

***Preserving Self in the Face of Death and Dying: A Grounded Theory of End-of-Life Care Needs of People with Intellectual Disabilities.***

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**“How people die remains in the memory of  
those who live on.”**

Dame Cicely Saunders (1989, pp.624)

Founder of the Modern Hospice Movement

## Declaration

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I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Doctor of Philosophy is entirely my own work, that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

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# ABSTRACT

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## ***“Preserving Self in the Face of Death and Dying: A Grounded Theory of End-of-Life Care Needs of People with Intellectual Disabilities”.***

**Kumaresan Cithambaram**

### **INTRODUCTION**

There is evidence to show that people with intellectual disabilities receive poor and inconsistent care at end of life, and that inclusion of people with intellectual disabilities in research to shape their health care delivery is sporadic. Therefore, this study is concerned with exploring the end-of-life care needs of people with intellectual disabilities from their perspectives and family members.

### **AIMS AND OBJECTIVES**

The aim of this study was to explore the needs of people with intellectual disabilities at the end of life and to develop a substantive grounded theory that explains these care needs. The objectives were 1) to explore attitudes, perceptions and preferences of people with intellectual disabilities about their end-of-life care needs, 2) to explore perceptions and experiences of family members about the end-of-life care needs of people with intellectual disabilities and 3) to develop a model of service delivery for people with intellectual disabilities at the end of life.

### **METHODOLOGY**

Using a constructivist grounded theory, 19 in-depth interviews, including 11 participants with intellectual disabilities and 8 family members, were conducted. The data were systematically analysed by using constant comparative methods to produce findings that are grounded in participants’ data.

### **FINDINGS**

These findings suggest that people with intellectual disabilities require holistic care at the time of dying, including physical, social and spiritual care. Dependency at the time of dying is an issue for many people with intellectual disabilities as they suspect that their individuality and dignity might be compromised. They also believe that familiarity at end of life would ensure their safety and comfort and improve their quality of life and quality of care. In addition, they value the importance of disclosure, of their disease prognosis, and plan of care, because this helps them to let other people know about their wishes and preferences. Finally, they want to have their spiritual needs met, which many feel would allow their souls to rest in peace.

### **CONCLUSION**

Based on findings that were grounded in the data, a care delivery model has been developed to meet the end-of-life care needs of people with intellectual disabilities. At a time when many people with intellectual disabilities suffer from life-limiting illnesses and receive inconsistent and inadequate service, this study is both timely and necessary.

# CHAPTER 1- INTRODUCTION

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## **1.1 INTRODUCTION**

Many research studies have expressed concerns regarding the quality of end-of-life care offered to people with intellectual disabilities. Also, people with intellectual disabilities receive less attention in research when compared to the general population. In order to provide good quality end-of-life care, it is imperative that service users be involved and their opinions and views heard. With this in mind, this study involves people with intellectual disabilities as they express the kind of service they would like to receive at their end of life and how their needs should be met. Based on their perceptions, wishes and views, a model of service delivery was developed in order to meet their needs at end of life. The opening chapter of this thesis consists of three sections. The first section introduces the research, context and justification for the study. The second section gives an overview of palliative and end-of-life care policy development in Ireland, and the final section provides a brief overview of the subsequent chapters of the thesis.

## **1.2 PRESENTATION AND JUSTIFICATION FOR THE STUDY**

This study focuses on the end-of-life care needs of people with intellectual disabilities. It draws upon, and adds to, an existing body of research in the area. The need for research on end-of-life care needs amongst people with intellectual disabilities is essential in the Irish context given that a growing number of people with intellectual disabilities are now reaching old age due to advanced medical technologies, increased social support and an improved standard of living (Health Research Board 2015). In addition to this, people with intellectual disabilities are more likely to suffer from ill health than their non-disabled counterparts (Burke, McCallion and McCarron 2014).

This is due to social problems such as unemployment, lack of physical exercise, restricted social activities, obesity, poor dietary habits and other additional health problems such as epilepsy and Down syndrome (Gazizova et al. 2012; Sinai, Bohnen and Strydom 2012). Similar to the general population, people with intellectual disabilities can also experience cancer, dementia, stroke and other life-limiting illness. As they die from life-limiting and chronic illness, this population has the same requirement for palliative and end-of-life care as the general population. Therefore, it is necessary for disability services and professionals who care for people with intellectual disabilities to meet their needs at their end of life.

In the past, there have been a number of studies carried out to explore the end-of-life care needs of people with intellectual disabilities using qualitative research approaches (McLaughlin et al. 2015; McLaughlin et al. 2014; Tuffrey-Wijne 2013; Tuffrey-Wijne 2010; Ryan et al. 2011a; 2011b; 2010; McCarron et al. 2008). In the vast majority of these studies, end-of-life care needs have been explored from the perspectives of professional carers, largely ignoring the views of people with intellectual disabilities. This is regrettable, given that it is a policy aspiration to include service users in planning, developing and delivering health services (Department of Health and Children and Health Service Executive 2008). With this in mind, the current study adopts an alternative approach to explore this issue: it concentrates specifically on people with intellectual disabilities and their family members by focusing on their personal experiences, views and opinions in relation to end-of-life care needs of people with intellectual disabilities. Moreover, this study develops a model of care delivery that best meets the needs of people with intellectual disabilities at end of life from their and family members' perspectives.

The specific research questions driving this study are as follows:

- What are the experiences, views and opinions of people with intellectual disabilities at the end of life?
- What are the experiences, views and opinions of family members of people with intellectual disabilities at the end of life?
- What factors impact upon, facilitate or hinder the dying experiences of people with intellectual disabilities?
- What strategies will help to improve the dying experiences of people with intellectual disabilities?

In answering these research questions, this study contributes to existing knowledge in the field of intellectual disabilities, palliative care and end-of-life care studies. By helping to identify barriers and facilitators in providing and receiving end-of-life care, the study develops strategies that help to improve end-of-life care to people with intellectual disabilities. Furthermore, by focusing on people with intellectual disabilities and their family members, the need for greater attention to the service user's perspective in shaping and delivering health service is addressed. In addition, by adopting a qualitative approach to studying the end-of-life care needs of people with intellectual disabilities, this study explores how individuals define and understand the concept of end-of-life care.

### **1.3 AIM**

The aim of this study was to explore the needs of people with intellectual disabilities at the end of life and to develop a substantive grounded theory that explains their care needs.

## **1.4 OBJECTIVES**

- To explore experiences, views and opinions of people with intellectual disabilities about their end-of-life care needs.
- To explore experiences, views and opinions of family members about the end-of-life care needs of people with intellectual disabilities.
- To develop a model of service delivery for people with intellectual disabilities at the end of life.

## **1.5 SETTING THE STUDY IN THE CONTEXT OF CURRENT POLICY DEVELOPMENT IN IRELAND**

In the late 1970s and early 1980s the modern hospice movement gained momentum in Ireland, with Our Lady's Hospice in Dublin (1979) and Marymount Hospice in Cork (1984). Milford Care Centre in Limerick was commissioned to provide specialist palliative care from the 1980s. During the 1990s other hospices such as St Francis Hospice Dublin, North West Hospice, Galway Hospice, Donegal Hospice and Blackrock Hospice were commissioned with the aim of providing specialist palliative care services through inpatient admissions, day care provision and home care to the local catchment areas. They also engaged in providing education to professionals, commissioning research, and auditing and evaluating palliative care provision throughout the country.

The Irish Government's commitment to further developing and improving palliative care services is reflected in the National Health Strategy (Department of Health 1994). This document highlighted the goal of developing services to provide care in a structured manner in order to achieve the best possible quality of life for both patients and families. Further, to improve services for people with cancer the government published another policy called the *'National Strategy for Cancer Services in Ireland'* in

1996 (Department of Health 1996). This policy aimed to give preference to service users' wishes and recommended allowing them to express their preferences and choices about where they want to be cared for and spend time at the end of life. Also, the strategy highlighted a flexible service provision to move service users to other care settings freely according to their care needs. The ultimate aim of this strategy was to provide specialist palliative care for those that required it. However, there was no agreed plan or strategy to promote and deliver palliative care either locally or nationally.

In recognition of the deficiency found in the *'National Strategy for Cancer Services in Ireland,'* a National Advisory Committee on palliative care was established in 1999. As the result of this, the *'National Advisory Committee Report'* was developed in 2001 (Department of Health and Children 2001). This report made several recommendations on structure of delivery, specialist palliative care, education and training, funding, and bereavement services. As per the recommendations, palliative care should be delivered at three levels of specialisation, each requiring different sets of skills and expertise based on progressive specialisation (Table 1).

#### **TABLE 1 LEVELS OF PALLIATIVE CARE PROVISION**

**Level 1** - Palliative Care Approach: Application and engagement of palliative care principles by all health care professionals.

**Level 2** - General Palliative Care Approach: This is the intermediate level of expertise, where a group of patients and families will benefit from the palliative care approach however the professionals do not engage in a full-time palliative care service but they are equipped with some palliative care training.

**Level 3** - Specialist Palliative Care: This is the territory of palliative care service, whose core activity is to provide palliative care service. Where the professionals are specialists equipped with knowledge and expertise to provide palliative care for people with complex and demanding palliative care needs.

In order to reduce inequalities and improve equity health service provision for all sections of people, the Department of Health (2001a) published a landmark policy called '*Quality and Fairness-A Health System for You*'. It recommended each regional health board carry out a needs assessment for specialist palliative care services. Also, there was a commitment to providing palliative care services for the non-cancer population.

The Irish Government accepted this as the national policy in providing palliative care. The government then made a commitment to provide the necessary resources. Despite their promise to provide resources and the existence of eight specialist palliative care services, a review carried out by the Irish Hospice Foundation (2006) found several gaps in providing palliative care. In particular, they identified that there were no dedicated inpatient specialist palliative care beds available in the Southeast of Ireland and limited service provision for the population of the Midlands. Further, the review criticised the unequal distribution of resources among regions, lack of provision of training, inadequate funding and poor integration among different care settings. In addition, this report also highlighted that there was a lack of palliative care provision for people with non-malignant illnesses. However, the focus has changed from traditional views of providing palliative and end-of-life care to the cancer population to non-malignant sufferers due to a few influential studies and reports including: End-of-life care for older people in acute and long-stay care settings in Ireland (O'Shea et al. 2008), Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks (Health Service Executive and Irish Hospice Foundation 2008), Health Information and Quality Authority's (HIQA) standards for residential care settings (2009) and the Hospice Friendly Hospice (HfH) programme (2006-2010).

Even though importance of specialist palliative care approach is highly valued and acknowledged, the studies by O'Shea et al. (2008) and HIQA highlight the importance of providing quality end-of-life care, training, education and resources in residential care settings. This is a clear indication of the need to adopt a palliative approach at primary and secondary care settings to manage physical, psychological, social and spiritual needs of people who are dying. The Palliative Care for All (Health Service Executive and Irish Hospice Foundation 2008) report highlighted the importance of providing end-of-life care to patients living with chronic obstructive pulmonary disease, dementia and heart failure throughout their illness trajectory. This was another milestone in palliative care policy development in Ireland that aimed to reduce inequality and promote provision of palliative care for all irrespective of diseases and settings. The Hospice Friendly Hospital (2006-2010) programme supports the principles of palliative care for all patients irrespective of disease condition and service settings. This programme aimed to implement hospice principles into hospital practice to ensure the existence of a systematic quality service available to achieve good death within the hospital setting. Ultimately, the aspiration of the programme was to establish a culture of providing end-of-life care that would become part of the everyday care provision within all care settings.

Increasing needs for a palliative approach among a population with chronic, progressive and life-limiting conditions forces generalist medical teams to equip and provide appropriate care to dying people at their present care settings. However, input from a specialist palliative care team can be accessed to manage complex needs. It is an aspiration of the National Palliative Care Policy (Department of Health and Children 2001) that provision of palliative care is everybody's responsibility and all patients who require palliative care should receive optimal care regardless of care settings and disease. Therefore, to realize the vision of the National Palliative Care Policy in Ireland,

all care settings, including primary, secondary and residential, must provide this end-of-life care without discriminating based on disease condition and care settings. The study was carried out with the assumption that professionals who care for people with intellectual disabilities at end of life are responsible for facilitating peaceful death.

## **1.6 STRUCTURE OF THE THESIS**

This study is driven by participants' experiences, views and opinion about their end-of-life care needs. A theory of preserving self in the face of death and dying is developed. The theory shows how people with intellectual disabilities expect to preserve their sense of self throughout the dying trajectory and after death. This theory highlights the factors that facilitate and hinder care provision at the end of life.

The thesis has eleven chapters. The second chapter gives an overview of the previous research on end-of-life care needs of people with intellectual disabilities. Chapters Three and Four provide an account of the chosen methodology and its practical application. Chapters Five to Eight present the details of the study findings. Chapter Nine discusses these findings in the context of existing literature and Chapter Ten presents a theory of preserving self in the face of death and dying and a model of service delivery. Finally, Chapter Eleven concludes the study. A detailed outline of the thesis is given below.

**Chapter Two** highlights the changing profile of people with intellectual disabilities and their end-of-life care needs, and focuses on discussing notions of good death and the relationship between end-of-life care and quality of life at the end of life. In addition, this chapter sheds light on the end-of-life care needs of people with intellectual disabilities and barriers in providing optimal end-of-life care to this population. Finally, the chapter identifies gaps in current knowledge and draws up research questions to address these.

**Chapter Three** focuses specifically on the methodological approach utilised in this study. It outlines detailed information about the appropriate methodological approach and issues. This includes discussion about the chosen research methodology of grounded theory and the specific version of constructivist grounded theory. This chapter also gives an account of the implications of choice and application of constructivist grounded theory methodology in this study.

**Chapter Four** discusses the research process, and the procedures employed both to collect and analyse data. The data was collected in an intellectual disability service that provides care for adult people with intellectual disabilities who reside in both community and residential areas. Over a period of eight months, 19 interviews, including eight family members and 11 people with intellectual disabilities, were conducted. This chapter also gives an insight in to various issues regarding recruitment, data collection and analysis.

**Chapters Five to Eight** present the findings of the study. **Chapter Five**, Holism, focuses on the importance of providing and receiving holistic care at the end of life. The sub-category Surrendering Independence highlights the expectations of people with intellectual disabilities that care providers meet their physical needs and ensure their health and safety. The sub-category Social Connectedness deals with the social needs of people with intellectual disabilities at the end of life. The participants explain how desperately they want to be with other people and the way in which this can be operationalised at the end of life. Finally, Spiritual Reconciliation gives an insight into the spiritual needs of people with intellectual disabilities when they come to terms with their illness and struggle to make peace with their past.

**Chapter Six**, Familiarism, discusses the importance of maintaining familiarity at the end of life. The participants feel that maintaining continuity through following routine,

living and dying around familiar people and staying in familiar environments enhances the quality of dying experience. **Chapter Seven**, Disclosureism, focuses on the importance of maintaining communication with people with intellectual disabilities who are dying, and issues of disclosure and discussion of their diagnosis, prognosis and future plans. It highlights the importance of having advance care directives in order to provide optimal end-of-life care. **Chapter Eight**, Respectivism, deals with the care needs of people with intellectual disabilities after death. It explains how people with intellectual disabilities long for recognition after their death. The participants believe that returning to their place of origin after death and remembering and respecting their wishes after death are of great value. Finally, they want to have spiritual care that will enable their souls to rest in peace after death.

**Chapter Nine** discusses the research findings in the light of the existing literature and how this study related to previous research in the area. **Chapter Ten** presents the theory of preserving self in the face of death and dying and also recommends a model of service delivery at the organisational and operational level. Finally, **Chapter Eleven** reviews and evaluates the study findings. In addition, this chapter discusses the contribution the study makes in the field of intellectual disability and end-of-life care, recommends areas for further study and draws some final conclusions.

# **CHAPTER 2- LITERATURE REVIEW: END-OF-LIFE CARE AND PEOPLE WITH INTELLECTUAL DISABILITIES**

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## **2.1 INTRODUCTION**

The life expectancy of people with intellectual disabilities has increased in recent decades. Since this population is surviving into old age, they live with common age-related illnesses such as dementia and life-limiting conditions like cancer, renal failure, cardiac failure and stroke. Therefore, they require the same end-of-life care as the general population. The aim of providing good end-of-life care is to improve quality of life and promote dignity while dying and after death. In order to provide good quality end-of-life care, it is imperative to explore the issues and needs from the perspectives of service users and their family members.

This chapter sheds light on trends of ageing and related issues and considers the magnitude of life-limiting conditions among the population of people with intellectual disabilities. It also discusses the importance of providing good end-of-life care for this population, while reviewing research on issues and barriers in the provision of this care at end of life. Finally, it explores various strategies to improve end-of-life care for dying populations with terminal illnesses in general, and specifically people with intellectual disabilities.

## **2.2 SEARCH STRATEGY**

The literature search for the study was carried out by using a wide range of databases, including: PsychArticles; PsychInfo; Cumulative Index to Nursing and Allied Health Literature (CINHAL); The Cochrane Library; Medline; Blackwell; Pub Med; and Science Direct and Synergy. Electronic searches were also carried out using the DCU

Online Research Access Service (DORAS) to find published theses from Dublin City University (DCU) and other universities. A search was carried out to find out policies from the Irish Government, the WHO, the United Kingdom, Northern Ireland and Council of Europe. Literature was also searched from voluntary organisations such as the Irish Hospice Foundation, Help the Hospices, Palliative Care for People with Learning Disability (PCPLD) network and All Ireland Institute of Hospice and Palliative Care (AIIHPC). Hand searches were carried out through Google Scholar and other journals to find other relevant literature.

The following search terms were used: ‘learning disability’, ‘intellectual disability’, ‘mental retardation’, ‘developmental disabilities’, ‘palliative care’, ‘end of life care’, ‘hospice care’, ‘supportive care’ and ‘terminal care’. There was no time period set to search materials and the literature review was confined to English language materials only.

### **2.3 PALLIATIVE CARE, END-OF-LIFE CARE AND QUALITY OF LIFE**

Palliative and end-of-life care mainly focuses on providing comfort, effective management of pain and other symptoms, improving individuals’ ability to cope, and maintaining quality of life (Grant and Sun 2010). Definitions of palliative care integrate the physical, psychological, social and spiritual components of the person and their family (Department of Health and Children 2001a). According to the WHO (2014):

*Palliative care as an approach that improves the quality of life for patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and impeccable treatment of pain and other problems, physical, psychological and spiritual.*

It is suggested that the role of palliative care is not only to manage pain and symptoms and control complications, but also to help address psychological and spiritual needs of

sufferers (Milligan 2012). In addition, palliative care helps to effectively manage the transition from a curative approach to a palliative approach, discussing prognosis and treatment options and recognising the signs of end of life (Burns and McIlfatrick 2015). Finally, palliative care provides support during dying and after death through a multi-disciplinary approach (Nakanishi et al. 2015). Palliative care begins with diagnosis and continues with curative treatment. In other words, palliative care provides comfort along with other curative interventions for patients who are suffering from life-threatening illness (Izumi et al. 2012). Further, Izumi et al. (2012) elaborate that throughout the disease trajectory palliative care offers palliation to the patients through assessment and management of pain and provides comfort. Consequently, this helps to improve quality of life at the time of dying.

End-of-life care is a continuation of palliative care when death is imminent and life expectancy is limited to a number of days, hours or less (Health Service Executive and Irish Association of Palliative Care 2012). This study uses the term “end-of-life care”, proposed by the UK National Council for Palliative Care (2006) and accepts as a working definition for “end-of-life care strategy”:

*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 2008, p.47)*

According to Kubler, Heidrich and Esper (2005) the term “end-of-life care” is a component of palliative care, which is the continuum of palliative and supportive care and extends to bereavement (Kubler, Heidrich and Esper 2005). As such, end-of-life care is an integral part of palliative care, which helps all people with incurable and advanced disease to live comfortably and die peacefully (Department of Health, Social Services and Public Safety 2009). The General Medical Council (2010) in the UK

proposes that end-of-life care begins when it is expected that an individual will die within the next 12 months, including those who may die within weeks, days or hours. In Ireland, the Irish Hospice Foundation and Health Service Executive (2008) outlines that end-of-life care begins when there is existence of chronic disease, or symptoms, or functional impairments that persist but may also fluctuate and the symptoms or impairments resulting from the underlying irreversible disease require formal or informal care that can lead to death.

In line with palliative care, end-of-life care also deals with the needs of physical, psychological, social and spiritual aspects of the individual (Hodo and Buller 2012; National Council for Palliative Care 2007). With this perspective, end-of-life care can be successfully extended to all life-limiting illnesses such as heart failure (Price and Jones 2013), chronic obstructive pulmonary disease (Leung 2012), chronic liver disease (De Siqueira da Silva and de Paula 2011), stroke (Gardiner et al. 2013), renal failure (Huijberts, Buurman de Rooij 2016; Brown 2012; Hopkins et al. 2011) and dementia (Jones et al. 2016; Peacock 2013). It is, therefore, clear that end-of-life care is applicable to all care settings and to a variety of clinical conditions and involves longer time frames than merely days or weeks before death to improve quality of life.

The primary goal of providing end-of-life care is to promote dignity and enhance the quality of life at the last stage of life by considering a dying person as a whole person rather than a group of symptoms (Grant and Sun 2010). Researchers found several areas of care that are very important at the end of life in order to improve quality of life. These are: participating in health care decisions, adequate preparation and addressing concerns for the family, symptom management, social connectedness, and support (Stead and McDonnell 2015; Brown 2012; Engelberg et al. 2010).

It is recommended by Boot (2016) and Tang et al. (2014) that participating in health care decisions and having control of medical treatment be considered important to improving quality of life at the time of dying. This includes having a good relationship with health care professionals, having control of medical treatment, and making decisions as well as acquiring adequate information (Amjad, Towle and Fried 2014). Further, Mori et al. (2013) consider that lack of end-of-life care discussion reduces the quality of life at the end of life. Consequently, they advocate that explicit discussion about end-of-life care such as care options and other treatment choices with the patient and family will facilitate service users in making their own choices about their end-of-life care.

It is suggested by Nelson (2013) that early discussion and commencement of palliative care benefits people with life-limiting illness. Despite this suggestion, health care professionals are reluctant to engage in such a conversation with patients as they feel that this may decrease their hope of surviving (Lewis 2013). White et al. (2013) explore views of health care professionals in ICU and proposes that professionals are not reluctant to discuss the issues associated with life-limiting conditions at the early stage but it is very difficult for them to predict the survival of patients with acute illness, so they postpone a discussion to the later stages of a terminal disease. However, having a discussion between health care professionals, family and the patient helps to develop advance care planning that includes their choice of treatment, wishes and preferences (Amp et al. 2016; Stead and McDonnell 2015). Advance care planning reduces stress, depression and anxiety among patients and family, consequently helping to meet and respect the wishes and preferences of the patients at the end of life (Sinclair, Oyebode and Owens 2016; Amjad, Towle and Fried 2014; Deterring et al. 2010).

Gardner and Kramer (2009) suggest that most people at the end of life have concerns for their family members. Therefore, they recommend that relieving the burden on family members and helping to strengthen relationships with loved ones is equally as important as relieving pain and providing a sense of control. Brown (2012) agrees and elaborates that caregivers' burden (CB) and self-perceived burden (SPB) of service users, such as worries about being a burden to the family, fear of dying and regrets about life, influence the nature of end-of-life care provision, and the place of care. In order to reduce these concerns, Lee et al. (2015) advocate that adequate preparation, addressing issues faced by family members such as placing undue responsibilities for making decisions about loved ones upon them, and assisting patients to talk frankly about their feelings about being a burden to their family would help to improve quality of life at end of life.

Rosenberg, Bullen and Maher (2015), Dy et al. (2011) and Woo et al. (2011) report that managing pain and symptom control are most important actions at the end of life to promote quality of life. Alexander, Goldberg and Korc-Grodzicki (2016), Hermann and Looney (2011) and Cordner et al. (2010), suggest how symptoms like pain, nausea and fatigue should be controlled and explain how these symptoms interfere with patients' enjoyment of life, enjoyment being crucial to quality of life at this time. In accordance with these recommendations end-of-life care aims to reduce pain and other associated complications, promote communication to identify preferences, and prevent or reduce anxiety and stress among patients and their family members; finally, it helps to reduce the caring burden of service providers (Vollenbroich et al. 2016; Curtis et al. 2011). To achieve these benefits, Stilos et al. (2016); Ouimet Perrin and Kazanowski (2015) and Devi (2011) recommend that early referral of complicated cases to a specialist palliative service was essential as it helped the patient, family members and care providers to

understand each other's needs, wishes and preferences and also facilitated building relationships and trust between patient, family and service providers.

Receiving support and personal wellbeing at the end of life is another indicator that determines quality of life at this time. Herber and Johnston (2013) and Prince-Paul (2008) identify that social connectedness and relationships with family members and friends at the end of life are crucial for people who are dying. The social domain is concerned with how confident the dying person is to share their thoughts with family and friends and how often they spend quality time with them (Cramer 2010). They consider this as essential as other aspects of care provision. This includes helping and encouraging other people, giving meaning to life by engaging in local and national activities (Wiebe 2104; Abresch et al. 2009) as well as expressing their wishes to their loved ones and having peace and spending time with family (Gardner 2012). These elements are considered essential to measuring quality of life at the end of life in order to determine whether the death was good or bad.

Quality of life is a good indicator to determine the quality of care that was provided during the last phase of life (Hendricks et al. 2014). Though there are few measures available to measure quality of life at the end of life, for professionals, the Quality of Dying and Death (QODD) checklist is considered the most effective measurement tool (Sellers et al. 2015; Downey et al. 2010). This tool can be administered to family members or caregivers as a patient's proxy when a dying person cannot participate in communication (Khandelwal 2014), and is intended to highlight a dying person's experiences (Hales, Zimmermann and Rodin 2010). This checklist consists of six domains which are important indicators to show the quality of care that is provided at the end of life: pain and symptom control; communication and discussion; involvement

of family and friends; choice and control over care decision; and a holistic approach (Sellers et al. 2015).

In summary, there is a consensus that the physical comfort, psychological, spiritual and social wellbeing of patients and family are important. In addition, communication among patients, caregivers and family members, control and choice over care decisions, continuity of care and bereavement support for the family are considered essential factors to improve quality of care at the end of life. Good quality of care provided at the end of life contributes to good death experiences to dying people.

## **2.4 THE NOTION OF GOOD DEATH**

Achieving good death is one of the main objectives of providing end-of-life care. This concept has been given more attention recently due to increased expectations of service users and pressure from international policies (Department of Health 2008; National Council for Palliative Care 2006). What could be considered a good death varies from individual to individual and culture to culture (Burles, Peternej-Taylor and Holtslander 2016), and has been explored from the perspectives of service users (Ko, Kwak and Nelson-Becker 2015), care providers (Da Silva, Pereira and Mussi 2015) and family members (Holdsworth 2015). However, there is so far no universal agreement on what constitutes a good death (Haishan et al. 2015).

A modern concept of good death are when pain is controlled and a patient can choose when, where and how they die (Hattori and Ishida 2012). In other words, a good death is free from avoidable pain and suffering on the part of patients and family and is congruent with their wishes (Brady 2013). In contrast, Ko et al. (2013) bring a different perspective: that a good death is not measured on the basis of a pain-free and peaceful death because some people do not want to surrender hope and want to fight against

death. Therefore, in their opinion, a good death is what is appropriate and requested by an individual patient.

Even though there is a lack of consensus as to what a good death is (Shaw 2015; Gallagher 2013), it is generally accepted that a good death is one that is anticipated, informed and accepted by the individual who is dying (Granda-Cameron and Houldin 2012; Gott et al. 2008; Cheng et al. 2008). It is further noted that a good death is where a person has control over clinical decisions, feels comfortable and their dignity is maintained throughout their dying trajectory (Haishan et al. 2015). However, Russell (2015) and Cheng et al. (2008) suggest that these characteristics of a good death cannot be generalised to the entire population as the characteristics of a good death have different contexts for different people based on geography, religion, culture, and socio-economic situation; some people while dying do not want to make any decisions and transfer the decision-making responsibility to family members and health care professionals (Lind et al. 2013).

According to Cipolletta and Oprandi (2014) and Gott et al. (2008) a good death is when someone is aware of their impending death and is able to control this event as it progresses. Furthermore, the dying person can discuss it with their family, accept their death, and is able to make decisions regarding their treatment and other affairs. Additionally, open communication amongst patient, family and care providers is essential to discuss progress towards the end of life, which helps them to make funeral arrangements and facilitate family members in saying goodbye to their loved ones (Ko, Kwak and Nelson-Becker 2015). Meanwhile, in Korea, Shin et al. (2015) explore patients' preferences in relation to disclosure of their diagnosis where the participants prefer not to have open communication about their impending death as, the participants believe, it may cause psychological distress and loss of hope (Zhang 2015). However,

Ko et al. (2015) found in their study that older people at end of life expect to receive adequate information about their clinical condition, prognosis and care options and consider this to be a physician's obligation to their patients. Recent policies and guidelines focus on patient informed consent and patient-physician communication (Huang et al. 2015); therefore physicians should find an appropriate strategy to establish open communication with dying people and honour their wishes.

It is suggested that providing a place with adequate staffing and that is quiet facilitates a good death (Brereton et al. 2012). In addition, being cared for in a single room may promote family relationships and also improve and preserve patient dignity at the end of life (Lee, Woo and Goh 2013; Miyashita et al. 2008). In contrast, Hunt, Shlomo and Addington-Hall (2014) argue that even though provision of a single room provides privacy and dignity that is important at end of life, sometimes people feel that they are isolated and deprived of psychological and emotional support and staff vigilance (Aleksandrova-Yankulovska and Ten Have 2015). Consequently, Slatyer (2015) suggests patients' wishes and preferences should be taken into account.

Health care providers perceive that good death is having awareness about self, acceptance of the clinical condition, preparation for eventuality, having peace and caring with dignity (Scarre 2012; Paddy 2011). Smith (2013) and Adamson and Cruickshank (2013) suggest that the place of care also influences the quality of care at the end of life; this ultimately determines the dying experience. Da Silva, Pereira and Mussi (2015) view good death as consisting of a long fulfilling life (Yang and Lai 2012) and a smooth dying process that occurs at home surrounded by familiar faces (Adamson and Cruickshank 2013; Paddy 2011). Miyashita (2008) advocates that environmental, physical and psychological comfort promote good death. On the other hand, life-prolonging treatments such as antibiotics, artificial feeding and artificial ventilation are

considered barriers to a good death (Miyashita 2008). Morita et al. (2014) and Tayeb et al. (2010) find that: self-esteem; dignity and privacy; spiritual and emotional support; pain relief and symptom control; the ability to say goodbye; control of what happens; and avoiding unnecessary life-prolonging treatment are considered important elements of good death.

To help health care providers to assess what constitutes a good death and evaluate the quality of end-of-life care provisions in all health care settings, a UK policy organisation, Age Concern, developed guiding principles in 1999. The guiding principles are: to know when death is coming and to understand what can be expected; to be able to retain control of what happens; to be afforded dignity and privacy; to have control over pain relief and other symptoms; and where death occurs whether at home or elsewhere.

To summarise, death can be dignified and should be congruent with the way the person lived and with their wishes. The involvement of a palliative care team in managing complicated and complex symptoms in some cases may be required to assist and to provide optimal end-of-life care as the palliative care team has specialist knowledge, skills and experience (EAPC 2015; Smith 2013; Granda-Cameron and Houldin 2012). To this end, a good death is a death in which the individual has been able to choose the way they want to die (Miyashita et al. 2015; Haishan 2015; Ko, Kwak and Nelson-Becke 2015). The notion of good death does not necessarily apply only to the general population but also to marginalised, underprivileged and vulnerable populations such as those with intellectual disabilities.

## **2.5 THE CHANGING PROFILE OF PEOPLE WITH INTELLECTUAL DISABILITIES**

In Ireland, nearly 27,691 people with intellectual disabilities were registered as care recipients at the end of December 2014 (Health Research Board 2015). This represents a prevalence rate of 6.04 per 1000 population. Intellectual disability is a term that is recommended in Ireland (Department of Health and Children 1990) to identify people with limited ability to comprehend and understand new and complex information.

According to the WHO intellectual disability is defined as:

*...a significantly reduced ability to understand new or complex information and a reduced ability to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development (World Health Organization 2014).*

Overall, in Ireland, the number of people living with intellectual disabilities has increased by 41% since the first time this information was included in 1974. More importantly, the number of people with intellectual disabilities who are aged over 35 has increased from 29% in 1974 to 49% in 2011 with nearly 12.6% aged over 55 years. It is expected that the population with intellectual disabilities who are over 55 years will continue to grow in the future due to better medical and social care and improved lifestyle (Intellectual Disability Supplement to The Irish Longitudinal Study on Aging 2014). The changing demographic profile means people with intellectual disabilities are living longer and suffering from one or more chronic age-related medical problems, similar to the general population (McCarron et al. 2015; Haveman et al. 2010). Consequently, over the years many people with intellectual disabilities will require long-term and, for some, complex care.

The Intellectual Disability Supplement to The Irish Longitudinal study on Aging (2011) also found that people with intellectual disabilities suffer from the same age-related illnesses as the general population, such as cardiovascular diseases (Davis 2006); renal

diseases (Black and Hyde 2004) and respiratory diseases (Patja, Eero, and Iivanainen 2001); pneumonia (Read and Thompson-Hill 2009); dementia (IDS-TILDA 2011); and cancer (Todd 2005). There have been a number of large-scale studies carried out to identify patterns of disease prevalence in this population in the UK, the USA and Finland. These studies found that deaths due to age-related problems and cancer have increased dramatically (8-13%) over the last decade (Haveman et al. 2011; Read and Thompson-Hill 2009; Black and Hyde 2004). This is a similar mortality rate to the general population (Haveman et al. 2011).

It was also found that most people with Down syndrome develop some form of neuropathic changes after 40 years and 50% of the population with Down syndrome develop Alzheimer's dementia (AD) at the age of 60 (Burke, McCallion and McCarron 2014). The incidence of dementia among the intellectually disabled population aged 65 years and above is five times greater than the general population and this peaks after 75 years of age (Strydom et al. 2013). In addition, older adults with intellectual disabilities can suffer from other medical problems, such as pneumonia, which may increase the severity of the dementia process (Patti and Tsiouris 2006). This evidence clearly shows us that the prevalence of malignant and non-malignant life-limiting illness among people with intellectual disabilities is in line with the general population.

The recent IDS-TILDA (2011) study found that living longer might also lead to social disadvantages such as lack of health care service provision and social isolation. As a result, people with intellectual disabilities have the same end-of-life care needs as their non-disabled counterparts but they experience service inequality (Department of Health 2011; Stein 2008). Consequently, they suffer unnecessarily due to inadequate and inappropriate end-of-life care provision (Michael and Richardson 2008). To ensure

equality and to promote a good dying experience, the population with intellectual disabilities is in need of similar end-of-life care provision as their non-disabled peers.

## **2.6 END-OF-LIFE CARE FOR PEOPLE WITH INTELLECTUAL DISABILITIES**

It is evident from the report developed by the Health Research Board (2015) that people with intellectual disabilities are getting older and living longer than before. The changing demographic profile means this population faces the same issues, such as chronic life limiting illness and ageing problems, as the general population. The WHO has identified people with intellectual disabilities as a disadvantaged, vulnerable and marginalised group (Davies and Higginson 2004), who experience inequality in accessing health care services including end-of-life care (Sheerin 2012; Tuffrey-Wijne 2010; Davies and Higginson 2004). This may be due to under-referrals and lack of understanding by professionals working with people with intellectual disabilities about palliative and general hospital services (Botsford and King 2010; Tuffrey-Wijne et al. 2007).

Professionals feel that communication is a key area in end-of-life care that plays a crucial role in promoting quality of life at the end of life (Hales et al. 2014). Yet quality of life of people with intellectual disabilities at end of life is very much affected by lack of communication between service users and health care providers about their disease condition and other related issues (Tuffrey-Wijne and McLaughlin 2015; Ryan et al. 2011a; Tuffrey-Wijne 2010). This may be due to the carer's lack of knowledge in communicating effectively (Ronnerberg et al. 2015; Ryan et al. 2011a) or the lack of cognitive ability of people with intellectual disability to understand and interpret the situation (Tuffrey-Wijne et al. 2010, 2007; Mencap 2007).

There is an anxiety among professionals about disclosure when caring for people with intellectual disabilities at the end of life (Ryan et al. 2011a). Many parents of people with intellectual disabilities want to protect their loved ones from knowing the truth about their terminal illness because they feel that the truth may cause psychological and emotional stress to their loved ones (Todd 2007; Davis 2006). In addition, studies by Ryan et al. (2010) and McCarron et al. (2008) found that professionals expressed that there was a lack of engagement by medical professionals with people with intellectual disabilities regarding disclosing their clinical condition and other issues. Similarly, a study by Marlow and Martin (2008) revealed that family members suggested non-disclosure of their loved one's clinical condition and impending death as this would upset and terrify them. As a result, parents and professionals prefer to make the decisions for people with intellectual disabilities regarding their end-of-life care needs (Bekkama et al. 2015). Despite this, most people with intellectual disabilities want to know what is going on and wish to be informed of their condition before it is communicated to their family and carers (Foster et al. 2006). In their study, McLaughlin et al. (2015) found that people with intellectual disabilities valued the importance of providing appropriate information that is easily understandable. In their study, Tuffrey-Wijne and McEnhill (2008) suggest assessing the level of comprehension and communication on an individual basis before communicating with people with intellectual disabilities regarding their disease progression and impending death.

The theory of normalisation emphasises that individuals with intellectual disabilities are members of society and as such they have a choice about where to live, be cared for and die (McCarron et al. 2008; Foster et al. 2006). Read and Cartlidge (2012) find that people with intellectual disabilities were not given an opportunity to express their wishes in relation to their final place of care and funeral wishes. At the same time, family members take the role of decision maker for their loved ones but they also

expressed concerns that they were not sure about their boundaries and other legal aspects surrounding decision making (Wagemans et al. 2013). In addition, many family members often feel anxious and insecure when making decisions for their next of kin as they are unsure of their loved one's wishes and preferences. As a result, they suffer the burden of and responsibility for making decisions for others (Wagemans et al. 2013). To reduce this stress and anxiety, family members feel that they should be getting support from professionals in making decisions (Bekkema et al. 2015). There is also a concern from family members that at times there will be different perspectives between family members and professionals as to what constitutes good end-of-life care (Bekkema et al. 2015). It can be concluded that patients' family members are willing to make decisions for their loved ones at the end of life regarding foregoing treatments, continuation of some treatments and more importantly resuscitation status. They expect health care professionals to provide help in making decisions at this difficult time. Since people with intellectual disabilities have the same rights and choices as the general population they should be given more opportunity to discuss and dictate their own care needs for their end-of-life care issues (Tuffrey-Wijne and McLaughlin 2015). Consequently, this would reduce the anxiety and burden on family members and professionals and ensure the wishes of the person with intellectual disabilities were respected.

People with intellectual disabilities are often moved to other care settings to receive care at the time of dying due to a lack of knowledge and skills of staff working in the intellectual disability service (Tuffrey-Wijne 2010). However, people with intellectual disabilities do not want this change and want instead to be surrounded by and near to familiar people (Tuffrey-Wijne et al. 2007). Other reasons why people with intellectual disabilities are reluctant to move to general care settings are that they experience feelings of isolation and negligence (Brown et al. 2012; Tuffrey-Wijne 2010). As such, people with intellectual disabilities want to die in their usual place of residence and also

they are aware that they could be moved to other care setting such as a hospice or hospital if they could not manage at home (Martean et al. 2014). In previous encounters with general care settings, family members expressed that professional reassurances and accommodating people with intellectual disabilities in an appropriate way would ensure that mainstream health care settings could make people with intellectual disabilities and family members feel safe (Marlow and Martin 2008).

Despite the higher demand and expectation to provide end-of-life care to people with intellectual disabilities, they often receive poor, inadequate care and inappropriate care (Dunkley and Sales 2014; McLaughlin et al. 2014; Tuffrey-Wijne 2009). People with intellectual disabilities are excluded, marginalised, and prevented from receiving appropriate care by existing services (Read and Thompson-Hill 2009). This is due to poor inclusion of people with intellectual disabilities in planning and developing services in spite of their right to have a choice, independence, equality, rights and inclusion. It is therefore necessary to include their voice, opinions and views in developing an appropriate end-of-life care model to meet their changing needs at the end of life. In order to include their voices and views, it is important to promote their autonomy and decision-making.

## **2.7 AUTONOMY AND DECISION MAKING**

One of the major principles of the United Nations Convention on the Rights of People with Disabilities is:

*respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons* (United Nations General Assembly, 2006, article 3).

Achieving and maintaining the principle of autonomy is a key indicator of providing good care for people with intellectual disabilities. Yet, this goal is not a lived experience for many of these people due to lack or limited cognitive ability or them requiring

assistance to exercise the components of autonomy such as choice, control and decision-making (Harris, Heller, Schindler and Van Heuman 2012). According to Stainton (1994, p.21) autonomy involves:

*'...The agent's freedom from both internal and external constraints, to formulate and pursue self-determined plans and purposes'* (1994, p.21)

Therefore, it can be concluded that people with intellectual disabilities should be expected to live their lives the way they want to and fulfill their wishes and needs. However, Lotan and Ells (2010) argue that people with intellectual disabilities who live in supported facilities find it difficult to articulate the concept of autonomy and are compelled to live with constraints imposed on them. Even though evidence shows that people with intellectual disabilities have the ability to make choices and exercise their autonomy, the presence of regimentation and structure in some of the support services prevent people with intellectual disabilities from executing their rights (Synder and Mitchel 2006; Antaki et al. 2006). Gray-Stanley et al. (2010) and Wilson, Clegg and Hardy (2008) argue that staff in support services face struggle themselves to promote autonomy among people with intellectual disabilities due to such factors as lack of staffing, high turnover of staff, inadequate training and skills, and challenging ethical issues.

There is a common perception that people with intellectual disabilities have inadequate skills to make decisions that affect their lives especially regarding medical decisions (Wullink et al. 2009), and it is assumed that people with intellectual disabilities are unable to involve themselves fully and autonomously in society (Petner-Arrey and Copeland 2014). However, the United Nations Convention on the Rights of People with Disabilities compels governments to support people with intellectual disabilities to be autonomous and independent. As a result, the Irish government has implemented Assisted Decision-Making (Capacity) Act 2015 for the implementation and protection

of the rights of people with cognitive disability. The Act provides a range of provisions for people to make decisions themselves. The first provision in the Act encourages the individual to make decisions by themselves with minimal support by providing easy-to-read information and pictorial explanations. The second provision is supported decision-making, whereby people with intellectual disabilities who cannot make a decision by a level 1 provision will be assisted and supported by someone who they trust to make a decision. The third provision is facilitated decision-making; this is used as a last resort where the previous two options are not possible and where the person's will and wishes are not known. In this arrangement representatives who are well known to that person will decide what would be the best for that person based on their best understanding of that person's interest, wishes and preferences.

This Assisted Decision Making Act (2015) will have significant implications on provision of safe person-centred end-of-life care based on an individual's rights and choice. The act respects individuals' right of autonomy and self-determination through an enduring power of attorney and advance health care directives. In addition, the act places a legal requirement on service providers to comprehensively enable service users to make decision through providing appropriate support and information based on their cognitive ability and needs. This facilitates the legal requirement of service providers to discuss the caring process to people with intellectual disabilities or their legal representatives to make appropriate decision around end-of-life care. Consequently, this reduces the rights of family members and care providers to make decision for service users with intellectual disabilities.

Making decisions and executing autonomy with regard to health-related issues is very important especially at end of life (Petner-Arrey and Copeland 2015). In their report, the WHO highlight the importance of autonomy in palliative and end-of-life care among

older people, stating that irrespective of the person's difficulties and their uncertain future, autonomy is an important human rights principle and must be maintained to preserve the value of society and health services (Davies and Higginson 2004). The Department of Health (2005) proposes that to exercise autonomy, the patient is expected to have competency to make decisions. However, while in the phase of end-of-life care, many people exhibit reduced or altered mental capacity. In order to facilitate the concept of autonomy, choice, and rights of dying people, the Department of Health (2008) emphasises the importance of developing advance care planning when an individual is in a good mental state. However, Goodman et al. (2013) find in their study that older people view trust and continuous dialogue, rather than developing a formal plan, as essential when receiving end-of-life care. To support this, Harris and Fineberg (2011) in the UK and Frank and Anselmi (2011) in the US identified that less than a quarter of patients have their advance care plan completed by end of life.

Respecting the autonomy of people with intellectual disabilities at end of life is challenging for caregivers and family members. In order to respect their autonomy, family members and caregivers should engage with people with intellectual disabilities at an earlier stage when they are healthier and able to communicate their preferences and wishes (Tuffrey-Wijne and McLaughlin 2015; Foster et al. 2006). At the same time, relatives and professionals should monitor the changing needs and wishes of people with intellectual disabilities as this will alter when their condition deteriorates and these changing needs should be accommodated as required (Stein and Kerwin 2010). However, Bekkema et al. (2014) caution that eliciting care needs, and understanding the wishes and preferences of people with severe intellectual disabilities is very difficult. On the other hand, the wishes and preferences of people with mild intellectual disabilities are easily explored but that conflict with family members and caregivers, which creates the dilemma of whether to carry out these wishes or not (Bekkema et al.

