and afterwards?</td>
</tr>
<tr>
<td></td>
<td>How was (is) the support demonstrated?</td>
<td>Did staff ask you ‘<em>how were you feeling?’</em> about your relatives’ end of life care?</td>
</tr>
<tr>
<td></td>
<td>What information did you receive?</td>
<td>Did staff guide you in what to expect, during death and afterwards?</td>
</tr>
<tr>
<td></td>
<td>Who gave it to you?</td>
<td>Did you receive formal information(from staff/manager)? Or did you get information from friends and informal sources, (church, media sources)</td>
</tr>
</tbody>
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Appendix 8: Organisation of Data analysis and management

Figure 8A: Organisation of Data Management and Analysis

Phases of data analysis

Organisation of interview data
APPENDIX 8 B: REFLECTIVE MEMOS FOLLOWING INTERVIEWS
 Appendix 8 c Coding tree - selective coding  

Core category and categories
APPENDIX 8 D OPEN CODING AND DATA ANALYSIS

Phase 3 - Selective Coding

<table>
<thead>
<tr>
<th>Code</th>
<th>Name</th>
<th>Sources</th>
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<tbody>
<tr>
<td>104</td>
<td>Comfort - person</td>
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<td>100</td>
</tr>
<tr>
<td>19</td>
<td>Dignity</td>
<td>10</td>
<td>237</td>
</tr>
<tr>
<td>19</td>
<td>Life before death</td>
<td>10</td>
<td>109</td>
</tr>
<tr>
<td>12</td>
<td>peaceful death</td>
<td>12</td>
<td>43</td>
</tr>
<tr>
<td>19</td>
<td>support for carers</td>
<td>19</td>
<td>192</td>
</tr>
</tbody>
</table>

But we had a nurse and she’s gone. She was so good and she is gone now. So good a C she retired last February. She was so in tune.

Reference 11: 0.01% Coverage

Reference 12: 0.01% Coverage

His daughter was in England his only daughter, she used to keep ringing up his father (I had desamita a bit) has a lot of money you know he got a load of money from the sun or homes deal, but the daughter was living in Manchester and used to keep stipping her. Does say “I want money for this that and the other”. She didn’t have time to come to the sun and he used to call for her. My darling Anna, and that’s why he used to speak abo Anna (the ward manager), she kind of made it easier. I think she kind of made it easier after his death. I think she wrote to her and told them things about her father. She didn’t be
APPENDIX 8 E: FOURTH PHASE OF ANALYSIS

Coding analysis - memos/annotations
Early conceptual map to depict model of end of life care.