2014). It is also found that lack of involvement and an inability to involve people with intellectual disabilities in end-of-life care discussion is a difficult issue that undermines the autonomy of people with intellectual disabilities (Wagemans et al. 2013; Stein 2008). In order to facilitate autonomy among people with intellectual disabilities at end of life, Bekkema et al. (2014) propose to employ Agich's (2003) notion of 'actual autonomy' by which caregivers and family members help people with intellectual disabilities to pass through end of life by using their relationship. It is also suggested that when people with intellectual disabilities are physically and mentally impaired, relatives and professionals should devise an advance plan in order to meet the wishes and preferences of people with intellectual disabilities by involving them and exploring what their likes and wishes in the past were by utilising their relationship (Tuffrey-Wijne and McLaughlin 2015; Bekkema et al. 2014).

## **2.8 BARRIERS TO PROVIDING EFFECTIVE END-OF-LIFE CARE FOR PEOPLE WITH INTELLECTUAL DISABILITIES**

People with intellectual disabilities are in many ways considered marginalised, underserved and vulnerable; this is particularly salient when it comes to death, dying, loss and bereavement (Watchman 2012). There are many barriers that affect people with intellectual disabilities when receiving good end-of-life care. These barriers include both specific issues related to people with intellectual disabilities, such as lack of communication and cognitive abilities, as well as general service related issues such as fragmentation of care; the culture of organisation in providing care; lack of education and training of professionals in providing end-of-life care; inadequate resources; as well as lack of spiritual and psychological support.

## **2.8.1 Communication**

It is found that poor cognitive ability (Goldsmith, Hendrix and Gentry 2006), difficulty in communication (Tuffrey-Wijne and McEnhill 2008) and reduced ability to understand information (Ryan and McQuillan 2010) make people with intellectual disabilities marginalised, under-privileged, and more disadvantaged in society (Heslop 2013). In addition, people with intellectual disabilities often fail to notice and communicate their health problems to their health care providers, even though they have greater health care needs (Ryan et al. 2011b). As a result, people with intellectual disabilities receive fewer screening tests than the general population, thus resulting in late presentation to specialist health care services (Disability Rights Commission 2006). This may lead to late diagnosis of severe illness resulting in less favourable outcomes (Tuffrey-Wijne 2010; Read and Thompson-Hill 2009).

Communication is an essential element for the accurate and early diagnosis of medical conditions (Tuffrey-Wijne et al. 2007a). Nearly 50% of people with intellectual disabilities suffer from some form of communication difficulty such as impaired hearing, cognitive impairment, visual defects, speech and language difficulties and social interaction difficulties (Stein 2008). These are added difficulties for people with intellectual disabilities when it comes to expressing their problems to professionals; consequently, professionals find it hard to identify and assess medical conditions at an early stage (Tuffrey-Wijne and McEnhill 2008). Furthermore, health care providers misinterpret the medical symptoms of people with intellectual disabilities as part of their intellectual disability or challenging behaviour (Dunkley and Sales 2014). As a result of this, illness amongst people with intellectual disabilities is identified at later stages; subsequently, prognosis and treatment outcomes become poor (Li and Ng 2008).

When it comes to the end of life, it is found that reciprocal communication between service providers and service users is an essential element to understanding the emotions and preferences of service users by service providers (Cross et al. 2012). A pain assessment tool called DisDAT (Disability Distress Assessment Tool) was developed (Regnard et al. 2007) to reduce the misinterpretation of medical symptoms and help professionals to identify medical problems at earlier stages in people with intellectual disabilities. This tool helps to identify symptoms of pain or distress through the functional assessment of behavioural observation in people with intellectual disabilities (Regnard et al. 2007). Mckenzie, Smith and Purcell (2013) concur with Regnard et al. (2007) with regard to pain assessment; however they caution that not all manifestation of distress might be due to pain; rather they recommend a careful clinical examination to rule out possible causes. Finally, they propose training for those working with people with intellectual disabilities to improve staff understanding as well as the recognition of and response to pain exhibited by people with intellectual disabilities (Reddall 2010).

It is advocated by Read and Cartlidge (2012) that good reciprocal communication is fundamental between service providers and service users during death and dying to improve choice and control among people with intellectual disabilities. Furthermore, the reciprocal communication about impending death may give a sense of control over the dying process. Consequently, this facilitates discussing the patient's concerns and making their own plans for a peaceful and good death (Ryan et al. 2011b). In contrast, the news of imminent death is hidden from the dying person with intellectual disabilities and their relatives (Read 2006). The lack of open communication by professionals may prevent the dying person from making a care plan to be implemented at the time of death (Read 2006). In addition, family members are sometimes excluded from the dying process of their loved ones, thus prohibiting meaningful interaction; consequently, there

may be potential for difficult bereavement (Read 2006; Ellershaw and Ward 2003). Read (2006) described this as a disenfranchised death, when the imminent death is deliberately hidden from the dying person. The person is socially excluded from the decision-making process of dying. There may be different reasons as to why impending death is not openly acknowledged to the dying person or their relatives. Van Soest-Poortvliet et al. (2015) found that deaths among people with intellectual disabilities and older people are often sudden, therefore it is difficult for professionals to identify that the person is actually dying at an early stage (Bulsink and Georges 2013). Lack of knowledge and skills of how to break bad news to dying people and their families, coupled with the paternalistic approach of professionals to protect the person with intellectual disabilities from the impact of bad news, are perceived to be a cause of non-disclosure of the impending death to service users (Tuffrey-Wijne 2013).

### **2.8.2 Fragmented care**

Most often when service users transfer from one care setting to another during acute illness, they receive poor, inconsistent and fragmented care due to poor communication between services (O'Shea et al. 2008). In addition, multiple professionals care for service users, and sometimes this move is less than smooth (O'Shea et al. 2008). Communication amongst professionals during this period is often lacking; this creates confusion among professionals about how to manage the service users when they are sick and dying (Friedman, Helm and Woodman 2012). Sometimes, service users will be moved abruptly to other services for emergency care, thus creating a discontinuity of regular care provision (Leff et al. 2015). More often than not, people with intellectual disabilities may be transferred to other settings that provide aggressive treatments, rather than receiving care in familiar surroundings, due to lack of training and resources (Patti, Amble and Flory 2010). Rocker, Simpson and Horton (2015) find that moving

from one care setting to another for the elderly population is a disruption to their care and causes confusion and deterioration in their condition.

### **2.8.3 Organisational culture**

The philosophies of organisations in providing care shape staff perception of providing end-of-life care to service users (Casey et al. 2011). Todd (2004) proposes that intellectual disability services are built around the concept of providing supported living and they do not expect to provide care for those who are dying. In addition, most of the professionals working in intellectual disability services do not expect that they will be required to provide end-of-life care to people with intellectual disabilities (Ryan and McQuillan 2005). McCarron et al. (2008) reason that traditionally, care given by intellectual disability service providers to children and adults with intellectual disabilities mainly promotes and maintains their health, and that these providers are not expected to provide end-of-life care. When people with intellectual disabilities began to grow older and live longer, these services struggled to provide adequate support to their service users at the end of life due to lack of preparedness (Dunkley et al. 2014). However, recent research has encouraged disability service providers to change their ethos and engage with other organisations such as hospices and general hospitals to promote good end-of-life care to people with intellectual disabilities at their place of living or more appropriate places (Bekkema et al. 2015; Ronnerberg et al. 2015; McLaughlin et al. 2014).

### **2.8.4 Training and education**

There are issues for both professionals in providing end-of-life care for people with intellectual disabilities and for people with intellectual disabilities in receiving appropriate end-of-life care (Tuffrey-Wijne and McEnhill 2008). Many non-intellectual disability health care providers feel that it is difficult to provide end-of-life care for

people with intellectual disabilities due to their lack of caring experience in dealing with people with intellectual disabilities (Tuffrey-Wijne 2010; Li and Ng 2008). As a result, health care providers find it hard to assess and diagnose the specific problems that individuals with intellectual disabilities suffer from (Bekkema et al. 2014). It has also been pointed out (Read and Thompson-Hill 2009) that personal, professional, and practical misunderstanding between palliative care services and intellectual disability services create barriers in accessing appropriate palliative care. Todd (2005) notes that most people with intellectual disabilities die in residential settings without receiving appropriate end-of-life care. This is due to a lack of awareness and understanding about the importance of providing end-of-life care to people with intellectual disabilities among care providers (Cartlidge and Read 2010).

The lack of education and training of care providers in intellectual disability service sectors prevents them from providing good end-of-life care for people with intellectual disabilities (Read and Cartlidge 2012; Tuffrey-Wijne 2010; McCarron et al. 2008). Staff in palliative care settings lack knowledge of how to communicate with and care for people with intellectual disabilities, resulting in difficulties in providing holistic end-of-life care (Cross et al. 2012; Ryan et al. 2011a). Hence, a training programme for professionals on palliative care was recommended (Read and Cartlidge 2012). Furthermore, inadequate knowledge on providing physical care and operating specialised equipment, along with a lack of communication skills, forces service users to transfer to other health care settings unnecessarily. O'Shea et al. (2008) find that a lack of training and education among professionals in providing palliative care impedes the quality of care provided at the time of dying. Even though it is true that training of professionals will improve the end-of-life care, the training of managers is also required to support changing care practices and organisational structures as it is necessary to promote good quality of care in any care setting (Morton-Nance and Schafer 2012).

### **2.8.5 Spiritual support**

The WHO (2004) recognised that spiritual and psychological support is one of the important domains of end-of-life care. Wynne (2012) also stresses that the spiritual needs of people at the end of life are essential to promote quality of life. In Saunders' (2015) opinion, spiritual and psychological support is essential to respond to the total pain of the dying person. Furthermore, Kisvetrová, Klugar and Kabelka, (2013) suggest that spiritual care is an integral part of searching for self, consisting of existential and religious aspects. Shim and Hahm (2011), Milligan (2011), and Nixon and Narayanasamy (2010), propose that being available to listen to patients' feelings, treating them with dignity, arranging spiritual leaders to attend patients, and providing privacy are important elements of providing spiritual care. Despite the importance of providing spiritual care at the end of life, many professionals feel uncomfortable and nervous discussing religious and spiritual beliefs with patients thus leading to patients receiving inadequate and inappropriate spiritual care at this critical time (Nelson-Becker et al. 2015).

Even though people with intellectual disabilities have similar spiritual care needs as the general population at the end of life (McCarron et al. 2008), there is limited literature that explores their spiritual needs at this critical time (Dunkley and Sales 2014). The research shows that their spiritual needs are overlooked and that they receive inadequate spiritual care at the time of dying (Read and Morris 2008). In general, Balboni et al. (2014) argue that limited staff, role blurring over who is responsible for providing spiritual support, and an emphasis on providing physical care prevents effective provision of spiritual support at end of life.

## **2.9 COLLABORATIVE WORKING TO IMPROVE END-OF-LIFE CARE AMONG PEOPLE WITH INTELLECTUAL DISABILITIES**

When compared with the general population, people with intellectual disabilities and their representatives struggle to receive medical services to maintain their health and survival. In addition, individuals with intellectual disabilities, their family members and their carers are sceptical about providing their suggestions and recommendations to the hospice and palliative services due to their distrust of the medical system (Savage et al. 2010). To alleviate mistrust, reduce marginalisation and promote end-of-life care, better integration and collaboration between acute, chronic and palliative care services is required (McCarron et al. 2010). The recent work of Tuffrey-Wijne and McLaughlin (2015), McLaughlin et al. (2014), Cross et al. (2012), McCarron et al. (2011) and Ryan et al. (2011a) provides evidence for promoting end-of-life care for people with intellectual disabilities through collaborative and integrated work.

Research suggests that collaborative work between the intellectual disability service, acute hospital and specialist palliative care services helps to promote good end-of-life care for people with intellectual disabilities (Tuffrey-Wijne and McLaughlin 2015). Providing training for intellectual disability care professionals in the area of palliative care and palliative care professionals familiar with the needs of people with intellectual disabilities is important in the caring process (Ryan et al. 2010). The collaborative approach between the intellectual disability service and other services enables people with intellectual disabilities to die at their own place and be cared for by familiar people; this facilitates continuity of care (McLaughlin et al. 2014; Cross et al. 2012). In addition, Read and Morris (2008) suggest that in a collaborative approach, fusion of knowledge and skills between all professionals is possible and helps to provide improved end-of-life care. It is acknowledged that partnerships working across the care setting are essential to providing effective and optimal end-of-life care.

Even though research studies acknowledge the importance of working partnerships, at a practical level there are difficulties in achieving this. Acknowledging and understanding each other's needs, weaknesses and strengths of professionals, and mutual trust and respect across care settings are all essential for working partnerships, which at times are difficult to achieve (Cross et al. 2012). In addition, late referral from the intellectual disability sector to specialist palliative care professionals makes it difficult to establish the required relationships (McLaughlin et al. 2014). In order to achieve optimal end-of-life care for people with intellectual disabilities, intellectual disability service providers must engage and collaborate with other service providers to establish a working relationship and understand each other's role and needs. Also, an early collaborative working relationship helps other service providers to establish communication and trust with service users.

## **2.10 OTHER INITIATIVES TO IMPROVE END-OF-LIFE CARE IN ALL CARE SETTINGS**

Initiatives have been introduced in the UK and in Ireland to improve quality of end-of-life care to people with life-limiting illness. The hospice movement has been very successful in providing good quality care to people with cancer; therefore, the same principles are applied to other non-malignant and life threatening diseases. The Gold Standard Framework (GSF) is now being adopted in long stay settings to assess and provide care at the end of life (Birmingham 2008). Also, the framework serves as a communication tool across all relevant care agencies to maintain continuity, communication, and co-ordination of essential care (Griffin and Sawkins 2009). This is considered a systematic approach to people who are nearing their end of life. This framework ensures that palliative care patients are identified, and their needs are assessed and recorded.

Preferred Priorities of Care (PPC) is another specific tool developed in the UK by the Department of Health to improve end-of-life care for people with life threatening illness (National Health Service 2011). This handheld tool is designed to help professionals facilitate a service user's choice regarding end of life issues (NHS 2011). By initiating reciprocal communication about a preferred place of care among professionals, service users, and their family members, and by documenting it, The PPC tool allows service users to receive appropriate care as per their wishes (Fields, Finucane and Oxenham 2013). The explicit recording of service users' and their family members' wishes helps to prevent inappropriate interventions and procedures at the end of life. Conversations are recorded in the service user's care plan and their choices are to be respected. In addition, the PPC is a process, which facilitates the service review that helps professionals to negotiate the service requirements for the service users as their needs change.

In Ireland, The Hospice Friendly Hospital (HFH) programme was initiated by the Irish Hospice Foundation in Ireland to focus on making end-of-life care central to all health care settings. This programme was initiated because half of people die in hospital where end-of-life care is either a core activity or included in their service plan. Therefore, the Hospice Friendly Hospital programme makes end-of-life care central to hospital care, which is reflected in the participating hospitals' culture, systems and structures. The core aim of the Hospice Friendly Hospital programme is to develop a capacity to provide quality end-of-life care in all health care settings and to change the culture in relation to dying, death and bereavement.

## **2.11 IMPLICATIONS OF LITERATURE REVIEW AND FORMULATION OF RESEARCH QUESTIONS**

The current literature illustrates the complexity of providing end-of-life care to people with intellectual disabilities. It is important to note that although policies and research aim to involve people with intellectual disabilities in developing, shaping and delivering health services (Northway 2011; Disability Rights Commission 2007; National Disability Authority 2007) there is conspicuous scarcity of research specifically focusing on this population. This suggests that there is a general lack of attention given to this underprivileged group. This may be due to a range of ethical issues in involving people with intellectual disabilities in research or a perception that this population is not able to contribute towards the issues that they face. As a result, there is a lack of understanding of the dynamics of providing end-of-life care to people with intellectual disabilities from the perspectives of people with intellectual disabilities and their family members, including what their wishes, preferences and experiences are. As users of the service, they are central when developing a service; therefore, they should be consulted.

Compiling the findings from the existing literature highlights a number of important issues, which eventually inform research questions. Firstly, studies from many researchers indicate that although people with intellectual disabilities suffer from the same terminal illnesses as the general population, they receive poor and inappropriate end-of-life care. Secondly, people with intellectual disabilities can benefit from a collaborative approach between general medicine, palliative care and the intellectual disability service. The lack of a working relationship between these services is one of the causes of poor end-of-life care. Thirdly, a lack of cognitive ability and poor communication skills of the service users and lack of knowledge, training and skills of the care providers causes caring discrepancy between desired caring expectations and actual caring experiences. Finally, studies on end-of-life care and intellectual disabilities

have not engaged with people who have intellectual disabilities, despite the fact that many researchers acknowledge the central roles of service users in planning, shaping and developing service policies. This is unfortunate, given that engagement with people with intellectual disabilities is necessary in order to understand the factors which impact upon the provision of optimal end-of-life care from their perspectives and to develop strategies to improve caring practices.

Keeping all of these in mind, further research is required to understand the end-of-life care needs of people with intellectual disabilities from their perspective. Such research is not only necessary to understand their end-of-life care needs but also to inform policies, which recommend good end-of-life care. Given the significant increase in the life expectancy and related life limiting illnesses of people with intellectual disabilities in Irish society and the related lack of research on this topic in Ireland, the need for this kind of research is all the more urgent. Moreover, it is evident that there must be engagement with people who have intellectual disabilities in order to understand their experiences and perspectives.

In consideration of these implications, my strong personal interest in this specialty and working in this area has led me to develop specific research questions guiding the research study. These questions are follows:

- What are the experiences, views and opinions of people with intellectual disabilities at the end of life?
- What are the experiences, views and opinions of family members of people with intellectual disabilities at the end of life?
- What factors impact upon, facilitate or hinder the dying experiences of people with intellectual disabilities?

- What strategies will help to improve the dying experiences of people with intellectual disabilities?

In addressing these research questions, it is hoped that this study can make a valuable contribution to existing knowledge in the field of intellectual disabilities and end-of-life care in the Irish context specifically and also add to the growing body of international research.

## **2.12 CHAPTER CONCLUSION**

Eliciting end-of-life care preferences and their related issues may be challenging, especially in the context of people with intellectual disabilities. In order to improve and provide the best level of care to all dying patients, it is essential to seek and respect the views of all people, not only irrespective of diagnosis, but also irrespective of gender, age, religion, ability and capacity. As such, consumer involvement in shaping appropriate health services has been gaining momentum. As a result, the voices of people with intellectual disabilities must be included in developing and providing end-of-life care services, and the need to value disability is one of the key factors to accomplishing equality in health care. With this in mind, this study intends to explore the end-of-life care needs of this population from their own perspectives. The study also explores the end-of-life care needs of people with intellectual disabilities from the perspectives of their family members. Finally, the findings from this study may serve as a basis for future research.

It is evident from the literature review that people with intellectual disabilities have the same life-limiting illnesses as the general population. Therefore, this population has the same end-of-life care needs as their non-disabled counterparts. Health care professionals have several difficulties in assessing and dealing with people with intellectual disabilities resulting in a negative impact on providing end-of-life care for this

population. Furthermore, people with intellectual disabilities are excluded from planning and developing services, which can lead to them receiving inappropriate and subpar service at the end of their lives. Having an aim to involve people with intellectual disabilities, this study has great potential to explore their care needs at the end of life in relation to providing recommendations for future research, practice and policy.

# CHAPTER 3- RESEARCH METHODOLOGY

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## 3.1 INTRODUCTION

The first part of this chapter provides a discussion about what is a suitable methodological approach to address the research questions and achieve the aim and objectives of this study. An overview of grounded theory is explored in detail including its origin, different versions of the methodology and associated disputes among them. The current study is in line with the “constructivist version” that is mostly associated with the work of Charmaz (2006). The chapter gives an insight into the specific principles of grounded theory and explores the sampling technique that is appropriate to a grounded theory approach. In addition, this chapter reviews the procedures that were undertaken to collect information from the study participants. Finally, the criteria that are useful in evaluating the quality of a grounded theory study are discussed. The chapter concludes with a debate on the role of the literature in a grounded theory approach.

## 3.2 RESEARCH FRAMEWORK

The research framework is a set of actions or principles that are chosen to best answer the research questions (Silverman 2011). The amount of research and available evidence in the selected phenomena will have an influence on what kind of research framework would fit for a particular study (Creswell 2007). In this case, the preliminary literature review on end-of-life care needs of people with intellectual disabilities has shown a paucity of available studies that involve these people in exploring these needs. Therefore, a qualitative approach would be the right choice when there is a lack of evidence or lack of information on the specific phenomena (McCusker and Gunaydin,

2015). Further to this, the research aim and questions greatly influence the research framework (Quick and Hall 2015).

As this study aims to explore the end-of-life care needs of people with intellectual disabilities, a qualitative approach was chosen as it would enable the researcher to gain a better understanding of the phenomena under investigation (Tomlin and Swinth 2015). Additionally, the study's research questions cannot be answered by a positivistic paradigm that emphasises testing and verifying existing theories, investigating cause and effect relationships or emphasising measurement and explanation (Silverman 2011). The research questions are exploratory and aim to understand the experiences, views and opinion and gain insight into the given phenomena (Silverman 2011). Finally, the primary aim of this study was to develop a substantive theory that best describes and interprets the specific social process of people with intellectual disabilities, specifically, the narrowed empirical area of end-of-life care issues. For these reasons, this study naturally fits into the qualitative paradigm of inquiry.

End-of-life care needs of people with intellectual disabilities are under researched and few researchers have explored the care needs of people with intellectual disabilities. Researchers such as Sue Read (2013), Stuart Todd (2013), Bekkema (2015), Irene Tuffrey-Wijne (2010), Karen Ryan (2011) and Mary McCarron (2011) are leading researchers in this field who explored the phenomenon from the perspectives of professionals, family members and persons with intellectual disabilities. However, the work of Irene Tuffrey-Wijne (2010) influenced this current research, as she explored the palliative care needs of cancer population with intellectual disabilities using an ethnographic approach. Her ethical approach, research strategies and dealing with participants had greatest impact on this research.

### **3.3 METHODOLOGICAL CHOICE**

Since there are many qualitative methodologies available, the challenge is to choose the most appropriate methodology (Farrelly 2013). Even though there are many approaches, all qualitative approaches share common principles. These are: multiple interpretations of data; engagement with selected phenomena and real life experiences; capturing data on the perceptions of participants and exploring how they understand; taking action; and managing their everyday situation (Creswell 2010).

Having explored various modes of research inquiry, grounded theory was chosen over other qualitative methodologies to provide the best means of achieving the objectives of the study. For example, phenomenology helps to deepen and broaden understanding of the immediate experience (Converse 2012). But the aim of the study is to construct a substantive theory about issues faced by people with intellectual disabilities at the end of life and a way of meeting their care needs. Also the particular way of working with the data, as outlined in grounded theory, confirmed the development of theory grounded from the data as opposed to thick description produced by other methodologies, for example, ethnography (Charmaz 2014). The theory is more relevant and a better fit when derived from the data that is collected from the social world (Glaser 2007; Glaser 1998; Glaser and Strauss 1967). Therefore, it was decided to use grounded theory based on the assumption that the theory from the study will inform, explain and predict the care needs of people with intellectual disabilities at the end of life. The following subsections discuss grounded theory in general and specifically explore the constructivist version of grounded theory (Charmaz 2006) and how it fits into the study to achieve the aim.

### 3.3.1 Development of grounded theory

Two sociologists, Barney Glaser and Anselm Strauss, developed grounded theory in the 1960s (Parahoo 2009). In their initial research, they were looking at the experiences of dying people, which resulted in two classic studies: *Awareness of Dying* (Glaser and Strauss 1965) and *Time for Dying* (Glaser and Strauss 1968). This led them to write a methodology book, namely, *Discovery of Grounded Theory* (Glaser and Strauss 1967). Grounded theory gained more attention from scholars because Glaser and Strauss explained how researchers could discover a theory from data by applying an inductive procedure (Rickard and Clarke 2015).

Grounded theory aims to understand the reality from the point of view of the social actors. The social actors construct meaning about certain objects or contexts; this helps the researcher to gain knowledge and understanding of their issues and problems (Cooney 2011). A grounded theory approach is very useful when exploring human interaction and behaviour (Pestinger 2015) and the methodology became more popular and heavily cited in the social sciences in general (Bryant and Charmaz 2007b) and nursing in particular (Parahoo 2009). The nature of grounded theory's flexibility and adoptability means it has undergone various modifications since its development including positivist realism (Glaser and Strauss 1967), social constructivism (Charmaz 2014; 2006; 2000), hermeneutics (Rennie 2000) and postmodernism (Clarke 2003).

Following the successful collaboration between Glaser and Strauss, they went their own separate ways. After the creation of grounded theory Glaser moved away from the research arena; in the meantime, Strauss continued to work with his student Juliet Corbin.

### **3.3.2 Glaserian grounded theory versus Straussian grounded theory**

Grounded theory has undergone many changes and refinements since the classic statement of both authors. The changes and developments in the original grounded theory led to the creation of two schools of grounded theory. The Glaserian version, based on the original work and subsequent development by Glaser, and the Straussian version, based on the refinement and changes made by Strauss on the original work in association with his student Juliet Corbin (Cooney 2011; Charmaz 2006; McCallin 2003). The main reasons for this divergence were methodological and analytical issues (Cooney 2011). The centre of the methodological issue is based on the ontological and epistemological assumptions of the author of the original grounded theory.

The original grounded theory, that is the Glaserian version, takes its ontological roots from critical realism. According to Annels, (1996) critical realism assumes that reality exists independently of knowledge and belief of the researcher; therefore, the researcher is considered to be independent of the research. On the other hand, the Straussian version of grounded theory derived its ontological roots from relativism. Relativism assumes that reality is related to the knowledge and belief of the researcher; therefore, reality can be interpreted. The Glaserian version of grounded theory takes the objectivist epistemological stand and this assumes that reality is waiting to be discovered by an unbiased researcher. Glaser assumes that objective natural reality can be discovered by a neutral observer (Glaser 2003; Glaser 1992), he also believes that reality is context free and generalisable (Lincoln and Denzin 2011). The Straussian version of grounded theory takes the subjectivist epistemology, which recognises that reality cannot be fully known but it can be interpreted; therefore, it recognises the role of the researcher in interpreting the reality (Cooney 2011).

Glaser has remained faithful and consistent with the original work since his divergence from Strauss's ideas in relation to the direction of the method. Discovery is fundamental to Glaserian grounded theory (Glaser and Strauss 1967). Glaser assumes that starting with openness and keeping the position of not knowing are essential factors in grounded theory (Charmaz 2006). Glaser (1992) believes that theory directly and rigorously emerges from data; therefore, he is very clear that the researcher should not interfere or influence the research phenomena. On the other hand, the Straussian version of grounded theory assumes that reality is related to the knowledge and belief of the viewer; therefore, he acknowledged the influence of the researcher.

The second difference between the Glaser and Strauss version of grounded theory is how the data is collected, analysed and interpreted (Ghezeliéh and Emami 2009). Strauss (1987) examined how to do data analysis in grounded theory; he commenced with open coding and he also introduced new ways of thinking when doing data analysis. He described the process of "axial coding" using a coding paradigm. Through this process, Strauss (1987) believed that theoretical categories could be developed through finding sub-categories and identifying relationships among them. They introduced the "conditional matrix" as a tool for representing complexity and identifying inter-relationships among conditions relating to a particular category (Strauss and Corbin 1990). Strauss and Corbin (1990) suggested that this is a more structured way of doing data analysis than in the original grounded theory (Glaser and Strauss 1967) because data analysis in the original grounded theory was loosely structured.

This approach was however criticised by Glaser (1992, p.124) who commented that this approach to data analysis is 'forced, full and conceptual description'. In addition, he proposed that Strauss and Corbin's revision is not a version of grounded theory but an

entirely different methodological approach (Cooney 2011). Glaser further objected to the idea of open coding that was accounted for by Strauss (1987), in which small data fragments are labeled individually. From Glaser's (1992) perspective, the single incident analysis ends up producing too many properties and categories. Furthermore, Glaser disagreed with Strauss and Corbin's (1990) notion of imposing preconceived questions on the data. Glaser (1992) claimed that the grounded theory researcher should only ask two questions concerning the data; they are:

*What is the chief concern or problem of the people in the substantive area, and what accounts for most of the variation in processing the problem? And secondly, what category or what property of what category does this incident indicate? One asks these two questions while constantly comparing incident-to-incident, and coding and analyzing. Soon categories and their properties emerge which fit and work and are of relevance to the processing of the problem (Glaser 1992, P.4).*

In response to this criticism, Strauss and Corbin (1998a) suggested that the recommended approach consisted of guidelines only, and that researchers should not view them as commandments, but use this approach as a protocol and follow the procedures in their own way (Corbin and Strauss 2008). Despite these criticisms, many researchers prefer to use Strauss and Corbin's structured and programmatic approach, because some researchers appreciate that the explicit guidelines given in Strauss and Corbin's approach are more helpful rather than being restrictive (Nilsson, Rasmussen and Edvardsson 2013; Cooney 2011). They also acknowledge that it is more compatible with contemporary thinking of subjectivity. However, other researchers (Li et al 2015; Hoare, Mills and Francis 2012; Moore 2010) are in favour of Glaser's grounded theory because they agree with Glaser's notions of openness, emergence and objectivity.

Glaser's perceptions of discovery and openness underwent much debate; as a result, a newer version of grounded theory emerged, known as constructivist grounded theory.

### 3.3.3 Constructivist grounded theory

Glaser (2003, 2005) suggests that researchers should not possess any kind of theoretical pre-assumptions before commencing a grounded theory study and stresses that theoretical concepts must earn their way into a grounded theory study. Glaser also proposes that the relevance for the particular theoretical concept should emerge from data analysis, believing that grounded theory is a general method that should be free of any particular perspective. The notion of Glaserian, and to a lesser extent of Strauss and Corbin's objectivity and emergence, has been criticised by several researchers (Kelle 2005; Bryant 2003) who argue that truth cannot simply be found and will not emerge; in other words, they argued that truth should be created and constructed (Charmaz 2014, 2006, 2003; Clarke 2005). Therefore, they strongly opposed Glaser's notion of the detached observer and acknowledged the role of the researcher in creating and constructing the social process.

In response to this claim, a reflexive approach was advocated (Birks, Chapman and Francis 2006) which acknowledged the role of a researcher in the research process and asked the researcher to examine how their own perspectives affect every part of the research steps. In acknowledging the reflexive approach, Charmaz (2006, 2003) developed a new version of grounded theory, namely constructivist grounded theory, based on the promise that:

*Neither data nor theories are discovered. Rather, we are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvements and interactions with people, perspectives and research practices (Charmaz 2006, p.10).*

Charmaz firmly believes that constructivist principles can be successfully applied to grounded theory because data does not provide reality on its own rather the discovered reality is the outcome of interactions between the researcher and the participants (Charmaz 2006). The constructivist version of grounded theory (Charmaz 2014; 2006;

2003; 2000) has its ontological roots in relativism like the Straussian version. Epistemologically, constructivism emphasises the subjective interrelationship between the researcher and the researched (Mills et al. 2006). In other words, the constructivist grounded theorist takes a reflexive stance and gives close attention to the empirical realities being studied and finding their role within these realities (Charmaz 2014). Also, epistemologically, constructivists affirm that it is difficult to separate the researcher from what they are researching and acknowledge their role in creating data that emerges from their interaction with participants (Charmaz 2006).

Charmaz describes this approach as a systematic, inductive and comparative process for the purpose of constructing a theory (Byrant and Charmaz 2007a). Constructivists actively engage in interpreting the participant's information, believing that there are multiple realities that can be interpreted in different ways by different people based on their previous experience and culture (Charmaz, 2006; Mills et al. 2007), whereas in Glaserian grounded theory, the researcher is an external observer, who does not influence the emerging theory and takes a position of not knowing (Kelle 2005). The Glaserian grounded theorists believe themselves to be patiently waiting for the theory to emerge; sometimes this will be frustrating and demanding for the researcher. In contrast to this, constructivists take an integral part in the research process. Constructivists listen to and interpret the participant's information, which is influenced by past and present involvement of the researcher, and his or her own experience and perspectives (Jeon 2004). Charmaz (2006) emphasises that the theory derived from the constructivist grounded theory method is an interpretive work of the researcher.

An important element of constructivist grounded theory is that it maintains a balance between researcher and participants. The above claims sit with my approach as I concur with the relativist ontology and subjectivist epistemology. The philosophical

underpinning of the constructivist research approach is more appropriate to this study. While I acknowledge that this is not the only way of understanding this research study, Charmaz's (2014, 2006) position of constructing reality from the data, the role of the researcher in the research process and the interactive relationship between researcher and participants is a good fit for this study. As a result, the researcher influences the constructed theory and the theory is the co-production of both participants and the researcher.

Constructivist grounded theory, incorporating patient-centred research techniques, was found to be the most appropriate method of enquiry. It was assumed that reality was co-constructed by the participants: people with intellectual disabilities and their family members, and myself as a researcher in line with the constructivist grounded theory approach.

### **3.4 APPLICATION OF CONSTRUCTIVIST GROUNDED THEORY**

Generally, grounded theory approaches do not have a predetermined assumption about participants' experiences or their lives (Gardener 2006). By adopting a constructivist grounded theory approach, this research recognised people with intellectual disabilities as co-constructors and included their voices and opinions, with their role acknowledged as experts and active participants in the research process. In the study, people with intellectual disabilities were consulted in a meaningful way about their care needs at the end of life, thus increasing the understanding of their care requirements.

According to Charmaz (2014), the constructivist paradigm sheds light on our social world, which consists of multiple realities that can be explored by obtaining the views and beliefs of people with a common interest. The researcher interprets the views and beliefs of the people and constructs meaning about the phenomena of common interest. However, the researcher should remain aware of his or her role in interpreting and

constructing the meaning of people's social world. Charmaz (2014) stated that it is impossible to disassociate yourself from who you are, what you know, and what experiences you have had.

The application of grounded theory is common in many health care settings such as critical care (Gallagher 2015), mental health (Gardner McCutcheon 2015) and maternity care (Clark, Beatty and Reibel 2015). The benefit of adopting grounded theory analytical principles in intellectual disability research is evident from research in the field (Bernert 2011; Dunn, Clare and Holland 2010; Caldwell 2007; Dowling et al. 2006). The value and effectiveness of using a grounded theory method in the area of palliative and end-of-life care is also well established; several researchers have employed a grounded theory method to discover the main concerns for service users (de Guzman 2015; Roberts and Bowers 2015), service providers (Hussein and Hirst 2016; Gallagher et al. 2015; Smith, Leslie and Wynaden 2015) and families (Babatsikos and Miles 2015; Kita and Ito 2013).

In relation to the current study, my experience of working with people with intellectual disabilities suggests that individuals and their interactions offer different understandings and meanings that are not always comprehensible (Tuffrey-Wijne 2010). From my perspective, interactions with people with intellectual disabilities are complex and dynamic that informs multiple perspectives. The complexity of this interaction suggests that there is not only one version of the truth but that there are different perspectives and meanings. In particular, the study area of end-of-life care is a complex and social phenomenon that cannot be understood by detached observations. Furthermore, the nature and context of the study, my background as a nurse working with people with intellectual disabilities, and my perceptions and beliefs all sit comfortably with the

philosophy of constructivist grounded theory (Hussein and Hirst 2016; Luxardo, Vindrola Padros, Tripodoro 2014; Penz and Duggleby 2011).

This approach enabled me to obtain collective views from people with intellectual disabilities and from family members as well as providing the scope to interpret and construct meaning from the data and to develop a theoretical framework (Charmaz 2014). Consequently, this approach helped to explain the needs of people with intellectual disabilities at their end of life and guided analysis to develop a model of service delivery to meet their needs. While constructing reality, the participants' views were not forced into pre-defined concepts but were allowed to emerge, and then codes and categories were constructed.

### **3.5 PRINCIPLES OF GROUNDED THEORY**

There are many ways of approaching grounded theory that are based on the chosen ontological and epistemological perspectives (Charmaz 2006; Clarke, 2005; Strauss and Corbin 1990; Glaser and Strauss 1967). However, there is a consensus among researchers regarding certain core principles that are essential for grounded theory research (Currie 2009). These include (Dunne 2011; Currie 2009):

1. Theoretical sampling,
2. Constant comparative analysis,
3. Developing codes and categories from data,
4. Development of theory,
5. Memo writing.

These core principles are discussed separately in the following sub sections.

#### **3.5.1 Theoretical sampling**

A grounded theory study begins with selective, purposive, non-probability (Barratt and Lenton 2015; Lee-Jen, Hui-Man and Hao-Hsien 2012) and maximum variation

sampling to elicit initial concepts (Draucker 2007). Through the initial sampling, study participants are recruited on the basis of having special characteristics to gain basic understanding of the study phenomena (Kandola et al. 2014). This process of purposive sampling allows the researcher to interview any participant, view any document, or observe any event that meets the special characteristics. After the initial data is gathered and analysed, the researcher can follow a specific issue, event or phenomena that emerges from the data (Currie 2009). This will guide the researcher to choose the participants as per the evolved concepts (Bagnasco, Ghirotto and Sasso 2014). In other words, decisions about further data collection are based on the development of the categories from the initial data, to elaborate its properties and relationship. This is called theoretical sampling (Charmaz 1990). The subsequent data collection is carried out for the purpose of elaboration and explanation of categories. The process continues until no new data is found to expand or refine the particular category; a concept known as theoretical saturation (Glaser and Strauss 1967).

In a grounded theory study, calculating sample size and choice cannot be determined at the beginning of the study; however, it can be calculated retrospectively (Glaser 1998). The choice of the sample in a grounded theory study is determined by the emerging concept or hypothesis, and the size of the sample will be determined by the theoretical completeness (Liv, Mathiassen and Svendsen 2011). According to Glaser and Strauss (1967) theoretical sampling begins by asking what group should be turned to next for data collection, and for what theoretical purpose? These questions will be used to move the study forward as the researcher carefully chooses the characteristics of the sample to meet the theoretical relevance of the particular stage of the research. Therefore, it is clear that the theoretical sampling is based on the principles of theoretical completeness and theoretical relevance of the study (Glaser 1978).

While it is clear that the theoretical sampling is an integral part of grounded theory (Corbin and Strauss 2008; Charmaz 2006; 2005; 2000; Glaser 1998; 1978), there are differences of opinions on how to do it, and who to include in the research. The choice is dependent upon what will shed more light on the emerging theoretical ideas, and whether to refute or confirm them (Parahoo 2009). Corbin and Strauss (2008) however, suggest that doing sampling by a list would fulfill the purpose of theoretical sampling if the researcher keeps the aim focused because natural variations occur among participants. Researchers therefore do not need to look for variations or other things as long as the participants have the special characteristics that are related to the research phenomena. They further suggest that there are both ideal and practical ways of doing theoretical sampling on which the researcher has to decide. To conclude, theoretical sampling is not about representativeness but is about completing the emerging hypothesis and theory completeness (Parahoo 2009).

### **3.5.2 Constant comparative analysis**

Constant comparative analysis is one of the core strategies in grounded theory (Robert 2008). In constant comparative analysis, the data are constantly compared and contrasted to discover the commonalities and differences among emerging concepts and categories (McDonald 2014). In a grounded theory study, data collection and analysis occur concurrently to compare the data, to expand it, and to develop the emerging categories so that the data collection, analysis and theory development will have a reciprocal relationship with each other (Thompson, Betty and Scholes 2014). According to Creswell, data analysis in grounded theory is a:

*'Zigzag' process – out to the field to gather information, analyse the data, back to the field to gather more information, analyse the data, and so forth (Cresswell 1998, p.57).*

For this reason, the data collection and analysis in grounded theory is not a step-by-step process but happens at the same time (Abdul Hafidz et al. 2010; Coyne and Cowley 2006).

The concurrent data collection, analysis, and emergence of theory in grounded theory gives clear direction for further data collection to explore the research phenomena (Glaser 1978; Glaser and Strauss 1967). Parahoo (2009) contends that comparison in grounded theory does not happen between the incidents and categories but also with similar phenomena; this will broaden the understanding of what we are studying, and help the researcher to understand and interpret the data more deeply to develop a theory that is grounded in the participant's information (Roberts 2008).

Overall, there is a relationship between constant comparative analysis and theoretical sampling. In a similar manner to theoretical sampling, constant comparative data analysis stops "when categories are saturated" (Charmaz 2006, p.113). Categories are considered to be saturated when new data affords no new theoretical insights (Charmaz 2006).

### **3.5.3 Developing codes and categories from data**

Coding and categorisation of data is one of the essential features of grounded theory. Charmaz describes coding as an act of attaching a label to certain segments of data that simultaneously categorises, summarises and accounts for each piece of data (Charmaz 2014).

Charmaz (2014) explains that coding data serves as a tool to draw a logical conclusion or extract meaning from the data; it assists the researcher in condensing and breaking up data into manageable units so as to enable further analysis. The labels that are attached to the data are called codes, and these codes can be attached to words, sentences, phrases or entire paragraphs (Berthelsen, Lindhardt and Frederiksen 2014). Therefore,

coding assists in reducing the data, which helps to organise and retrieve the data (Dantas et al. 2009). In grounded theory, coding is a means to link raw data with the emerging categories and explains how the categories are drawn from the raw data, which in turn contributes, to increasing the rigour of the study (Charmaz 2014). While different authors advocate different methods of coding (Glaser and Strauss 1967; Strauss and Corbin 1990; 2008), constructivist grounded theory (Charmaz 2006) follows a three-stage coding paradigm: initial coding; focused coding and theoretical coding, all of which are outlined below.

#### **3.5.3.1 Initial coding**

This is the first phase in data analysis where the researcher intimately engages with data by interpreting and eliciting meaning from the data. Charmaz (2006, p.50) advises that the researcher should keep the code “simple, short, active and analytic”. Furthermore, Charmaz (2006) claims that the labels attached during this stage are only provisional and can be changed as analysis progresses. The important element of this stage is developing *in vivo* codes. These are “codes of participants' special terms” (Charmaz 2006, p.55) and are particularly important because they directly convey the participants' views and actions. To this end, the initial coding assists the researcher to understand the hidden meaning of the data by interpreting these codes and direct further data collection and analysis (Charmaz 2006).

#### **3.5.3.2 Focused coding**

This is the second and major stage of the coding process where the researcher compares and contrasts the data to create analytic categories and develop theory. This stage is more conceptual than the initial coding. As Charmaz (2006 p.57) suggests:

*Focused coding means using the most significant and/or frequent earlier codes to sift through large amounts of data. Focused coding requires decisions about which initial codes make the most analytic sense to categorize your data incisively and completely (Charmaz 2006, p.57).*

During this stage, the researcher has to analyse the initial codes extensively in order to develop conceptual categories as the initial codes explain the properties of categories. The categories in grounded theory are developed from the data given by the participants themselves and should be easily recognisable to them. Charmaz (2006) considers this to be working close to empirical data.

### **3.5.3.3 Theoretical coding**

This is the higher level of data analysis and moves towards the more abstract level (Glaser 1998). During this stage, the researcher not only concentrates on the development of categories but also explores the relationships among the different categories, which emerge during focused coding (Charmaz 2006). This will direct further data collection for further exploration if the researcher finds gaps in the emerging theory. During this phase, the researcher finds one or more core categories, which explain the nature of the phenomena; therefore, theoretical coding is central to theory building in grounded theory (Charmaz 2006). These three stages of data analysis help to develop a theory that is grounded in the data.

### **3.5.4 Writing memos**

Writing memos is an important element during the process of data analysis to produce theory from different categories (Glaser 1998). Memo writing in grounded theory is an internal dialogue that occurs within the researcher (Birk, Chapman and Francis 2008). The researcher continuously writes about theoretical ideas during the coding process, especially regarding the relationship among properties (Charmaz 2014). The researcher is encouraged to write memos in different ways through the use of text, graphics, diagrams, matrices, tables or pictures (Charmaz 2014; Glaser 1998). A memo is a

critical reflection of the data that sparks new ideas and identifies gaps in the data analysis (Charmaz 2014). A memo also acts as an audit trail that helps to identify how the researcher makes decisions and develops theory (Hunter et al. 2011; Montgomery and Bailey 2007).

### **3.5.5 Development of theory**

Theory development offers a bridge between practice and research (Southern and Devlin 2010). The main aim of grounded theory is to develop a theory inductively from data that explains and describes the basic psychosocial processes of the study participants (Glaser and Strauss 1967). According to Dey (1993, p.51), a theory is “simply an idea about how other ideas can be related”. Grounded theory typically produces a substantive rather than formal theory (Hunter et al. 2011). A substantive theory intends to uncover the basic socio-psychological process that is adhered to by an individual or a specific section of population when they experience specific social problems (Kearney 1998). While a formal theory has a broader base and is more generalised, it occurs in a variety of distinct and theoretically similar social situations (Kearney 1998).

Glaser and Strauss (1967) suggest that the substantive theory must help the person who uses it to have enough control in everyday situations. Also, the developed theory helps the layman to see the theory fits in with real life situations and earns their trust.

## **3.6 EVALUATING THE QUALITY OF CONSTRUCTIVIST GROUNDED THEORY**

Judging the quality of grounded theory is an integral part of the process and this is carried out throughout the study from the data collection and analysis to theory development (Cooney 2011). Glaser (1978) developed the concepts of fit, work, relevance and modifiability to assess the quality of grounded theory. All these criteria

are closely and internally related to each other and are treated equally. The theory that is generated from the empirical data should fit and work in practice and should be relevant. This study follows the principles of a constructivist approach; therefore, it is logical to use the criteria of credibility, originality, resonance and usefulness as advocated by Charmaz (2006). The specific questions that Charmaz uses to evaluate each criterion are listed in Table 2.

**TABLE 2 CRITERIA FOR EVALUATING CONSTRUCTIVIST GROUNDED THEORY**

<b>Criteria</b>	<b>Specific questions</b>
<b>Credibility</b>	<p>Has the research reached intimate familiarity with the research setting or topic?</p> <p>Do data sufficiently support your claims?</p> <p>Have systematic comparisons between categories been made?</p> <p>Do categories cover a wide range of empirical observations?</p> <p>Are there strong logical links between the data and the argument and analysis?</p> <p>Is there enough evidence for claims to allow the reader to make an independent assessment and agree with your claims?</p>
<b>Originality</b>	<p>Are categories fresh?</p> <p>Do categories and analysis offer new insights?</p> <p>What is the social and theoretical significance of this work?</p> <p>How does the theory challenge current practices, ideas and concepts?</p>
<b>Resonance</b>	<p>Do the categories portray the fullness of the studied experience?</p> <p>Do the findings make sense to those people who are central to the phenomena?</p> <p>Do the findings offer these people deeper insights into their real worlds and lives?</p>

<b>Usefulness</b>	<p>How can analysis be applied to everyday settings?</p> <p>Do analytic categories suggest any generic process?</p> <p>Can the analysis spark further research in other substantive areas?</p> <p>How does the work contribute to knowledge?</p>
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### **3.7 ROLE OF THE LITERATURE REVIEW IN A GROUNDED THEORY STUDY**

It is very common and a traditional procedure to review the existing knowledge about the phenomena of interest before embarking on the actual research (Hallberg 2011). While it is agreed by researchers in grounded theory methodology that the literature review is essential, there is disagreement as to when and how this should be undertaken (Dunne 2011; McGhee et al. 2007).

Glaser (1978) argues against the use of existing literature before conducting the research because he believes that it pollutes and stifles the research process. He further argues that the core element of grounded theory is discovery and emergence and assumes that a literature review in the substantive field might guide the researcher to force the data at hand (Dey 2007). As the result, the developed theory is guided by existing knowledge rather than from the data that gives new insight into the study (Heath 2006). Glaser (1998) also feels that researchers would waste precious time doing a literature review at the beginning of the study because it would be irrelevant to the study phenomena. Glaser suggests that researchers could better spend time on doing actual grounded theory research (Dick 2007). Therefore, Glaser licenses researchers to do the review in unrelated areas, being wide, vociferous and diverse (McCallin 2003; Smith and Bailey 1998). However, Dunne (2011) argues that vociferous reading in unrelated areas might be totally irrelevant and not useful for researchers so this could also be an equally

inefficient use of time. Another caution raised by Glaser is that there is an influence of prominent researchers that generates a preconception among novice researchers because these researchers may agree with reputed authors. Therefore, Glaser (1998; 1978) strictly advises researchers not to do a literature review prior to the commencement of research.

Chiovitti and Piran (2003) and Creswell (1998) caution that a researcher's previous knowledge directs and shapes the research process and its outcome; therefore, it is difficult for the researcher to obtain a new point of view. But Hallberg (2010) suggests that a literature review helps the researcher to find a gap in existing knowledge, helps the researcher to understand how the phenomena were explored before, and assists in exploring the phenomena from a new point of view. Also in Lincoln and Denzin's (2011) opinion, a literature review aids researchers in familiarising themselves with research phenomena. In addition, McGhee et al. (2007) and Coyne and Cowley (2006) argue that a pre-literature review gives the researcher a rationale and justification of why the study should be carried out as well as the reason for a specific research approach employed. Furthermore, this increases the theoretical sensitivity of the researcher (Yarwood-Ross and Jack 2015; Maijala, Paavilainen and Astedt-Kurki 2003; McCann and Clark 2003b; Strauss and Corbin 1998). At some point, Glaser himself agreed that the pre-research literature review is essential for research students and research grant applications as they are considered formal requirements, accepting that fighting these requirements would be useless and time wasting (Glaser 1998).

Having explored the contrasting perspectives, researchers have a responsibility to make an informed decision on whether to do a literature review in advance or not (Dunne 2011). If they decide to do a literature review then they have to decide when to do it, in what area and how much to do. In this current study, as a novice researcher seeking

reassurance and confidence about what I was doing, I therefore, carried out a review of the literature before embarking on the study. Morse (2001) said:

*Ignoring the literature is a strategy that is fraught with danger for a new investigator. Literature should not be ignored but rather "bracketed" and used for comparison with emerging categories. Without a theoretical context to draw on, new investigators find themselves rapidly mired in data - the very state that Glaser himself warns against (Morse 2001, P.9).*

As a nurse caring for dying people with intellectual disabilities, I am expected to be equipped with a certain level of knowledge and skills. Therefore, I acquired some knowledge about the needs of people with intellectual disabilities at the end of life even before I commenced the study. In addition, I was required to submit a proposal to the School of Nursing and Human Sciences to satisfy the School Research Committee and my supervisors to register as a PhD student. Furthermore, the Research Ethics Committee required information about my study to give approval. All of these have helped to equip me with some level of knowledge about the substantive area of my study. Consequently, this helped me to understand what participants meant during the data collection and analysis (Walls, Parahoo and Fleming 2010).

### **3.8 CHAPTER CONCLUSION**

The first part of the chapter gives a comprehensive account of the aims and objectives of the study and a way to achieve it. It also provides an overview of grounded theory, through a discussion of Glaserian and Straussian schools of thought. Justification for the constructivist version of grounded theory as the research methodology was provided. Explicit discussion was presented about the general principles of grounded theory and how a grounded theory study could be evaluated. Finally, a rationale has been given for reviewing the literature before commencing the study. The following chapter provides a detailed account of the research process, including an overview of the setting and participants, data collection and analysis.

# CHAPTER 4- THE RESEARCH PROCESS

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## 4.1 INTRODUCTION

In this chapter, the research process is explained, commencing with a discussion on the setting, sampling technique and recruitment strategy used. Initially, a purposive sampling method was undertaken but further sampling was directed by emerging categories in accordance with grounded theory principles. In addition, an overall profile of the participants is presented. A discussion about the ethical considerations that are relevant to the study, such as informed consent, capacity to consent, discussing sensitive topics, and confidentiality and privacy, ensues. Finally, the data collection method, data analysis, and relevant issues are also discussed. Even though data collection and analysis are discussed separately, in reality they were carried out simultaneously. In keeping with grounded theory principles, data analysis commenced immediately after the completion of the first interview and continued until saturation was achieved.

## 4.2 DATA COLLECTION

### 4.2.1 Setting

The study was conducted in a Health Service Executive location that provides service to people with intellectual disabilities in Dublin. Decision to conduct the research in this area was a pragmatic one and was influenced by two factors. Firstly, I work in this service, and this facilitated my discussion with service providers to identify problems and formulate objectives that were relevant to the service users; secondly, the service comprises both residents and people who live in the community, as well as people with intellectual disabilities of varied levels including a large older population. This service

provides care for about 300 people with intellectual disabilities and 50% of them are aged 50 and above.

#### **4.2.2 Sampling strategy - purposeful and theoretical**

Initially, the study employed purposive sampling to recruit participants. As Gerrish and Lacey (2006) suggest, purposive sampling aims to locate a setting and a person who can provide a rich source of information. Furthermore, Kandola (2014) notes that purposive sampling could be used to obtain multiple views of participants with different backgrounds and experiences. According to Bluff (2006), in grounded theory, sampling begins with purposive sampling so that the researcher can interview participants with specific characteristics. Therefore, initially, the study employed purposive sampling with specific inclusion and exclusion criteria to explore the views of people with intellectual disabilities and their family members regarding their end-of-life care. The inclusion criteria for participants were:

- People with mild or moderate intellectual disabilities, who can articulate, are able to engage in a conversation, aged over 40 years, and are able to give informed consent to participate in the study.
- People with intellectual disabilities who receive services from the specific service providers.
- Family members of people with profound and severe intellectual disabilities whose relatives receive services from the specific service providers.

The exclusion criteria were:

- People with intellectual disabilities who have suffered bereavement in the last six months.
- People with intellectual disabilities who cannot verbalise.
- People with intellectual disabilities who were unwilling to give informed consent.
- Family members of people with intellectual disabilities who have suffered bereavement in the last six months.

Participants who were recruited by purposive sampling were interviewed and the data was analysed concurrently according to grounded theory principles. The data analysis showed that some concepts were repetitive, therefore further sampling aimed to expand these concepts and develop and refine categories. According to Glaser and Strauss (1967) grounded theory is a study of concepts, so that once concepts are found within the data then further data collection aims to proceed with theoretical sampling to develop these concepts and categories. There is no clear strategy as to when to change from purposive sampling to theoretical sampling. In their study, Caron and Bowers (2003) shifted their sampling strategy from purposeful to theoretical after three interviews; however, Draucker et al. (2007) advises researchers to use their discretion. In this study, after five interviews, concepts about holistic care and familiarity with the environment, and people and clinical conditions, emerged. Therefore, in the following interviews I concentrated on further exploring the importance of these concepts and also opened the interviews to other areas of end-of-life care (Sandgren et al. 2006).

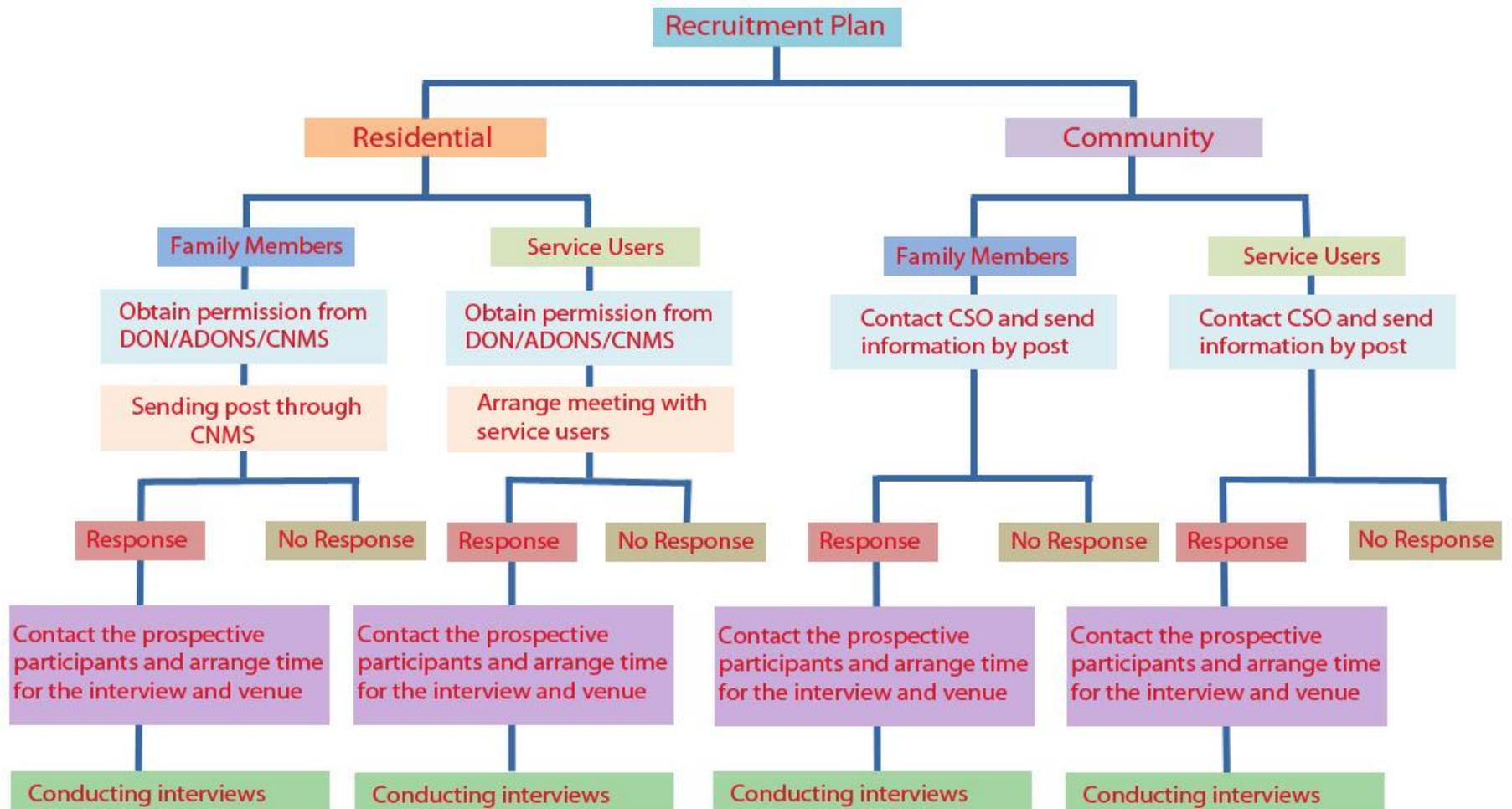
In this study, theoretical sampling was used to expand and refine the concern of the participants in order to develop the categories (Slatyer, Williams Michael 2015). Some

patterns began to emerge from the data, after which, the categories “being dependent” and “keeping familiarity” were constructed; further interviews were conducted to explore these two categories and seek new concepts. After the 11<sup>th</sup> interview, based on the new concepts, these two categories were renamed “holism”, “familiarism” and “disclosurism” and also a new category named “respectivism” was constructed. Here the sampling aimed to develop and refine the categories. After the 17<sup>th</sup> interview, no further information was obtained from the participant interviews to gain new insight into existing categories or to construct a new category at which point it was decided that the theory was saturated (Elliot and Jordon 2010). Data collection was discontinued after the 19<sup>th</sup> interview on the basis that saturation had been reached.

### **4.3 RECRUITMENT**

This study aimed to draw upon perspectives from two different groups of people, people with mild and moderate intellectual disabilities and their family members, in order to ascertain the different perspectives. Since the study included distinct groups of people, the study employed various strategies to recruit participants. After the study received ethical permission from the DCU Research Ethics Committee (Appendix A), the research proposal and necessary forms were submitted to the study setting to obtain local approval. As soon as approval from the study setting was obtained, the Director of Nursing was approached to gain permission to conduct and recruit participants for the study. After permission was granted, the recruiting of potential study participants commenced. Figure 1 is a diagrammatic explanation of the recruitment plan for this study. This is discussed in detail in the following sub-section.

**FIGURE 1 RECRUITMENT PLAN**



#### **4.3.1 Recruiting people with intellectual disabilities from residential service**

Initially, the nature and purpose of the study was discussed with the clinical nurse managers of each unit, each of which provides services for people over 40 years of age with intellectual disabilities, in order to obtain permission to contact the service users. Following this, an informal discussion about the nature and purpose of the study with a group of people with intellectual disabilities was held. After the discussion, the information sheet (Appendix B) was distributed to each person in the group and they were asked to register their interest with their clinical nurse managers if they were willing to participate in the study. This process was repeated and each unit was re-visited after a week to collect the list of potential participants who were willing to participate in the study (Gibbs, Brown and Muir 2008). Following this, each person was contacted personally to check for eligibility criteria and to discuss the study. Also, a psychologist who was a member of the multi-disciplinary team was employed to assess the service user's capacity to consent to participating in the study (the process of assessing capacity is discussed later). After it was confirmed that the participant had the capacity to consent and was able to engage in a meaningful conversation, a meeting was arranged to hold an interview at a convenient time and venue (Gibbs, Brown and Muir 2008).

In order to recruit people with intellectual disabilities who lived with their families, envelopes containing an information sheet (Appendix B), a participant acceptance card (Appendix C), and a self-addressed envelope were given to the office staff that provide community service. These were posted to people with intellectual disabilities who met the inclusion criteria. No responses were received from the service users who lived with their families. It was assumed that family members might have a potential effect on whether or not people with intellectual disabilities participate in a research study.

Jessiman (2013) describes family members or any other gatekeepers as playing a crucial role in recruiting participants as they potentially block eligible participants, consequently affecting potential participants' autonomy to make decisions. However, Keneshia et al. (2014) supports the behaviour of family members in protecting their loved ones from the potential risk of participating in research and suggests that their behaviour might be due to past negative experience and mistrust of researchers. In addition, Nicholson, Colyer and Cooper (2013) and Swaine et al. (2011) suggest that family members of people with intellectual disabilities are commonly content with the situation and frequently perceive that there will be no benefit from participating in a research study. Most importantly, service receivers may be afraid that making negative comments in a research study could have an impact on receiving care for their loved ones (Becker et al. 2004). In total, 11 people with intellectual disabilities were recruited to the study. Of these, five were categorised as having mild intellectual disability and six having moderate intellectual disability. All of them were living in a residential service.

#### **4.3.2 Recruiting family members of people with intellectual disabilities from residential service**

Similar envelopes, which contained an information sheet (Appendix D), a participant acceptance card (Appendix C) and a self-addressed envelope, were given to the clinical nurse managers of each residential unit and office staff who provide community service to people with intellectual disabilities. These were posted to the parents of people with intellectual disabilities. The potential parent participants were asked to return the acceptance card if they were willing to participate in the study. After receiving the response from the potential participants (n=2), they were contacted through their preferred medium and a meeting was arranged. After being found eligible (n=2), any queries or questions that they had were clarified and a suitable time and venue for them

to be interviewed was arranged. Only two parents of people with intellectual disabilities were recruited using this method out of 22 invitations. In total 13 (n 13) participants were recruited from residential service including 11 (n 11) participants with intellectual disabilities and 2 (n 2) family members.

## **4.4 CHALLENGES IN RECRUITMENT**

### **4.4.1 Issues of accessing the participants living in residential service**

It was thought that once ethical approval from the teaching institution and research site was obtained, reaching potential participants would be relatively straightforward, but in reality, there were many hurdles to overcome before speaking to the participants with intellectual disabilities. This might be due to the paternalistic attitude of the staff (Forbat and McCann 2010) or staff may be trying to protect their vulnerable service users (Fyson and Kitson 2007). After ethical approval was obtained from the university and research site, the Director of Nursing informally asked me to contact the area Assistant Directors of Nursing and Clinical Nurse Managers concerned before seeing the prospective participants. Therefore, all area Assistant Directors of Nursing were contacted personally and after explaining the study, their approval was obtained. I also met all Clinical Nurse Managers personally where the potential participants lived. The study was explained to all unit managers. They were informed that Dublin City University, the service and the area Assistant Directors of Nursing had already approved the study. Some of the managers asked me to contact family members before I spoke to the prospective participants with intellectual disabilities.

A similar experience was reported by Clapton (2008), who reflected that it appears that the individuality, rights and freedom of the person with intellectual disability to participate in a research study was being both compromised and protected. This illustrates the issue of disempowerment of people with intellectual disabilities; they

cannot decide for themselves whether or not to participate in a research study (Atkinson 2010; Wilson, Clegg and Hardy 2008). It is also proposed by Hamilton and Atkinson (2009) that staff in residential settings exercise more power because they think people with intellectual disabilities lack cognitive ability and life experiences. From the service provider's perspective, this could be interpreted as protecting people who are vulnerable and potentially easily exploited (Fyson and Kitson 2007). In addition, service providers may also feel that people with intellectual disabilities could be coerced (Cambridge and Forester-Jones 2003) or they might be caused psychological harm by participating in research (Stalker 1998). Some people may think that people with intellectual disabilities have a lack of understanding (Huntington and Robinson 2007) or that they are unable to weigh up the risks and benefits of the research process (Yan and Munir 2004). Often these kinds of protective attitudes will place an excessive limitation on people with intellectual disabilities to participate in research (Lai, Elliot and Ouellette-Kuntz 2006; Becker et al. 2004). A positive outcome of this study was that no managers or parents refused permission to contact the service users. This might be due to the fact that I work in the research site and the case may have been different if a person from outside undertook the research (Iacono 2006).

The area Assistant Directors of Nursing and some of the Clinical Nurse Managers were more concerned about the nature of the study and its context, and talking about death and dying to service users. The same attitude was found in a study carried out by Morton-Nance and Schafer (2012). In their study, participants believed that talking about death and dying may upset and distress people with intellectual disabilities. Therefore, I explained the nature of the interview process and that the issues would be raised in a generalised not a personal way. It was further explained that a story would be told before the commencement of the interview and that questions would be based on the story (Boxall and Ralph 2009). Despite the concerns of service providers, no service

users interviewed raised any issues regarding death and dying; on the contrary, they were all very happy to talk about the subject and proud to share their opinions in the hope that this would improve service provision for people with intellectual disabilities at the end of their lives. One service user who participated reflected the following sentiment:

*[I] Feel very happy being with you and sharing all my stories and thoughts with you. Look after sick people, look after each other, and my thoughts may help the sick people to care for (Conor).*

Another participant shared the following opinion:

*No problem and I am very, very happy to share my opinions and thoughts, I will do whatever I can do for you to help the sick and dying people like us (Rebecca).*

#### **4.4.2 Issues accessing family members and service users who live with their family members**

Initially, letters of invitation were sent to each potential participant, both service users and family members. Envelopes that contained an information leaflet, the participant's acceptance card and pre-stamped return envelope were given to the Assistant Director of Nursing who is responsible for the office that provides services to people with intellectual disabilities who live in the community. She was asked to post it to the potential family members and service users. After three weeks, two family members replied out of thirty potential participants, but no replies were received from service users. After a meeting with my supervisors and extensive discussion with my colleagues, it was concluded that two reasons might have prevented them from participating in the study. One might be that people are reluctant to speak about death and dying and another is that they fear their identity will be revealed. Therefore, it was decided to send another letter to all potential participants but ask them to reply to me instead of the service provider. Surprisingly, after a week two replies were received, however both potential participants were unwilling to participate in the study. The reason stated in the first letter was that they had good faith with the current service

providers in providing good end-of-life care and the second reply stated that they had no strong opinion on end-of-life care for their son. This reflected the problem that was faced by Kadushin (1997) in his study, where the participants refused to participate because they feared loss of their privacy and confidentiality. Other possible reasons that may have prevented them from participating in the study include the perspective that end-of-life care discussion is ambiguous, threatening, unfamiliar and debatable (Claire et al. 2011) or they might have felt a lack of interest or lack of perceived benefit (Yancy, Ortega and Kumanyika 2006).

Recruiting people with intellectual disabilities is difficult but working closely with key workers can yield a way to recruit potential participants. For their TILDA-IDS study, McCallion et al. (2012) recruited participants with intellectual disabilities by working with carers of people with intellectual disabilities. Payer and Campell (2012) also encountered the same problem when they recruited participants for their study; therefore, they worked with professionals and established a relationship before recruiting their participants. Hence, the office that provides community service was contacted and I began to work with them closely and visited a few family members. Parents and friends associations were also contacted and their meetings were attended and the study discussed. It was a worthwhile exercise because in this way, I recruited six family members (N6) from community service but all the family members requested me not to speak to their sons or daughters with intellectual disabilities. Again, this shows the protective attitude of parents to prevent their sons or daughters from being exposed to risks (Davis 2011). As a next step, I attempted to recruit people with intellectual disabilities through an advocacy network. However, this was not successful. The reasons were that, firstly, the study was carried out with a specific service provider and no service users from this service were actively involved in any advocacy group, and secondly, family members of people with intellectual disabilities requested me not

to speak to their adult children and I wanted to respect their wishes. These kinds of attitudes from parents and professionals mean that people with intellectual disabilities avoid risks altogether; this therefore results in them compromising their choices and making them less responsible for their actions (Department of Health 2007). To facilitate people with intellectual disabilities in engaging with research studies, Boulter and Pointu (2006) suggested that with adequate assessment of risks and support they will make the right choice, so people should understand there is a fine balance between safeguarding people with intellectual disabilities and empowering them.

#### **4.5 PARTICIPANT PROFILE**

This study involved people with mild and moderate intellectual disabilities and their family members. In total 11 people with intellectual disabilities and 8 family members were recruited. Table 3 provides the characteristics of the participants with intellectual disabilities, including information about age, sex, level of intellectual disability and living facilities. Table 4 provides a description of the family members of people with intellectual disabilities, giving an insight into the age of the family members who are looking after their children at home with minimal support from the service. It might be assumed from the age profile of the parents that as most of the parents are getting older they themselves will require some kind of support from a service; therefore, this indicates that their adult children might require residential support in the near future. Participants are assigned with pseudonyms to prevent their identification and anonymise them.

**TABLE 3 PARTICIPANTS WITH INTELLECTUAL DISABILITIES**

<b>Name</b>	<b>Age</b>	<b>Sex</b>	<b>Level of intellectual Disability</b>	<b>Living Arrangement</b>
Conor	56	Male	Mild	Hostel
Sean	51	Male	Moderate	Hostel
Jack	54	Male	Mild	Hostel
Aoife	52	Female	Moderate	Hostel
Sarah	65	Female	Moderate	Hostel
Ciara	67	Female	Moderate	Hostel
Emma	63	Female	Moderate	Group Homes
Rachel	58	Female	Mild	Group Homes
Rebecca	72	Female	Mild	Hostel
Lauren	63	Female	Moderate	Hostel
Katie	67	Female	Mild	Hostel

**TABLE 4 FAMILY MEMBERS OF PEOPLE WITH INTELLECTUAL DISABILITIES**

<b>Name</b>	<b>Age</b>	<b>Sex</b>	<b>Status</b>
James	72	Male	Father
Adam	68	Male	Father
Michael	81	Male	Father
Emily	49	Female	Sister
Nicole	62	Female	Mother
Roisin	71	Female	Mother
Tara	65	Female	Sister
Eimear	62	Female	Mother

## **4.6 ETHICAL CONSIDERATIONS**

The impact of exploring sensitive issues such as death and dying, particularly among people with intellectual disabilities, raises ethical issues (McCarthy, Weafer and Loughrey 2010). Having acknowledged the issues, and after extensive discussion about potential ethical issues with supervisors and staff from the study, strategies were developed to minimise or prevent them. The fundamental ethical principles of capacity to consent, informed consent, discussing sensitive topics, and maintaining anonymity and confidentiality were discussed.

### **4.6.1 Capacity to consent**

Attempting to get consent from people with intellectual disabilities is part of a responsible relationship and is an essential requirement for a transparent research process (Department of Health, Social Services and Public Safety 2008). In the consent process, all adults are presumed to have a capacity to consent unless it is proved otherwise and this is very much the same for people with intellectual disabilities (Department of Health, Social Services and Public Safety 2009; Clapton 2008). However, to safeguard the safety of the participants with intellectual disabilities, the ethics committee recommended having an independent party assess their capacity to participate in the study. When each potential participant was identified, their suitability was discussed with a psychologist, a member of the multi-disciplinary team, and a relevant unit manager. The following procedures were employed to make sure the potential participant had the capacity to consent to participate in the study.

Once the potential participant was identified, a psychologist who was a member of the multi-disciplinary team assessed the participant's capacity to take part in the study. During this process, the psychologist gave the information sheet to the service user and explained the study. Then the service user was asked a few questions regarding the

nature and purpose of the study, and the risks and benefits of the study and what was expected from the service user was explained. These questions were asked to ascertain whether the service user could understand the information required to make an informed decision to participate in the study, and also whether they understood their right to participate or withdraw from the study at any time without any consequences. Additionally, the process was used to ascertain whether the service user was able to communicate his or her decision (Taua, Neville and Hepworth 2014). Once the psychologist was satisfied that the person had the capacity to consent then he or she was recruited for the research.

#### **4.6.2 Informed consent**

Providing information that is suitable for the participants to understand is a prerequisite for obtaining informed consent (Swaine et al. 2011; Brodin and Renblad 2000). In order to obtain informed consent, an easy-to-read information sheet and a consent form were developed (Appendix B) (Iacono and Carling-Jenkins 2012; Tuffrey-Wijne 2009) with the help of an adult with an intellectual disability, a speech and language therapist, a Montessori teacher and an assistant director of nursing with previous experience in this area. The easy-to-read information sheet and consent form contained pictorial explanations of the research which detailed the nature, purpose, anonymity, confidentiality, dissemination and risks involved in taking part in the study (Inglis and Swaine 2012; Swaine et al. 2011). This was done to help the participants with intellectual disabilities to make an informed decision about their participation (Inglis and Cook 2011). The information sheet and consent form was piloted with adults with intellectual disabilities and also given to the Montessori teacher to work through with potential participants. Based on their feedback, the information sheet and consent form were modified (Cook and Inglis 2012).

Informed consent was obtained from each participant before the interview commenced. The information sheet with pictorial explanations gave them a better insight and understanding of what the study was about and what was expected from them. Adequate explanations were given with regard to their concerns before they signed the consent form. In order to obtain informed consent, time was invested with participants, during which the purpose of the research was explained and they were asked to read and assimilate the information about the research. Potential participants were encouraged to ask for clarification about the research prior to consent being sought. Furthermore, the participants were supported in communicating their preferences regarding their right to consent, their right to refuse consent or their right to withdraw consent. To facilitate informed consent among the family members of people with intellectual disabilities, each participant was given the information sheet and consent form that explained the nature and purpose of the research study. Furthermore, they were reassured of their anonymity and of confidentiality.

#### **4.6.3 Discussing sensitive topics**

It is recognised that participating in sensitive research has the potential to create physical and psychological harm (Jepson, Abbott and Hastie 2015; Kendall et al. 2007). Lindop (2006) suggests that there is a chance of inflicting harm on people with intellectual disabilities when discussing a sensitive topic. On the other hand, Tuffrey-Wijne (2010) successfully included people with intellectual disabilities in her study of death, dying and cancer. As I am a novice qualitative researcher with no previous experience of researching sensitive topics such as death and dying, this study was closely monitored and mentored by the study supervisors. This process enabled the interviews to be carried out in a gentle and caring manner, thus minimising stress for the participants.

At the start of the interview, all participants were informed that the interview would be terminated if they felt upset or uncomfortable. During the interview process, three participants with intellectual disabilities were upset when they recounted their experiences of their friend's death. They revealed that even though their friends' deaths were imminent and that had suffered from life limiting illness, this was hidden from the participants. They felt regret that they could not see their friends after their death and did not have the chance to say goodbye to them. This is mirrored in the study by Cordner et al. (2010), who found that friends of people with intellectual disabilities were not aware of their friends' diagnoses and impending deaths, therefore they could not prepare in a better way to face the loss of their friend and to resolve any conflicts. The above participants became silent and sad; they were reassured and the interviewer checked whether they wanted to continue or stop the interview. They appeared comfortable and continued after a few minutes. Ongoing verbal consent was obtained during the interview to confirm continued willingness to participate in the study.

After the interview, follow-up phone calls were offered to check how participants were feeling but everybody declined these. However, a few participants with intellectual disabilities wanted to see me again to have a chat. I visited these participants as promised after a few days and we had a non-research conversation. This opportunity to see them again face-to-face helped me to assess their emotional state after the interview (Walls et al. 2010; McIlfatrick 2007). When ethical permission was sought from the university, the Ethics Committee raised the issue of after-study care of the participants (McDonald and Keys 2008). To provide care after the study, a bereavement counseling service in Dublin agreed to accept any referrals from the study if required. All of the participants were given the information. Clinical nurse managers of the location of the service users who participated in this study were also informed. However, to my knowledge nobody availed of this service.

#### **4.6.4 Privacy and confidentiality**

Participants' privacy was respected by conducting interviews in their choice of venue, for example in a participant's home or in an agreed location. The interviews were conducted in a separate room and the door was closed as per the participant's preference. In this study, most of the interviews were conducted in a private room in the residential intellectual disability service where the study was conducted. The room was situated in a quiet place where there was minimal disruption and interruption from other people.

In order to protect the confidentiality of the participants, the data was assigned pseudonyms and these names were used throughout the study in all related documents. All data was stored in a computer, which was protected by a password and only accessible by the research team. Hard copies such as transcriptions, field notes and audiotapes were locked in a filing cabinet. For future dissemination of the outcomes of the study through conference presentations, publications or professional presentations, all the information will be anonymised to protect the confidentiality of the study participants.

### **4.7 INTERVIEWS**

Interviews are considered a traditional and popular way of exploring opinions to construct meaning about the phenomena of research interest (Rosetto 2014; Pope 2006). There are many forms of interviews available; however, most commonly, unstructured, semi-structured and structured interviews are used to explore the phenomena of interest (Kvale and Brinkmann 2009). In a grounded theory study, it is accepted practice that at the beginning of the interview researchers should be unfocused and wait for the unknown (concept) (Wimpenny and Gass 2000). Once researchers know that something (concept) is coming out from the data, they should focus on this concept and construct

what it is (theory) (Rose 1994). Therefore, semi-structured interviews give more opportunity to researchers to focus on what they want to look for and provide more flexibility to sequence the questions to develop a theory that explains the research phenomena (Bristow et al. 2015). This is congruent with grounded theory. Duffy, Ferguson and Watson (2004) and Silverman (1998) suggest that unstructured and semi-structured interviews are more appealing and suitable for qualitative researchers. Gladwell (2015) found that semi-structured, individual in-depth interviews would allow the interviewer to be deeply involved with and understand the social and individual accounts.

This study adopted semi-structured interviews to explore the end-of-life care needs of people with intellectual disabilities. Employing interviews to explore life experiences and perspectives among people with intellectual disabilities is well documented. Wilkinson et al. (2011) used interviews to explore the experiences of undergoing mammography among women with intellectual disabilities, while Bernert (2011) adopted semi-structured interviews to examine the issues around sexuality. Crossley and Withers (2008) successfully employed interviews to look at the experiences of taking anti-psychotic medication, and Tuffrey-Wijne (2009) utilised semi-structured interviews to probe the experiences of living with disabilities and dying of cancer. Tuffrey-Wijne (2010) found that people with intellectual disabilities feel inhibited and were sometimes reluctant to discuss issues when other individuals were around them. Therefore, a semi-structured interview with one-to-one contact was chosen to collect the views and opinions of people with intellectual disabilities and their families regarding end-of-life care needs. The interview guide is attached in Appendix E.

The choice of interview as a method of data collection in this study was felt to be more valuable due to its ability to explore meanings and perceptions on a more personal level (Murray 2003). Even though exploring palliative and end-of-life care needs is sensitive

and talking about death and dying is uncomfortable, several researchers have employed interviews to answer a wide range of questions in this area (Holdsworth 2015; Malhotra et al. 2015; Aoun et al. 2015; Gillian, Seymour and Payne 2012; Momen et al. 2012). For example, interviews have been used to explore end-of-life care experiences (Bollig, Gjengedal and Roseland 2015); preferences (Holdsworth 2015; Momen et al. 2012), issues around care (Ouimet Perrin and Kazanowski 2015) and evaluating care intervention outcomes (Holdsworth et al. 2015).

#### **4.7.1 Carrying out the interviews**

After obtaining approval from the DCU Research Ethics Committee and permission from the research site, the interviewing process commenced with two pilot interviews. After this, the interview guide, content and the approach were modified, based on the feedback. Overall, 19 interviews were carried out between June 2012 and January 2013. During the interview, a story from the book called *Am I Going to Die?* was discussed and questions were raised from the story to facilitate the thinking of people with intellectual disabilities (Aldridge 2007; Booth and Booth 2003). The participants were interviewed in a convenient place; some of the participants were happy to be interviewed at their own homes and some participants were interviewed in a room at the research site.

As Bernert (2011) encountered, recruiting and interviewing people with intellectual disabilities was an issue. During the actual interview, a few participants with intellectual disabilities struggled to reveal information as it was not about their real life situation and there were no concrete issues for them to discuss. Even though they revealed minimal information, it was useful to understand their concerns about the needs of people with intellectual disabilities at the end of life. This is closer to Glaser's opinion that everything is data in grounded theory (Glaser 1978). So, I was happy to give an opportunity to these participants to raise their concerns around the issue of end-of-life

care rather than worrying about not obtaining sufficient information about the research. Throughout the interview process, the participants with moderate intellectual disabilities were encouraged to give their views and opinions. In addition, trigger questions were used to assist the flow of conversation and to help them to reflect on their experiences, such as “how did you feel?” and “why did you feel so?”.

#### **4.7.2 Reflection on interviewing people with intellectual disabilities**

Involving people with intellectual disabilities, a marginalised and under-represented community in research, is essential as recent health and disability policies support the involvement of service users (McLaughlin et al. 2015; McClimens and Allmark 2011; Tuffrey-Wijne et al. 2006). Interviewing this population was sometimes challenging (Gibbs, Brown and Muir 2008) because they often found it difficult to articulate their views and opinions with sufficient description in a logical order (Conder et al. 2010; Booth and Booth 1994). In the opinion of Conder et al. (2010), interviewing people with intellectual disabilities is not an issue if the researcher knows how to do it. I as a nurse have been working with people with intellectual disabilities for more than thirteen years and have experience of discussing various topics with them without much difficulty. Therefore, general conversation with people with intellectual disabilities during the interview was comfortable. However, having a dialogue around death and dying was both anxious and difficult. This was a valuable experience as I learned how to conduct conversations with people with intellectual disabilities for the purpose of research.

During the interview, the participants with intellectual disabilities enjoyed talking about their day, work, friends and their family. For me, it was difficult in the beginning to discuss issues not related to the study as the interview had a research aim and objectives. Therefore, it was a struggle to discuss things that were not related to the research objectives. After a few interviews, I recognised that the most important thing for the participants was to have a personal conversation and that any topic may arise at

any time during the interview. For example, one of the participants talked about her sister and family and about Christmas presents in the middle of an answer to an unrelated question. In the beginning, there was confusion as to whether to continue with personal conversation or to stop engaging with the participant at this point. I learned after a few experiences that I should try to focus on the research topic and allow the participants to finish their personal digressions. Therefore, it was preferred that the participants complete their personal conversations before proceeding with the interview. An important learning outcome from this experience was that participants with intellectual disabilities frequently go beyond the scope of the research purpose in their conversation topics. However, it was understood that this was the only opportunity for some people with an intellectual disability to speak about private albeit unrelated issues. Therefore, it was decided to let the participants continue for a short period and slowly bring them back to the research topic. Most of the time, they were happier to talk about personal and everyday events rather than the specific purpose oriented issues.

In one incident, after arranging an interview with a person with an intellectual disability, on the day of the interview she refused to talk to me about the study; however, we talked about other things such as how the day was, what was she doing and how she was feeling. The conversation made her happy, even though it was disappointing for me because I had travelled for half an hour to reach the interview location and had arranged for somebody to look after my children. From this experience, I realised that it was her choice to pull out from the research; therefore, researchers should prepare themselves for this kind of disappointment at any time. However, they should remain professional and give participants support if required.

There was another issue in having an abstract and hypothetical conversation with people having moderate intellectual disabilities as the topic of conversation was about death and dying. During the interview, most of the time, participants required a concrete and

real life example. When discussing the story, from the easy-to-read book *Am I going to Die?*, most people with moderate intellectual disability asked me who John was in the story and where did he live and who were the doctor and nurse. I had to tell them several times that it was a story and not real. Then they referred to a unit that provided care to the sick and dying people and mentioned a few names of people who had died recently. The conversation continued from there. Interviewing people with mild intellectual disabilities was not difficult, as they did not need the story to tell them about the issues because they were aware of most of the issues. The participants talked about abstract and hypothetical issues when given adequate time to think and respond.

A further issue was that it was difficult to terminate the interview because some of the participants wanted to talk more. I allowed this to happen on several occasions but a few times, I had to leave and terminated the interview. The situation was explained and I told the participants that I would visit them on another occasion. A few days later I visited them as promised, had a general conversation, and a cup of tea with them. Another issue was engaging the participants and obtaining sufficient data. Most participants with intellectual disabilities interviewed were fluent and revealed their experiences quickly but when it came to the concept of death and dying, they required prompting. For example, when a woman was interviewed the following questions were asked:

Interviewer: *What would be good care at the time of dying for a person with intellectual disabilities?*

Aoife: *Looking after them.*

Interviewer: *How would you look after them?*

Aoife: *Make them happy.*

Interviewer: *How would you make them happy?*

Aoife: *Give them good care.*

Interviewer: *What would be good care?*

Then she started to think for some time and gave her response. It was quite challenging sometimes to make the person with an intellectual disability articulate. A lesson learned from this experience was that irrespective of the degree of intellectual disability, all participants were happy to share their views and opinions. Also, most of the participants with intellectual disabilities asked me to play back the recorded interviews afterwards for them. They enjoyed listening to their voices and asked me to play back the interviews more than once.

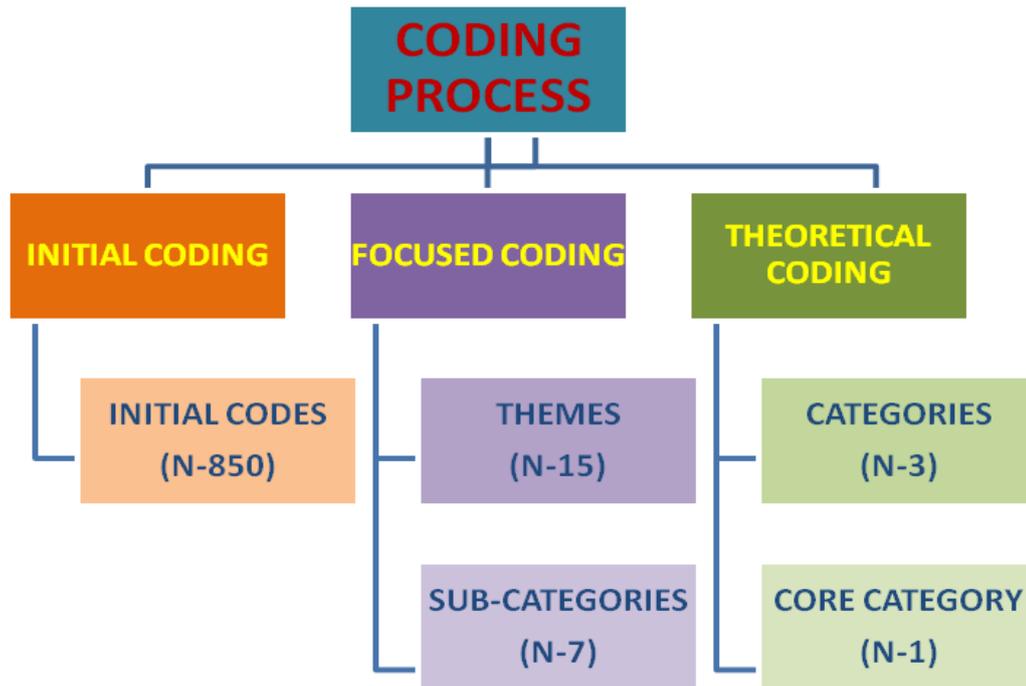
#### **4.8 DATA ANALYSIS**

Before commencing data analysis the audio files were listened to carefully, sometimes two or three times, to gain insight into the participant's responses because they contained broken sentences, hidden meanings, brief responses and incomplete sentences. Then the data was transcribed into written words. The verbatim transcription was carried out carefully and thoroughly. After the transcription process, the audio files were listened to again to check the accuracy of each transcription by correcting errors.

Since the study was underpinned by constructivist philosophy, the data analysis process was guided by the principle developed by Charmaz (2006). In this guiding principle, initial coding, focused coding and theoretical coding were central to the analytical process. In keeping with constant comparative analysis, the emerging codes and categories were constantly compared and contrasted against the data, codes and categories that had emerged previously (Durry, Francis and Chapman 2008; Roberts 2008). In the data analysis process the initial codes were constructed using line-by-line

coding, then concepts, sub-categories and categories were developed by using focused coding. Finally, a core category was constructed by the use of theoretical coding. Figure 2 illustrates the coding process.

**FIGURE 2 CONSTRUCTION OF A CORE CATEGORY**



The following sub-sections provide a detailed description of how the data analysis was approached and how sub-categories, categories and core categories were constructed.

#### **4.8.1 Initial coding**

There is considerable interest from qualitative researchers in using computer programmes for data storage, retrieval and analysis (Banner and Albarran 2009). Responding to this trend, I had a few lessons about how to use software to assist in the coding process and coded the first four interviews by using NVivo9. Often I felt that my initial coding through the use of software was unsuitable when the dialectical relation between coding and memoing was applied. As a result of this, the names of concepts were changed repeatedly. Therefore, I felt that this could be better achieved through pen and paper rather than with technological assistance. However, I continued to use NVivo

to store data, memos and codes because of ease of retrieval (Bergin 2011). While coding, a label was attached to each segment of data that it intended to explain (Charmaz 2006). Throughout the entire process of the initial coding, the four questions as suggested by Charmaz (2006) were kept in mind, as follows:

- What is this data a study of?
- What does the data suggest or pronounce?
- From whose point of view?
- What theoretical category does this specific datum indicate?

By following Charmaz's (2006, p.46) suggestion that "through coding, you define what is happening in the data and begin to grapple with what it means", the initial coding started. The initial codes were either forced (Strauss and Corbin 1998) or emerged (Glaser 1978) but they were constructed by a combination of my own abstract words (conceptual coding) and the participant's words (in-vivo coding). Also, during the initial coding, it was difficult to follow the guidelines of Charmaz (2006) to code swiftly and spontaneously. In the beginning, I frequently struggled to give an appropriate label to a segment of data. Therefore, I approached a colleague, who had recently completed his PhD using the constructivist version of grounded theory, to clarify how some parts of the data could be coded. In addition, two coded interview transcripts were sent to my supervisors to get feedback on the coding to ensure quality and consistency. Table 5 provides an example of the initial coding process.

**TABLE 5 AN EXAMPLE OF THE INITIAL CODING PROCESS**

Initial Codes	Transcript
<p>Being with dying people</p> <p>Being surrounded by parents and friends</p> <p>Letting the parents know of dying</p> <p>Getting help from parents</p> <p>Receiving help from professionals</p> <p>Disclosing what is happening to the dying person</p> <p>Letting the parents know about dying</p> <p>Being shocked about not knowing information</p>	<p>Mary would you please tell me what the needs of people with Intellectual Disabilities at the time of dying are?</p> <p>If the people are really sick, the doctors and nurses should be there all the time and make them realise that they are going to the other world and the gate is being ready to open. Their parents and friends stand beside their beds. It is not right to tell their parents after someone has died. They should stay right beside their bed, right from the beginning. Stay with them and help them out. The doctors and nurses should work closely with them and find out exactly what happened to them. People who are really dying should know exactly what is happening to them. They should ring the family immediately and the family should stay with them right from the beginning. I am really shocked when I heard about poor xxx. I do not know whether he was dead or alive or he got back from xxx hospital. I know one morning he was shifted to xxx hospital at 3 o' clock and I haven't heard nothing since then.</p>

The stage of initial coding was a really challenging and time-consuming experience as it was confusing and uncertain as well as a thought-provoking and intellectually stimulating exercise. While coding, I was conscious about not forcing the codes to fit into the emerging categories even though I realised that large numbers of initial codes made analysis more difficult. Overall, the initial coding process produced 850 codes.

#### **4.8.2 Focused coding**

During the process of initial coding and interviewing, I noted that some of the significant and frequently recurring codes gave rise to conceptual categories. Therefore, interviews, initial coding and focused coding were carried out simultaneously. By using constant comparative data analysis, existing and emerging initial codes, which provided similar meanings and understanding, were grouped into themes (Hunter et al. 2011). By doing so, 15 concepts from the initial codes were constructed. Following this, possible connections among concepts were made. This produced eight sub-categories, which were subsequently reduced to three categories. An explicit example is provided in Appendix G about how the category of holism was constructed from the data.

On reflection, the procedure was demanding because of my desire to follow the process logically and methodologically so as not to force the data to develop codes and construct abstract categories too early to answer the research questions. In the data analysis process, some of the codes were removed from the data analysis as advised by Creswell (2007) because they were not relevant to the constructed conceptual categories and theory development. It was not easy in the beginning as different sub-categories with different codes were constructed, for example, sub-categories like “hope”, “awareness”, and “nobody belongs to them” were developed. A discussion with my supervisors and a colleague who had finished his PhD in the area of palliative and end-of-life care using grounded theory ensued. Based on their feedback, different categories

were constructed. This was carried out to make sure that the data was not forced to fit the existing categories. Some of the codes that were constructed in the beginning did not fit with the new categories; therefore, they were removed and kept for future research. These were reviewed on several occasions as new categories were constructed. Even though this process was time consuming, complex and difficult, it was nevertheless a positive and worthwhile experience. The next step was equally challenging because it explored the possible relationships between these constructed categories so as to develop a core category.

#### **4.8.3 Theoretical coding**

To identify and specify the possible relationship between sub-categories, theoretical coding (Charmaz 2006) was employed. During the process of theoretical coding, constructing categories and a core category that was central to the phenomena of end-of-life care needs from the perspective of service users and family members was attempted. The constructed core category aimed to encapsulate the sub-categories that were constructed during the focused coding as well as connecting them with possible links. As Charmaz (2006) suggests, the theory is a by-product of the researcher's intellectual, thoughtful effort of grouping and organising the interaction between the researcher and participants. By doing so, a core category named "continuity and ultimatum" was constructed. Then, after some time the data analysis process was looked at again and after discussion with my colleagues and supervisor regarding the appropriateness of the core category. As a result, the core category was renamed "Preserving Self in the Face of Death and Dying". This was due to the fact that the data from the participants and sub-categories revealed the importance of keeping the self intact at the end of life for people with intellectual disabilities.

The following flow chart (Figure 3) illustrates the theoretical concept of the end-of-life care needs of people with intellectual disabilities. It explains how the core category of

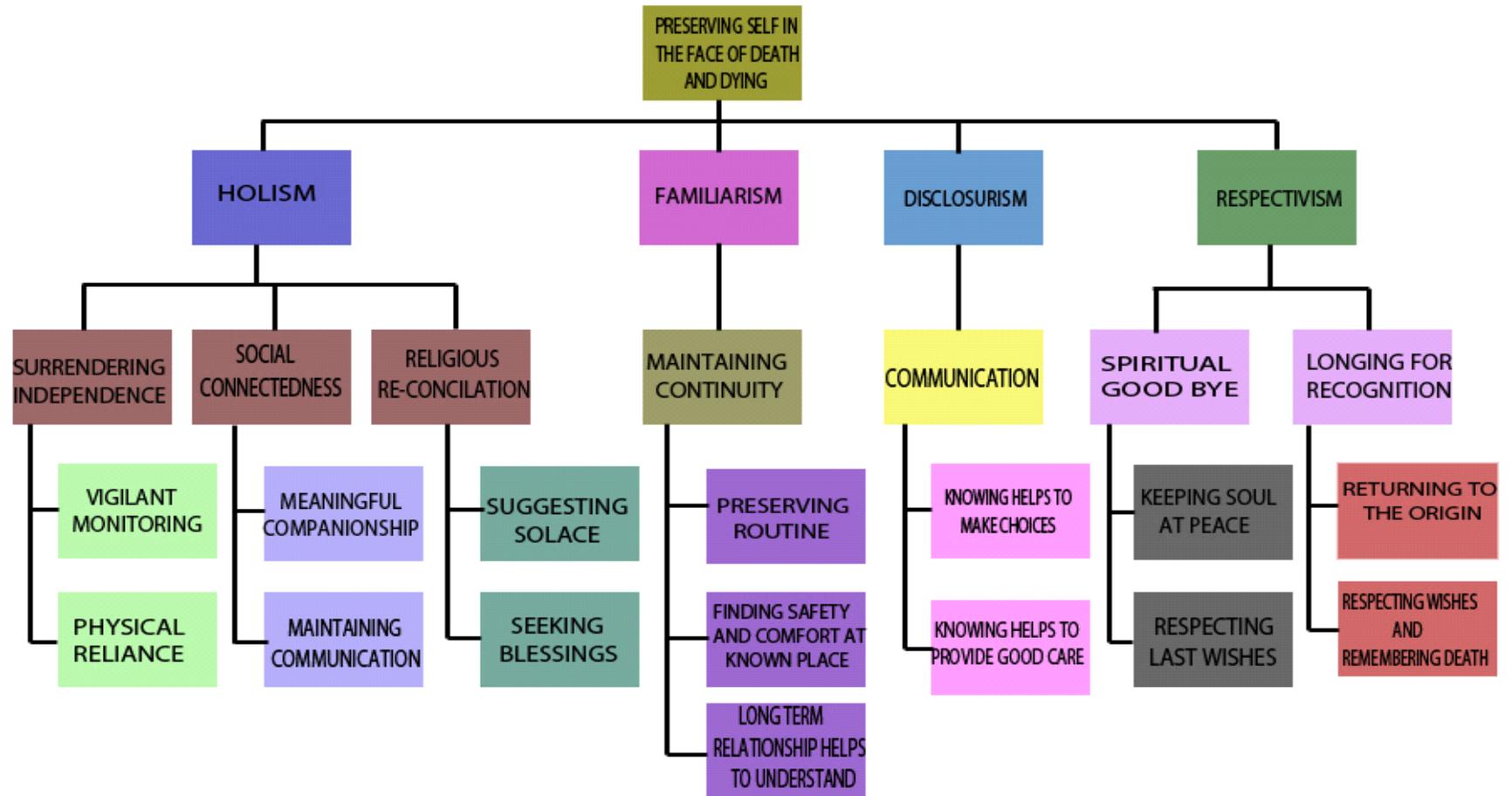
“Preserving Self in the Face of Death and Dying” was developed and how the categories and sub-categories are inter-related and inter-connected with each other.

The flow chart provides a visual explanation of preserving self of people with intellectual disabilities at the time of death and dying. During the interview and data analysis phases, it was found that there was a significant concern from the participants to protect and preserve their sense of self at the end of life. Keeping this self intact was their main concern at the time of dying and after their death.

The category holism was constructed from the participant’s concern that they wanted to protect and preserve their physical, psychological, social and spiritual self at the time of dying. The participants felt that this could be achieved through the provision of physical support and comfort. Furthermore, participants wished to be accompanied and have conversations with people who liked them because they did not want to be left alone and isolated. In addition, they sought religious reconciliation to preserve their spiritual self.

The category familiarism was constructed from the participants’ concerns that considered familiarity with place, people and activities were essential to preserving their sense of self at the time of dying. They wanted to keep everything in their life intact at this critical time. The category disclosurism reflected the participants’ desire to know what was happening to them in order to make choices and plan. In the opinion of the participants, the holism, familiarism and disclosurism categories were essential during the dying phase. They believed that this would protect and preserve their embodied self.

**FIGURE 3 DEVELOPMENT OF THEORY**



The category respectivism reflected the main concerns of people with intellectual disabilities after their death. Participants in this study believed that their soul remains alive even after their physical death, therefore, they believed that saying a spiritual good bye, paying last respects and respecting last wishes were fundamental to preserving and protecting their soul self.

The theory of preserving self in the face of death and dying explains and predicts the care needs of people with intellectual disabilities at the end of life. Throughout their end of life trajectories, people with intellectual disabilities strive and expect professionals and carers to keep their physical, social, psychological, spiritual and soul self intact. The theory also describes how a dignified death can be achieved through preserving self of people with intellectual disabilities at the time of death and dying.

#### **4.9 WRITING MEMOS**

Writing a memo is an integral part of grounded theory (Charmaz 2006), Charmaz explains that memos are a researcher's method to develop ideas about codes and their relationships. Most of the time, especially in the beginning, the memos are awkward and their significance may be unknown but their potential effect will be realised when the researcher elaborates conceptually (Hoare, Mills and Francis 2012; Montgomery and Bailey 2007). The boundaries of the memos are defined by the evolving categories. As suggested and described by Birks and Mills (2011), a memo was written whenever I had an idea about the codes and categories, without worrying about writing style or grammar. Furthermore, the memos can be modified and shuffled around to gain an insight and to identify relationships between categories and develop a core category. In one situation, when reading a story that was thought to be unrelated to the study, the concept of "being silent" came up. It was the wish of one of the study participants that their friends and parents be with them, even if they are silent when they are dying. On

occasions, I spontaneously perceived the meaning and essence of some of the concepts. This was one example of the way insight was gained into the participant's concerns.

During the initial and focused coding process, whenever concepts were found that showed any kind of pattern that were new or had new aspects, a memo was written. This memo was compared with existing and new categories, sub-categories or concepts. From the basis of the memos, further data analysis was done then compared with the data that had been analysed previously to reconceptualise the concepts. Throughout the data analysis, there was an intention to develop a further understanding of the concepts. On most occasions, memos were written as soon as possible but sometimes were left late. Memos were written in the way they were thought, quickly and freely without paying too much attention to grammar, style and sentence.

#### **4.10 CHAPTER CONCLUSION**

The constructivist version of grounded theory (Charmaz 2006) was adopted for the purposes of the study. In this chapter the actual process of conducting the research is discussed, including theoretical sampling, recruitment, data collection and data analysis. Some insights related to the issues of recruiting participants and interviewing people with intellectual disabilities are outlined. Despite numerous difficulties, the research process produced rich and significant findings. The data analysis generated seven sub-categories, four categories and one core category. The findings and their significance are discussed in detail in the following chapters.

# CHAPTER 5- HOLISM

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## 5.1 INTRODUCTION

This chapter focuses on exploring holism, one of the study's categories. Holism was identified as one of the requirements of people with intellectual disabilities that enable them to preserve their sense of self at the end of life. This chapter gives an insight into how holism is perceived, and why it is believed to be important at the end of life. The data revealed "surrendering independence", "social connectedness" and "religious reconciliation" to be sub-categories of the holism category.

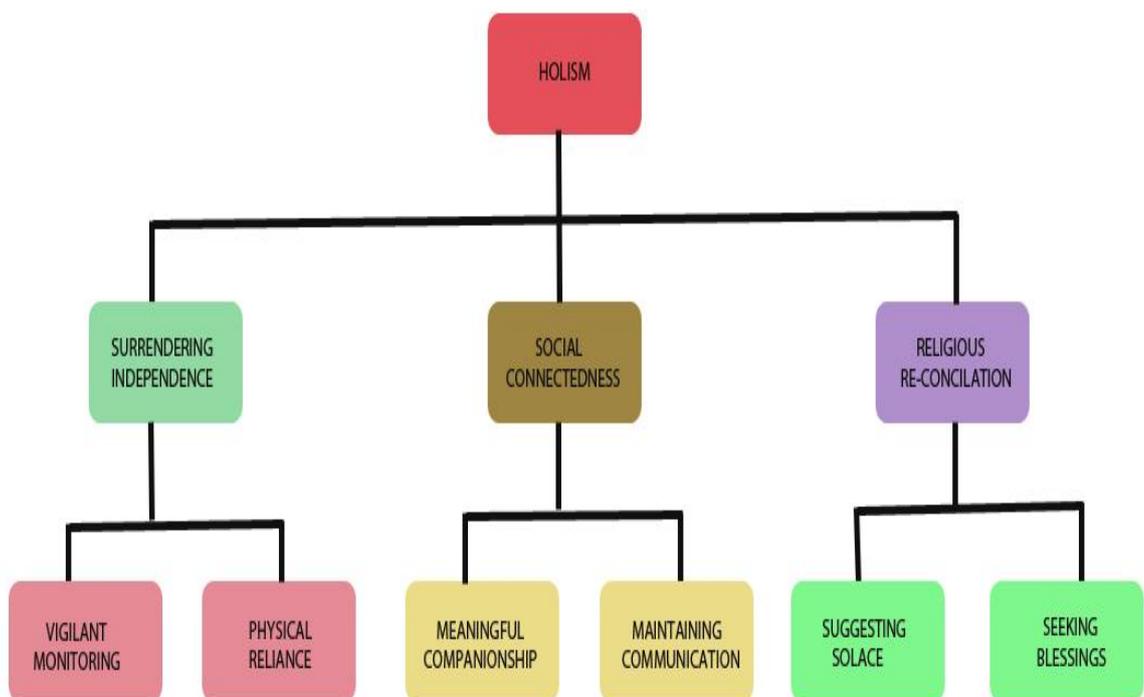
## 5.2 HOLISM AND END-OF-LIFE CARE

Holism is a concept based on the whole, where all entities are connected together and related to each other (Wilson 2013). In a bio-psycho-socio model of health care, physical, psychological, emotional, social and spiritual dimensions are viewed as an integrated whole instead of separate identities or a collection of parts (Maher and Hemming 2005). Furthermore, holism is concerned with promoting the interrelationships and wellbeing of body, mind and spirit in an ever-changing economic environment of health care (Arvindsson et al. 2006). In contrast, individualism considers that the properties are separate and that isolated entities exist without any interaction (Adams 2002). The notion of holism acknowledges that any problem or imbalance in any one of physical, psychological, social and spiritual domain has an impact on other things; therefore, it is necessary to view them as integrated (Archibald 2012). Holism also relates to an individual's perceptions and experiences that deal with their emotions, fears and worries (Hjelm et al. 2005). The holistic principle views the patient as an individual with unique characteristics and suggests devising a plan that

incorporates this (Efstathiou and Clifford 2011). The interaction and interlinks of holistic properties make holism a cyclic, continuous and dynamic model (Boswell, Cannon and Miller 2013).

The participants highlighted the principles of holism throughout the study. They believed that providing physical and intimate care, supervising when they are in need, offering a social presence, safeguarding from loneliness and improving spiritual comfort are necessary, and consequently protect and preserve their sense of self towards the end of their life. Figure 4 illustrates the interrelationship among various sub-categories and its properties.

**FIGURE 4 HOLISM**



The following are sub-categories of holism: “surrendering independence”, “social connectedness” and “religious reconciliation” are discussed in detail in the following sections from the perspective of participants.

### **5.3 SURRENDERING INDEPENDENCE**

Participants in the study acknowledged that people with severe and profound intellectual disabilities are generally dependent on others for their physical care. This is particularly true at the end of life due to increasing fragility and progressive loss of mental and physical abilities. They surrender their independence due to their decreasing ability and capacity to look after themselves, combined with the increasing demand for care towards the end of their life. They reportedly rely on others to meet their physical needs, requiring assistance to get in and out of bed, bathe, eat and drink. In addition, participants acknowledged that they depend on others to meet their medical needs, when complying with medications, suctioning and tube feeding. Furthermore, they turn to other people to fulfill their social and spiritual needs. Most notably, the participants in this study acknowledged that people with intellectual disabilities require vigilant monitoring to provide a sense of comfort, support and to ensure their health and safety.

Surrendering independence at the end of a life is not only a concern for people with intellectual disabilities but also to the general population (Walshe and Luker 2010; Gardner and Kramer 2009). People with intellectual disabilities increasingly rely on their carers towards the end of their life to identify, communicate and to carry out their physical, psychological and other needs (Tuffrey-Wijne 2010). While this dependency on other people can make them vulnerable (Tuffrey-Wijne 2010), it is no different to the general population (Jayawardena and Liao 2006). In this current study, the participants perceived that people become fragile and lose their physical and mental capacity towards the end of their life. Consequently, their dependency on others to meet their physical, social, psychological, emotional and spiritual needs increases. The following sections describe the constituents of "surrendering independence", "physical reliance" and "vigilant monitoring".

### **5.3.1 Physical reliance**

Physical reliance is a concern that was raised by most of the participants. Being self-reliant is a basic source of happiness, achievement, attaining prosperity and having self-worth (Brown, Johnston and Åstlund 2011). In addition, self-reliance helps people to help others. However, towards the end of life it is difficult to maintain the sense of self-reliance as physical and mental capacity declines (Brown, Johnston and Åstlund 2011). The decreased mental and physical capacity combined with increased care demands towards the end of their life forced the participants to physically rely on others, especially their carers, to fulfill their needs.

The loss of independence and assumption of dependence is a difficult change to accept and for many people it is a struggle to fit in to the new identity (Cole and Miller 1999). This reliance is based on hope and expectations that their carers will provide optimal care towards the end of their life. There is an expectation on other people to provide physical care when the sick and dying person's capacity to look after themselves decreases. Therefore, most participants acknowledged that people towards the end of their life are physically dependent on other people to maintain their everyday routine, which can include bathing, brushing their teeth, managing incontinence and feeding. This also includes medical care assistance such as getting tablets and tube feeding. Therefore, physical reliance on others to meet their care needs is one of the concerns of dying people with intellectual disabilities.

The study participants agreed that people with intellectual disabilities live in care homes for a long period and people with severe and profound intellectual disabilities are dependent on carers to meet their everyday needs even before they become ill. They valued this kind of support and acknowledged that the same care approach at the time of dying is essential:

*Handicapped people are living here long and some people are dependent on other people for everything and should be looked after by other people. This is very much important at the last days of life (Emma).*

Conor, a participant with mild intellectual disability, claimed that towards the end of life, people with intellectual disabilities require both professional assistance and the help of those they live with. It is possible that professionals can transfer skills or 'up skill' others who are living with people with intellectual disabilities to involve in the caring process in order to care for their friends. Conor suggested:

*Other people can show how handicapped people are looked after and other people can keep an eye on them, say like other people who live in the house (Conor).*

Connor believed that participation in everyday life activities inclusive of dying is a part of life that people with intellectual disabilities want to engage in. He expected most households to have members that are there and able to help dying people. Therefore, he believed that this kind of help could occur in houses where people with intellectual disabilities live too.

Physical reliance on carers is an aspect of everyday life but in some instances, people with intellectual disabilities themselves help friends who are sick and dying. Many people with intellectual disabilities acknowledge the need for physical help when they were sick. Therefore, they agreed that they relied on other people for their care near the end of their life. In this caring process, people with intellectual disabilities were proud to help and care for their friends. They perceived and recognised the importance of their peers being involved in their care and also felt honoured helping their friends at the end of their life (Stanish and Temple 2012). A participant with a moderate intellectual disability, Lauren, recounted her experience:

*People living in the house; I do a lot of work for them while I am in X house I will do different kinds of work there and if anybody asks for help I will help them, for example, if other people cannot plug in I will help them to plug in or help giving urinals or bedpan etc. Really, I am proud to think that I was helping other people at this stage (Lauren).*

Rebecca, a participant with a mild intellectual disability, stated that some people with intellectual disabilities couldn't hear or speak; therefore, carers should look after them well. She also said that people with intellectual disabilities are equal to everybody else; therefore, they should get the same care. Some people, especially those who have severe and profound intellectual disabilities, have complex problems and cannot interact and communicate their needs; therefore, their reliance on carers to identify and provide appropriate care is complete (Tyler and Noritz 2009; Hatzidimitriadou and Milne 2005):

*Some people here have no speech and cannot hear, so we should be giving them more care than everybody else. The people who are dying should be looked after, by bathing them, feeding them, giving them plenty of fluids. I want them to be looked after as much as possible and care for them as everybody else. They all need attention. All I want to say is the people like us should be looked after well (Rebecca).*

Ciara, a participant with a moderate intellectual disability, concurred:

*Care of end of life is say like old people who are sick and dying and cannot look after themselves. Look after them well. These people can't express themselves and are unable to look after themselves (Ciara).*

Sarah, a participant with moderate intellectual disability, identified that some people with intellectual disabilities did not have family members; therefore, this population depended totally on professional carers for all of their needs. Davys, Mitchell and Haigh (2011) asserted that some people with intellectual disabilities have no contact from their family members once their parents have died because their siblings are reluctant to participate in their care. The result can be that some people with intellectual disabilities feel isolated and abandoned:

*Sick and dying people with special needs can't talk, eat, and walk. We have to feed them, help them to walk. They should be looked after all the time. They have nobody only nurses and carers to look after them (Sarah).*

A participant who was the mother of a person with an intellectual disability reiterated the comment made by Sarah and stated that many parents die before their children with intellectual disabilities. Also, she claimed that not many of the siblings of people with intellectual disabilities are involved in their care. Therefore, this population depended solely on the staff that provided care:

*Nowadays many parents of people with ID die before their sons and daughters and only few people, not many, have their siblings or relatives involved in their care. So, the people with intellectual disabilities completely depend on the staff in providing care (Roisin).*

Another parent of a daughter with an intellectual disability who lived at home was confirmed that her daughter was living with them at the moment but she wondered what would happen if she and her husband died. In fact, many parents who cared for their son or daughter with an intellectual disability at home experienced uncertainty regarding their loved one's future. This was due to their own ageing process and increased longevity of their adult children with intellectual disabilities (Hole et al. 2013). Most parents feared that they might die before their loved ones with intellectual disabilities.

As Tara described:

*I would like to see them looked after or get some type of care at the end of life just like everybody else. She is totally depending on us for everything but I worry what will happen if I die. My worry is who is going to look after her once I die. Definitely, there should be some kind of support or care for my daughter at the end of life (Tara).*

James echoed the same concern as others that people with intellectual disabilities need to have residential support towards the end of their life as their parents were getting older and their siblings rarely got involved. Therefore, it is very difficult to meet the care demands near the end of life. Many parents, especially when ageing, felt frustrated and were too physically and psychologically exhausted to provide end-of-life care at home due to the physical burden and inability to cope with psychological and emotional stress (Lee et al. 2013):

*At the time of death and dying or nearer the time to death, there should be some kind of residential service who knows her to provide all the care she needs including physical care. At this time my daughter is living with us but we are getting old and it is hard to look after her especially at the end of life, sometimes we feel it is good if our daughter dies before us because we always worry what will happen if we die before her (James).*

Aoife, a participant with intellectual disabilities, was also concerned about people with intellectual disabilities who lived in the community or with their family. To reduce the concerns of family members in the caring process of dying people at home, Aoife expected professionals and volunteers to go to community houses and family where people with intellectual disabilities reside to support them at the time of dying and to meet their care needs. As she claimed:

*The handicapped people who live in the community or in the home need other people to go with them, volunteers to go with them so that they can go to their home and provide support to them (Aoife).*

James, a father of a person with intellectual disabilities, agreed that providing care at the time of dying was physically and emotionally exhausting as well as being frustrating for the family members. Therefore, Aoife's expectation that professionals and volunteers provide support at the time of dying at the individual's home is essential to share the care burden of family members and also to fulfill the preferences and wishes of the dying person to be cared for in a familiar place (Gardner and Karmer 2009; Given et al. 2004). Penz and Duggleby (2012) produce the same findings among the general population. McKee, Kelley and Guirguis-Younger (2007) agree that volunteers provide practical support to dying people and their families, especially in rural and remote areas where professionals cannot visit often. However, Herber and Johnston (2013) stress that professionals' roles are very important in the community to provide and enhance quality care at the time of dying at home.

Generally, the perceptions and expectations of family members of those with intellectual disabilities were the same as people with intellectual disabilities. Both

groups acknowledged the increasing care demands of people with intellectual disabilities at the end of life. Adam, a parent of a person with an intellectual disability, said that medical care and other general care, such as physical care, were essential to ensure comfort. He believed that this would make the final journey as peaceful as possible for people with intellectual disabilities:

*Medical care and other general care such as physical care, keeping them comfortable, meeting all their needs are very important at the end of life for people with intellectual disabilities I assume this makes the final journey as peaceful as possible for the individual (Adam).*

A father of a person with an intellectual disability, who visited his son three times a week even though he was more than eighty years old, reasoned that people with intellectual disabilities have complex needs and therefore were completely dependent on carers toward the end of their life for everything including bathing, feeding and other needs. As a father, he was concerned about his son's wellbeing and care needs at the time of dying. He stated that family members were generally very concerned about their loved ones' care near the end of their life as they wanted to protect the dying person's identity as well as aim to provide a peaceful final journey (Brazil et al. 2012):

*The people with intellectual disabilities at the end of life completely depend on the staff in providing care because they have complex needs and they depend totally on carers for everything including bathing, feeding etc. (Michael).*

It is clear from the participants' perspectives that people with intellectual disabilities fear being physically dependent on other people, especially on their carers, to meet their basic and physical needs. This is particularly important, as most people with intellectual disabilities do not have family members to care for them. Furthermore, many people with intellectual disabilities have complex needs resulting from severe intellectual disabilities, hearing impairments, physical deformities and a greater susceptibility to cognitive and physical impairment due to early ageing. Therefore, it is evident that one of the basic constituents of holism, that is physical care, is paramount to people with

intellectual disabilities near the end of their life, and in order to achieve this they physically rely on their carers.

### **5.3.2 Vigilant monitoring**

Requiring vigilant monitoring towards the end of their life was a recurring issue throughout the participant interviews. Participants reported that vigilant monitoring was required to understand and respond to the needs of the dying person and their family members (Thompson, McClement and Daeninck 2006). They also suggested that this created a sense of being secure and safe (Griffin, McWilliam, and Oudshoorn 2012). Therefore, providing vigilant monitoring helps carers to understand and become familiar with the dying person and their medical needs; consequently, the dying person feels safe and comfortable.

Most of the participants interviewed in this study proposed that people with intellectual disabilities towards the end of their lives require supervision because they are fragile and unable to look after themselves. For example, one of the participants in the study, Conor, who had mild intellectual disabilities, suggested that people should check on the person with intellectual disabilities at the end of life around the clock to make sure they are safe. Cartwright and Kayser-Jones (2003) found that dying people expect to be monitored and supervised by carers in order to identify and respond to their care needs:

*Sick people need other people to check on them all the time 24hours a day, they have to check on them to see how they get on to make sure they are safe (Conor).*

Sean, a person with moderate intellectual disabilities, held a similar view, claiming that the “handicapped people” (the participant’s words) should be looked after and nurses should monitor their health when they are sick and dying. He held the following opinion regarding the act of monitoring:

*Specially handicapped people need nurses to stay with them to look after the sick and dying people to ensure they are safe and comfortable (Sean).*

The participants were also concerned that the people who looked after those with intellectual disabilities should ensure they received treatment, food and drinks. The participants with intellectual disabilities believed that they had nobody who belonged to them. Therefore, they felt that they depended on professional carers such as doctors and nurses. Consequently, it was the responsibility of professional carers to closely monitor those with intellectual disabilities towards the end of their life:

*Giving them a good care. To make sure that they get their medicine, food, plenty of fluids and maybe if a doctor examines that person because most people with mental disability have no family and nobody belongs to them (Katie).*

One of the family members of a person with an intellectual disability echoed the voices of people with intellectual disabilities and responded that this population required regular attention. She also claimed that it was a common expectation from everybody to have regular attention from the carers to provide a sense of safety and security. However, she commented that this was more important for people with intellectual disabilities as they were vulnerable and had complex needs:

*Regular attention should be given to these people. That will be very very important. I suppose myself, if I was bed-ridden these are the things I will be looking for. These people are vulnerable and have complex needs; therefore, nurses and carers should provide regular supervision for them. This will give them a sense of security and safety (Eimear).*

Another parent, Michael, whose son had a severe intellectual disability, reasoned that people with intellectual disabilities could not express what they wanted and could not look after themselves; therefore, close attention from professional carers was crucial near the end of life:

*These people can't express themselves and are unable to look after themselves. Regular attention should be given to these people. That will be very very important (Michael).*

All participants with intellectual disabilities felt that the help of nurses and doctors towards the end of life was very important. One participant said that she highly regarded

the roles of professionals in monitoring and providing support at the time of dying. At the same time, she preferred to be left alone away from her family members and friends to spend time on her own. Brereton et al. (2012) describe that dying people need to have a balance of being left alone, to think and cherish events from their past and to come to terms with the present, and spending time with their friends and relatives to meet their current social needs.

*When you know somebody is sick and dying leave them alone and the doctor and nurse will look after them and help them (Ciara).*

Most of the participants in the study explained the importance of keeping a vigil over dying people; they felt this was the best way to monitor the care needs of their loved ones or people under their care who were at the end of life. Participants in the study with intellectual disabilities felt that they would feel safe and secure if people gave them enough attention and supervision. In addition, they clearly indicated that people with intellectual disabilities should be monitored and supervised regularly to identify their needs and provide appropriate care.

## **5.4 SOCIAL CONNECTEDNESS**

Connectedness or social relatedness was a constant theme in all interviews. The participants felt this was very important to help them maintain their self-worth and self-identity. They perceived that social connectedness or being with other people preserved their self-identity and made them comfortable and happy. A study among the general population found that people towards the end of their life felt anxious, depressed, fearful, and had many concerns (McCourt et al. 2013). During this time, carers and professionals sometimes avoided the dying person because they had a fear of staying and making conversation with them (Lewis 2013). The dying person would consequently feel isolated and neglected (Lewis 2013).

This situation is no different for people with intellectual disabilities. Ryan et al. (2011a) found that stress and tension was created in the caring environment due to the lack of communication skills of professionals, such as the inability to have a discussion about the individual's clinical condition and not being able to provide adequate information to their queries. As the result, professionals avoided people with intellectual disabilities at the time of dying. In contrast, this population near the end of their life wanted to be socially connected with other people, including professionals, family and friends. Therefore, the dying person with intellectual disabilities should be accompanied by professionals, family and friends to preserve their self-worth and identity.

In this study, participants suggested ways to keep dying persons with intellectual disabilities safe and comfortable; namely "meaningful companionship" and "maintaining communication". The following sub-sections describe the value of physical companionship and making conversation as perceived by participants at end of a life.

#### **5.4.1 Meaningful companionship**

Being in the company of people who love and care about them is very important for people with intellectual disabilities, and to the general population, near the end of their lives (Nicholls et al. 2013; Tuffrey-Wijne 2010). It is recognised that the simple act of physically touching, such as holding hands, provides a close personal message that makes people feel connected to those he or she loves (Nicholls et al. 2013). It is evident from the participants' quotes that people need love and companionship at the end of life. In addition, physical closeness from parents and friends gives the dying person energy and reassurance (Tuffrey-Wijne and Davies 2007). Companionship is vital at the end of a person's life because it helps the dying person to realise they are not abandoned; therefore, their life and death matter to their friends, parents and carers (Sweers et al. 2013).

Lack of physical companionship creates feelings of isolation, neglect and desertion (Loeb et al. 2013). Physical isolation is difficult and it makes people frightened and uncertain (McKee, Kelley and Guirguis-Younger 2007). One of the study participants with an intellectual disability said:

*Somebody who knows them should stay with dying people, sit with them and speak with them. If possible, people can stay with them some more time (Conor).*

From Conor's perspective, people with an intellectual disability want to stay with somebody who they are comfortable with. They enjoy spending time and sitting with them. He proposed this would give people with intellectual disabilities the reassurance and comfort that they are craving. Being with somebody may give a feeling of connectedness.

*Talk to them and sit with them. Give them reassurance you know, the dying people they want us to be with them (Sarah).*

Esther, another participant with intellectual disabilities agreed with Sarah and responded:

*Sit with him you know. The people come to him and stay with him (Esther).*

Sarah, a participant with Moderate intellectual disability, concurred that talking and sitting with people with intellectual disabilities towards the end of their life gives them reassurance. In addition, she claimed that holding hands of people with intellectual disabilities provides hope and reassurance.

It is evident from this study that people with intellectual disabilities wanted to have meaningful companionship from other people at the end of their life. Roberts and Compell (2011) suggested that the act of touching at end-of-life care brings an emotional closeness and gives reassurance. As a participant asserted:

*Talk to the people who are sick and dying. Stay with them. Talking to them, being with them, holding their hands. Visits from their own people like parents, uncles*

*and friends. People should spend time with dying people and stay with them. Be with them and holding their hands will give lots of messages to them, even if they don't speak to them (Sarah).*

Marianne agreed with Sarah and stated:

*Being with dying people is very important, this gives them hope and assurance (Mariane).*

From the participants' perspectives the company of friends and family was important even in the absence of verbal communication. The study participants with intellectual disabilities reiterated that a physical presence towards the end of their life was very important. People with intellectual disabilities also appreciated others staying with them and being silent at the end of their life. Being silent suffices as a language in a way and can be understood by all (Bearden et al. 2011). Furthermore, this is also a suitable language for people who do not want to engage in conversation or people who are not able to engage in a verbal communication (Osterlind et al. 2011). Therefore, stillness and presence sends a message to the dying person and makes them realise that people are there for them to help and to look after them (Cohen et al. 2012).

Rebecca perceived that being with dying people gave them hope and continuous support throughout their dying process. She said:

*If the people are really sick, the doctors and nurses should be there all the time and make them realise that they are going to the other world and the gate is ready to open. Their parents and friends stand beside their beds. The support is to stay with them help them and look after them. If someone is dying, you need to stay with them, sit with them and hold their hands because sometimes they can't talk. So, we have to let them know we are here to look after them. They need to be there all the way through and the person who is dying needs a lot of support and care. Be with dying people and give them whatever they want, in and out all the time with them (Rebecca).*

Conor, a participant with a mild intellectual disability, concurred and suggesting that good care towards the end of life for people with intellectual disabilities consists of friends, parents and carers staying with the person and giving them support. He also

acknowledged that some people who are in long-stay settings have no family; therefore, staff need to stay with them:

*Say you think the person is going to die, I am not saying they are dying. If somebody is dying in the house like X or anywhere in the world, the good care is, you stay with them, and the people you are working with they want to stay with them. If the person is living in the home, they have a family to support them; their own parents and family members are with them. But people who stay in the mental hospital, they have staff with them; they have other people living in the house with them. So, anybody needs people with them all the time (Conor).*

Adam, a family member of a person with an intellectual disability, felt that the needs of people with intellectual disabilities at the end of their life, including medical or psychological needs or anything that created peace at the end of life should be carried out:

*I think facilitating their needs whatever arises during that time is very important maybe medical or psychological you know everything that surrounds us at the end of life and everything that makes it peaceful (Adam).*

A participant with a mild intellectual disability advocated that somebody should stay with the person who is going to die and speak to them, hold their hands and reassure them that people are there for them. She also preferred that the dying person be in a separate room and people can go in and out to see them. This will give them privacy and comfort:

*I think if somebody is going to die, we have to talk to them and hold their hands and tell them that we are here for them. Be there with them. People should be in separate room, friends, family and staff can go in and out and it gives privacy and comfort. Be with them and talk to them (Rachel).*

Throughout the study, participants expected to have the company of other people including their friends, parents and carers around them towards the end of their life. In addition, it was acknowledged that some people with intellectual disabilities did not have family; therefore, it was important that friends and carers stay with them. There is clear evidence in this study that participants wished to have a physical presence and touch towards the end of their life as they believed this would give them a feeling of

comfort, reassurance, safety and support. This is reflected in Lavoie, Blondeau, and De Koninck (2008)' s study.

#### **5.4.2 Maintaining communication**

Conversation helps individuals to relax and gain a perspective on what other people think and what they have on their mind (Van Gorp et al. 2013). Conversation is a channel that is used to establish and sustain relationships; consequently, this helps to understand what other people think and feel (Waldrop and Meeker 2012). People are happy to talk and speak to people they know and it gives them reassurance that they are in a safe place (Van Gorp et al. 2013). Communication creates hope and belief for people and they feel respected and included; therefore, communication is essential, especially when people are sick and dying (Lee et al. 2014).

A participant with intellectual disabilities said that talking to people with intellectual disabilities at end of life was very important as it created a feeling of comfort. The participant also felt that even if we know people are definitely going to die we can reassure them and give them hope by talking to them. Parry (2013) agrees with the participant's expectations and holds the view that talking to dying people is very important as they, most often, want to talk about what matters to them, their concerns and feelings. Ciara, with moderate intellectual disabilities, said:

*Talk to them you know what I mean we have to talk to them and let them know that we are here for them. If they very sick give them tablets, you know... if they are dying there is nothing more we can do. Talk to them, People should stay with him speak to him this will give them comfort. Sit with him you know. The people come to him (Ciara).*

Sarah, another participant with moderate intellectual disabilities, said that people should listen to those with intellectual disabilities near the end of life. This would give them hope, provide an opportunity to ask questions, seek clarification and share concerns about their care. As Sarah said:

*Listen to them and we have to do whatever they ask for them (Sarah).*

Listening skills are very important for conversations with other people and are considered to be fundamental in providing good health care (Lopes Veríssimo and Cruz-Pontífice Sousa 2014). In addition, listening is a prerequisite for good communication; through listening carers can understand and predict the needs and concerns of other people (Robertson 2008). Though listening is highly valued for effective conversation, some people consider conversation to be merely relaxing and chatting about inconsequential matters (Shannon, Long-Sutthall and Coombs 2011). The right kind of listening is essential when dealing with issues concerning illness and death (Newson 2012). People who are suffering and dying expect carers to listen and absorb their concerns, expectations and life experiences (Jones and Cutcliffe 2009).

The participants in this study preferred to have a conversation with family members, friends or care providers. It is a reasonable expectation from people with intellectual disabilities to have a conversation, especially when they are ill and dying (Tuffrey-Wijne 2010). In the following excerpts, the study participants describe how important conversation is for them towards the end of their life:

*Nothing we can do much if he is going to die. Really, we can talk to him (Lauren).*

*People should be at peace and happy in their last days of life. We have to look after the dying people well. You know what I mean. We have to talk to them I think that makes the person happy and sit with them you know. Staff are wonderful to the dying people you know. I think everybody has to do his or her own part (Rachel).*

*Speak to them you know...speaking make them easy and happy (Katie).*

During conversation, family and friends can talk about the importance of their relationship to the dying person (Campbell 2013). For example, parents can share how important their child is in their lives and how much he or she means to them (Keeley and Generous 2014). Friends can relate how much they value years of friendship,

memories and companionship because sharing memories of good times near death is another way of finding peace at the end of life, and this can be comforting for everyone (Lowey 2008; Holmberg 2006). It can also help when family and friends who cannot be present at the bed send a recording of what they would like to say or they send a letter that can be read out loud (Nelson 2013). It is possible that even if a person with intellectual disabilities is unconscious, he or she might still be able to hear. Reilly (2008) suggests that it is probably never too late to say how you feel or to talk about fond memories. Therefore, it is always nice to talk to rather than about the person who is dying (Nelson 2013).

It was evident in this study that participants expected to have social connections through companionship and communication towards the end of their lives. They clearly felt that this was essential in order to experience feelings of comfort and safety. Some participants regarded providing an opportunity for social connections to dying people to be necessary, as it gave them reassurance and hope of having a good death. Having explored the importance of keeping people with intellectual disabilities physically, emotionally and socially comfortable with their parents, friends and caregivers at the end of life, the next section explores the importance of meeting the spiritual needs of people with intellectual disabilities at the end of life.

## **5.5 SPIRITUAL RECONCILIATION**

In addition to the physical, psychological and emotional needs, participants in this study highly valued the importance of spiritual care near the end of life. Spiritual care near the end of life is as important as any other care (Milligan 2011), helping the dying person to find meaning in their life and reconcile disagreements with others and the self, if possible (McDonald, Murray and Atkin 2014). The dying person might find peace by resolving and ending unsettled business with their friends or family or themselves

(Royal College of Nursing 2011). Such resolution can be achieved through visits from a social worker, counsellor or any other people who the dying person trusts (Chang et al. 2012). Many people nearing death find solace in their own faith and find comfort and peace through praying, talking to and receiving blessings from their religious community leaders, reading religious books, or listening to religious music (Chang et al. 2012). The following sub-sections explain the spiritual expectations of people with intellectual disabilities near the end of their life in order to achieve spiritual comfort and wellbeing.

### **5.5.1 Suggesting solace**

Having spiritual comfort and peace at the end of life was desired by most of the participants in the study. Participants reported that achieving spiritual comfort was as essential as any other comfort and they also suggested how it could be achieved. They firmly believed that prayers bring comfort and peace near the end of life and they were convinced that this was the only means of communication with God. Furthermore, participants stated that saying prayers at the end of life was more important than at any other time in their life. Therefore, they believed that prayer provided comfort, hope, strength, peace and trust for the dying person (LeBaron et al. 2014).

Michael, a family member of a person with an intellectual disability, declared that praying for dying people with intellectual disabilities at the end of life provided hope and brought peace to the dying person. He firmly believed that being with and praying for dying people was very important. He felt that prayers help people to connect with an eternal power. Grossoehme et al. (2011) stated that praying was one of the ways to connect with God and people found intimacy and the ability to cope from an eternal power through prayer. As Michael said:

*Pray for the dying people and be with them, it is important and this will give them hope and peace, this is one of the ways to connect with God (Michael).*

Another participant with moderate intellectual disabilities, Ciara, commented that saying prayers was the last thing anybody could do for a dying person. She suggested that praying and caring for the person who is dying brings comfort at the time of dying. Kisvetrová, Klugar and Kabelka (2013) support this view and state that praying for a dying individual, along with caring for them, provides spiritual comfort and reduces agitation and anxiety. As Ciara said:

*Bring them to the hospital and probably they will be all right, but what we can do is pray for them and they will die. All we can do is pray for them and care for them; this will give them comfort (Ciara).*

Another participant with moderate intellectual disabilities, Lauren, declared that prayer was the only thing people can do for dying people and she believed that prayers give the dying person peace. Other participants with intellectual disabilities also concurred with this belief and called for prayers for people with intellectual disabilities:

*Talk to them you know what I mean we have to pray for them if anybody dies and pray for them this is the only thing we can do for them. This will help them to be in peace (Lauren).*

*It is very sad is it not. We have to look after them. I feel very sad for them. Pray over them (Katie).*

*Say the prayers over the dying people; it is very good for the sick people you know we all have to do this (Conor).*

King et al. (2013) find that praying has a unique power that brings psychological comfort, peacefulness, harmony and optimism to the dying person and this is the only hope when everything else fails. It was evident that participants expected to have spiritual comfort at the time of dying and they believed that saying prayers was one of the ways of achieving this. They strongly felt that praying was the only way, sometimes, to alleviate discomfort and suffering. Participants in this study believed that seeking comfort, peace and strength through prayer was important towards the end of life.

### 5.5.2 Seeking blessings

Making inner peace before somebody died was preferred by most of the study participants. Participants in this study believed that reconciliation with God, other people or within themselves were important to resolve conflict with other people or within themselves. Consequently, they believed this was one of the best ways to achieve inner peace before dying. Resolving conflict and accomplishing inner peace was one of the spiritual needs of the participants towards the end of life. Wynne (2013) finds that resolving conflict and accomplishing inner peace is one of the spiritual needs towards the end of life.

Conor, a participant with intellectual disabilities, proposed that having a priest at the time of dying and asking him to bless the dying person would make that person happy and peaceful. He also suggested that the dying person should be anointed and blessed by a priest.

*Bring a priest in and ask the priest to bless the dying person it may make the sick people happy and give them peace. Let me think...the person should get anointed. The priest should come and bless the person (Conor).*

Another participant with moderate intellectual disabilities, Emma, concurred with Conor's perspective and echoed that blessings and prayers from a priest could make the dying person comfortable and peaceful at the time of dying. She also suggested that blessings from a priest helped to absolve the sins people had committed during their life and that dying people should find a way to resolve conflict with others:

*The doctor or nurse should contact the priest and the priest should come in and bless the dying person. People get blessings for all their sins and solve problems with others to bring comfort and peace (Emma).*

Ciara, with moderate intellectual disabilities, concurred with other participants and believed that a priest should talk to and bless the dying person. Most of the participants

with intellectual disabilities expected dying people to be blessed by a priest and have prayers said for them:

*Any person who is dying the priest is always coming with you. They stay with the person who is dying and bless him all the way through and talk to him (Ciara).*

Michael, a father of a person with intellectual disabilities, thought that a priest or somebody else from the individual's religious faith should bless the dying person with intellectual disabilities:

*Then the dying person and the family members must be blessed and say prayers by a priest or somebody in line with their religious faith (Michael).*

Eimear, a mother of a person with intellectual disabilities, said that she was not sure how much religious faith her son had. However, her son attended mass every Saturday night. She, therefore, preferred for her son to be blessed by a priest at the end of his life. She also agreed with Michael that all people with intellectual disabilities at the time of dying should be provided with some kind of religious care in accordance with their beliefs. Eimear strongly concurred and expected that spiritual care should be provided to dying people with intellectual disabilities irrespective of their awareness of a belief system:

*Also, I think their spiritual needs are important and should be met, he goes to mass every week but I don't know how religious he is. He goes to Saturday night mass. The service should call somebody to provide some kind of religious stuff. Certainly, somebody has to talk to him. Definitely he cannot make any decision at the time of dying but the people who nurse him at that time should be able to make decide what is good for him (Eimear).*

Sarah, a person with intellectual disabilities, stated that blessings and praying at the time of dying gives inner peace to the dying person:

*Talk to them and sit with them. Saying prayers for them and blessings from a priest helps to give them inner peace (Sarah).*

It is evident from the participants' perspectives that saying prayers, making peace and reconciliation are very important towards the end of life. Many participants preferred to

achieve spiritual comfort and spiritual wellbeing through religious means. In their opinions and views, receiving and providing spiritual comfort was as necessary as any other comfort at the time of death and dying.

## **5.6 CHAPTER CONCLUSION**

It is clear from the participants' concerns that people with intellectual disabilities surrender their independence physically and emotionally, to other people at the end of their life to meet their holistic needs. This dependency can be accomplished in a positive manner by providing physical care and providing vigilant monitoring for people with intellectual disabilities in order to preserve their dignity, make them feel safe and secure and provide physical comfort.

Participants expressed their concern of being anxious and emotionally threatened. Care providers can reduce this situation by giving people with intellectual disabilities meaningful companionship and maintaining communication with them. People with intellectual disabilities preferred the presence of other people such as parents, friends and family members. Finally, people with intellectual disabilities sought spiritual comfort. Most of the participants wished to receive spiritual comfort through religious means, such as their parents and friends saying prayers and receiving blessings from their religious leaders.

# CHAPTER 6- FAMILIARISM

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## 6.1 INTRODUCTION

This chapter sheds light on the category “familiarism”. This is one of participants’ recurrent expectations throughout the study and was considered central to maintaining and preserving the sense of self at the end of life. Many participants in this study agreed that interaction and orientation within familiar surroundings, the maintenance of their routines, and familiar people were very important at the end of life. They believed that keeping this familiarity while dying was vital to improving their dying experience. Figure 5 gives a visual outline of the category.

**FIGURE 5 FAMILIARISM**



The category “familiarism” has one sub-category, “maintaining continuity”, and this has various constituents: “preserving routine”; “finding safety and comfort in a familiar place” and “long-term relationships”.

## **6.2 FAMILIARISM AND END-OF-LIFE CARE**

“Familiarism” describes how participants wanted to keep their identity within their recognisable space, with familiar people and usual routines. This is a social characteristic that creates a high degree of solidarity between self and surroundings, thus leading to an inner sense of belonging and being safe and secure (Liao, Shimojo and Yeh 2013). According to Sullivan-Bentz et al. (2010) the concept of familiarity at a time of transition is very important. Transition fosters uncertainty and destroys hopes (Sullivan-Bentz et al. 2010) and as such, it is important to provide hope, support and certainty at the time of transition. Dying is also a transition from well-being to ill-being (Renz et al. 2013); therefore, it is very important to maintain familiarity at this challenging time in order to provide hope and certainty (Hui et al. 2014).

## **6.3 MAINTAINING CONTINUITY**

Continuity can be defined as consistency in terms of people, places and activities that are carried out regularly over time (Björkelund et al. 2013) and can be achieved by maintaining the same environment, people and activities (Gjevjon et al. 2013). Having continuity provides more hope and opportunity to understand needs (Medina-Mirapeix 2014). In contrast, when people lose this sense of continuity they become fatigued, anxious and feel lost (Medina-Mirapeix 2014). Due to loss of continuity, people with intellectual disabilities suffer deeply because they have limited life experiences, exposure and relationships (Tuffrey-Wijne 2010). In this study, participants expressed that maintaining continuity at end of life was essential because they believed that unfamiliar people lacked knowledge about participants’ health and life situations. During end of life, people with intellectual disabilities may feel scared, anxious, upset, depressed and guilty; therefore, maintaining continuity is vital (Tuffrey-Wijne 2010).

### 6.3.1 Preserving routine

Preserving routine for people at the end of life is essential as it provides hope, comfort, a feeling of worth and increased self-esteem (Chochinov 2006). In addition, people are happy to continue with what they are doing and what they are comfortable with. Consequently, preserving “sameness” is very important particularly for some people with intellectual disabilities as it is hard for them to deviate from their daily routines (Wigren and Hansen 2005). Also, introducing new things to people with intellectual disabilities presents further difficulties because it is hard for them to learn and adapt at this challenging time (Ollington et al. 2012). Routine or sameness involves repetition of activities, and these repeated activities involve predictability; this gives stability and ensures security (Goldsteen 2006). People crave routines as it makes them feel safe and secure, especially at the end of life (Chochinov 2006). It is assumed that maintaining routines reduces the power imbalance between carers and sick people (Handley et al. 2014). Also, routine helps to create a co-operative environment that reduces anxiety and stress (Handley et al. 2014). Despite their preference for preserving their routines, sick and dying people have little control over what is happening to them and this is particularly true for people with intellectual disabilities (Tuffrey-Wijne 2010).

In this study, Sean, a participant with an intellectual disability, claimed that continuity is “what people like” in their life and was very important at the end of life. Sean acknowledged that watching football and listening to music were his favourite things and he argued that these would still make him smile at the end of life. Therefore, he suggested that different things make different people happy at the end of life:

*Staying with family and friends, watching the football is important to me. Playing music makes dying people happy, give him a smile and make him smile, this may be different for other people but I like it even though I am sick and dying (Sean).*

Another participant with intellectual disabilities, Ciara, commented that people at end of life should be allowed to continue their routine and have their wishes facilitated. She believed that care provided at the time of dying should be individualised and person-centred, and should meet the realistic expectations of the dying person and give consideration to their past wishes, likes and hobbies. She believed that this would make the dying person happy and feel better. As she said:

*Does he smoke? If he smokes, let him smoke then he will be happy and bring him out for a meal if he goes out regularly. Getting out for a while and playing music for them will be good for them (Ciara).*

Another participant with intellectual disability, Sarah, agreed with Ciara and further proposed that continuing with everyday activities helps to maintain normalcy in the life of people with intellectual disabilities at the end of life. Sarah believed that this was very important for dying people with intellectual disabilities:

*If they like, have a chat and let them listen to music if they like, bringing them out for walk will make them happy. Let them smoke if they want and sing a song for them, I think these are the things that are very important for dying people (Sarah).*

Rebecca, another service user, claimed that looking after the wishes of dying people at the end of life was very important as this helped them to smile. She agreed with the previous participants' perception that maintaining normalcy and providing personalised care were essential at the end of life. Rebecca also suggested that acknowledging the need for assistance and providing support was valuable for people with intellectual disabilities at the end of life. In Rebecca's opinion, supporting, allowing freedom, acknowledging and accommodating needs and wishes were considered essential for people with intellectual disabilities at their end of life. Rebecca stated that:

*Looking after their wishes and likes for say if they like to go out, bring them out or any other thing they want to do, let them do it or do it for them, say for example, turn on music for them. In my case, I used to go on the bus during the weekend, I*

*will be happy if somebody brings me out when I am very sick. I think these things put a smile on their face (Rebecca).*

Emma, a service user, advocated allowing and supporting the dying person to carry out activities which they liked and which facilitated their happiness. Emma suggested that people with intellectual disabilities highly value their everyday life where simple activities such as watching football, listening to music and watching soaps were considered essential.

Participants wanted to live day-by-day, highlighting the importance of living in the moment. They also reported the importance of socialising by seeing their friends and sharing their experiences; they believed this would help them to revisit their past memories and stay connected with their friends. The participants clearly articulated the stages between independence, interdependence and dependence and they expressed a wish to be independent in the early stages of their medical condition where they could look after their needs but also seek support from health professionals. They also acknowledged that when their clinical condition progressed and their physical and mental ability declined, they required assistance from their health providers to maintain their routine. Emma stated that:

*Doing his or her own stuff makes the person happy and gives good death. Letting him to do whatever he wants to do like watching soaps, football, seeing friends etc. (Emma).*

A parent, Michael, concurred with the above and suggested that it was very important for his son to get out, arguing that confining his son within the unit or in his room would only isolate him and disrupts his routine; this was not good for him. He further commented that professionals might have different opinions about his son's ill health but that he was entitled to follow his normal activities. Therefore, he suggested that professionals support dying people with intellectual disabilities to realise their wishes

and desires. He concluded that quality of life at the time of dying should reflect how people lived. Michael commented as follows:

*So, I can think from the point of my son xxx because I can't think otherwise. I used to take him for a drive. So, I don't want to let him lie on the bed or sit on the chair. I love to bring him out for a drive. The professionals may say no but xxx is entitled to do whatever he wants to do. It is not nice to be sitting or lying all day. Let him do whatever he likes to do. Taking him out is the most important thing. For quality of life, they should die the way they live. These are his routines and this is what he loves to do (Michael).*

Another family member, Tara, recalled her brother's experience stating that health care professionals objected to him being taken out. However, she realised that this was his routine and he enjoyed it. Therefore, she decided to take him out and she was happy doing it. Tara commented:

*Still I can remember that my brother who has the same problem as my son and when he was sick he was lying on the bed all day, we wanted to bring him out but the nurses and doctors said no. My brother wanted to say he wants to go out but he could not speak. I could read his mind and I straightaway told nurses that I was going to take him out. Before xxx died, we brought him out for a drive and a walk. These are two things he likes most and are part of his routine (Tara).*

Parent Roisin also agreed, stating that performing mainstream activities such as attending day services, joining their friends at the social clubs and having meals with their friends at the time of dying were essential. She objected to people with intellectual disability being isolated and keeping them away from the things they liked do and were familiar with. Roisin said:

*Keep them doing mainstream things not isolate them, it is unfair to keep them away from the things they like to do. When they are conscious do not completely isolate them (Roisin).*

Another parent, Nicole, agreed with Roisin and said that it was better for people with intellectual disabilities to continue their routine and engage with activities they enjoyed. She reasoned that engaging with activities and being occupied with their routines would enable people with intellectual disabilities to forget their illness and disease. Further,

she argued that keeping to a routine as far as possible was better for people with intellectual disabilities. However, Nicole also concurred with Roisin that this depended upon the ability and level of sickness of the individual:

*I think it is better to continue the routine, it is good for them to engage and do what they like, and it will help them to forget their illness and disease. As far as possible, it is better to keep their routine, if they can. If they are very sick, that will be different (Nicole).*

Most of the participants in the study recognised the importance of having a person-centred and individualised care path that enabled people with intellectual disabilities to keep to their routines and to maintain a normal life at the time of dying, such as listening to music and watching soaps and football. This suggests that the preservation of routines helps to maintain continuity, thus allowing dying people to feel safe and happy, which participants considered essential for people with an intellectual disability. It was also evident from the participants' perspectives that most people with intellectual disabilities preferred to live day-by-day and in the moment. Provision of person-centred and individualised care that promoted and maintained the normalcy and continuity of day-to-day routines was one of the means of achieving familiarity at the end of life. It was also evident from the data that safety and comfort in a familiar place during the person's final days was important.

### **6.3.2 Finding safety and comfort in a familiar place**

Aoun and Skett (2013) state that having a feeling of being safe and comfortable at the time of dying is crucial. This will improve the mood and emotional state of a dying person (Fields, Finucane and Oxenham 2013). In keeping with this, familiar places provide a sense of security, as well as physical and emotional comfort for the dying person (Goodman et al. 2013). While acknowledging that sometimes it is not possible to keep them at home because of the nature of the illness and available resources (Gott et al. 2004; Beland 2013). Most of the participants in this study suggested that being at

home or where they lived would provide comfort and a sense of security at the time of dying as this would give an opportunity to be with their friends and family. This is reflected in (Venkatasalu et al. 2014)'s study.

Roisin, the mother of someone with an intellectual disability, commented that caring for a person in a familiar place provided a sense of comfort, safety and security and offered an opportunity for that person to be with their friends and other familiar people. She admitted that some people with intellectual disabilities did not have family members and in other cases, family members could not visit them due to location and distance issues. She acknowledged that professional carers and friends acted as a surrogate family for people with intellectual disabilities. Therefore, Roisin suggested that an unfamiliar place can lead to feelings of loneliness for people with intellectual disabilities. She suggested that a familiar place creates a safe environment for dying people:

*Caring people at known surroundings will be more helpful. In the hospital, you will be lonely and isolated from people. A lot of people have no family and this is a big trouble for them. For some family members it is hard to visit because it is too far to visit. Therefore, it is important to be in the known place and with the known people. This creates a safe environment for the dying people (Roisin).*

Service user, Ciara, suggested that dying at home facilitated meeting with friends during the person's final days. She expressed the idea of having lived together for a long time, which gave an opportunity to share old memories and have a laugh together before that person died. Ciara pointed out that for a dying person staying at home during the final days provided a comfortable environment and an opportunity to say goodbye to their friends, which contributed to a peaceful death. She expressed this as follows:

*It is always nice to die where they live because friends can visit them before they are buried. We lived together for long time, so it is nice for everybody to have a laugh together and say final goodbyes (Ciara).*

According to service user Conor, if it is certain that somebody with intellectual disabilities is going to die, they should not be moved away from where they have been living and should be with the people who have shared their lives. People with intellectual disabilities when dying want to stay and rest in the place where they have lived for years at their end of life. Conor argued that a person dying in a familiar place was a better option than dying in an ambulance on the way to hospital. He stated:

*If they are dying just leave them there in their house you don't move them from there and leave them with the people who lived with them and reared them. So anybody dying in this hospital or anywhere else or home just think of them where they were born and reared, that is the place they want to die and that's the place they want to rest for an hour or two or for a few days. Rather you bringing him in the ambulance and dying on the way to hospital on the ambulance (Conor).*

Participants argued that a person being at his or her familiar place at the time of dying not only gave the person an opportunity to see his or her friends and parents but it was also a chance for that person to follow their everyday routines and preserve their dignity. The participants proposed that being at their place of living provided an opportunity to be connected with their friends and family members. Emma, one of the participants with disabilities, expressed the following opinion:

*Wherever they live is their home so they should be left there to die. If everybody knows that the person is going to die, they should be cared for at the place where they want to stay at the end of their life. Then at least they have a chance to live with their friends and family members and also they can do whatever they want to do (Emma).*

The benefit of staying in their own place while dying, from parent Michael's perspective, was that people were connected to each other when they lived together for a long time, thus they felt safe and comfortable. Therefore, they would be protected at the end of life. He was against the idea of moving people with intellectual disabilities somewhere for care at the time of dying. Michael suggested that the intellectual

disability service should be committed to revisiting their service agenda and vision to facilitate keeping fragile, elderly and dying people at their home. He commented:

*I would not like him to be sent somewhere to care for him at the end of life. It may be contradictory to the service agenda but I would strongly believe that these people should be staying here and shouldn't be sent off anywhere. Because they have lived here for so long, they are connected to each other and feel comfortable and safe in their own environment. This is very much important at the end of life (Michael).*

The participants felt that living and being cared for at their own place provided peace, comfort and the individual attention that they required at the time of dying. Participants recommended that providing care in a familiar place was good for dying people, and that this experience created less anxiety and tension among people. Participants believed that this was very important at the end of life for people with intellectual disabilities.

Adam, a father, was concerned that moving the dying person into hospital or a hospice would create a strange environment for that person, possibly resulting in the person being anxious and tense, which was unwanted at the end of life. Adam further stated that it was a poor decision to move people with intellectual disabilities at the end of life to other places when there was no beneficial outcome. He commented:

*Keeping them somewhere they are familiar with rather than sending them to an unfamiliar and strange place at the end of life is very essential. If somebody is approaching their end of life and taking somebody from here, to hospital or hospice, care is going to be strange and it is going to create anxiety and tension for the people. These are unnecessary at the end of their life. I would say it is insane to move people around with intellectual disabilities when they approach death if there is no fruitful outcome (Adam).*

In relation to finding safety and comfort at a familiar place when dying, service user Katie further acknowledged that dying people sometimes required special treatment. To this end, they have to be moved to special hospitals because they have specialised nurses, skills and machines to provide good care. However, she also stated that the best place to die is in the place they are familiar with; this helps them to see their friends and

parents before they die. Finally, she observed that people with intellectual disabilities feel safe in their familiar environments:

*I think the best place to die is... where the person lives. Sometimes we need to bring them somewhere else to get treatment, like xxx hospital because a special hospital has nurses, skills and machine to look after the dying people. But if they die, here is the best place because friends and parents can visit them and know everybody. We feel safe here (Katie).*

Service user Rebecca reiterated that it was hard and upsetting for people to go to unfamiliar places to die. She stated that since people have lived in a place where they are comfortable and resided there for a long time, they should be entitled to stay there when they are dying. She recounted feeling very sad if people die in other places where they could not be visited by their friends and parents.

Rebecca expressed a sense of belonging to the place where she had lived all her life and also where she had a deep connection to the people who she lived with. She wished to maintain those connections till the end. Her final wish was to die where she lived and to be buried nearby. Rebecca stated:

*It was hard and upsetting. A few of my friends went to the hospital and they died there after a couple of days, when you look at this, people are living here for a long time and they are sent out to other hospitals to die, this is no good and they should be here and die here. It is sad and nobody could go there and see them including their friends and parents. Most of us live here throughout our lives and it is our home so better to stay here and die here. If anybody wants to die here, they should be looked after. I want to die where I have lived and to be buried where I belong (Rebecca).*

Rebecca recalled a previous experience of her friend's death, which she articulated as being horrible, as her friend died alone without seeing friends and carers who she had known for years. From Rebecca's point of view, dying in an unfamiliar place was not good for people with intellectual disabilities. She pointed out that visiting dying friends in other places was impossible for many people with intellectual disabilities:

*I remember my friend being admitted in xxx hospital one time and I went to see her on Friday morning, took her clothes for washing and I went back to see her on Saturday morning, they said she had died. It was horrible. She was dead there without her friends and carer who cared for her for years and years. So I think it was not a nice place to die for people like us. It is very hard for people like us to go there and see them; it is too far, how are we going to see somebody there? (Rebecca)*

One participant suggested that general hospitals accommodated a variety of individuals who required a lot of attention; therefore, professionals were not able to offer sufficient care due to their responsibilities and workload. This would result in people with intellectual disabilities getting less attention, which could lead them to express challenging behaviour that staff could not understand or manage because people with intellectual disabilities were not familiar to the place or the people.

In recounting a personal experience, family member Tara spoke of her brother, who suffered in a general hospital due to a combination of noise and a crowded environment. He was deprived of personal attention from professionals. Tara suggested that he should have been left in the place where he had lived and been cared for. She argued that if her brother had stayed in his own place he could have received better care and attention before he died. As Tara said:

*Yah... I know my brother died a year ago in xxx hospital, he suffered from throat cancer and they have taken his voice box out, he had no communication. I think they were much stretched you know. It was a mixed unit there were people with Alzheimer's and a chap who used drugs you know. He had no peace over there, as it was very noisy. He stayed up there for a month and died. We felt he should have stayed here. Also, they could not handle him because he was hitting out at nurses you know because they are new to him. The hospitals are over stretched at the moment you know and it is hard to give individual attention you know. I think the places like here may give more attention and may be one to one care (Tara).*

The participants suspected that care provided in a mainstream service for people with intellectual disabilities would be sub-standard due to a lack of knowledge and skills of health care providers about the needs of people with intellectual disabilities. They

expressed this perception because of previous experience of dealing with these services either as a friend or family member of a person with intellectual disabilities. The reasons put forward for sub-standard care at the end of life in mainstream services were: a strange environment; that it is crowded and noisy; that it is populated with unfamiliar carers; and they are unwelcoming places for friends and parents to visit.

Service user Rachel recounted her experience; she said that she felt very sad when one of her friends died in a general hospital. She said she was very fond of him and they had lived together for a long time but she could not see him before he died. In her opinion, it would have been better to spend his last days at home. Residential care homes become home for many people with intellectual disabilities because they have been living there from a young age and they know no other home. Therefore, they want to spend their last days somewhere they are familiar with, as it gives them comfort and peace. Rachel commented:

*I like xxxx and am fond of him. I am really sad even I could not see him before he died. I think it is always better to spend your last days at your home. For many people like me, this is our home and we want to spend our last days here and die here. It gives comfort and peace to us at the very end of our life (Rachel).*

Participants in this study expressed their wish that people with intellectual disabilities be allowed to stay in their familiar place at the time of dying because it is where they grew up. They felt that it was unnecessary to send them to other places to care for them at their end of life. Participants expressed that there was a strong bond with their living space and that they did not want to miss it at the end of life. They felt that they could draw peace and comfort from their familiar place.

Parent Michael assumed that unnecessarily moving a person with intellectual disabilities outside was a form of euthanasia. He expressed the opinion that transferring a person with an intellectual disability to an unfamiliar place put the individual under

unnecessary emotional and psychological stress; this may hasten the individual's death.

Michael said:

*I am too suspicious about the care outside of this institution and it would be a form of euthanasia (Michael).*

Parent Eimer recounted her experience and agreed that this population should not be removed from their own place to provide care at the time of dying and that moving them was not a good idea because they had grown up and stayed in the same place for many years. She suggested that any place other than their home was a foreign environment where it was difficult to understand people with intellectual disabilities and that they missed their personal space and the feeling of being secure and safe. Eimer stated:

*They should feel they are not in a foreign environment that would be a better world; they should not be shifted to another hospital where they don't know anything. I know few people from the service who have died. I know a person who died of cancer and was moved everywhere at the end of his life to care for his cancer. I strongly feel that he should have stayed in the same place where he lived. If they are going to be removed from where they know, it is not a good idea. I think they should be allowed to continue to stay where they live. This is their home where they have grown up and stayed for a long time. By saying that, it is a shame to send them somewhere else to be cared at the end of life (Eimear).*

Eimer also said that she did not know where the best place was for people with intellectual disabilities to be cared for at the end of life. However, she proposed that in situations where people with intellectual disabilities have complex needs, having a place that is dedicated to the needs of those who are dying would be a good option. People with intellectual disabilities who live in an environment that provides specialist care feel comfortable because the professionals and carers best understand the needs of people with intellectual disabilities. Eimear expressed the following opinion:

*At the very end, I really do not know. There is no better place for dying for people with intellectual disabilities... there should be a unit that is specifically set up for dying people with intellectual disability (Eimer).*

Most of the participants suggested that dying in a familiar place provided comfort and feelings of safety and peace. Parent, Nicole, expressed a similar view indicating that it was better for people with intellectual disabilities to stay in their own place. She stated that palliative care in their own place would be ideal because they can meet their friends, live in their own surroundings and stay with their own carers. She rationalised that it would not be the same for all individuals with intellectual disabilities because, for example, if somebody suffered from Alzheimer's they could not understand where they were or what they were doing. In such cases, she suggested, a place of care may not be as significant an issue. Nicole stated:

*I think the hospice should come to them. It is better for the people with intellectual disabilities to stay at their own place and if they receive hospice care at their living place this would be ideal because they still can live in their own surroundings, meet their friends and they can stay with their own carers. Anyway, it could work for some people but it does not work for some other people. For example, if the person suffers from Alzheimer's they don't know where they are so in such cases I don't think it makes a big difference. If they have their own mind, it is better to stay in their own place and bring the hospice near to them (Nicole).*

Most of the participants preferred to die in a place that was familiar to them, which, they believed, would be comfortable, happy and peaceful. They expressed the idea that care in a familiar place provided an opportunity to live in their own personal space, share experiences with their friends and family members, and carry out their routine. In contrast, an unfamiliar environment was staffed with unfamiliar carers who did not understand their needs, was noisy and overcrowded, and a place where participants felt that they would be neglected and isolated. However, some of the participants realised that moving to other places was necessary if they required specialised care. Despite this, the majority of participants wished to remain in a familiar place, encouraging professionals to bring the necessary expertise to their home.

### **6.3.3 Long term relationships help to understand the needs at end of life**

Participants preferred to stay with familiar people at their end of life, as they believed that the long-term relationship offered more security, a feeling of control, trust, emotional support, and additionally minimised risks (Aldred, Gott and Gariballa 2005). Furthermore, it was assumed that long-term relationships enable understanding of the changing needs of individuals at the end of life (Peacock, Duggleby and Koop 2014). In this study, participants with intellectual disabilities and their relatives advocated that it would be better for people with intellectual disabilities to stay with familiar people as they could identify their needs through their body language and other non-verbal cues and therefore provide good care.

Conor commented that people with intellectual disabilities who lived in a residential setting developed important relationships during their life. He perceived that staff who worked in the services became attached to residents with intellectual disabilities, suggesting relationships were mutual and strong. Therefore, he believed that at the time of dying people with intellectual disabilities should stay with their own carers. In his opinion, this created a sense of being in a safe place and he also thought familiar carers better understood the needs of this population. To illustrate this, people with severe and profound intellectual disabilities who could not speak, hear or verbalise their needs could be understood by staff who worked with them long-term. The staff could identify their needs through their facial expressions and body movements. Therefore, Conor indicated that it was better to stay with familiar carers who had developed long-term relationships with residents at the time of dying. Conor stated:

*People always become attached with somebody. This is especially true for handicapped people who live here in xx or yy house or any other places where people come to, work with them and become attached with them. Also, the staff can understand from their facial expressions and body movements even if they don't speak. So, they should be staying with them at the time of death (Conor).*

Service user Ciara proposed that it was better for people with intellectual disabilities to die where they had lived because friends and family members could visit them before they died. Furthermore, she thought that it was better for people with intellectual disabilities to stay with their family members during their last days of life. Ciara stated:

*It is always nice to die where they live because friends can visit them before they are buried. People who die, just leave them and let them stay with their friends and parents. Staff can ring the family and ask them to stay with them before they die (Ciara).*

When service user Rebecca recounted her friend's death in a general hospital, she felt terrible and was upset. She described her friend's death in the general hospital as "an isolated death" because her friends and her carers who looked after her for years could not see her. She imagined that her friend would have felt the same and missed them in the last days of her life.

Rebecca concluded that any place other than the person's home was not a nice place to die because people with intellectual disabilities felt deprived and disconnected from their friends, carers and family members. As Rebecca said:

*It was hard and upsetting. XXX went to the hospital and she died there after a couple of days, when you look at this, people are living here for a long time and they are sent out to another hospital to die. It is sad and nobody could go there and see her including her friends and parents (Rebecca).*

Parent Michael indicated that some people with intellectual disabilities could not communicate; therefore, it was difficult to understand their needs and hard to find out the problem because they could not express themselves verbally due to their cognitive impairment. For these reasons Michael placed his trust in familiar carers who were able to understand these needs. He believed that familiar carers would take the appropriate steps and give medication based on need. Michael thought that his son would not get proper care if he were moved from the place where he lived. Michael looked for an

equal standard of care regardless of where people with intellectual disabilities were cared for and by whom. Michael expressed his views as follows:

*From the point of view of my son xxx, who has communication difficulties and is hard to understand: what are his needs? It is hard to find out the problem because he won't be able to tell you. Certainly, I like people to be here with their carers who have a better understanding of these people. Therefore, it is imperative that my son should stay here when he is dying. I hope the carers here take appropriate steps say for example with medication. In fact, xxx's care at the end of life is not too different from other people if the known carers are working with him. My overall worry is that if he moves away from here I think that he won't get proper care (Michael).*

Michael showed his understanding of the complex needs of the intellectually disabled person at the end of life; therefore, he suggested that professionals who have special skills in providing end-of-life care should do so at the intellectual disability service location. Alternatively, professionals from the intellectual disability services could go to hospices to obtain skills to manage people at the end of life. He had negative feelings about moving people with intellectual disabilities away to receive care at the end of life. He expressed a preference for care to be provided in a familiar place with familiar people who could understand people with intellectual disabilities' needs, respond appropriately and spend time with them. He was convinced that people with intellectual disabilities could be looked after well in their own surroundings and by the usual staff. He expressed the importance of a good working relationship between the hospice and intellectual disability service where professionals from each entity could learn from each other and share their knowledge and skills. Michael articulated his views as follows:

*I would like to see all staff involved in the care of persons with intellectual disability, probably I would like to see all professionals coming here to care for these people rather than sending them to hospice. Otherwise, the staff from here can go to the hospice and spend some time there and learn new skills rather than shipping people away. They may be best professionals in the world in the hospice but they do not have much experience in caring for people with intellectual*

*disabilities. I want to see my son cared for by the person who knows him and spends time with him at the end of life. I can't see what else the hospice brings to my son. I have respect for the hospice staff and no doubt about that (Michael).*

James, a parent, concurred with the above. He suggested that people with intellectual disabilities felt safe and comfortable in their own place at the end of their life, as familiar carers could better understand their needs. He also stated that hospitals and other places do not want to keep people with intellectual disabilities as this population takes up beds. He was of the opinion that professionals in the intellectual disability services develop a better understanding of people with intellectual disabilities through long-term relationships. As James said:

*It would be lot harder for people with intellectual disabilities and families and carers if they move people with intellectual disabilities to other places when they are dying. I feel this kind of residential service would be better for our daughter because here people have experience of dealing with people with intellectual disabilities and know these people very well. Hospitals and other places really don't want these kinds of people you know, they think that these people are taking up the beds (James).*

James further stressed that this population could be sent to hospices but he believed that the hospices were already overstretched. He also pointed out that staff who were working with people with intellectual disabilities should be trained to provide end-of-life care for them as this would help to keep dying people in their familiar place. James said:

*I know that we can send them to xxx Hospice but they are overstretched and they cannot look after everybody. I strongly feel that people working in the intellectual disabilities service should be trained to provide end-of-life care (James).*

Family member, Tara reiterated the importance of carers being familiar with people having intellectual disabilities at the end of their life. She agreed that familiar carers made people with intellectual disabilities feel safe and comfortable.

Tara concurred with the previous participant's suggestions that familiar carers best understand the needs of people with intellectual disabilities and manage these in a better way. In her words:

*I think in my opinion it's the same for all dying people they need a lot of support and familiar carers should stay with them all the time then they feel safe and comfortable you know. They would understand and I think staff are trained well enough to look after them. But I would say some places like xxx they cannot handle her. They have to ring the Intellectual Disability Service to get people to manage her. So... I think they should be cared and managed by specially trained people like here to look after her, definitely you need somebody specialised to look after them you know, that would be a big one anyway (Tara).*

Another parent, Adam, said that people with intellectual disabilities should receive good medical care like everybody else. He also acknowledged the importance of being close with their friends, family and carers at the end of life.

*The people with intellectual disability first of all should receive good medical care when somebody is dying of cancer or any other disease and added to that there is also the closeness of friends, staff and you know the families (Adam).*

Eimear, another parent, stated during her interview that people with intellectual disabilities should be staying with known and familiar people like friends, carers and family members who understand their needs at the time of dying. She also believed that people with intellectual disabilities should receive appropriate nursing care and their needs should be met at the end of life:

*Possibly friends should be around them and staff members to deal with necessary needs and make sure that he gets the correct nursing care. That would be the issue really. I think they should be with them over the years. Make sure that somebody is with them all the time and their family members should be present at all times. I think these are the main things really. I feel generally family members and friends should be around the dying people (Eimear).*

Emily, another family member, suspected that when people with intellectual disabilities were moved other sites nobody cared about them. She recalled her own experience when her sister was moved to a general hospital where nobody talked to her sister so

she felt isolated, detached and neglected. She preferred that her sister be cared for by a familiar person and reiterated that if her sister had to go somewhere then a person who was familiar to her should accompany her. Emily said:

*I know once when my sister went to the hospital nobody talked to her so she felt isolated and detached. She has to go around and find people to talk to her. I think even though xx doesn't know the people at least I prefer to have people who know my sister to understand her needs and understand her non verbal cues. I felt when she was in the other hospital nobody talked to her and she felt isolated and neglected. I strongly feel that if she goes to hospital or a hospice, I prefer her to go somebody who knows her to accompany her and stay with her (Emily).*

From the above perspectives it is clear that long-term relationships are important in understanding the care needs of people with intellectual disabilities. In addition, the study participants felt that staying with familiar people provided a sense of safety and a feeling of comfort at the end of life. In contrast, while staying with and being cared for by unfamiliar people, most participants felt that they would be neglected, isolated and detached from their normal life. People with intellectual disabilities preferred to live and die in their familiar place, doing familiar things, surrounded by familiar people. Participants recommended that a working partnership between all services as well as education and training for professionals in the area of end-of-life care would help people with intellectual disabilities die in their preferred place with preferred people.

## **6.4 CHAPTER CONCLUSION**

Throughout their conversations, the participants talked about the components of good death and how to achieve them. They strongly believed that preserving the routines of people with intellectual disabilities, care at their familiar place, and care by familiar people at end of life would provide a good experience and facilitate good death.

Familiarisation at the end of life was proposed by most of the study participants. Participants in this study expect to be cared for at their familiar place by familiar people

and surrounded by their parents and friends. Also, they desired to have their routines followed at the time of dying. Most of the participants in this study expressed the view that familiarisation with place, people and activities at the end of life made people with intellectual disabilities feel comfortable, safe and secure. In addition, they reported that familiarisation provided an opportunity to be socially connected with their friends, family members and carers. On the other hand, receiving care at an unfamiliar place by unfamiliar carers increased anxiety and nervousness as well as making people with intellectual disabilities feel neglected and isolated.

# CHAPTER 7. DISCLOSURISM

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## 7.1 INTRODUCTION

In this chapter, one of the study findings that relates primarily to the expectations and wishes of people with intellectual disabilities to know their clinical condition and prognosis is reported. Most of the participants with intellectual disabilities reported that they expected to be involved in any communication about dying and their own impending death, if the opportunity was provided and that they would discuss their wishes with health care professionals when it was time. They also expressed the desire to make their own decisions in relation to death and dying. In contrary, family members of people with intellectual disabilities disagreed with the expectations of people with intellectual disabilities and preferred avoid having conversation with their loved ones regarding diagnosis, prognosis and impending death.

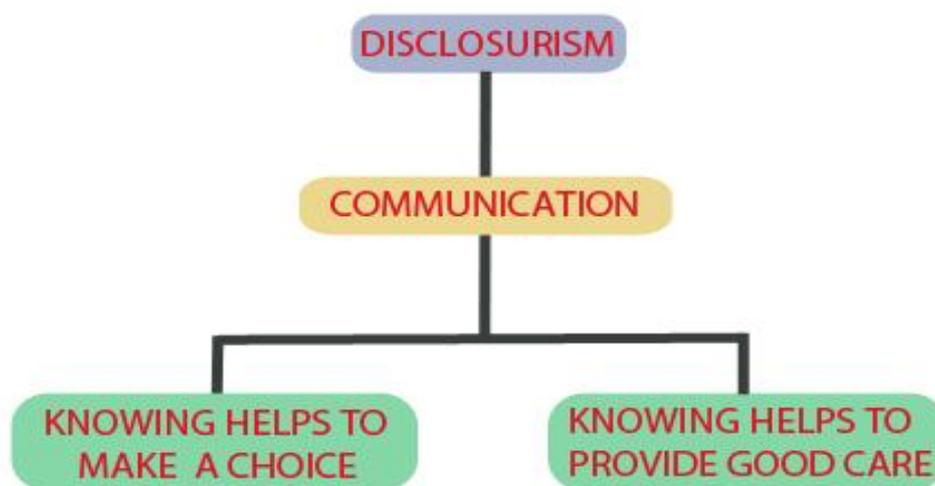
## 7.2 COMMUNICATION AND END-OF-LIFE CARE

Communication is an essential tool to providing good medical and nursing care. This skill is required especially when providing end-of-life care. It has been found that health care professionals often struggle to communicate with the dying person or their families due to cultural prejudices and expectations, the service user's clinical conditions, and the professional and personal experience of care providers (Voorhees et al. 2009). However, breaking bad news or sharing information about terminal illness is a critical juncture in patient-professional relationships (Robertson 2008). Tuffrey-Wijne (2013) advised that a step-wise approach would be beneficial and appropriate for service users.

In this study, participants with intellectual disabilities wanted to be informed about what was happening to them. This "knowing" was not only about their diagnosis but also

about future care needs and care arrangements. In addition, they wished professionals to know what they wanted and how they needed to be treated at the time of dying and after death. The sub-categories of disclosurism are: “knowing helps to make a choice” and “knowing helps to provide good care”.

**FIGURE 6 DISCLOSURISM**



The following sections explain how telling the truth helps people with intellectual disabilities to make choices and how it helps service providers to provide good care at the end of life.

### **7.2.1 Knowing helps to make a choice**

Study participants acknowledged that understanding their clinical condition and prognosis help to familiarise them with their physical and physiological changes and predict the future. Consequently, they believed that this help them to make a plan for their future in the way that they wanted. Conversely, relatives of people with intellectual disabilities felt that knowing create a feeling of anxiety and destroy all hope in their loved ones. As a result of knowing, they suffer heavier burdens and more stress. However, in this study most of the participants with intellectual disabilities were very eager to know what was happening to them, and they thought this would help them to

make a choice about their present and future life. Tuffrey-Wijne (2010), Tuffrey-Wijne and Davies (2007) and Todd and Blackmann (2005) found in their study that some people with intellectual disabilities wanted professionals to relay their clinical condition to them.

This is no different among general population; Waleed et al. (2016) and Koh, Kim and Kim (2016) found that patients with cancer expected health care professionals to communicate their diagnosis, prognosis and possible end-of-life care. Despite patients' willingness to know and understand their own clinical issues, family members act as a communication channel between patients and physician, as a consequence passing selective information to patients and controlling what patient should know and what should not know (Lee et al. 2013). This is due to family member fear that their loved ones may suffer from anxiety and emotional pain when they know their clinical condition. However, Shin et al. (2015) found in their study that there is discordance between patient preferences and family carers' preference in relation to place of care, life sustaining treatment and place of death.

In the same way, in this study, participants with intellectual disabilities have shown willingness to familiarize themselves with and understand their clinical condition, prognosis and implication of the disease on their life. However, family members argued against the preferences of people with intellectual disabilities about their right to know and took a paternalistic view about communicating issues. Until people with intellectual disabilities know what is happening to them, they cannot make any decision or convey their opinions and preferences in relation to their own end-of-life care. Consequently, unless we, as care providers, hear, listen and understand their needs, desires and choices, we cannot provide optimal end-of-life care to people with intellectual disabilities. Eventually, they may receive inappropriate and inconsistent care at their end of life and we fall short of providing appropriate end-of-life care.

Sean, a service user, said that professionals should let intellectually disabled people know what was happening to them. He thought that this was very important so they could make the choice of where to die, how to die and where to be buried. He also expected that others should listen to them and respect their wishes. Participants in this study looked for an open awareness of their diagnosis and prognosis, thus enabling them to make a plan of their day-to-day activities. In Sean's words:

*People like us should know what is happening to us because ... we have choices to make like...where to die, how to die, how to be buried. Yah...the person who is dying should know everything and people should let them make choices. Listen to them and we should do whatever they ask (Sean).*

Another participant with intellectual disabilities, Katie, said that doctors and nurses should tell people with intellectual disabilities what was wrong with them. She believed that most people with intellectual disabilities want to know what is happening to them. Participants with intellectual disabilities assumed that knowing their clinical condition was not only their right but also helped to predict their future. Katie said:

*Doctors and nurses should talk to the people and let them know what is wrong with them. People like me really want to know what is happening to us (Katie).*

Service user Rebecca said that parents of people with intellectual disabilities should know what was happening to their loved ones and that people with intellectual disabilities should also know what was happening to them. She strongly believed that parents should be aware of their sons' or daughters' situation and should stay with them from the beginning. In Rebecca's words:

*It is not right to tell their parents after someone has died. They should be right beside their bed, right from the beginning. Stay with them and help them out. The doctors and nurses should work closely with them and find out exactly what happened to them. People who are really dying should know exactly what is happening to them. They should ring the family immediately and the family should stay with them right from the beginning. All I want to say is let the dying person know that there are people who belong to them and care for them because they are also human beings (Rebecca).*

Rebecca added that nurses and doctors should inform people with intellectual disabilities about their condition so that they realise they are dying. She also felt that it was the responsibility of the professionals to enable people with intellectual disabilities to understand that there was nothing more that could be done to cure them. Rebecca felt that professionals should provide adequate and appropriate support to the dying person with intellectual disabilities and their family. Knowing helps people with intellectual disabilities to understand their changing physiological processes and prepares them for these unavoidable changes, which in turn reduces their anxiety and stress. As Rebecca stated:

*The nurses and doctors should make people realise they are dying. They definitely need a lot of support; the family and the person who is dying should know that nothing more could be done for them. When there is no cure, the family needs a lot of support. They need to be there all the way through and the person who is dying needs a lot of support and care (Rebecca).*

Lauren, another participant with intellectual disabilities, echoed the above claims and said that people like herself should be looked after well at their end of life and they should know what is happening to them. She stated that the doctors should not hide things from people like herself, as knowing was their right. She felt that the right thing was to let the individual know what was happening. In Lauren's words:

*All I want to say is the people like us should be looked after well and tell us what is happening to us. The doctor shouldn't hide things from us. I don't think it is the right thing to do. The right thing is to let us know what is happening to us (Lauren).*

Service user Emma agreed that the clinical condition of a person with intellectual disabilities who is dying should be communicated. Furthermore, she suggested a way in which this could be achieved. According to Emma, doctors should convey the message to the family members and the family members should relay the information to the dying person with intellectual disabilities. Nonetheless, she agreed that if family

members struggled to convey the message to the dying person then the nurses and doctors could help the family members to do it. Emma stated:

*The doctors and nurses should let the family members know what is happening to the dying person and the family members can tell the information to the dying person. If the family members struggle to do this, nurses and doctors can help the family members (Emma).*

When Eamon, a father, spoke about communication it appeared that he was referring to appropriate information in relation to disease condition, prognosis and future care in a simple and understandable way. He clearly agreed that information was crucial, especially for family members, at the end of life. He expected to be informed about everything that happened to his daughter. In Eamon's words:

*Communication is very essential and there are different ways, some people say total communication and some say no. I think communication is crucial especially with family members as to what is happening so, the professionals should let family members know what is happening to their loved ones (Eamon).*

When Eamon was asked about the right of the dying person with intellectual disabilities to know about their impending death, he said that it was too hard for them to understand and even if they understood then it would be difficult for them to accept the situation. Eamon felt that it was better for people with intellectual disabilities not to know about their situation and he preferred not to disclose information about dying. Eamon said:

*Mm... I would say certainly not because it is difficult for them to understand and even if they understand it will be very hard for them to take. I prefer not to tell them anything (Eamon).*

Eimear, a parent, strongly agreed that the family members of people with intellectual disabilities should know what is happening to their loved ones, as this helps family members to make choices about care. However, she was reluctant to convey the clinical information to people with intellectual disabilities, as she did not see any point in telling them. Eimear worried that disclosing the truth to people with intellectual disabilities

would cause unnecessary distress and upset. Eimer preferred that they were happy until they died:

*Also certainly, I feel the professionals should give all the information to family members to make appropriate choices. That's really important but I really worry about telling this to people with intellectual disabilities because this will cause distress and make them upset. I don't know what is the point of telling them everything; let them be happy until they die (Eimer).*

Participants with intellectual disabilities in this study expressed their right to know what was going on with them whereas the family members wanted to protect their loved ones from exposure to the truth. Professionals' colluding with family members and the subsequent withholding of information undermines the autonomy of people with intellectual disabilities.

The family members displayed a paternalistic attitude and believed that they knew what was best for their loved ones. However, it is my opinion that the individual service user is the best judge to decide what he or she wants to know and how much he or she wants to know, and, indeed, the service users with intellectual disabilities in this study expressed a desire for openness from professionals and family members. Family members clearly feared that telling the truth would cause emotional pain, distress, anxiety and be a burden to people with intellectual disabilities. However, disclosure may bring positive consequences if people with intellectual disabilities can understand their symptoms, engage with their friends and make meaningful future plans. Finally, disclosing the truth may pave a way for providing appropriate care at the end of life such as the involvement of a specialist palliative care team to manage and control complex symptoms.

Tara spoke about her brother who had intellectual disabilities and his subsequent death. She indicated that she was frustrated with the doctors, as they did not listen to relatives. Her brother was unable to speak. Tara recounted that in the hospital, investigations and

scans were carried out but neither the doctors nor nurses informed them of the outcome. Tara and her family were left in the dark, hoping that her brother would be all right. However, the family was only informed after her brother's condition deteriorated. Tara pointed out that this was inadequate, suggesting she and her family should have been involved in the discussion and decision making from the beginning and "we should have known what was happening to my brother". As she recalled:

*It was a frustrating experience, xxx couldn't speak and the doctors didn't listen to us, really, it was frustrating. I feel that the family certainly should be involved, definitely when they make these kind of decisions. Also I want to tell you one thing that they took so many scans and tests, the doctors and nurses did not tell what is going on, we thought he will get better, we were all left in the dark and they told us only when things got worse. This shouldn't be right. They should have discussed things with us. We strongly think that family should know what is happening. (Tara).*

Parent Nicole also suggested that professionals should inform family members about what is happening to their loved ones. She believed that the information would help them to make appropriate decisions such as what to do and who to contact. She indicated that open communication leads to clarity, thereby eliminating confusion and anxiety. Nicole stated:

*I think professionals should inform the family members of what is happening to them. This will help the family members to make an appropriate decision and they know what to do and whom to contact. It will clear all the confusion and anxiety (Nicole).*

Rachel, a service user, disagreed with the family members' stance of not letting people with intellectual disabilities know about their clinical condition. She recalled her own experience in a hospital, expressing anger at the staff for not letting her sign her own consent form. She felt that professionals perceived that people with intellectual disabilities could not make decisions by themselves and she considered this to be discrimination. In the same way, she believed that dying people with intellectual disabilities should know what was happening to them. Rachel said:

*It should be discussed with a person with ID. For example in my case when I went for the operation, the staff signed the consent form for me. It made me angry and I was not allowed to sign my own form. I thought that this is very selfish you know what I mean...really they should have asked me to sign my own form you know. I was really angry at xxx hospital you know, I am very very angry with them. I thought that it was unfair not to sign your own form. The same way, I think the dying person should know what is happening to them. Yes, they should absolutely know what is happening to them (Rachel).*

Rachael continued that it was unfair to deny the dying person knowledge about their situation. In her opinion, somebody should disclose all relevant information to the dying person with intellectual disabilities and stay with them. She acknowledged that, although it was hard to talk about death, somebody has to prepare them and explain it in a way that can be understood by people with intellectual disabilities. She suggested that this would help people with intellectual disabilities to prepare for the future. In Rachel's words:

*It is unfair not to let the dying know about his situation. I think somebody has to disclose everything to the dying person and stay with them for a short while. It is really hard to tell about death you know I think the person has to prepare them and explain in a way they can understand you know.... Once they know they can prepare themselves (Rachel).*

Rachel suggested that when dealing with people with severe and profound intellectual disabilities who cannot tell what they want, or in some cases cannot understand what they have been told, that disclosure by family members was appropriate. Rachel expressed her views as follows:

*People specially people with special needs like xxx and for other people, they wouldn't be able to tell you what they want and they can't understand what you say. You know what I mean. In that situation, I think the family members should let the people with special needs know this, not the doctors or nurses. I think family members are the right people to let them know the real situation because they speak heart to heart. Doctors or nurses should talk to the parents first and parents should try to explain the best they can to the person with special needs who is dying (Rachel).*

It is clear from participant accounts that there is tension between family members and service users. Family members wanted to protect their loved ones from the traumatic news of impending death and keep them happy until they die. Family members suggested that people with intellectual disabilities could not cope with such bad news and thus would become distressed and upset. However, the service users felt that they had a right to know what was happening to them. From their perspective, people with intellectual disabilities were able to handle the bad news with adequate support. Both parties agreed that knowing what was happening would help to make informed choices, future plans and decisions.

### **7.2.2 Knowing helps to provide good care**

Knowledge of what is happening to dying people helps to predict their future care, plan and choices (Johnson et al. 2012). As a result, they are able to convey their care wishes and preferences through advance care planning (Black 2014). The participants perceived that if the professionals knew the wishes and preferences of dying people, this would help them to provide good care (Ryan et al. 2011a). Furthermore, understanding the expectations of the service users and their family members helps the service providers to plan and give appropriate care (McMahan et al. 2013). This in turn reduces the tension and anxiety among people involved in the caring process (Pereira 2011).

Service user Emma commented that professionals should encourage people with intellectual disabilities to write or express their wishes before they get really sick. She suggested that people with intellectual disabilities can write about where they want to spend their time and with whom at the end of life. Also they can leave a message about how their last rites should be carried out and about their funeral arrangements. She also suggested that if the person with intellectual disabilities could not speak or write, their family members or professionals could make a decision about their care at the end of life. Finally, she noted that an advance care plan consisting of all information about the

dying person with intellectual disabilities should be kept in their clinical file at all times.

Emma stated:

*Make the person write or tell their wishes before they really get sick. How they should be cared or looked after and where they want to spend their time and with whom. How their last rites should be conducted and about funerals. If the person cannot speak or write, then ask the family members to do it for them or the team has to make a decision. It is important that the wishes of that person should be in their file all the time (Emma).*

Katie, another service user, said that the service should make them write down their wishes on paper or tell the nurses, doctors or parents about their wants and wishes at the end of their life. She further suggested that this document would be a good resource for health providers to give appropriate care, because this document would eliminate any confusion related to end-of-life care and everybody involved would know what to do and what was expected of them:

*Also, they have to make us write down our wishes in a paper or tell the nurses, doctors and parents what are our wishes. This will clear all confusions and everybody will be in the same line of care (Katie).*

Nicole, a mother, commented that it was a good idea to have a clinical file where the person with intellectual disabilities and their family members can give directions to the professionals about what to do in the event of an emergency. Thus, everybody would know what to do and what was expected from him or her. She also mentioned that she could write about funeral arrangements. She felt that this information would help professionals to provide good end-of-life care to people with intellectual disabilities.

Nicole commented:

*I think it is a very good idea to have everything on the clinical file. It will give a clear direction to the professionals about what to do at the time of emergencies and everybody knows what to do and what is expected of them. For example, I want to write that she should be looked after well and I want to mention that once xxx died she should be buried in our mum and dad's graveyard. This information will be very helpful for the professional to provide good care at the end of life (Nicole).*

Adam, another parent, noted that the service providers should offer some provision for family members to give their opinions about care provided during their loved ones' final journey. He strongly believed that family members' views and opinions should be respected and also that this should be recorded in their file. He thought that this practice was not only good for people with intellectual disabilities but also for professionals to provide excellent care at the end of life for people with intellectual disabilities.

*There should also be a provision for family members to give their opinions during and after the Death. I definitely think that family members' views and opinions should be respected and followed during this period. They should make a record of everything we want. This is not only good for us but also for professionals to be clear and provide excellent care at the end of life (Adam).*

It is clear from the views of the participants with intellectual disabilities that they wanted to register their wishes about their care needs at the end of their life. They confirmed that their registered wishes in their advance care planning should be respected and carried out. They clearly believed that recording the individual wishes would help the professionals to provide quality care with less tension and confusion.

Disclosing the clinical situation to the service users and their family members paves the way for making appropriate decisions and choices. At the same time, disclosing the wishes and expectations of service users and family members through an advance care plan helps health care professionals to provide appropriate care at the end of life for people with intellectual disabilities. Advance care planning is a means of communication between service users and health care professionals that helps care providers to achieve the provision of optimal care at the end of life (Brinkman-Stoppelenburg, Rietjens and Van 2014).

### **7.3 CHAPTER CONCLUSION**

The concept of disclosurism was explored on the basis that participants with intellectual disabilities wanted to know about their impending clinical situation and their future

care. Participants with intellectual disabilities believed that knowing about their clinical situation and impending death helped them to make appropriate choices and relay these to parents and health care professionals. Consequently, they assumed that this would help health professionals to provide better care at the end of life. On the other hand, family members felt that it was inappropriate to discuss such sensitive matters directly with their loved ones, as this would distress them. Family members in this study preferred to protect their loved ones from the disclosure of bad news. However, participants in this study with intellectual disabilities showed significant maturity and preferred to make their own choices.

# CHAPTER 8- RESPECTIVISM<sup>1</sup>

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## 8.1 INTRODUCTION

The previous three chapters explored and discussed the concept of “self” of people with intellectual disabilities and how this could be maintained and protected at the time of dying. This chapter explores how this is maintained after death. It deals with the issue of how much people with intellectual disabilities want their death to be respected and their life celebrated. It also discusses the expectations of people with intellectual disabilities in keeping their soul-self intact after their death.

## 8.2 RESPECTIVISM AND END-OF-LIFE CARE

According to the NHS (2011):

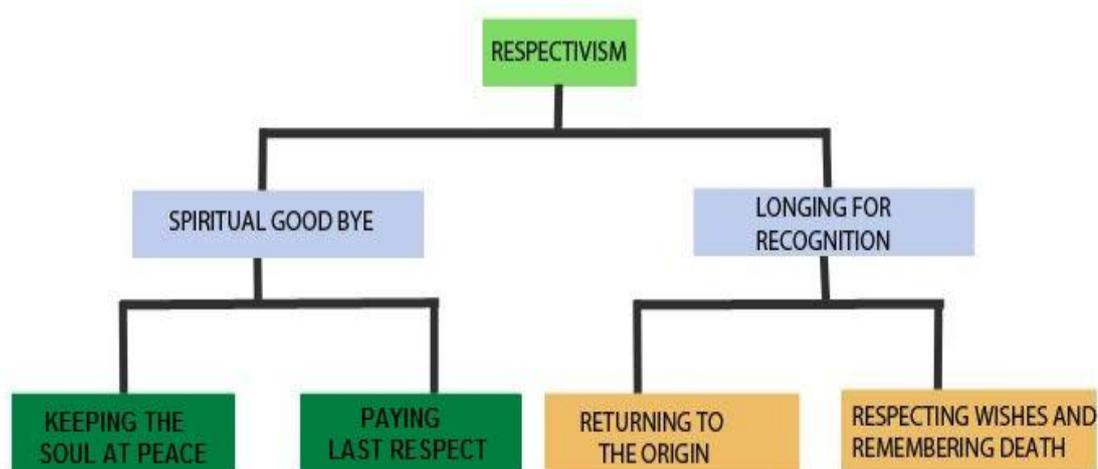
*Good end-of-life care does not stop at the point of death. When someone dies all staff need to follow good practice for the care and viewing of the body as well as being responsive to the wishes of family and friends (NHS 2011, p.33).*

End-of-life care begins when somebody with general fragility and co-existing life-limiting conditions is likely to die within 12 months, and continues after death if necessary (National Council for Palliative Care 2011). End-of-life care does not stop with death; rather it continues after death. The category “respectivism” (Fig 7) in this study deals with how the study participants want their death to be recognised, respecting their last wishes, spiritual care after death, and funeral arrangements. In this study, participants gave the same importance to care after death as care before death. Most of the study participants felt that their death commemoration should be on par with their non-disabled counterparts.

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<sup>1</sup>The word Respectivism was coined to reflect the participants’ wishes to maintain their individualism and their identity after death.

**FIGURE 7 RESPECTIVISM**



The following sections discuss the sub-category of respectivism, namely: “spiritual goodbye” and “longing for recognition”.

### **8.3 LONGING FOR RECOGNITION**

Most of the participants in this study felt a need for recognition after their death. There was a feeling among the participants that their death was not valued and recognised the same way as others in society. The participants in this study felt that they should be valued as human beings and therefore wished for their funeral arrangements and last wishes to be recognised and carried out (Todd and Read 2010). Most participants, in this study, worried about what would happen when they die because of unpleasant experiences in the past. “Returning to the origin” and “respecting wishes and remembering death” are the constituents of the sub-category “longing for recognition”, these are discussed in detail in the following sub-sections.

#### **8.3.1 Returning to the origin**

Most of the participants with intellectual disabilities preferred to see their friend’s final remains before they were buried or cremated and they wished to have their remains

brought to the place where they lived (Todd, Bernal and Forrester-Jones 2013). By expressing this wish, the participants with intellectual disabilities wanted to maintain their attachment with their place even after their death due to their emotional bond with their environment. This demonstrates attachment with the place and dependence upon it (Walsh et al. 2012). The occurrence of place dependence may be due to a functional attachment to a specific place and awareness of the uniqueness of the setting (Walsh et al. 2012). The place identity and dependence describes one's profound connection between a place and their personal identity. Moreover, people have a sense of belonging to places through a communal bond with other people through people-place interaction (Walsh et al. 2012).

Participants with intellectual disabilities wished to return to their place of origin not only to maintain their bond with their place but also to protect the bond with their friends. As such, the participants with intellectual disabilities wanted their remains to come back to the place of residence once they died. This would facilitate, they believe, their friends to say a final goodbye. The participants felt that if a person with an intellectual disability died in a residential setting, their friends would be able to see their remains, but if somebody died outside of their normal residence, it would be a problem for their friends to travel and see. Accordingly, people with intellectual disabilities urged professionals to bring their friends' remains back to their original place. They assumed that this was one of the ways of showing respect and recognition. Service user Sean states:

*Even if the people died outside, we all want to see them so bring them back here and leave them here for a while. We are friends and have grown up together; we want to see them (Sean).*

Service user Ciara agreed with Sean and declared that some people with intellectual disabilities could not travel outside to see their friends' remains so she requested that

the final remains be brought to their place before being buried or cremated. Ciara also acknowledged that many people with intellectual disabilities could not travel due to cognitive and physical disability and even if somebody wanted to travel, they required the assistance of another (Forrester-Jones 2013). Sometimes it was not possible due to lack of staffing or poor understanding of service users' needs to see their friends' final remains; consequently, their request to go and see their friends would be declined by their carers. As Ciara said:

*We cannot go anywhere and if we want to go anywhere we need other people to bring us, sometimes they won't allow us to go. We want to see them please bring them back here, it is their place, they lived here for a long time. We want to see them before they are buried or cremated (Ciara).*

Another service user, Rebecca, concurred with other participants and stated that people with intellectual disabilities want to be recognised for who they are and where they come from. They are people who are attached firmly to their original place and they wanted to return there after dying. Their feeling was that they had lived in that place for many years and had a sense of belonging regarding that place so they wanted to come back and be buried there. The attachment was so strong that they felt a sense of comfort and belonging to their place. Rebecca commented:

*For me wherever I die I want to come back here and be buried in xx place. That is my wish from the beginning. I want to die where I had lived and to be buried where I belonged (Rebecca).*

It is clear that people with intellectual disabilities believed that home was where they had lived and were reared; therefore, they wanted to come back, wherever they die. They had a sense of attachment with their place and wanted to be buried or cremated there.

Family member Eimear declared that funeral and other arrangements were the responsibility of the service provider if the person with intellectual disabilities had no

family (Todd, Bernal and Forrester-Jones 2013), so the service provider should respect the preferences of the service user. However, for participants with family, the family members acknowledged that they should take full responsibility for the funeral after their loved ones died. As Eimear said:

*Once there are family members they will take care of everything, Yah... some of them are brought down to the countryside to be buried. Also, people who are attached with a service so the service will look after everything. I know xxx service and I talk from that perspective. The service should look after everything. The service that my son is attached with has family members and no issue arises because family members are there to look after him. If they don't have family members, it is the responsibility of the service to look after them and respect their preferences (Eimear).*

Nicole, a family member of a person with intellectual disabilities, stated that people with intellectual disabilities should be brought to their own place not only to respect their attachment to their place but also to facilitate friends and carers to see the body before burial. Nicole assumed that it would be difficult for friends and carers if they did not see the burial therefore she felt it important that the person's body be brought back to their place to facilitate their friends and carers seeing them. In Nicole's words:

*I think that their final farewell should be carried out in line with everybody else in the country. They should be washed and appropriately covered and keep them somewhere to visit by their friends and carers because they are their family. It will be hard on their friends, if they can't see them before the burial. Therefore, they have to bring them back to where they have lived (Nicole).*

There was strong agreement among participants about the importance of bringing the remains of people with intellectual disabilities to their original place after they have died. People with intellectual disabilities themselves wanted to return to their place after their death. This was possibly because they had a strong attachment to the place and also they felt that their soul would have a sense of comfort (Forrester-Jones et al. 2012). Family members and people with intellectual disabilities concurred that this practice would help their friends and co-habitees to see them before burial (Murray, McKenzie

and Quigley 2000). People with intellectual disabilities strongly believed that the home was where they lived.

### **8.3.2 Respecting wishes and remembering death**

Respecting wishes and remembering death is one of the ways of recognising soul self. Respecting wishes means listening to other peoples' decisions, views and opinions (Todd, Bernal and Forrester-Jones 2013). The voices and opinions of people with intellectual disabilities are important so professionals and others should value and respect their wishes and preferences.

Emma, a person with moderate intellectual disabilities, felt that people with intellectual disabilities should be remembered after their death. She proposed that they should be remembered for the good things they did in the past, that their funeral rites should be respected and that professionals should execute their expectations and wishes. Also expected to remember and respect their life after death. Emma commented that:

*They should be remembered after their death for their good stuff, the dying person's funeral rites should be respected all the time. Keeping flowers and lighting candles on special occasions like their birthday would be a way of remembering and respecting somebody's life after death (Emma).*

Rachel, a participant with mild intellectual disabilities, recounted her experience of her friend's death. She felt that her friend's wish to be cremated was not recognised and respected in the way he wanted it to be. She commented that her friend's wish was to be cremated but his family members decided to bury him after his death. There was a clear contradiction between what the individual with intellectual disabilities wanted and what actually happened. She further explained that if her own wish after death was to have her body cremated, and if this wish was not carried out then that was immoral and dishonest. As Rachel recounted:

*Really, I am worried about the way xx was buried. I really feel that their rights are not heard and carried out. I know from the beginning he wanted to be cremated but his family wanted him to be buried. After his death, he was buried not cremated. His wish was not looked after. This is totally unfair. Say for example really once I die I wanted to be cremated, if they don't do it that is unfair and an injustice (Rachel).*

Service user Ciara acknowledged that disabled people were no different to other people so they should be cremated or buried in the way they wished. She believed that the wishes of people with intellectual disabilities should be respected and their last rites carried out just as they would be for any other person. As Ciara said:

*We pray for them, to be buried or cremated in the way they want, bring them to xxx place and put them in a coffin box and bury them. That's what we do for people who are dying. Disabled people are not different so they need the same service as anybody else (Ciara).*

Emily, the sister of a person with intellectual disabilities, echoed that funeral and other services should be organised in line with the normal procedure. She also recommended maintaining the dignity of the deceased with intellectual disabilities during the funeral process (Todd, Bernal and Forrester-Jones 2013). Emily said:

*Ideally I suppose organise the funeral and other services in line with normal procedure and maintain dignity throughout the process (Emily).*

Nicole, another sister of a person with intellectual disabilities, asserted that the wishes of people with intellectual disabilities should be respected and valued. She thought that their last wishes should be carried out irrespective of whether they wanted to be buried or cremated:

*As for everybody else, there should be a funeral mass in this church and the coffin should be blessed and pray for their soul. They should be either buried or cremated according to their wish. It is very important to respect their wishes at the end; this is my opinion on it (Nicole).*

James, a father, on reflection said that people with intellectual disabilities should be remembered and recognised for who and what they were (Todd 2013). They are people,

therefore, they should not be forgotten after they are dead. He also recommended a few ways of remembering and recognising people with intellectual disabilities: keeping photos of the dead and having an annual mass for them. As James described:

*It is important that people with intellectual disabilities should be remembered and recognised for what they are and for who they are. They cannot be forgotten once they are dead. The service has to remember them. I think that keeping their photos, their art work, painting or a DVD about their life in the service and observing an annual mass or other type of things are necessary to remember them (James).*

Adam, a father of a person with intellectual disabilities, concurred that death and its commemoration should be observed in the usual way as for the general population including the last service and burial. In Adam's words:

*Probably something that myself and along with others assume that it is done in line with the usual manner. If somebody dies in this service and if there is no family member involved, I would expect that the service and burial and things are carried out as usual (Adam).*

Michael, a father, expected family members of people with intellectual disabilities to carry out the funeral service. However, in the case of people with intellectual disabilities having no family members, he said the service providers have a responsibility to recognise and carry out funeral arrangements in line with general expectations. Michael commented:

*If there is a family member I hope they carry out everything. If there are no family members, the service should carry out everything in line with general expectations (Michael).*

Rebecca, a service user, concurred with Michael that some people with intellectual disabilities have no family. Consequently, they depend on professionals for everything. So, there is a clear indication that professionals who work with people with intellectual disabilities and their friends have a significant role to play regarding their final journey (Todd 2013). Rebecca stated that:

*There are many sick people here and nobody belongs to them, I really worry about them. For them nurses, doctors and friends are more important (Rebecca).*

Rebecca had the impression that some people with intellectual disabilities were not recognised as human beings by their family members. She was frustrated that family members did not visit these people when they lived in the service. She felt that family members had abandoned these people with intellectual difficulties and did not want to see them for the rest of their lives. However, the family members suddenly appeared as soon as they heard that they had died (Todd 2013). This made her angry and she came to the conclusion that these family members did not care about people with intellectual disabilities until the time of their death. So, she felt strongly that not only the lives of people with intellectual disabilities should be respected and valued but also their deaths:

*They knew their sons or daughters are here but they never tend to see them but they will be up here once they are dead. This makes my blood boil. My conclusion is that they put the people down here and don't want to see them for the rest of their life. As soon as they hear they are dead, they just come up here and looking for what is left for them. This is what happened to so many people here. That would make me angry (Rebecca).*

These were concerns raised consistently from people with intellectual disabilities and family members. They stressed that the wishes and rights of people with intellectual disabilities should be recognised, respected and carried out by family members or by the service. They believed that funeral rights and the wishes of people with intellectual disabilities should be observed with dignity and that this population should be recognised for what and who they are (Forrester-Jones 2013). In short, they claimed that the values and wishes of people with intellectual disabilities should be heard and recognised.

## **8.4 SPIRITUAL GOODBYE**

Study participants expected that people with intellectual disabilities should receive a good farewell after their death, including spiritual comfort (Todd and Read 2010; TuffreyWijne 2010). They believed that spiritual comfort allowed their soul to be at peace. Like physical, psychological and social comfort, spiritual comfort is essential at the end of life for people with intellectual disabilities. Most of the study participants believed that spiritual comfort after death should be provided irrespective of their religion and in line with their beliefs. They perceived that there were appropriate ways of meeting spiritual needs after death, which puts the soul at peace. “Paying last respects” and “keeping the soul at peace” are the constituents of the sub-category “spiritual goodbye” and are discussed in the following sections.

### **8.4.1 Paying last respects**

Participants with intellectual disabilities in this study wanted their death to be respected and cared about by other people. Most of the participants in this study received care from an institution and their experience of the process of death and dying, especially care after death, was very poor. The participants thought that when people with intellectual disabilities died, their death was not valued and respected, especially when these people did not have family (Hadders 2007). Therefore, participants believed that paying respect to a person's death might instill hope for other people and create a good experience for them (Komaromy 2000).

When Conor, a participant with mild intellectual disabilities, recounted his past experience he articulated that people who had died in the institution were dumped in the graveyard. He perceived that those with intellectual disabilities who had died were not given enough respect, treated as refuse and furthermore there was no ceremony:

*All the patients who died here in the mental hospital were dumped in the graveyard. They were all stuffed in to a black bag and they were dumped into the graveyard. There was no gravestone or nothing that belongs to them. People who have a family like father, mother, aunty, uncle, nephew should be thinking ahead what to do (Conor).*

There is a strong feeling among people with intellectual disabilities that death among this population is treated unfavourably (Todd and Read 2010). Even though the practice towards death and dying had changed in residential settings, people with intellectual disabilities still believe that their death is undervalued and unrecognised by other people (Help the Hospice 2009). Rebecca, a participant with mild intellectual disabilities, urged professionals to respect the policies and guidelines of the hospital and rules of God:

*You just cannot say that the person died in this house and put them in the box and take them away. Also follow the rules of the laws like policy of the hospital, Gardai and GP and we have to follow the rules. You just cannot go to the house and find the person dead and drive them and throw them in the street or in the bin that is a sin doing that to the handicapped people (Rebecca).*

There were consistent perspectives among people with intellectual disabilities that their death would not be considered as important as other people's. They believed that their soul remained with their bodies because they had been living in the same residential setting for years so they asked professionals to leave the bodies of those who had died there for a while in the place they had lived. They believed that people working for the service did not want bodies to be kept in the residential setting for a while and furthermore wanted bodies to be disposed of as soon as possible. As service user Jack said:

*Anybody else who is dying in the hospital grounds or unit x or unit y or wherever they die for example if anybody died in z house, the staff go and see that he or she is dead and just get a bag and wrap the body in the bag. It means you are breaking the law and breaking God's rules. Taking somebody from the hospital and dumping him or her in the bin, you cannot do that. You just leave him until he dies, you leave him there for few days, that is where his soul is and that's where he wanted to be (Jack).*

People with intellectual disabilities believed that their soul would still be around after their death. Therefore, they wanted their body to be kept temporarily in their house or other place where they lived. In their opinion, this was a form of giving respect to their soul self after their death.

There was a real expectation from the participants that they wanted to see their friends' bodies and pay their last respects (Forrester-Jones 2013). They believed that this was the last chance to see them. Lauren, another service user, agreed with this in support of other participants:

*The person who dies in a place, they should stay for a good while, you just cannot bring out the people because they are dead, we want to see them so keep them for a while where they lived (Lauren).*

There was a clear concern from the participants that death was not valued and respected. Furthermore, they suspected that most of the time professionals removed a dead body as soon as possible thus making space for other people (Todd 2002). Therefore, participants looked for recognition and hoped for respect from other people.

#### **8.4.2 Keeping the soul at peace**

Participants believed that a soul existed even after somebody's physical death, therefore it was essential to put the soul to rest. Like any other comfort during dying, they articulated that comfort of the soul was very important after death. They believed that even though the physical body was dead the soul remained (Todd et al. 2013). Therefore, looking after the soul is a prime responsibility of health care professionals and parents. Participants also offered suggestions on how to keep the soul at peace and keep it in comfort.

Most of the study participants thought that allowing the soul to be at peace was very important after death and felt that doing so in a religious way was appropriate. They also suggested facilitating the dead person's friends and parents to see and say goodbye

to that person. They wanted professionals, friends and parents to attend the funeral and pray for people with intellectual disabilities who had died. Service user Katie proposed the following:

*Once they have died, ring the church and bring a huge coffin. They have to be washed and wearing robes, keep rosaries in their hands and lay them down in the coffin and keep them there for a while as they lived their life. Let their friends and parents say goodbye to them. Go to the graveyard and say prayers, friends, parents, nurses and doctors can go to the funeral and the priest can bless the coffin, so their soul would be at peace (Katie).*

Another participant with intellectual disabilities, Ciara, reiterated that if anybody died, professionals and friends should attend mass and go to the graveyard. Furthermore, she believed that the dead person needs blessings from their religious order to put their soul at peace after their death:

*If he dies, they have to go to the mass then they have to bring him to the graveyard and bless the coffin that makes his soul rest in peace (Ciara).*

There was a suggestion from service user Conor that if anybody died, professionals should leave a space for his or her friends and parents to spend time with their loved one. He also recommended leaving the deceased's remains at their place for a short period as he felt that the dead person's spirit would be around. He further commented that a priest should be called to bless the dead person's remains:

*When somebody had died, close the door, and leave him with the family members and friends. Leave him there, where his spirit is, call the priest and bless them (Conor).*

Service user Lauren agreed with other participants and said that the dead person's soul would be in the place where they have lived for most of their life; therefore, she advocated that people should pray for them. She believed that this would help the soul to rest:

*I think their soul would be still around where they have lived for years, so we all have to pray for them to rest their soul in peace (Lauren).*

Parent James suggested that this was not a one-off event and there should be a mass every year for the deceased with intellectual disabilities. Furthermore, he said there should be blessings at the graveside, which should be attended by family members and friends. He expected that this should happen every year. As James said:

*There should be a mass every year and blessings at the grave and family and friends should attend the prayers that happen every year as for everybody else (James).*

In parent Adam's opinion, the final journey should be carried out in a peaceful way for the individual, for example by having a mass and prayers for the deceased. He also thought that friends and parents should witness their final journey respecting the dead person's wishes:

*The final journey should be as peaceful as possible for the individual. What I mean is having a mass, involving their friends and parents and respecting their wishes. These make their soul at peace (Adam).*

According to another parent, Roisin, people expected to have a respectful final journey. She insisted that the final journey should happen in a dignified way that was appropriate to their religious expectations. She reiterated that it was important for friends to attend the ceremony. Finally, she recommended keeping a memorial in the form of stone or a marker to indicate the name, date of birth and death of the deceased. Rosin said:

*They should be buried in a dignified way in line with their religious expectations. I hope, whoever they live with and friends should take part in the service in some way possible. I think there should be some sort of stone or marker to say their name and date of death, whatever it is appropriate (Roisin).*

It was repeated throughout the interviews that people with intellectual disabilities should receive the same kind of treatment as any other person in the community. Therefore, they were expected to have a funeral mass, blessing from a priest according

to their beliefs, and prayers for their soul. It was also assumed that they should be buried or cremated in the way that they wanted. It was also envisaged that the dead person's wishes would be carried out at the end of life. A parent, Michael, commented:

*As for everybody else, there should be a funeral mass in this church and the coffin should be blessed and pray for their soul. They should be either buried or cremated according to their wish. It is very important to respect their wishes at the end; this is my opinion on it (Michael).*

It was the expectation from people with intellectual disabilities that their death should be observed like any other person's death. They wanted to receive the same kind of respect from their friends, professionals, parents and society. They believed that receiving blessings and prayers helped to keep their soul in comfort and in peace after death. As service users Jack and Lauren suggested:

*After death, they should be washed and get the priest to bless the coffin (Jack).*

*Prayers and blessings after death may make their soul happy. Going to mass, buying a mass card and lighting candles are also important (Lauren).*

There was a strong feeling among people with intellectual disabilities that they lacked family or even if they had family, that family members did not want to visit them. Therefore, they felt that they belonged to nobody and nobody belonged to them. Some participants felt sad and believed that friends and professionals were very important to them. Katie asked all people who were close to deceased people with intellectual disabilities to pray for them. She thought that this would help their souls to rest in peace:

*There are many sick people here and nobody belongs to them, I really worry about them. For them nurses, doctors and friends are more important. We all have to pray for them to rest their soul in peace (Katie).*

In summary, People with intellectual disabilities believed that their soul remained on earth even after their physical death. Therefore, they were of the opinion that they should receive the same care as anybody else. For many participants receiving blessings

and prayers were important after death. Finally, enabling their friends and parents to witness their final journey was important.

## **8.5 CHAPTER CONCLUSION**

Participants in this study felt that the deaths of people with intellectual disabilities were not recognised and valued like others. They demanded that these deaths and their own death should be valued and given equal importance as the general population. They admitted that many people with intellectual disabilities were longing for recognition. They considered that returning to their place of origin, wishing to be recognised and paying last respects were considered very important. Finally, the participants accepted that a spiritual farewell for their soul was an appropriate way for the soul to rest in peace.

# CHAPTER 9- DISCUSSION OF FINDINGS

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## **9.1 INTRODUCTION**

The findings presented in the previous three chapters were grounded in the research data and supported by participants' voices. The constructed conceptual codes and categories also supported these findings. From the perspective of participants, the findings suggest that care needs at the end of life are complex phenomena that are informed by multiple, interrelated factors. This chapter describes the concepts and issues that have been identified in the research findings and reviews these findings in relation to the existing literature.

## **9.2. HOLISM AS THE MEANS OF PRESERVING THE SELF IN THE FACE OF DEATH AND DYING**

Most of the participants in this research study stated that people with intellectual disabilities should receive holistic care at the end of their life. Ronnerberg et al. (2015) claimed that people with life-limiting illnesses are dying with unmet physical, social, emotional and spiritual needs as well as great suffering from uncontrolled physical pain and spiritual distress. In order to reduce suffering, dying people need a holistic approach to their care to address their physical, psychological, emotional, social and spiritual concerns. This holistic approach would allow them to use their inner strength to improve their quality of their life and prepare them to face their ultimate mortality (Bekkema et al. 2015). The aim of end-of-life care is to provide a good dying experience to all people irrespective of their illness, age, gender and culture (Burns and McIlfatrick 2015; Pringle, Johnston and Buchanan 2015). Although having a good death encompasses many other factors such as the place of death and good symptom management (Watts 2012), it is evident from the participant's perception that providing

physical, psychological and spiritual comfort are considered essential in promoting an individual's acceptance of their impending death and allowing them to exercise their autonomy. Moreover, the participants asserted that care at the end of life should meet the needs of the whole person, thus safeguarding the physical, social and spiritual self. In the same way, holistic care, which encompasses the same elements of physical, psychological, social and spiritual care is one way to improve a dying person's experience in order for them to achieve a good death.

### **9.2.1. Surrendering independence**

Participants in this study raised the concern that people with intellectual disabilities at the end of life are surrendering their independence by relying on other people for care due to their physical, mental and functional decline. Robinson et al. (2015) reported among the general population that dying people are more dependent on other people for their care. Decreased energy coupled with physical and functional fragility affect people's autonomy at the end of life. This is a worrying issue for many people at this time (Gardner and Cramer 2009). As such, people with intellectual disabilities are no different to the general population as all people irrespective of their cognitive ability surrender their independence in varying degrees nearer their death (Tuffrey-Wijne 2010).

Participants reported that progressive loss of independence due to increasing fragility and capacity to look after themselves was a major concern for people suffering from life-limiting illness and going through the dying process. In addition, participants perceived that at the end of life they rely on carers for help with everyday activities such as feeding, visiting their friends, reading and having conversations; sometimes they were totally dependent on their carers for additional activities such as bathing and changing. Also, due to their functional decline they felt that surrendering their independence to other people was necessary in order to protect their privacy and dignity

at the end of life, as they cannot maintain this by themselves. Similarly, Gestsdottir et al. (2015), Sweers et al. (2013) and Aoun et al. (2012) report that among the general population people at the end of life rely on their carers to meet their physical needs in varying degrees.

Among the general population, Russ et al. (2015), Hall, Longhurst and Higginson (2009), Pleschberger (2007) and Franklin et al. (2006) find that people worry about loss of their independence due to increasing fragility, illness progression and decreasing bodily function and control. As a consequence, participants in these studies felt that their dignity was threatened by a loss of independence. While participants in this current study did not report issues of loss of dignity directly due to their care dependency, they expected to maintain their individuality and identity. Hall et al. (2014) found that maintaining individuality and protecting the identity of an individual is part of preserving dignity; therefore, they suggested that providing choice, control, privacy and respect was essential and that providing comfort and care, maintaining good communication and treating people as human beings was equally important at the end of life (Hall et al. 2014). Participants with intellectual disabilities did worry that they may need to compromise their identity and individuality. This may be due to their lack of life experience or they may define dignity in a different way. However, they clearly expressed that their identity and individuality should be maintained throughout the dying trajectory. It is assumed that protecting individuality and identity is a part of maintaining dignity. Therefore, professionals should never assume the capacity of an individual with intellectual disabilities and should always include them in making plans and decision-making, respect their uniqueness, their opinions, and value their life.

Participants indicated the need to be involved, for instance with their friends in providing informal care to their peers when one of them was sick and dying, which could increase their bond and closeness. This resulted in experiences of being valued

and proud of helping their peers. Harding (2013) reports that amongst the general population, elderly people with life-limiting conditions prefer to have informal care from their family members and relatives; however, demand for formal care increases as they get nearer death. Tuffrey-Wijne (2010) reports that despite the willingness of people with intellectual disabilities to help their peers at the end of life, their contribution towards their care is neither acknowledged nor respected by carers. This may be due to professionals undervaluing the contribution of people with intellectual disabilities in the caring process.

Participants were also concerned that they depended on others to manage their daily activities, maintain their health and safety, and meet their nutritional and medical needs. They appreciated “having somebody there” to monitor their health and provide appropriate care at the end of life. This finding reflects the study by Todd et al. (2013), which finds that professionals who care for people with intellectual disabilities at the time of dying expressed that being there for them is a great privilege. Lee et al. (2014) find that the general population at their end of life expect care providers to offer support and care around the clock. In addition, they feel that inconsistency in providing care at this time might result in a negative experience. Even though the expectations and preferences of “being there” and “being with them” at the end of life is common among people who are dying irrespective of personal, physical and physiological differences (Lee et al. 2015; Todd et al. 2013), this is more evident in the participants in this study, who expected carers and professionals, to monitor and supervise their medical, social, emotional and spiritual needs. The reasons given for the continuous monitoring and supervision were that people with intellectual disabilities suffer from complex needs and multiple disabilities such as epilepsy, hearing and visual impairments, communicative difficulties and impaired cognitive ability. Such disabilities make them

unable to recognise and communicate their changing needs, physical deterioration, medical needs and pain (Brown et al. 2012).

Previous studies highlight that close monitoring and supervision provides a sense of safety and security to dying people and helps them to develop a mutual trust and harmonious relationship (Herber and Johnston 2013; Griffin, McWilliam, and Oudshoorn 2012; Vosit-Steller et al. 2010; Tuffrey-Wijne et al. 2010 and 2007; Thompson, McClement and Daeninck 2006). In this study, participants wanted to be monitored by their friends and expected nurses to take care of their needs and respond to them appropriately. The participants consistently stated that the presence of professionals provides a sense of comfort and safety to dying people and promotes dignity at the end of life. In addition, they expected that close monitoring by professionals would help to monitor the changes resulting in appropriate response.

The participants in this study expected to receive care that was person-centred and met their physical, physiological, emotional and spiritual needs, which they suggested was essential to improve quality of life at the end of life. This is reflected in a study by Banks (2015), Nelson-Becker (2015), Ranse, Yates and Coyer (2012) and Thornton (2012) which finds that providing personal care such as bathing, mouth care, hair care and care of the pressure areas is important at the end of life. At the same time, caregivers feel stressed and challenged when trying to meet the changing needs of individuals due to the functional decline of people at the end of life (Gardner and Cramer 2009). Waterworth and Jorgensen (2010) report that older people with terminal illness are afraid of being dependent, bedridden and a burden on others. As a consequence, they worry about loss of dignity rather than quality of life and their care (Hanratty et al. 2012). Older people prefer to have a sudden death as it prevents loss of dignity and personhood, dependency on others and having a longer dying trajectory (Waterworth and Gott 2010). Unlike the concerns raised among the general population,

participants in this study were confident that they would receive good care due to the relationship developed over the years with health professionals. It was evident in this study that participants had a continuous relationship with service providers from the early stages of their life so they had trust and belief in professionals to provide good care at the end of life.

In summary, similar to most individuals at end of life, progressive physical and functional decline and surrendering independence were a concern for participants in this study. However, people with intellectual disabilities in this study were optimistic and confident that they would receive good care at the end of life as they had a good and long term relationship with care providers. This relationship developed trust and understanding between people with intellectual disabilities and care providers.

### **9.2.2 Social connectedness**

Participants in this study reported that being socially connected with other people was an important element at the end of life. They indicated that having meaningful companionship and maintaining communication were considered essential factors to help dying people to be socially connected. The participants expected to be with their friends and family members at their end of life. This is reflected in the studies by McCourt et al. (2013) and Brown and Walter (2013) which find that dying people are anxious, depressed, fearful, concerned about their situation and they want to be accompanied by somebody. In contrast to the preferences of the dying individual, professionals often avoid the dying person at this time due to feeling unsure of how to respond and make conversation with them (Lewis 2013). This creates an isolating environment for dying people (Lewis 2013) and causes stress and tension among professionals (Ryan et al. 2011a). Likewise, Aoun et al. (2015) produce the same findings among the general population, suggesting most people at the end of life wanted to be socially connected to their family and friends to promote their sense of belonging

and reduce their feelings of isolation. They also stress that being with other people at this time enhanced their feeling of wellbeing, sense of security and peace of mind.

Palliative and end-of-life care emphasises the importance of presence or being with and bearing witness to the experiences of a dying person. In this study, the participants expressed the view that company for dying people was critical even if they cannot communicate; being touched at this time produced comfort. This is reflected in Blackman and Todd's (2005) study, which claims that to have a true presence, words and language are not necessary. Bracegirdle (2012) publishes similar findings, reporting that non-verbal communication, such as smiling and touch, was very much appreciated by participants at the time of dying.

The participants claimed that they wanted to keep normalcy and routine therefore; they preferred to watch TV and read books and newspapers at this difficult time. There was a general consensus that people who are dying prefer to have human contact but this was on their own terms. In contrast to the expectations of dying people, professionals in other studies say that they lack support due to inadequate staffing levels and busy day-to-day work routines which prevent them from being with dying people (Casey et al. 2011). As a consequence, there is tension between the expectations of dying people and the reality of care provided to them; this creates anxiety and stress among professionals and patients (Brown, Johnston and Åstlund 2011).

The participants in this study expected to have the “real presence” of other people when they are dying. They suggested that this could be achieved through touch, gaze, lingering presence and silent immersion. They also suggested that listening was a way of responding to the needs of people at end of life, as they perceived that it was like relaxing and chatting with others, which provided comfort and reduced psychological distress. Todd (2013) highlights the importance of being with and being a true presence

for people with intellectual disabilities who are dying. He believes that this promotes a powerful unintentional inter-human relationship, unconditional loving as well as witnessing the changing needs of the dying person and their family.

Lavoie, Blondeau and De Koninck (2008) publish similar findings, also suggesting that suffering and dying opens up an inter-human relationship between the suffering person and others. The suffering person requires the presence of other people; this can be conveyed by a look, other times by a warm smile and a hug (Nicholls et al. 2013). Touch gives pleasure, calmness, helps to reduce feelings of anxiety, hopelessness and frustration and it gives rise to relaxed and comfortable conversation and promotes connection (Nicholls et al. 2013). Listening and having conversation with dying people is necessary to understand the emotional state and interior mental state of the dying person (Lopes Veríssimo, Cruz-Pontífice Sousa 2014). Saunders (2000) believes that being with, rather than doing for, dying persons promotes good death. Therefore, it is important for professionals to understand the relationship between the dying person and their friends and family to improve care for the dying person.

Participants in this study expected to be socially connected with other people including physical and psychological companionship, and engage in meaningful conversation. Previous studies in the area of intellectual disabilities and the general population highlighted the importance of social connections and social dependency. In this study, people with intellectual disabilities themselves acknowledged the influence of social connections at end of life. Despite the claims of strong social connections, at the end of life, people with intellectual disabilities who are dying suffer greatly from social loneliness and deprivation. Unlike the general population, most people with intellectual disabilities live with their friends and carers for long periods of time in homes or in residential settings. Therefore, maintaining social networks and relationships is essential to people with intellectual disabilities at end of life.

### **9.2.3 Spiritual reconciliation**

In this study, most participants suggested that spiritual care of people with intellectual disabilities at the time of dying is essential in order to achieve a sense of peace and comfort. The World Health Organization's definition and national policies (National Consensus Project for Quality Palliative Care 2009; Health Service Executive and Irish Hospice Foundation 2008) make clear that spiritual care is a core component of end-of-life care. Despite this guidance, spiritual care is often neglected in practice and research (Penman, Oliver and Harrington 2013), especially in the care of those with intellectual disabilities. There is limited research on the spiritual needs of people with intellectual disabilities at the end of life (D' Haene et al. 2014; Ryan et al. 2011a; Ryan et al. 2010). A case study conducted by Marriot, Marriot and Heslop (2013) explores the wishes and preferences of a person with intellectual disability after death, such as disposal of the body. Dunkley and Sales (2014) carried out a literature review over the previous ten years and found that no literature tried to explore the spiritual needs of people with intellectual disabilities from their perspective. The current study produced rich findings in relation to the spiritual needs of people with intellectual disabilities at the time of dying.

According to Timmins et al. (2016) each person has a spiritual centre that suffers along with a diseased physical body; therefore, it is necessary to provide appropriate healing. It is suggested that the spiritual needs of a dying person change over time, therefore continuous assessment is necessary (Benito, Gomis and Barbero 2016). Webb and Stouffer (2014) consider that death and dying are not a biological process as such and that spiritual care is more important at this time. A study conducted by Nelson-Becker et al. (2015) finds that understanding spiritual distress and responding to spiritual needs are important. To add to this existing wider body of research, this study contributes by

providing an insight into the spiritual needs of people with intellectual disabilities at the end of life.

The participants in this study acknowledged the importance of spiritual care at the end of life. In their opinion, prayers can bring hope, comfort and strength. Similarly, Van der Steen et al. (2014) and Balboni et al. (2014) conclude that among the general population spiritual care is essential at end of life and suggest that death and dying is a difficult and isolating concept that many people find difficult to understand and are frightened to accept. Consistent with existing literature, the participants in this study indicated that spiritual care was a crucial aspect in end-of-life care that helped to maintain the physical, social and psychological health of the dying person.

In this study, participants with intellectual disabilities and their family members wanted to achieve spiritual comfort and peace at the end of life. They valued the practice of a person with terminal illness observing prayers and said that prayers offered by their friends and family members were vital at this time, more so than at any other time in their life. They felt the prayers helped to make a connection with God. These findings reflected those of McDonald, Murray and Atkin (2013), Payne (2014) and Wynne (2013), who find that prayers and meeting the spiritual needs of dying people are necessary at the end of life to prevent dying people suffering spiritual pain. Shih et al. (2009) further reiterate that prayers and other spiritual support are more beneficial at this time of suffering.

The study findings reinforced Todd and Blackmann's work (2005), which assumes that carrying out religious beliefs and cultural customs at this juncture is more important than at any other time in life, and furthermore, prayers bring psychological hope and emotional relief to all parties including the dying person, their relatives, friends and carers. According to Kisvetrová, Klugar and Kabelka (2013) spiritual care not only

involves carrying out the religious expectations of dying people but also staying with them and making conversation, as dying people may be searching for meaning, and look to share and find intimacy. Despite the importance of providing spiritual care at the end of life, most patients received inadequate spiritual care at this time (Balboni et al. 2013; Astrow et al. 2007; Balboni et al. 2007). Similarly, the studies carried out by Kisvetrová, Klugar and Kabelka (2013), Nixon and Narayanasamy (2010), Van Leeuwen et al. (2006) and Penson et al. (2005) among the general population indicate that the dying understood spiritual care in an existential dimension and considered it to emphasise individualism, increase self-expression, and promote faith support through human contact, compassion and understanding

In this study, most participants were interested in receiving spiritual care; prayers from friends and relatives and blessings from their religious faith were very important to them. In agreement with other studies, people with intellectual disabilities clearly articulated the importance and necessity of spiritual care at end of life. However, the literature among the general population suggests that spirituality more than religion, culture, worship and prayers (Royal College of Nursing 2010). Researchers claim that spirituality is transactional which gives hypothetical and philosophical meaning to spirituality; therefore, it is difficult to understand and hard to achieve good spiritual care at the end of life (Blaber, Jones and Willis 2015). In contrast, people with intellectual disabilities in this study clearly indicate what constitutes spiritual care and they see concrete meaning in their spiritual belief. They assume that observing prayers, receiving blessings and rituals are essential components of spiritual care.

Webb and Stouffer (2014) and Penman, Oliver and Harrington (2013) discuss the importance of the presence of religious music, prayers or chants, and blessings from religious leaders at the end of life and consider this to be talking to God. Despite the importance of providing spiritual care at the end of life, Balboni et al. (2014) and

Ronaldson et al. (2012) report that lack of time, inadequate private space, and lack of training and education were barriers to providing spiritual care to patients at the end of life. Holistic care at the end of life is essential to people with intellectual disabilities. They expect their family members, friends and carers to look after them at this stage of their life due to their increased dependence and reliance on others to fulfill their physical, social and spiritual needs. Their expectations and wishes are the same as those in the general population; therefore, the professionals should focus on the similarities and needs rather than on the differences.

### **9.3 FAMILIARISM AS THE MEANS OF PRESERVING SELF IN THE FACE OF DEATH AND DYING**

Most of the study participants stated that familiarity at the end of life was important to preserve their privacy, dignity and eventually their sense of self. They wanted to maintain their normalcy during the time of dying and they preferred to spend their final journey at a familiar place and with familiar people.

#### **9.3.1 Maintaining continuity**

In this study, most of the participants stated that they wanted to maintain their routine as far as possible in order to continue a normal life. They wanted to tailor their care packages according to their specific needs. They felt that their involvement was not only to plan their future but also to plan their day-to-day activities and how they wanted to spend time, with whom, as well as considering activities they enjoyed. Similarly, Tuffrey-Wijne et al. (2007) indicate in their study that people with intellectual disabilities preferred to be occupied with leisure activities or other preferred tasks, and want people with intellectual disabilities to be involved in caring for them. Also, Tuffrey-Wijne (2010) reported similar findings in a study on people with intellectual disabilities who were dying from cancer, reporting that dying people with intellectual disabilities wanted to keep their routines and activities intact and to continue to do what

they liked. In other words, they wanted to tailor care services to the wishes and needs of people with intellectual disabilities. It is clear that irrespective of the cause of death, dying people prefer to engage with familiar activities and tasks to occupy themselves while dying.

In this study, participants said they would prefer to watch football, soaps or other programmes on the TV or listen to their favourite music to occupy their minds and forget their suffering. Similarly, in their study carried out among the general population to identify the domain of a good death, Miyashita et al. (2007) find that “maintaining hope and pleasure” and “having some pleasure in daily activities” are essential to achieving a good death. Similarly, in this study, participants stated that keeping their daily routines, such as watching what they liked on TV and visiting who they loved, were important at the end of life as these activities give them pleasure and happiness. Nakano et al. (2013) record similar findings among the general population, where dying people wanted to carry out their preferred activities such as knitting, gardening, watching TV, going out for a walk, going out in a wheelchair and having a meal and a drink. Nath et al. (2008) carried out a study among African American people about their end-of-life wishes. They report similar findings to the previous study; one of their participants stated: “I love life, I love to dance, I love to go to church, I love to do anything...” (p. 285).

Many participants in this study indicated that they wanted to enjoy and do what was important and meaningful to them at the end of life. In addition, the participants expected to maintain their normalcy by continuing to carry out familiar routines as far as possible. There is a similar expectation from dying people with intellectual disabilities and from the general population, which indicates that dying people prefer to be engaged in fun activities during their leisure time.

In this study, most of the participants with intellectual disabilities wanted to die at a familiar place, the place where they had been living since their childhood. They commented that dying in a familiar place provided comfort and safety. In addition, some of the participants suggested that they felt isolated and neglected in unfamiliar places. The previous studies carried out by Bekkema et al (2015), McLaughlin et al. (2014) and Todd (2013) find that professionals who care for dying people with intellectual disabilities prefer their service users to die in their homes rather than being transferred to hospital or a hospice; they considered a transfer to other places to die to be a failed death. In the current study, participants expressed that dying in a familiar place was the most appropriate and perfect place for an accompanied and peaceful death. Similarly, Marriot and Marriot (2013) find in their study that a familiar place provides a sense of comfort and safety at the end of life. In their study, Bekkema et al. (2015), Ryan et al. (2011a) and McCarron et al. (2010) report that most professional carers preferred to care for people with intellectual disabilities at their place of living. However, lack of skills, increasing care demands, inadequate resources and poor commitment from managers leads to difficulties in caring for them in their own homes. Tuffery-Wijne (2010) reports that people with intellectual disabilities wanted to stay and die at their familiar place when it is possible as it provided a sense of safety and comfort.

Participants in this study stated that they did not want to be admitted to a hospital as they felt that it was unnecessary to prolong their life as it would increase their physical and emotional suffering and they would feel isolated there. They associated hospitals with negative experiences and they wanted to stay where they lived. This is reflected in a study carried out by Venkatasalu et al. (2014) among older South Asian people where it is found that receiving care in a home-like environment provided safety, comfort and a sense of privacy and promoted the continuity of everyday routines. In addition, Auon

et al. (2012), Gibbs, Brown and Muir (2008) and Gomes and Higgins (2006) find in their study that unfamiliar places such as hospitals and hospices are frightening places while a familiar environment promotes freedom and independence and offers familiarity, memories and autonomy. Consequently in unfamiliar care settings, they receive poor care that is not compassionate and person centred (Brown et al. 2016). Professionals providing palliative care to people who are dying in community and nursing homes stated that adequate training and up-skilling is necessary to provide good end-of-life care (Smith and Porock 2009). A requirement for intensive resources often forces patients at the end of life to transfer to hospitals. Increasing care demands, budgetary restrictions and staff reductions are also other reasons for moving residents from care homes to hospitals (Waskiewich, Funk and Stajduhar 2012).

Death in a familiar place was preferred by most of the participants in this study. At the same time, they indicated that choosing the place of death was impossible due to the nature of the illness and severity of symptoms, availability of resources and cost. The participants clearly agreed that preferences of people dying at their familiar place would change due to their increasing needs, demand for more resources coupled with the psychological and emotional burden on fellow residents. Therefore, the decision to die in a familiar place cannot be made by the service users alone but must be made in agreement with professionals, service management and family members. This is reflected in Tuffrey-Wijne (2010)' study.

Participants in this study highlighted the importance and preference of dying in a familiar environment; similar findings among the general population highlight that people preferred to die at their usual residence. Both populations expressed a similar desire and choice to complete their journey at their intimate and recognisable place; in both settings, care providers attempt to accommodate their wishes. However, the efforts of care providers to entertain the wishes and preferences of dying people is not always

possible due to the complex needs of dying persons and lack of available resources and organisational support. Even though the preference to die at a familiar place was demonstrated by both the general population and people with intellectual disabilities, the population with intellectual disabilities has a greater need than the general population to die in a familiar place. The alienation and fear of an unfamiliar place, attachment with a familiar place, and complex needs are determining factors that drive people with intellectual disabilities to desire to stay in their familiar place.

The participants in this study stated that staying at home not only provided a sense of safety, security and comfort but also offer them an opportunity to see their friends and carers, thus facilitating them to say a final goodbye to everybody. Most of the participants in this study agreed that staying with a familiar carer promoted continuity of care and familiarity. They believed that this would promote understanding of the needs of people with intellectual disabilities, as some people with intellectual disabilities could not express their needs due to their cognitive impairment and other disabilities such as hearing and visual impairments. Furthermore, the participants said that an unfamiliar carer cannot always understand the needs of people with intellectual disabilities, especially those that are severely or profoundly disabled, and as a consequence they may feel isolated and their care needs might be neglected.

A previous study carried out by Todd (2013) among people with intellectual disabilities highlights the above findings and suggests that “being with” people who lived with them before they died helped to provide a sense of safety, comfort and peace. Similarly, McCarron et al. (2011) note that professionals and family members were frustrated, depressed and saddened when they sent people with intellectual disabilities elsewhere to be cared for in the last days of life. They further explain that this was usually due to a lack of training and skills of staff and inadequate resources in the intellectual disability service area. This is also reflected in a study by Ryan et al. (2011b) where the findings

established that staff members felt that they were part of the history of people with intellectual disabilities so they wanted to stay with them during the final stages of life. The professional carers who worked with people with intellectual disabilities felt they had a sense of responsibility to provide care at the end of life. When they were denied this opportunity, professional carers felt they had failed in their responsibility; they felt guilty, incompetent and isolated from the caring process.

In a study by Wagmans et al. (2013) familiar carers are shown to provide better care due to better understanding of a person's strength and their vulnerabilities. In addition, McLaughlin et al. (2014) agree that caring by familiar professionals promotes coordination and continuity of care to people with intellectual disabilities at the end of life. Similarly, Bekkema et al. (2015) and McCarron et al. (2010) find that knowing the person is very important at the end of life because they can understand the person's likes and dislikes and provide emotional security. In addition, they suggest that maintaining a relationship is essential at this time in order to maintain the bond as well as to make sure the people with intellectual disabilities are not dying alone and have support throughout the dying process. The findings from this study are consistent with those of previous studies. However, in the current study, the people with intellectual difficulties themselves articulated their wishes and preferences to stay with their friends and carers at the time of dying. To facilitate the wishes and choices of people with intellectual disabilities at their end of life, family members suggested providing adequate resources, increased staff ratios and an adequate skill mix. The participants viewed appropriate work force planning as being essential to promote the continuity of care to people with intellectual disabilities at the end of life.

The theme of familiar people is reflected in the study by McCarron et al. (2010) in which the participants consistently suggested that dying in a familiar place is about more than the physical location; it is where the presence of familiar people is considered

to be key. It is also assumed by participants that care given in a familiar place by familiar people is out of love, in contrast to care given by strangers in hospital settings. In addition, they felt that the familiar place provides comfort and autonomy whereas other settings impose discipline. This is highlighted by previous studies, which report that home has personal possessions and memories and that having someone to talk to and share experiences and memories with and receiving empathy are essential for dying people (Bökberg et al. 2015; Miller, Lima and Thompson 2015; Lee et al. 2015). In addition, seeing friends and family members at the time of dying provides meaning for their everyday life.

In this study, people with intellectual disabilities wished to maintain normalcy, so they hoped to carry out their daily routines with the expectation that care providers build care packages for them based on these routines. Participants also expected to be cared for in a familiar place, as they believed that familiar surroundings offered them a sense of safety, security and comfort. Finally, they believed that being cared for by familiar people at the end of life promoted dignity and a sense of belonging. These expectations of people with intellectual disabilities at the end of life were the same as those in the general population.

Participants stated that they wanted to maintain familiarity throughout the dying process in order to preserve their sense of self. People with intellectual disabilities live within a limited social network, forging close relationships, and thus have little contact with mainstream activities to develop other relationships. This leads to anxiety, nervousness and alienation among people with intellectual disabilities when they are exposed to unfamiliar social networks. However, people with intellectual disabilities realised that in some situations it was not possible to maintain familiarity, due to lack of resources and shortage of knowledge and skills. The participants suggested that providing appropriate training and learning skills in the area of palliative and end-of-life care by

intellectual disability professionals would help to manage people with intellectual disabilities in their familiar place at the end of life. Furthermore, working together and understanding and valuing individual roles between specialist palliative care services and intellectual disability service providers can help to achieve and realise the participant's expectations. This is reflected in recommendations made by European Association for Palliative Care (EAPC) taskforce on people with intellectual disabilities (Tuffrey-Wijne and McLaughlin 2015; McLaughlin et al. 2014).

#### **9.4. DISCLOSURISM AS A MEANS OF PRESERVING SELF IN THE FACE OF DEATH AND DYING**

Participants in this study expected care providers and family members to communicate their clinical conditions to them and believed that this would help them to plan their future care. In addition, as a consequence of knowing what is happening, they can communicate their wishes and preferences to their care providers and family members. This assists health care providers to provide good quality end-of-life care.

##### **9.4.1 Communication**

Communication is the sharing of information (Moir et al. 2015); service users with an intellectual disability at the end of life expected to receive information about their clinical condition, prognosis, complications and expected outcomes. They reported that this is not only their right but also helps to control and plan their remaining life. In addition, a clear understanding of the future gives them an insight into how their life can be; it allows them to communicate in advance to health care providers and others about their wishes, preferences and expectations for care at the end of life when they may not be able to communicate due to loss of cognitive ability. Similarly, Todd et al. (2013), Wiese et al. (2013) and Tuffrey-Wijne et al. (2013) claim that people with intellectual disabilities have a right to know about their death and if they are dying, they should be actively involved in the dying process. However, they conclude that the capacity of

some people with intellectual disabilities to understand would be a barrier to disclosure. This is also reflected in a study by Michiels et al. (2009), in which terminally ill patients were willing to discuss their diagnosis, prognosis and eventual fatality.

Shin et al. (2015) and Friedrichsen, Lindholm and Milberg (2011) find that patients within the general population with terminal illness wanted to know the truth about their illness but the content and context of the truth they want to know varied. In addition, they identify that patients' willingness to know the truth changed when they received bad news in real life. People who are dying, irrespective of cognitive ability, want to know what is happening to them. However, what they want to know and how much they want to know differed from individual to individual. Therefore, it is important to check how much and what aspect of their clinical condition patients want to know before disclosing the information.

People with intellectual disabilities in this study wanted to be updated on their condition by care providers in order to plan their future care and they felt that knowing their clinical condition is their right. Participants with intellectual disabilities articulated that if they knew the prognosis regarding their illness they could prepare for a peaceful journey. Tuffrey-Wijne (2010) suggests that some people with an intellectual disability want to know about the nature of their illness, progression and complications as they think it would help them to make choices. A few people with intellectual disabilities in her study did not want to know what was happening to them and they preferred to be happy until they died. However, in this study, all of the participants with intellectual disabilities claimed that they wanted to know about their clinical condition and prognosis.

In this study, most of the family members did not want their loved ones to know about their illness and impending death. The family members believed that their loved ones

could not cope with knowing about their life-limiting conditions and information about their impending death, suggesting it may cause emotional distress, pain and depression. The family members wanted to protect their sons and daughters from undergoing mental agony and other experiences of knowing. In earlier study by Ryan et al. (2011a) professionals felt that family members play a crucial role in communicating the clinical situation to their loved ones, and family members believed that hiding information may help people with intellectual disabilities to cope with their illness better. The above study reflected the findings of the current study. Tuffrey-Wijne (2010) and Tuffrey-Wijne et al. (2013) report similar findings, that family members of people with intellectual disabilities were reluctant to speak to them about their diagnosis and risk of dying as they believed this information would be upsetting and hard for them to understand and take in. It is clear that there is tension between patients who want to know the truth in order to understand their clinical issues and plan for their future and family members who prefer to hide the bad news to protect their loved ones from upset.

There is an assumption that withholding information from people with intellectual disability is probably due to fear of causing distress and uncertainty about how to support them. Ryan et al. (2011b) indicate that professionals working with people with intellectual disabilities find it hard to talk about diagnosis and prognosis of life-limiting conditions due to poor preparation in communicating challenging and complex news. Similarly, Tuffrey-Wijne and McEnhill (2008) report that the unwillingness of family members coupled with lack of knowledge and skills of professionals in communicating the message effectively prevented them from telling the truth to people with intellectual disabilities. Tuffrey-Wijne (2013) reflects that family members fear that people with intellectual disabilities would not understand the information about their clinical situation or that it would be too upsetting for them. As a consequence of not communicating information about their clinical condition and impending death the

voices of people with intellectual disabilities were absent from decision-making about their future care (Todd 2013). To promote communication to people with intellectual disabilities, Tuffrey-Wijne et al. (2013) suggest that prior to disclosing information to an individual, their cognitive ability and how much information they want to know should be assessed. She also advised that taking enough time in assessing the ability of an individual with intellectual disabilities and using simple language in disclosing the information would be the beginning of a successful communication strategy.

Petner-Arrey and Copeland (2015) and Thorns and Gerard (2011) propose that autonomy of the individual with intellectual disabilities and their right to decide upon their own destiny should be respected so it is important to check whether the individual who is dying really wants to know the truth. In this study, all participants with intellectual disabilities preferred to be told about their clinical condition, prognosis and future plan of care. From my experience, while carrying out this research, I identified that people with mild and moderate intellectual disabilities were able to make a decision with adequate and appropriate support. People with intellectual disabilities made a decision to participate in this study by being provided with information through the use of easy-to-read templates and through discussion. Furthermore, appropriate professionals such as a speech and language therapist, and a schoolteacher experienced in teaching people with intellectual disabilities were involved to facilitate communication and help the person with intellectual disabilities to make a decision. I understand that decision-making is context and time specific; however, with adequate support people with intellectual disabilities were able to make a decision that affected their life events. We have to be mindful that inadequate information about their clinical condition and future care leads them to prepare inadequately to face changes in their life and leads to an inability to make informed choices. However, when an individual with intellectual disability prefers not to receive information about their health, this needs to

be respected and somebody should be appointed to make decisions and plans for them. This needs to be documented in the clinical file of the individual with intellectual disability.

Advance communication helps care providers to meet the care requirements of the individual in line with their wishes and preferences (McEnhill 2013). Participants in this study wished to communicate their likes, preferences and desires about their end-of-life care. Participants with intellectual disabilities felt that this would help the professionals to make the correct decision at the time of dying when they would be unable to make those decisions and take control over their own life journey. The participants perceived that having their wishes and preferences respected at the time of dying and after their death would preserve their dignity and rights. Bollig, Gjengedal and Roseland (2016), Tuffrey-Wijne and McLaughlin (2015) and Brinkman-Stoppelenburg, Rietjens and Heide (2014) highlight that advance care planning would help service users to dictate treatment and other options in advance in an attempt to receive care consistent with their preferences when they are no longer capable of making those decisions.

Martin et al. (2016) and Abney et al. (2014) report similar findings, suggesting service users who receive end-of-life care consistent with their wishes and preferences are satisfied with their care. Ampe et al. (2016) and Storey and Sherwen (2012) state the importance of making an advance care plan but caution that care home residents are given fewer opportunities to make advance decisions about their future care. The current study found that most of the participants would prefer to register their preferences and wishes about their end-of-life care. They assumed that this would give direction to the health care providers in implementing care in line with the service user's desires. Furthermore, the participants also felt that family members of people with intellectual disabilities should be involved in planning their care when they were dying. Therefore, care providers who care for dying people with intellectual disabilities should

be trained to discuss with service users and their family members their wishes and preferences about their future care.

The participants in this study presumed the advance care planning process gives people with intellectual disabilities some control over their future care. This is reflected in the study by Sinclair, Oyeboade and Owen (2016) which claims that service users who have advance care planning feel a sense of control over their future care, including where to be cared for and how. The participants in the current study wanted an advance care plan to be included in their clinical file and transferred with them wherever they went and were cared for. Participants stated that when people with intellectual disabilities could not make decisions about their future care due to their lack of cognitive ability, such as in cases of severe and profound intellectual disabilities, their family members or proxy decision-makers should be involved in the decision-making process. Similarly, Stein and Kerwin (2010) suggest that when an individual with intellectual disabilities lacks the capacity to express their preferences and wishes in the advance care plan, health care professionals should have a discussion with their family members and health care proxy in relation to the end-of-life care.

In the advance care planning process, people with intellectual disabilities should be given an opportunity to make their own choices and preferences. During the decision-making process, health care professionals should avoid having a paternalistic attitude and using stereotypes about their lack of cognitive ability. Instead, they should be supported with skilled, careful assessment of their decisional capacity; health care professionals should develop strategies for supporting them and helping them make decisions and plan their future care.

The recent Irish Assisted Decision-Making (Capacity) Act (2015) offers a provision for decision-making by people with intellectual disabilities by themselves. This marks a

cultural shift away from a paternalistic and best interest approach to people with intellectual disabilities and towards a rights-based approach of choice, control and consent. The Act provides a provision for a co-decision-maker when an individual is found to lack mental capacity. The person with intellectual disabilities and the co-decision maker work together and facilitate the person with intellectual disabilities to make a decision. If a co-decision maker is not feasible, the state appoints a decision making representative to work with a person with intellectual disabilities to make an appropriate decision. The Act paves the way to a higher standard of decision-making without causing any harm to the individual and other persons.

## **9.5 RESPECTIVISM AS A MEANS OF PRESERVING SELF IN THE FACE OF DEATH AND DYING**

The provision of end-of-life care does not end with the biological death of an individual, but also continues afterwards. In this study, most of the participants reported the belief that there is a soul after physical death and so providing compassionate care after death is essential in order to keep their soul at peace. The participants in this study believed that they should receive the same care after death as before their death; they said that this would help their dignity to be preserved, their wishes to be respected, and that they would be protected.

### **9.5.1 Longing for recognition**

Participants in this study felt that their life and death should be remembered and recognised by all who are important in their lives. They perceived that their life has the same value as anybody else in society and expected it to be recognised and celebrated in the same way as everybody else's. In their opinion, even after their death, their reputation should be protected and maintained; they assumed that even though their physical body may be gone their astral body still remains and therefore their life should be valued and respected (Scarre 2012).

The participants in this study expected that their remains would be brought back to their place of origin and this was commonly requested, as they wanted to maintain their ties with established people and familiar places; they believed severing their own social connections was a natural desire. Similarly, in their study Read and Cartlidge (2012) find that people with intellectual disabilities preferred to have their last rites carried out at the place where they had settled and lived for many years. The place attachment for people with intellectual disability is stronger than in the general population as they often live their life in one place and are socially attached to their friends, and so their place holds a special meaning to them during their lifetime (Schuengel 2013). Most people with intellectual disabilities in the current study preferred to be buried near to where they had been living, as they believed this was their home. In contrast, family members often wanted the remains of the people with intellectual disabilities to be taken to their family homeland and buried in their home graveyard. There is conflict between people with intellectual disabilities and their family members with regard to where their home is. This has to be discussed with the service users and their family members when creating an advance care plan to prevent conflict and carry out the service user's wishes and preferences.

The participants wished to be remembered by their friends and parents after their death. They expected their life and death to be valued and respected in the same way that everybody else's is. They wanted to preserve their dignity throughout the process. During this process of life and death, the wishes and preferences of patients and family members should be respected. Olausson and Betty (2013) published comparable findings and recommended that the wishes of family and patients should be honoured at this time. It can be concluded that acknowledging and honouring wishes and preferences is vital for family members and other people surrounding them; this helps

family members to say a final goodbye, review the dying person's life, grieve, show love, and heal.

The participants in this study insisted that positive aspects of the lives and character of the dead should be celebrated and people should focus on the achievements and happiness of the dead person. An advance care plan that was prepared before death could be used to ensure that the patient's preferences and wishes are carried out after their death (Stein 2008). Further, Stein suggests that care providers and family members should carry out the wishes of patients regarding their funeral. The participants with intellectual disabilities in this study wished to be remembered for good things and wanted to leave a legacy behind them. Furthermore, the participants suggested ways in which this can be done such as displaying their art work, photos of them, paintings, DVDs of their life, lighting candles and placing flowers on special occasions. Conducting an annual mass is also another way of showing remembrance and respect. These acts of remembrance and legacy are reflected in Tuffrey-Wijne's (2010) study.

Even though the life of people with intellectual disabilities is underprivileged and unrecognised, they wished and were determined to live after death like the general population by leaving a legacy and expected their family members and professionals to recognise and respect their life and death. Hence, it is the responsibility of the service providers and their family members to observe the last rites in line with the existing social norms.

### **9.5.2 A spiritual goodbye**

People with intellectual disabilities in this study expressed their suspicion throughout the study that their deaths were not valued and respected by society. This may be due to past experiences of witnessing a friend's death or hearing stories from other people. In the past, people with intellectual disabilities lived in institutions; as a result, they were

segregated and hidden behind walls (Sudnow 1967). Institutionalised people were not treated well and their social death preceded their biological death (Blatt and Kaplan 1967). During that time, their deaths were not respected and the idea that people with intellectual disabilities might leave a social legacy was not accepted or anticipated. The recent changes in policy, rise of normalisation, implementation of the inclusive movement and acceptance of disability rights has highlighted the relevance of death and reduced social death (Baudrillard 1976). Doka (1989) highlight that people with intellectual disabilities suffer from disenfranchised grief where they are actively excluded from process of death and dying, and as a result their grief is not openly acknowledged, publicly mourned and socially supported. In addition, Raji and Hollins (2003) find that people with intellectual disabilities are denied participation in funeral rituals.

In recent times however the notion that discussing death with people with intellectual disability is taboo has been in decline but dying continues to be hidden from people with intellectual disabilities (Tuffrey-Wijne 2010). As people with intellectual disabilities live longer and suffer from life-limiting illness, service providers must understand the importance of providing end-of-life care to people with intellectual disabilities (Todd, Bernal and Forrester-Jones 2013). The participants in this study expected their final remains to be left in their room for a while not only to facilitate the viewing by their friends and family members but also to help their soul rest in peace. They believed that removing a body from the place of living immediately after death would be insensitive and inappropriate; they suggested that family and friends should be allowed to stay with the remains. In order to preserve the dignity of the deceased, service providers should create a warm and dignified environment in the room. They should also make an effort at the organisational level to assign a nurse to look after the deceased person to carry required duties and functions (Forsberg et al. 2014).

Participants in this study expected to have last respects paid to people with intellectual disabilities by their carers, friends and family. Furthermore, they said that during the funeral process, they wanted to have their favourite music played and wanted candles to be lit. Similarly, Holloway et al. (2013) suggest that a funeral should be carried out to celebrate their life; celebrants should be encouraged to remember their loved ones and friends in the way they wanted and be allowed to say prayers and give blessings. In addition, they suggest that friends and family should be allowed to see the deceased appropriately dressed and presented in what is called the final social event. Caswell (2012) and Adamson and Holloway (2012a), highlight that the common symbol used in the funeral mass is the lighting of a candle which is used by many religious people to convey resurrection whereby light illuminates the darkness of death and is a broader representation of hope. The expectations of people with intellectual disabilities are no different to other people, as they believe the funeral process shows the relationship between the deceased and the mourners and playing their choice of music would be a way of respecting their wishes. The funeral process is a way of respecting the deceased; acknowledging and accommodating the wishes and preferences of the deceased and their families are essential during the funeral service.

Participants in this study hoped that their friends and family members would attend their funeral service, visit their grave and say prayers. They believed this is a way of giving them respect and helps the soul to rest in peace. These findings reflect other studies. According to Hedtke, (2002) the funeral is a place of receiving and expressing social support; these rituals offer hope to the family and other persons with intellectual disabilities who witness these events. Romanoff and Terenzio (1998) encourage service providers to involve friends and parents in funeral rituals as this has healing properties that help find resolution to the grief. Dodd et al. (2008) propose that involvement of dead person's friends and family in bereavement rituals such as viewing the body and

attending funerals helps to reduce complicated grief issues such as separation distress among people with intellectual disabilities and also helps them to understand the finality of death. Studies carried out by Watters, McKenzie and Wright (2012), Campbell and Bell (2012), Blackmann (2008) and Read (2005) highlight the recent changes in intellectual disability practice, bereavement rituals and also importance of bereavement support. Similarly, Stuart et al. (2010) suggest that visiting graves and praying for the deceased would facilitate their soul to rest in peace and is a way of showing respect and caring. Furthermore, attending an annual service would be a way of paying honour to the deceased and giving the family members pleasure by returning to the last place where their loved ones lived their life (Vale-Taylor 2009).

People with intellectual disabilities clearly stated that they wished their friends, parents and carers to attend their funeral mass, graveyard, and say prayers, as they believe this not only helps the deceased but also other people who receive support and hope. In addition, conducting an annual mass for the deceased person with intellectual disabilities would be a way of paying respect and valuing them. Unlike the general population, people with intellectual disabilities articulated specifically their spiritual expectations which were concrete and easily carried out without any ambiguity.

## **9.6 CHAPTER CONCLUSION**

By presenting facilitating factors and barriers in providing optimal end-of-life care to people with intellectual disabilities from their perspective, the study has identified certain areas for further research to improve end-of-life care for people with intellectual disabilities.

Even though the general population and people with intellectual disabilities express concern about giving away their independence and fear about losing dignity due to care dependence on others, people with intellectual disabilities felt confident and trusted

their carers to provide dignified end-of-life care due to long-term relationships that were developed. People with intellectual disabilities also expressed a willingness to provide informal care to their friends but their readiness to be involved in care provision was not often approved by care providers due to the paternalistic attitude of professionals. People with intellectual disabilities wished to be monitored and supervised by care providers when they are sick and dying.

Participants highly valued the importance of social connections at end of life. The literature suggests that the general population also expresses the need for social closeness and engagement at end of life. Given the context of the close networks developed by people with intellectual disabilities in residential settings throughout their life, they craved social closeness at end of life. The participants with intellectual disabilities expressed that spiritual care at end of life is essential to them; unlike the general population, they have concrete meaning for their spiritual needs. They articulated that prayers, blessings and carrying out rituals are very important at end of life.

The participants wished to experience familiarity when receiving end-of-life care. As people with intellectual disabilities had been following the same routine for years, maintaining the same kind of relationships and living in a similar place for a long time, they considered that maintaining routines, living at their familiar place and staying with their friends and carers at end of life was necessary to receive optimal end-of-life care. They admitted that familiarity gives a feeling of safety, comfort and happiness at end of life. Although, the general population wished to maintain familiarity at end of life, people with intellectual disabilities expressed that this was more important to them due to the close relationships developed with their friends and carers. They had also established an attachment to their place of residence, which was coupled with suspicious feelings regarding unfamiliar carers and caring environments.

The participants expressed a wish to know their clinical condition and expected prognosis just as most of the general population did. Furthermore, they wanted to develop an advance care plan that gives direction to their care approaches with the help of parents and carers. Finally, participants revealed that they wanted the same care after their death as when they were dying. Participants wanted to be recognised and respected after their death and expected to receive spiritual care, which allowed their soul to rest in peace.

# **CHAPTER 10- THEORETICAL DISCUSSION AND PRESENTATION OF SERVICE MODEL**

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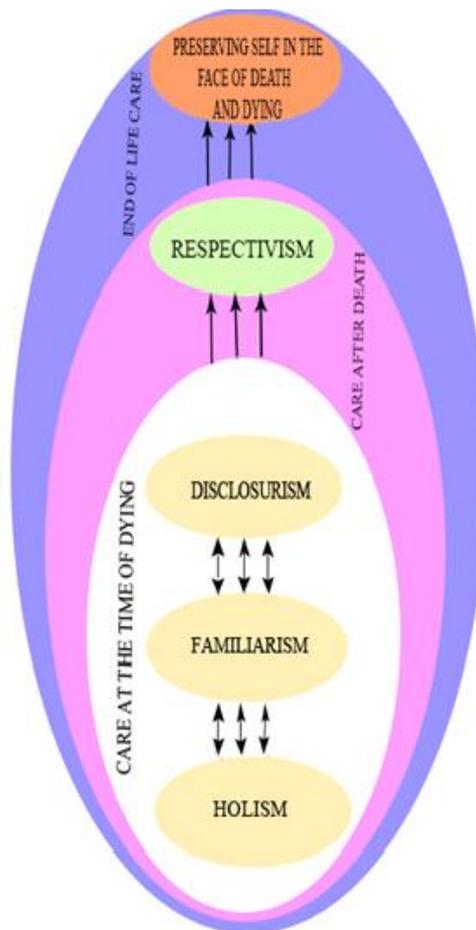
## **10.1 INTRODUCTION**

In this chapter, a theory of preserving self in the face of death and dying is presented and explains how each stage of the theory affects and influences other stages. The theory is reconciled with other existing theoretical frameworks and theoretical similarities are explored. The chapter concludes by presenting a service model in order to promote optimal end-of-life care to people with intellectual disabilities.

## **10.2 THEORY OF PRESERVING SELF IN THE FACE OF DEATH AND DYING**

Having discussed the study findings in relation to the existing literature in the previous chapter, a theory has been constructed from the participants' perspective. Based on the theory, a model of service delivery has been developed in order to promote end-of-life care for people with intellectual disabilities. Figure 8 illustrates the theory of preserving self in the face of death and dying. The previous chapters provide an in-depth discussion about each category; this section discusses how each category is interlinked at each stage of death and dying for people with intellectual disabilities.

FIGURE 8 PRESERVING SELF IN THE FACE OF DEATH AND DYING: A THEORY



The theory provides a comprehensive overview of end-of-life care needs of people with intellectual disabilities and highlights the dynamic nature<sup>2</sup> of the caring phenomena. The dynamic nature of the caring process focuses on the needs of people with intellectual disabilities at end of life. The theory insists that care provided at end of life should meet the holistic needs of an individual, paving a way to preserve their individuality and identity. As the theory explains, optimal end-of-life care consists of good care at the time of dying and after death. Care at the time of dying consists of three components, namely: holistic care, continuity (familiarity) care and disclosure. Each component of care directly influences the others positively or negatively. If one

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<sup>2</sup>Caring needs of people with intellectual disabilities at end of life are continuously changing and as a result care providers need to equip themselves to meet those needs.

component of care is not provided adequately it affects the dying experience of the person with intellectual disability both at the time of dying and after death and ultimately affects the quality of care that is provided at the end of life. In the same way, if a component of care that is provided after death is not carried out properly, it affects the quality of end-of-life care.

As the theory states, care at the time of dying should be holistic in nature and meet the individual's physical, social, emotional and spiritual needs. The theory assumes that people with intellectual disabilities at end of life are dependent on other people to carry out their day-to-day activities to meet their physical, emotional, social and spiritual needs and also to ensure their safety and health. Physical needs including food, bathing and elimination should also be met in order to achieve other higher order needs. It is suggested that people at end of life worry about their safety and security so their health must be cautiously monitored. People at the end of life also look to establish and maintain social relationships, so this must be facilitated. Finally, their spiritual concerns need to be addressed by saying prayers and organising religious leaders to visit and give blessings.

The theory advocates that holistic care alone does not provide a positive experience to people with intellectual disabilities at the end of life but that this care should be provided at a familiar place by familiar carers surrounded by familiar people. As such, the theory proposes that care provided for the individual at the time of dying should achieve familiarity. People with intellectual disabilities require a continuum of care throughout the dying trajectory. Furthermore, at the end of their life they need to stay in their familiar place where they are most comfortable. It is suggested that a continuum of care throughout the caring process, including acute, chronic and end-of-life care, is necessary to ensure quality care for people with intellectual disabilities at the end of life. In reality, people with intellectual disabilities at the end of life are often transferred to

other care settings such as hospitals or hospices to receive care (Patti, Amble and Flory 2010). With this in mind, the theory proposes that in order to facilitate familiarity for dying people with intellectual disabilities at the end of life, service providers should commit professionals to meet the end-of-life care needs of people with intellectual disabilities and establish collaboration with other services such as palliative care providers and general hospitals. Promoting staff training and collaboration with other services also helps people with intellectual disabilities to preserve their routines while facilitating them to stay in their familiar place and be with their friends and familiar carers.

If people with intellectual disabilities receive holistic care by unfamiliar professionals in unfamiliar territory, they consider this sub-optimal care. At the same time, if familiarity is maintained for dying people with intellectual disabilities at the end of life without providing holistic care, this negatively influences the dying experience. Both components of care influence each other; therefore, in order to provide good care at the time of dying, service providers should facilitate holistic care by familiar people in a familiar environment. Furthermore, disclosure is an important component at the time of dying where professionals and family members communicate and disclose the diagnosis, prognosis and impending death of the person with intellectual disabilities. Consequently, service providers should successfully involve the dying person with intellectual disabilities through advance care planning in order to meet their wishes and preferences. Providing holistic care that involves maintaining continuity and familiarity at end of life without including the dying person in their own caring process also negatively influences the dying experience. Therefore, disclosure is just as essential as the other components of care, holistic care and continuity of care, at the time of dying.

Disclosure is the final constituent of care at the time of dying where people with intellectual disabilities expect to receive adequate information regarding their prognosis

and future care. Furthermore, open disclosure between patients, family members and professionals helps people with intellectual disabilities to engage in developing an advance plan, which incorporates their care preferences and wishes. Often, people with intellectual disabilities are shielded from knowing their clinical prognosis due to fear of upsetting them; this is due to lack of both understanding and skills of professionals to deal with people with intellectual disabilities when they are upset. Failing to communicate information to people with intellectual disabilities may cause unintended consequences such as isolation and failing to address the real issues. In order to avoid this, professionals should find an appropriate way of communicating with people with intellectual disabilities such as using simple language, taking time and waiting for the service user's response, and gauging how much the service user wants to know. When people with intellectual disabilities know what is happening to them and are aware of their disease process and progress, they can successfully communicate their preferences and wishes.

The three components of care, namely holistic care, continuity, and disclosure, at the time of dying provide a positive dying experience for people with intellectual disabilities and their family members. This consequently improves quality of life while dying. At the same time the care provided at the time of dying provides an excellent opportunity to continue good care after death and gives hope and satisfaction to family members, friends and carers. Ultimately, the person with intellectual disabilities receives good end-of-life care.

The care provided after death is as important as the care provided at the time of dying, and greatly influences the quality of end-of-life care that the individual receives. Care provision after death should be in line with the individual's wishes and preferences. People with intellectual disabilities wanted to be remembered and respected for their life and death and wanted to receive spiritual care after death. Unlike the general

population, people with intellectual disabilities convey their spiritual needs after death in concrete terms, thus clearly spelling out their wishes regarding their funeral and other preferences. Participants preferred that the life and death of people with intellectual disabilities should be valued and respected as their life has the same value as anybody else's; therefore, their death should be celebrated in line with social norms. Finally, the theory suggests that attending funeral services, visiting graves and saying prayers helps to meet the spiritual needs of people with intellectual disabilities and is a form of remembrance.

Each constituent in this theory is dynamic and constituents directly influence each other. Each area of care approach at the time of dying should be adequately met to achieve a sense of good death. Care provided after death should be congruent with the wishes and preferences of people with intellectual disabilities. Finally, the above combination of good care at the time of dying and after death makes for optimal end-of-life care. If any of the constituents are not dealt with properly or adequately, this affects other constituents meaning that dying people would not receive good or optimal end-of-life care.

To conclude, care at the time of dying should be holistic in nature. Achieving familiarity in receiving and providing care, understanding the nature of the disease process, treatment options and prognosis, and making a plan for the future of people with intellectual disabilities would constitute good care at the time of dying. Furthermore, providing quality care after death, such as spiritual care, respecting the wishes of and remembering the deceased, are important elements of good end-of-life care after death for people with intellectual disabilities. A combination of good quality care at the time of dying and after death results in quality end-of-life care, eventually achieving good death for people with intellectual disabilities. The kind of care achieved

at each stage of the dying process can affect the dying experience positively or negatively.

### **10.3 DISCUSSION OF THEORY WITH REFERENCE TO EXISTING THEORIES**

Although a grounded theory approach can collect empirical data and develop theory, engaging with extant theoretical concepts is a vital part of the overall research process. While engaging with extant theory in grounded theory research, it is important to identify which concepts are more relevant to the research findings. There are many reasons why the research findings are related to existing theoretical concepts. Primarily, the research aims to make a significant contribution to existing knowledge; therefore, it is necessary for the researcher to be aware of and consider existing theoretical concepts. The quality and validity of the research can be improved by engaging with existing theoretical concepts and finally locating theories that are relevant to the current research findings; this may facilitate the researcher to place the findings on a broader theoretical level.

#### **10.3.1 Holistic approach to end-of-life care**

One of the major concepts that emerged from the study is that of holism. As discussed in Chapter 5, this concept focused on requiring holistic care at the end of life including physical, emotional, social and spiritual care. The concept of holism was derived by Smuts (1927), who proposed in his theory of holism that the whole is greater than its parts. The concept of holism is a systemic model in which physical, psychological, social and spiritual factors are seen as being interlinked and each factor influences every other. In order to achieve holistic care, physical, social, emotional and spiritual needs should to be met. The theory of holism advocates that there should be equilibrium between all domains of needs and if any of the care needs are inappropriately met, the equilibrium is disturbed and consequently holistic care cannot be achieved. In line with

holism theory, the theory of preserving self in the face of death and dying assumes that all people who are dying require holistic care. Holistic care should be achieved at the time of dying as people are desperately seeking to meet their physical care needs due to their physical fragility and inability to look after themselves as well as expecting to maintain their social relationships with friends, family and carers. Finally, this theory highlights the importance of providing spiritual care at the time of dying as it helps individuals to achieve spiritual peace.

Other caring models borrow principles from the theory of holism and evolution (Smuts 1927). For example, Orem (2001) proposes that when an individual suffers from a chronic or terminal illness, the focus of care provision is shifted towards providing comfort and improving quality of living. During the terminal phase of illness, the individual struggles to manage their health care needs due their physical decline; this causes self-care deficits. In order to compensate for these self-care deficits, care providers step into the caring process and actively engage with service users to meet their physical, social, emotional and spiritual needs (Berbiglia and Banfield 2010).

In line with the theoretical concept of this study, Debiens, Gagnon and Fillion's (2012) shared theory assumes that nurses and other care providers compensate for self-care deficit at end of life. This theory suggests that measuring fatigue, pain and symptoms is an integral part of care provision. Similarly, Reed's (2010) unitary caring model explains that each individual is unique in his or her history and experience, so the caring approach must be individualised while respecting the individual's emotional and social needs. Melei's transition model (Coffey 2012) documents that individuals require a comprehensive holistic approach to care when their needs are changed and the caring process needs to be adjusted based on the changing needs of an individual.

The theory of preserving self in the face of death and dying developed in this study explains that people while dying are not able to manage their physical needs due to their physical and functional decline. Furthermore, due to multiple disabilities and complex issues coupled with the dying process, people with intellectual disabilities expect to receive close supervision and monitoring of their needs. In addition, they expect to establish and maintain social relationships and finally they expect to achieve spiritual peace through their spiritual needs being met.

### **10.3.2 Familiarity at the end of life**

Another important concept that emerged from the study findings is the concept of familiarity. As discussed in Chapter 6, the concept encompasses the idea of attachment and familiarity at the end of life. This is evident within the data, as most of the participants preferred to be at a familiar place with familiar people. Within the study findings, it is evident from the participants' feelings that they are comfortable and safe with their friends and carers and in their own environment. In his attachment theory, Bowlby (1958) postulated that an emotional bond and interpersonal relationship developed between individuals, contributing to enduring beliefs, expectations, safety and security. It is believed that individuals who form a secure relationship consider themselves to be worthy of receiving care and others to be sincere in providing it (Bartholomew 1990). In addition, Böhm et al. (2010) propose that peoples' similarities help to not only confirm their value and belief system but also to reduce insecurity in their relationships. On the other hand, Tan, Zimmermann and Rodin (2005) posit that fearful attachment between individuals causes frustration, anxiety, perceived isolation and negligence. In the current study, the participants articulated that they wanted to remain with their friends and carers at the end of life and felt that they would be isolated and neglected in hospital and other care settings. There is perceived similarity between people with intellectual disabilities and attachment with their place and carers,

therefore, they preferred to stay in their familiar place with familiar people at end of their life (Singh and Ho 2000). Within the context of this study, the theory of preserving self in the face of death and dying assumes that people with intellectual disabilities would prefer to socialise with their own population cohort rather than with other groups because they feel comfortable, secure and safe when they interact with their familiar friends and carers.

The Merle Mishel theory of uncertainty (1998) explains that uncertainty occurs when people suffer from acute and chronic illness, where they cannot determine the consequences of illness, this uncertainty causes great psychological stress for people with life threatening diseases. Brashers et al. (1998) indicate that ambiguous patterns of symptoms, complex and changing treatments, and fear of being abandoned by society increase uncertainty among people with acute diseases. Furthermore, Mishel (2013) highlights that when a person lives continuously with uncertainty, this can affect the physical, social, spiritual and mental dimensions of their life as well as affecting their daily activities and quality of life. It is evident that people who suffer from life-limiting illnesses experience uncertainty. In order to reduce this uncertainty, to increase coping and lessen anxiety, Sajjadi et al. (2015) found in their study that social support decreases fear and stress. Similar to other studies, the participants in this study indicated that they experienced strong relationships with their friends and carers and they believed that this perceived familiarity reduced their anxiety and uncertainty (Bailey et al. 2009; Singh and Ho 2000).

The participants expressed that support received from familiar people helps them to understand the meaning of events and aids their ability to clarify uncertain events. To reduce uncertainty, the participants in this study suggested that maintaining continuity reduces their anxiety and they feel that they know what would happen next. In order to

promote familiarity at the end of life, service providers should develop strategies to provide continuity of care throughout the dying process.

### **10.3.3 Truth telling in end-of-life care**

The theory of preserving self in the face of death and dying assumes that people need information when they deal with other people and in order to make meaningful decisions. According to Babrow, Hines and Kasch (2000) people become uncertain when provided with information and situations that are ambiguous, unclear and impossible to predict. In addition, Babrow, Kasch and Ford (1998) claim that uncertainty produces anxiety when information is not available or is inconsistent and that unclear instructions cause uncertainty and confusion. Therefore, this theory envisages that the effective management of uncertainty helps to reduce anxiety and provides hope. Brashers et al. (2000) presume that people seek information to reduce uncertainty and anxiety, and with this information they either confirm or disconfirm their belief.

Glaser and Strauss' (1965) theory of awareness of dying explores the various levels of knowing the truth at the time of dying; this was categorised into four levels based on the information an individual received regarding their illness, prognosis, and impending death. Closed awareness refers to patients receiving no information in relation to their clinical condition, who then suffer from anxiety and uncertainty when their physical symptoms and functional decline disconfirm professionals' advice and instructions. During suspicious awareness, patients are suspicious about their physical condition through professionals' attitudes and other behavioural cues but are not able to confirm or disconfirm their suspicions. As a result, they suffer from psychological strain and are not able to prepare for their eventuality. Mutual pretence refers to the scenario where both patients and professionals pretend that the other knows about what is happening but they do not confirm. The mutual pretence leads to the open awareness stage where a

patient cannot hold their assumptions any longer and enquire from professionals. This is the starting point for professionals and patients to discuss clinical conditions, treatment options, prognosis and other viable options. At this stage, the patient completely understands their physical health, expects deterioration, prepares for the future and is able to write a will and develop advance care planning. Even if they are initially depressed, anxious and fail to accept their situation, dying individuals eventually prepare themselves to face the future with the help of family, friends, and professionals.

In this study, the participants reported that people with intellectual disabilities suffer from closed awareness and they appealed for open awareness. They assumed that lack of information about the clinical condition of people with intellectual disabilities caused them anxiety and hence they were unable to plan for their future care. Participants also assumed that inadequate information about the wishes and preferences of people with intellectual disabilities at the end of life was a source of confusion and stress for their care providers. It is normal that changes in physical health status, the presence of vague symptoms, and inadequate information about their diagnosis and prognosis would cause uncertainty and anxiety among people suffering from terminal illness. In order to avoid this, the participants expected to have adequate information about their clinical condition; they felt that this would help them to write an advance care plan which in turn would help care providers to meet the dying person's care needs without ambiguity and confusion.

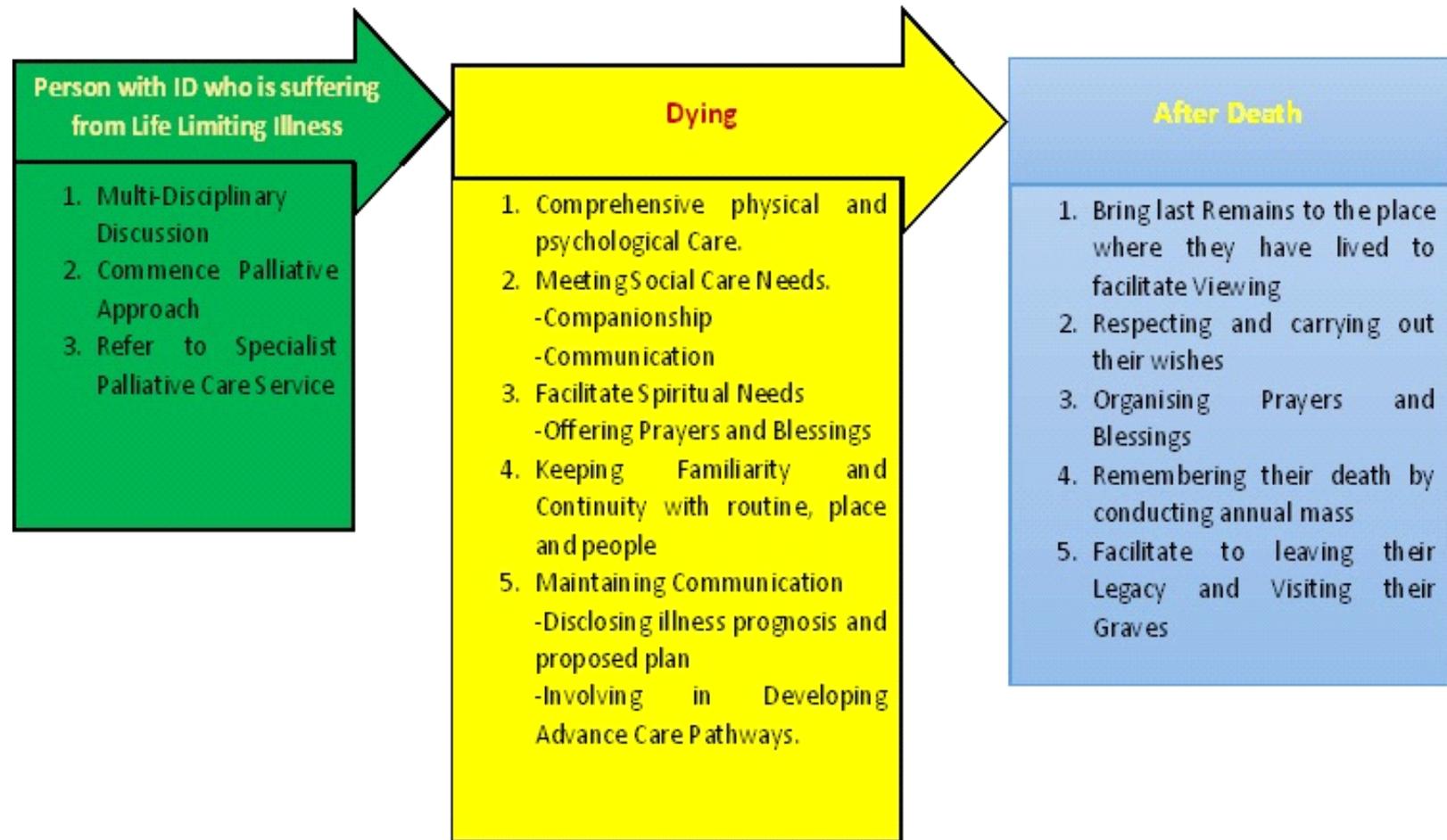
#### **10.4 PROPOSED SERVICE MODEL AT OPERATIONAL LEVEL**

The proposed service model shown in Figure 9 explains the care needs of people with intellectual disabilities at the end of life. This model can be carried out at the operational level where professionals engage with service users in everyday situations in order to provide good end-of-life care to people with intellectual disabilities. When a person

with an intellectual disability is diagnosed with a life-limiting illness, in consultation with their family members, they should be referred to a multi-disciplinary team. Then the care needs should be discussed in a meeting, considering the views and preferences of the person with intellectual disabilities, and agreed with that person. In line with the views and preferences of the person with intellectual disabilities and recommendations from the multi-disciplinary team, a palliative approach of care can be implemented in order to provide comfort. Referral to specialist palliative care can also be undertaken when necessary.

When an person with intellectual disability is actively dying, he or she should be provided with comprehensive holistic care congruent with his or her wishes and should be involved in setting goals for this care. People who are dying depend on others to look after their everyday needs and they also want somebody present to ensure their safety and comfort. Therefore, they should be provided with compassionate physical and psychological care and their safety and comfort should be monitored closely. Dying people with intellectual disabilities are frequently socially deprived as they have very limited contact with their friends and family (Patti, Amble and Flory 2010), so it is important to provide physical companionship and establish meaningful communication. In addition, people with intellectual disabilities expect to receive spiritual care to meet their spiritual needs. In order to meet these needs, service providers should organise a priest or spiritual leader to visit the dying person and facilitate blessings as well as the offering of prayers by their friends, family and carers.

**FIGURE 9 CARE DELIVERY MODEL AT OPERATIONAL LEVEL**



People with intellectual disabilities preferred to receive their care at the place where they lived and stayed with their friends, as they believed this provided comfort and safety. As such, a place other than their home provides a sense of alienation and isolation. This model proposes to maintain their routines and activities as far as possible to achieve normalcy, hope and prediction. In addition, it assumes that familiar people better understand the needs of people with intellectual disabilities. People with intellectual disabilities wished to be informed of their clinical condition, prognosis and future treatment either through professionals or family members as this helps them to make a decision and plan for the future. Further, they desired to make an advance care plan that helps them to achieve their last wishes and preferences. Overall, people with intellectual disabilities require comprehensive, holistic care including physical, social, emotional and spiritual care. Maintaining familiarity, disclosing the individual's clinical condition, and developing an advance care plan are necessary components of a care package at the time of dying.

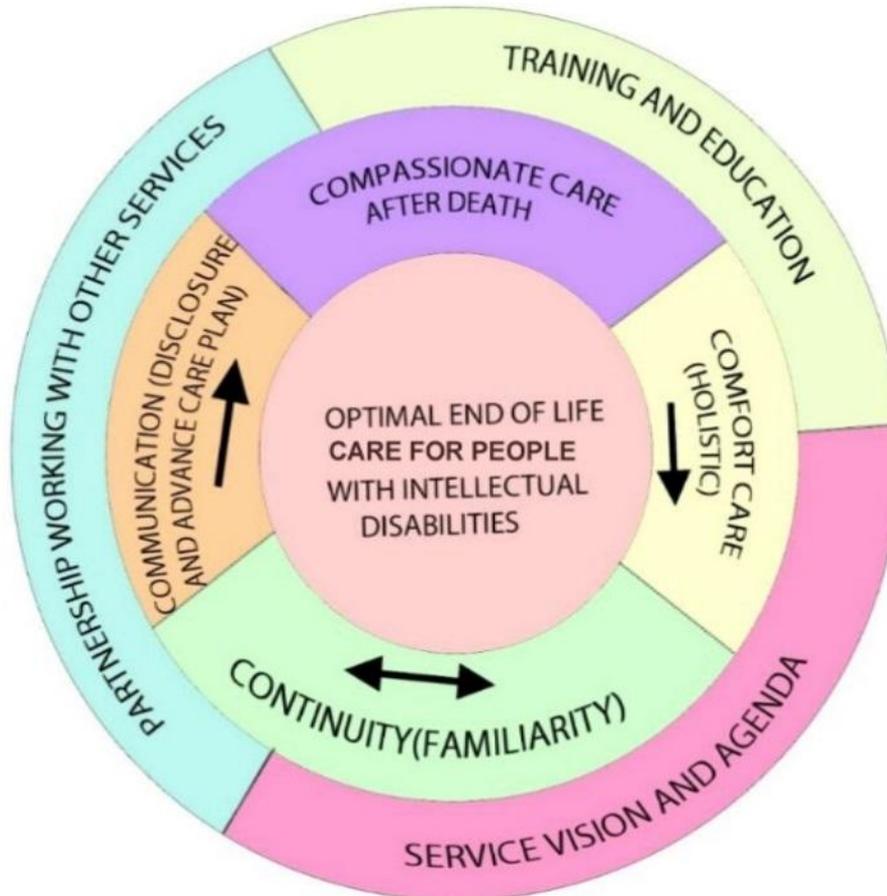
This proposed model considers that care provided after death is as important as care provided before death; consequently people with intellectual disabilities are able to have compassionate care after death. The model presumes that the final remains of people with intellectual disabilities are brought to the place where they have lived so that a final ceremony can be carried out. Finally, this model incorporates respecting the wishes and preferences of people with intellectual disabilities in relation to their funeral as well as remembrance of the deceased by having a mass and prayers.

## **10.5 CARE DELIVERY MODEL AT STRATEGIC LEVEL**

Figure 10 shows the proposed service model at the strategic level where service managers develop policies, protocol and guidelines for front line health care providers. The policies developed at the strategic level influence the care provided at the

operational level so as to provide good end-of-life care to people with intellectual disabilities.

**FIGURE 10 PROPOSED SERVICE MODEL AT THE STRATEGIC LEVEL**



The model recommends three main areas where an organisation should show commitment to improve and develop in order to promote care provision for people with intellectual disabilities at end of life. Traditionally, intellectual disability services are driven to achieve independence, empowerment and realisation of goals rather than supporting dependence and achieving a good death. As a consequence, these services are inadequately prepared in terms of knowledge, skills and resources to provide care for people with intellectual disabilities who are dying from ageing and life-limiting illness that requires palliative and end of life care. However, from the perspectives of people with intellectual disabilities and their family members, such commitment appears to be lacking. Until such commitment from the intellectual disability and

palliative care service is articulated and enacted, it is likely that the barrier to providing end-of-life care and the negative experience of care among people with intellectual disabilities will persist, and consequently, people with intellectual disabilities will die without receiving optimal end-of-life care.

The other area where strategic commitment is required is training and education of professionals who care for people with intellectual disabilities. The model shows that lack of professional knowledge and training of hospice professionals in relation to managing people with intellectual disabilities, and the struggle of intellectual disability care providers to provide palliative and end-of-life care to people with intellectual disabilities, is a significant barrier in providing optimal end-of-life care to people with intellectual disabilities. Professionals working in palliative care settings lack appropriate training and education when caring for people with intellectual disabilities as the latter have multiple disabilities and complex needs. The service has to develop a palliative care curriculum and educational programme for staff caring for people with intellectual disabilities residing in long-term care and palliative care settings. These educational modules should emphasise the principles of palliative care, spiritual and cultural issues, symptom assessment and management, principles of hospice care at the time of death and grief and bereavement.

People with intellectual disabilities feel isolated and alienated in other care settings and participants expressed that they receive unfavourable treatment in hospitals due to the negative attitude of caregivers. There is a lack of collaborative working and strategic commitment from senior management to establish a linked worker scheme to achieve a better understanding between the intellectual disability service and other settings in order to promote end-of-life care for people with intellectual disabilities (Brown et al. 2012). In order to create a better understanding of the care needs of people with intellectual disabilities, a more collaborative approach between acute and specialist

palliative care services is needed. This would be beneficial in improving end-of-life care for people with intellectual disabilities. Palliative and end-of-life care can be improved for people with intellectual disabilities through the proactive involvement of senior management in initiating and being accountable for developing end-of-life care policy and delivering quality service. To facilitate a collaborative approach, some NHS hospitals appointed a learning disability nurse to act as a liaison between the intellectual disability service and other care settings to promote caring and dying at their familiar places (Brown et al. 2012; Matthews, Gibson, and Regnard 2010). Therefore, collaborative working between intellectual disability and other services is essential to provide effective end-of-life care to people with intellectual disabilities. If the services do not work closely, this vulnerable population may die alone and may not achieve a good death. Overall, studies have repeatedly recommended that staff caring for people with intellectual disabilities require training to better understand the work of palliative and hospice services, while those working in hospices require training to understand the needs of individuals with intellectual disabilities.

## **10.6 CONCLUSION**

The chapter presents a holistic and dynamic end-of-life care model based on the research findings. It is envisaged from this model that an organisational commitment is paramount in promoting end-of-life care of people with intellectual disabilities. Theoretical concepts are also discussed that are relevant to the research findings. Finally, a service model is proposed to provide optimal end-of-life care to people with intellectual disabilities both at the strategic and operational level.

# **CHAPTER 11- CONCLUSIONS AND RECOMMENDATIONS**

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## **11.1 INTRODUCTION**

This final chapter gives an account of the overall study. It reviews each of the previous chapters and discusses the contribution that this study makes to the existing knowledge in relation to the end-of-life care needs of people with intellectual disabilities and methodological approaches for including people with intellectual disabilities in research. Also, this chapter evaluates the research findings according to set criteria. Finally, some recommendations for future research and practice are made before drawing final conclusions.

## **11.2 REVIEW OF CHAPTERS**

This study qualitatively explored the end-of-life care needs of people with intellectual disabilities. It specifically focused on the perspectives of people with intellectual disabilities and their family members by adopting qualitative interviews to collect data from them. The overall research process, including the final thesis, followed the principles of grounded theory.

Chapter 1 introduced the study and outlines the structure of the thesis. Chapter 2 contextualised the study by highlighting the changing profile of the population with intellectual disabilities and their changing medical and social needs especially at their end of life. The notion of good death was discussed as well as the care needs of people with intellectual disabilities at the end of life and barriers to receiving good care at the end of life. In Chapter 3, the methodological approach was discussed in detail; this

included examination of the various approaches of grounded theory and their implications for conducting research as well as engagement with existing theoretical knowledge. Chapter 4 outlined and justified the selection and recruitment of study participants, detailed the ethical approach encountered during the process, and outlined the non-linear process of data collection and analysis. Chapters 5, 6, 7 and 8 presented the findings of the study. These findings were grounded in the data from the participants and were constructed from the data analysis. In each chapter, the participants' comments were provided to support the study findings and to elicit the relationship between categories. Using a grounded theory approach, a theoretical framework of preserving self in the face of death and dying was constructed. This theoretical framework consists of four categories, namely holism, familiarism, disclosurism and respectivism, at the end of life, which were constructed from the data analysis. The validity of the study findings is based on the various methodological strengths and limitations of the research study, which include the level of intellectual disability of people with intellectual disabilities, issues associated with recruitment, and the language used in the interviews.

The study findings provide some insights into the perspectives of people with intellectual disabilities regarding their end-of-life care needs. The category holism explores the necessity of holistic care at the end of life including physical, social and spiritual care. The second category, familiarism, explores the importance of familiarity for people with intellectual disabilities at the end of life including people, place, life and activities. The third category, disclosurism, deals with the disclosure of the clinical condition and prognosis to service users and communication between service users and professionals regarding the wishes and preferences of the service users. Finally, the category of respectivism explores the needs of people with intellectual disabilities after their death.

Chapter 9 discusses the research findings with reference to existing knowledge. This process offers valuable insights, which help to explain many of the research findings and locate this study within a theoretical context. Finally, Chapter 10 discusses the theory of preserving self in the face of death and dying and concludes with presenting a model of service delivery that meets the care needs of people with intellectual disabilities at end of life.

### **11.3 EVALUATION OF THE STUDY**

There are number of criteria to evaluate the quality of qualitative research but this study applied criteria that were advocated by a constructivist grounded theory approach (Charmaz 2006) to ensure the quality of the final work. The four criteria used to evaluate the study are: credibility, originality, resonance and usefulness.

#### **11.3.1 Credibility**

For credibility, to identify the value of the study, Charmaz (2006) recommends that the researcher needs to be immersed in the research setting and the research topic. In order to achieve the recommended attachment to the study setting and topic, I actively engaged and included people with intellectual disabilities in parts of the research process, such as the preparation of an easy-to-read information sheet and consent form and the planning and recruiting of participants. The data collection was carried out over eight months; this prolonged engagement with the participants and the research setting helped me to develop a rapport with them and helped me to interpret and shape the data analysis.

The research explored the end-of-life care needs of people with intellectual disabilities from their perspectives and from that of their family members. Analysis of interviews with people with intellectual disabilities and their family members and careful observation during the interviews allowed me to get close to the expectations of people

with intellectual disabilities at their end of life. In line with a grounded theory approach, I acknowledge that the findings of the study are not absolute truths but are my own interpretation and understanding of the findings (Baillie 2015). In other words, the findings are not real facts but are constructed truths. The extent of viability and defensibility of the study findings depends on my presentation of them to a relevant audience in a way that is meaningful (Cooney 2011). Furthermore, the research process followed rigorous, detailed and thorough strategies to capture the end-of-life care needs of people with intellectual disabilities. In addition, listening, reading and rereading of audiotapes and transcribed texts were important ways of getting closer to the participants' perceptions and gaining confidence in the overall credibility of the study. The audio recordings of the interviews, detailed transcripts, observations and memos during the research process facilitated its dependability and reliability.

During the presentation of the study findings, each concept was supported with the participants' quotes and logical connections were made between concepts, categories and sub-categories and a visual model was presented in Figure 3 to illustrate important concepts and relationships. Furthermore, information provided in Appendix G adds further transparency to the research process. These processes help the reader to make an independent assessment of the claims made and to determine whether or not to agree with these because there is enough evidence provided to allow this (Charmaz 2006).

### **11.3.2 Originality**

The original contribution of this study is its construction of the theory of preserving self in the face of death and dying. This constructed theory sheds light on the needs of people with intellectual disabilities at the time of dying and after their death. This is one of the few research studies that explores the end-of-life care need of people with intellectual disabilities, and is the first study to explore their end-of-life care needs from their perspectives in an Irish context. The findings from this study add to the body of

work that already exists in the area of palliative and end-of-life care and intellectual disability nursing. Other qualitative studies have explored palliative care needs, cancer care needs and paid carers' perspectives. By including service users, this work offers a new dimension and a deeper understanding of the phenomena from the perspectives of people with intellectual disabilities. The work also contributes to the methodological knowledge related to including people with intellectual disabilities in a research process. The social and theoretical significance of the study findings influences the current practice of providing care for people with intellectual disabilities at the end of life.

### **11.3.3 Resonance**

The categories and their related sub-categories that are presented in the findings establish the range and breadth of the understanding of the issue under investigation. Findings from this study are supported by the theoretical explanations and existing literature for any reported behaviour and experiences by the participants. The presentations outlined in the findings shed light on the life of the participants. The findings may have some limitations in terms of its completeness due to a lack of cognitive ability of the participants to articulate their issues and needs, a lack of their life experience in witnessing death and dying and an interviewing style that might inhibit exploration of the life experiences of the participants.

In spite of this, this study conceptualises and conveys what is meaningful and necessary for people with intellectual disabilities at the end of life from their perspectives and so makes a contribution to the existing knowledge that we have in the discipline. The categories constructed in the data analysis conveyed the needs of people with intellectual disabilities at the time of dying and after death. Furthermore, links have been made between the individual expectations and opinions of people with intellectual disabilities and the wider literature that relates to palliative and end-of-life care and intellectual disabilities.

#### **11.3.4 Usefulness**

The usefulness of a theory depends on its ability to be used in everyday life. The theorising of this work would be useful in intellectual disability and end-of-life care nursing practice and where people with intellectual disability are facing death and dying. The increased understanding resulting from this study can influence the quality of care that is provided at the end of life to people with intellectual disabilities by including them in the caring process and by including them in research. This study also provides suggestions for future research in this area.

### **11.4 IMPLICATIONS FOR PRACTICE**

There are other studies that have explored the issues for care providers in providing end-of-life care for people with intellectual disabilities. Few studies have explored the needs from the perspectives of people with intellectual disabilities about their end-of-life care needs. However, this study captured the views, opinions, perceptions and preferences of people with intellectual disabilities through in-depth interviews about their end-of-life care needs including after death wishes and preferences. The people with intellectual disabilities and their family members clearly articulated their views in relation to their care needs at the time of dying and after death.

Factors which have been identified as improving end-of-life care to people with intellectual disabilities within the data are listed in Table 6 and have been discussed in detail in previous chapters.

**TABLE 6 HINDERING AND FACILITATING FACTORS**

<b>Hindering factors</b>	<b>Facilitating factors</b>
Physically reliant on others for physical care.	# Assisting and providing comprehensive physical care.
Inability to look after their safety and security.	# Close monitoring and supervision. # Providing frequent attention.
Having multiple disabilities such as cognitive disabilities, communication difficulties, physical disabilities, hearing and visual disabilities. Lack of knowledge and skills of professionals.	# Organising training sessions for professionals on intellectual disability service and palliative care services. # Working closely to understand their needs.
Feeling lonely and neglected.	# Having meaningful companionship and maintaining communication.
Lack of spiritual support.	# Understand the spiritual needs of service users. # Organising prayer groups including friends, parents and carers. # Inviting priests or religious leaders to bless the dying person.
Moving to other places for their care at the end of life, this leads to change of home environment, loss of friends' network and loss of caring touch of their own carers.	# Providing end of life care in their familiar environment. # Encourage the involvement of their friends and parents in their caring process. # Maintain their everyday routine, hobbies and wishes wherever possible. # Provide an opportunity to maintain contact with their familiar people including carers and friends. # Co-ordination between care services.
Lack of information provided on their diagnosis, prognosis and treatment options.  Lack of their inclusion in developing end of life care pathway.	# Convey their clinical information in a simple way that could be understandable by people with intellectual disabilities wherever possible. # Include service user's wishes, opinions and preferences when developing an end-of-life care pathway.
Failure to respect and remember after death.	# Provide an opportunity to bring remains to the place where they lived for years and leave there for some time. # Offer time and space for family members, friends and carers to spend some time with the remains. # Conduct a funeral mass as for everybody else. # Record the wishes of people with intellectual disabilities and carry them out. # Carry out the funeral service according to the person's wishes. # Observe a remembrance ceremony.

This study has stressed the importance of understanding the end-of-life care needs of people with intellectual disabilities from their perspectives. This study acknowledges that:

- Provision of quality care at the time of dying for people with intellectual disabilities requires true understanding of their care needs.
- Providing appropriate information to people with intellectual disabilities and their family members improves their caring experiences.
- Inclusion of service users' perspectives and their wishes when planning care for them should be a routine practice.
- The written advance care plan should be read by all professionals who care for people with intellectual disabilities at the end of life.
- When people with intellectual disabilities are transferred to other care settings, the advance care plan should be sent along with them and the intellectual disability liaison nurse or other designated person must ensure that all professionals familiarize themselves with the document and enact the plan.
- Professionals who care for people with intellectual disabilities at the end of life should act as their advocates.

Based on these, people with intellectual disabilities are looking for professionals and carers to lead in the caring process at the end of life. As such, one of the major findings of the study is familiarism where people with intellectual disabilities expect great commitment from professionals in facilitating familiarity throughout the caring process.

## **11.5 RECOMMENDATIONS FOR FUTURE RESEARCH**

The study provides some new insights from the perspectives of people with intellectual disabilities about their care needs at their end of life specifically in the areas of holism, familiarism, disclosurism, and respectivism. These are consistent with the existing literature in the field of intellectual disabilities and palliative and end-of-life care. This study recognises the importance of addressing physical, social, and spiritual needs, continuing familiarity until death, respecting the last wishes of people with intellectual disabilities after death, and keeping people with intellectual disabilities in their familiar and preferred place at the end of life. A retrospective study that explores the experiences, views, barriers and positives among friends and family members would be an ideal research project. This study recognises that there is a need to keep people with intellectual disabilities at their preferred and familiar place and with familiar people. However, what is not explored and what would be useful are the issues that relate to keeping people with intellectual disabilities at their familiar place and the solutions. Assessing spiritual distress and the importance of spiritual care in reducing spiritual distress would be beneficial.

Researching the care needs of people with intellectual disabilities from their perspectives can provide a deeper understanding of the phenomenon from the perspectives of people who experience it.

## **11.6 CONTRIBUTION TO KNOWLEDGE**

The research aimed to explore the expectations, wishes and preferences of people with intellectual disabilities at the end of life and to develop a substantive grounded theory that explains their care needs, and this aim has been achieved. The theory constructed from this study provides a conceptual rendering of the data that provides further understanding of the care needs of people with intellectual disabilities at the end of life.

The theory that has been constructed rests upon my own interpretation of the studied phenomena.

This study makes a significant contribution to existing research on intellectual disability and end-of-life care. First, this is one of the few studies that explores the end-of-life care needs of people with intellectual disabilities from the perspectives of service users. Furthermore, it represents one of the very few studies that explores end-of-life care needs of people with intellectual disabilities and their family members by adopting in-depth interviews. Given the higher life expectancy of people with intellectual disabilities and increasing chronic life-limiting conditions among people with intellectual disabilities, such research is timely, relevant and highly valued.

Second, this study highlights the value of qualitative research in exploring individual perceptions and experiences, as well as researching phenomena that is under explored to date. In particular, the study highlighted the value of grounded theory in developing concepts from the empirical data while seeking to understand how these concepts are related to extant theoretical concepts. This was reflected when the findings were presented in the participants' words to support the theoretical categories.

Third, instead of imposing any prior assumptions on the nature of care needs at the end of life for people with intellectual disabilities, this study encouraged the participants to articulate their perceptions; views and opinions about their end-of-life care needs. This process has produced rich and original findings in relation to the end-of-life care needs of people with intellectual disabilities.

Fourth, the study has identified the important concept of a holistic approach to care at the time of dying to meet the physical, social and spiritual needs of people with intellectual disabilities and eventually to preserve their physical, social and spiritual

selves. Familiarity and respect further improved end-of-life care for people with intellectual disabilities.

The substantive findings from the study will be useful to inform education for undergraduate and postgraduate nursing and other students. In addition, in-service training and other continuous professional development initiatives can also draw on the findings, for nurses from general adult, palliative, primary care and other settings. Moreover, consideration of the account of ethical issues and other methodological strategies employed in this study would be useful for future researchers.

It is planned to disseminate the research findings to the wider community in various ways. Firstly, the thesis will be kept online and hard copy in the library of DCU and the research site. Secondly, an executive summary of the study will be given to the managers and staff at the research site and family members, also an appropriate version of the executive summary will be given to participants with intellectual disabilities. Then the findings from the study will be presented at national and international conferences, in-service training programmes and carers' meetings. The findings will be published in national and international journals to reach the wider population, including those outside the specialty of intellectual disability practice.

## **11.7 REFLEXIVITY**

It is important to reflect upon the research process in order to understand how it impacted on me and how it may have affected participants who were interviewed. According to Berger (2015), the researcher and participants are not separate entities but are intertwined in the research process. When I think about the research process, I certainly think that conducting the research study has improved me as a researcher in the areas of planning, collecting and rigorously analysing data and disseminating research findings in an accessible manner. I feel in particular that my skills in

interviewing people with intellectual disabilities improved over the course of the data collection and as a result, the participants became more open, reflective and expressive. Furthermore, during the research process, I made personal connections with the participants' perspectives and drew on my own experiences as a nurse who had provided end-of-life care for people with intellectual disabilities. This included my lack of awareness about the importance of their friends at the end of life, inadequate skills in administering medication such as handling a morphine pump and monitoring stress and pain. However, I can now say that I understand the anxiety relating to the functional decline of people with intellectual disabilities, their social distance from professionals, their family and friends, their lack of awareness of their clinical situation, their uncertainty about their future care and bad experiences of end-of-life care. Similarly, I was concerned that lack of training and knowledge of professionals, inadequate support from management and the service agenda may negatively influence the effective provision of end-of-life care for people with intellectual disabilities.

During the discussion of key issues with participants, I reflected on my role as a nurse front line manager, a care provider, and how the role should include promotion of good end-of-life care to people with intellectual disabilities. I have implemented some of the suggestions made by the participants into my own practice to improve the quality of care at the end of life, including providing comprehensive nursing care, including their friends and family in the caring process, organising short day education classes regarding the philosophy of palliative care and training, as well as involving people with intellectual disabilities in making their own care plans. I believe that these changes have helped to improve the quality of care at the time of dying for people with intellectual disabilities but I have room for further improvement to the current practice.

It is clear from many of the participant's quotations that are used in Chapters 5 through 8 that the process of discussing these issues caused a number of participants to reflect

upon their own experiences and expectations and provide solutions in order to achieve good end-of-life care for the population with intellectual disabilities. I cannot say whether or not the discussion with the participants was satisfactory and provided me with a sense of pride. However, I am confident that asking people with intellectual disabilities about end-of-life care may have heightened their awareness about their own end-of-life care needs.

## **11.8 STRENGTHS AND LIMITATIONS**

Every research approach has its own stories, difficulties, limitations and successes. Acknowledging these limitations and difficulties does not reduce the quality and value of the study; instead it enriches the underlying assumptions and processes that are transparent and open to critique.

The findings from this study were drawn from 18 participants; some participants witnessed their friends or family members or cohabitants receiving end-of-life care. This study is firmly situated within the constructivist tradition as the analysis was contextually situated between participants' experiences and perceptions and the researcher's interpretations (Charmaz 2006). Therefore, the findings of this study cannot be representative of all people with intellectual disabilities who are at the end of life and it is impossible to generalise these findings. However, the concept of generalisation is not a concern in qualitative research as it recognises that there is no single truth. Notwithstanding this, qualitative research provides important insights and knowledge (Pearson et al. 2015). This work offers valuable insights to those who care for people with intellectual disabilities at the end of life to reflect upon, appraise, and challenge their current practices and experiences.

The small number of participants in this study may be one of the limitations of the work but this enables the researcher to investigate participants in greater detail. "The ultimate

quality of the study depends on the richness, depth, suitability and sufficiency of the data” (Charmaz 2006, p.18). This study did not look at the views of other stakeholders such as health care professionals and managers and this could be a limiting factor of the study. However, the primary aim of the study was to explore end-of-life care needs from the service users' and their family members' perspectives. The importance of exploring the views of health care professionals was acknowledged and it is understood that this gives us another dimension to understanding the care needs of people with intellectual disabilities.

A constructivist grounded theory study like this does not go far enough to advocate and change the care practices such as action research. However, giving a voice to vulnerable groups such as people with intellectual disabilities and their family members may change care practices and even transform service provision as a result of increased understanding.

## **11.9 CONCLUSION**

To conclude, the theory of preserving self in the face of death and dying provides some insights into the care needs of people with intellectual disabilities at the end of life. This study highlights the care needs of people with intellectual disabilities at the end of life in order to protect and preserve these individuals. Currently there is a social and political shift in the way care is provided for people with intellectual disabilities whereby their care provision has been adversely impacted. This research study has highlighted the importance of providing end-of-life care to people with intellectual disabilities, where their needs and the needs of their families are at center stage and it includes people with intellectual disabilities as active participants.

People with intellectual disabilities and family members were active participants in this study and primary informants into their own experiences, views and opinions.

Constructivist grounded theory is a methodology that provides increased understanding of how people with intellectual disabilities feel, expect and predict their care needs at the end of life. This study constructs a theory that explains and predicts the care needs of people with intellectual disabilities at the end of life from their own perspective and of family members.

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# **APPENDIX A ETHICAL APPROVAL LETTER (COPY)**

Mr. Kumaresan Cithambaram

School of Nursing and Human Sciences

18th May 2012

REC Reference: DCUREC/2012/073

Proposal Title: An Exploration of End-of-life care Needs of People with Intellectual Disabilities: Developing a Model of Service Delivery

Applicants: Mr. Kumaresan Cithambaram, Dr. Mel Duffy, Dr. Eileen Courtney

Dear Kumar,

Further to review, the DCU Research Ethics Committee approves this research proposal. Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee. Should substantial modifications to the research protocol be required at a later stage, a further submission should be made to the REC.

Yours sincerely,

Dr. Donal O'Mathuna

Chairperson

DCU Research Ethics Committee

# APPENDIX B PARTICIPANT (SERVICE USER) INFORMATION LEAFLET AND CONSENT FORM



## 1 Introductory Statement



**My name is Kumar and I am a nurse. I am a student at Dublin City University. I am doing a study about the care that need for people with intellectual disabilities who are at the end-of-life.**



**My supervisors are Dr Mel Duffy and Dr Eileen Courtney**

## 2 What is the Research About



**Life begins when a person is born. Life ends when a person dies. Some people live a long life until they are old. People with intellectual disabilities get old as the same as all other people.**



**They also suffer from same illnesses as other people.**



**There is little known about what their needs are at the time of death and dying**



Therefore, I would like to speak to you to find out what you think about the care needs of people with intellectual disabilities at the time of death and dying.

### **3 Why I am doing this Research**



It is important to find out how best we can provide a care to people with Intellectual Disabilities who are very sick and dying.



I would like to know what you think is good care at the time of death and dying for people with intellectual disabilities.



I would like to know what you think is not good care at the end of life for people with intellectual disabilities

#### **4 How will the information be used**



**I will listen to what you tell me about good and not good care at the time of death and dying for people with intellectual disabilities.**



**I will listen to your views and use it as part of my study.**



**My study will look like a report book when it is finished.**

#### **5 What will happen if you decide to take part in my study**



**Taking part in this study is voluntary.**



**If you decide to take part in my study I will have a discussion with you to find out what you think about the care given during the time of death and dying.**

## **6 How I will protect your Privacy**



**If you agree to be part of my study I will record what you say on a tape recorder.**



**I will be the only person who will listen to the tapes.**

**All the information gathered will only be kept by me.**

**My supervisors may read the transcripts.**



**I will not use your name to any other person or in any part of the study**

## 7 Benefits of taking part in the study



**You will get time to tell what you think is important for people with intellectual disabilities at the time of death and dying.**



**You will get a chance to be part of an important study for all people with intellectual disabilities.**



**You will help to improve the care that is given at the time of death and dying for people with intellectual disabilities.**

## 8 Are there any risks to taking part in the study



**There is no risk to you if you take part in the study.**

## 9 Changing your mind about taking part in the study



**You can change your mind and if you do not want to take part in the study it is OK to leave at any time without any problem.**

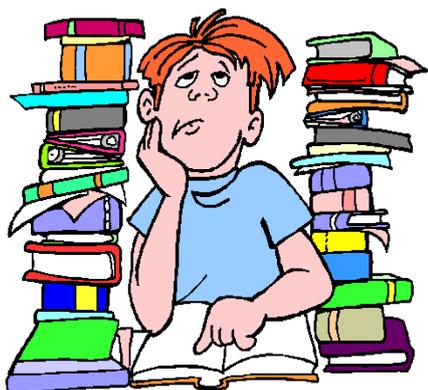
## 10 What will happen to the results of my study



**This information mainly will be used for my study.**



**I will discuss the results of my study with you all and I will tell you what can be done to make services better for all people with intellectual disabilities at the time of death and dying.**



**This information will be printed for people to read. It will be in the library. The study will be printed in books called 'journals'.**



The information also will be discussed with service providers to improve the care at the end of life for people with an intellectual disability.

## **11 Contact Details for further information**



If you want to know more about my study.



You can speak to me at any time.



Telephone 087-6533052.



If you are happy to help me and want to take part in my study please fill in the Consent Form.

# Service User's Consent Form

## Consent



**NO**



**YES**



I understand how I can help with this study to improve the care at the time of death and dying.



I am happy to help you with your study.



My questions about the study have all been answered.



I know that the conversation will be tape recorded.



I understand that if I do not want to take part in the study I can leave at any time without telling any reason.



**My Name:** \_\_\_\_\_



**My Signature:** \_\_\_\_\_



**Or My Thumb:** \_\_\_\_\_

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**Date:** \_\_\_\_\_

# APPENDIX C - PARTICIPANT ACCEPTANCE CARD

**Study Title: An Exploration of End-of-life care needs of People with Intellectual Disabilities: Developing a Model of Service Delivery.**

Dear Kumar,

I am interested in taking part in the research study to share my opinions and views about end-of-life care needs of people with intellectual disabilities. I understand that I will be contacted shortly to arrange a convenient time and place to participate in this study. I wish to be contacted at the following:

Name: \_\_\_\_\_

Preferred method of contact (please tick any of those you prefer)

E mail	Phone
--------	-------

Phone No: \_\_\_\_\_

E-mail: \_\_\_\_\_

## APPENDIX D - PARTICIPANT'S (FAMILY MEMBER) INFORMATION LEAFLET



**Title: An exploration of end-of-life care needs of people with intellectual disabilities: Developing a Model of Service Delivery.**

My name is C.Kumaresan and I am a nurse working in a residential intellectual disability services in North county Dublin. I am writing to you because you are a parent of a person with an intellectual disability. I carry out a study to explore the end-of-life care needs of people with intellectual disabilities. This research is being carried out as a PhD project with the School of Nursing, Dublin City University. My supervisors are Dr. Mel Duffy and Dr. Eileen Courtney and they can be contacted on 01-7005833 (Dr. Mel Duffy) and 01-7008525(Dr. Eileen Courtney).

It is found that people with intellectual disabilities live longer and suffer from the same illnesses as general population. Because of this, there is a growing recognition of the importance of providing good care at the time of death and dying for people with an Intellectual disability. Despite this recognition, there is little known about their care needs at the time of death and dying in Ireland. Therefore, this study aims to explore the care needs of people with intellectual disabilities at the time of death and dying. As a parent of a person with an intellectual disability, your opinions and views about the care that is given during the time of death and dying for people with intellectual disabilities are important and eventually help to improve the quality of care.

This study is completely independent of the services you receive and these will not be affected if you do not participate in the study. Taking part in this study is voluntary. It is up to you to decide whether or not to take part. If you choose to take part, you can contact me by signing the participant acceptance card and post it to me using self-addressed envelope. Once I received the acceptance card, I will contact you to arrange and discuss the venue for the interview.

Individual interviews will take place at a convenient place and time that suit you. The interview will be tape recorded and will take about 45-60 minutes. All interviews will be reported anonymously and kept confidential.

The results of this study will be used to extend an understanding of end-of-life care needs of people with intellectual disabilities. Moreover, the results will be shared with the practice development department of the intellectual disability service to enhance the service provision. In addition, the study outcomes will be published as a written thesis, and you will not be identified in any report or publication.

You can withdraw from this study at any time without any consequences.

If you have questions or concerns regarding my study, you may contact me at 0876533052 or at [kumaresan.cithambaram2@mail.dcu.ie](mailto:kumaresan.cithambaram2@mail.dcu.ie).

Thank you for reading this information.

**If participants have concerns about this study and wish to contact an independent person, please contact:**

The secretary, Dublin City University Research Ethics Committee, c/o Office of the Vice-President for Research, Dublin City University, Dublin 9. Tel 01-7008000.



Have you received satisfactory answers to all your questions? Yes/No

Are you aware that your interview will be audio taped? Yes/No

**Signature:**

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

Participants Signature: \_\_\_\_\_

**Name in Block Capitals:** \_\_\_\_\_

**Witness:** \_\_\_\_\_

**Date:** \_\_\_\_\_

# APPENDIX F - INTERVIEW GUIDE

## INITIAL INTERVIEW GUIDE FOR FAMILY MEMBERS OF PEOPLE WITH INTELLECTUAL DISABILITIES

What does end-of-life care mean to you?

How do you feel about discussing this topic?

Tell me about your experiences of someone receiving end-of-life care

Have you witnessed anybody getting care at the end of life?

### Prompts

Hospice

General hospital

Community medical team

In your opinion, what are the needs of people with intellectual disabilities at the end of life?

### Prompts

Physical needs

Emotional needs

Spiritual needs

Quality of life at the end of life

Quality of care at the end of life

Good Death

### Further interview guide

What are the choices of people with intellectual disabilities have to make at end of life?

What are the rights of people with intellectual disabilities at end of life?

What are your decision in relation to place of care and place of dying?

Disclosure regarding disease prognosis and impending death

Care needs after death

Describe how can we improve the end-of-life care to people with intellectual disabilities?

Do you want to say more that we have not discussed here?

### **Initial Interview guide for People with intellectual disabilities**

Tell me what do you think of this story John and describe what his needs are?

#### **Prompts**

How do you feel and what do you think of this story?

What are his needs?

How would he be made him comfortable?

In your opinion, what is good care for him?

In your opinion, what is good death for him?

### **Further Interview Guide**

Do you think somebody should tell him what is happening to him?

If you think so who would be a best person to tell him?

Do you think he should stay in the same place or he should be admitted somewhere else?

Do you think he needs a person to stay with him all the time? And in your opinion, will having somebody with him who he likes makes him better.

Do you feel that he should direct his own care?

What other things do you think will make him feel better at the time of death and dying?  
should his family be involved in his care?

Who else do you think should be included in his care

In your opinion, what is a good life for him?

How he should be remembered after his death?

Is there anything else you want to say about the care needs of people with intellectual disabilities at the time of death and dying?

## Appendix G - Category Holism developed from codes, themes and sub-category

Transcripts	Codes	Themes	Sub-Category	Category
Other people show them handicapped people how they are looked after them and get other people to have eye on them, like other people say like other people live in the house or people living outside (Conor)	Relying on other people to look after			
Handicapped people are living here long and dependent on other people for everything and should be looked after by other people (Emma)	Looking after			
The handicapped people in the special care or live in the community or in the home need other people to go with them,	Checking sick and dying people			

volunteer to go with them and every body go to their home and				
check on them. (Conor)				
People living in the house do lot of work for them while I am in xxx house there I will do kind of work there and if anybody ask for a help I will help the for example if other people cannot plug in I will help to plug in .(Conor)	Helping sick and dying people			
the people with intellectual disabilities completely depend on the staff in providing care.(Michael)	Depending for care	physical reliance		
If the handicapped people are sick, they should be looked after well you know. (Sarah)	Looking after well			

<p>and give them tablets. If they very sick give them tablets you know... if they are dying nothing more we can do.(Ciara)</p>	<p>Giving them tablet</p>			
<p>Sick and dying people can't talk, eat, walk. We have to feed them, help to walk (Sarah)</p>	<p>Helping sick people</p>			
<p>Take care of them. Look after them. Put them in a hospital and make sure they get all treatment that they needed.(Katie)</p>	<p>Taking Care</p>			
<p>Looking after the dying person all the time. Taking care of them. Look after their needs. Make sure they get special care. (Sarah)</p>	<p>Taking special care</p>			
<p>It is not right to</p>	<p>Getting help from</p>			

<p>tell their parents after someone was died. They should be stayed right beside their bed, right from the beginning. Stay with them and help them out (Mary)</p>	<p>parents</p>			
<p>Really there is no end of life, there is another world and people go there and will come back again. Before people die they need lot of support and care. (Lauren)</p>	<p>Giving support and care</p>			
<p>Some people here have no speech and hear so giving them more care than everybody else. (Rebecca)</p>	<p>Giving more care</p>			
<p>The people who are dying should be looked after, bathing them, feed them, giving them plenty of fluids.</p>	<p>Giving physical Care</p>			

(Rebecca)				
I want them to look after as much as possible and care them as everybody else. They need all the attention. (Rebecca)	Caring as normal people			
All want to say is the people like us should be looked after well (Lauren)	Looking after well			
Care of end of life is say like old people who are sick and dying cannot look after themselves (Katie)	Not being able to looked after themselves			
Look after them well. These people can't express and unable to look after themselves. (Ciara)	Looking after them			
Now days many parents of people				

<p>with ID die before their sons and daughter and only few people not many have their siblings or relatives involved in their care. So, the people with intellectual disabilities completely depend on the staff in providing care. (Michael)</p>				
	<p>Depending on carers</p>			
<p>I would like to see them looked after or get some type of care at the end of life as everybody else. (Tara)</p>	<p>Caring as normal population</p>			
<p>Definitely there should be some kind of support or care for my daughter at the end of life. (James)</p>	<p>Looking for assistance in providing care</p>			
<p>At the time of death and dying or the nearer time to death, there should be some kind of</p>	<p>Looking for a residential support</p>			

<p>residential service who know her to provide all the care she needs (James)</p>				
<p>From experience when I worked as a driver for xxx Hospice with people I drove appreciate the goodness of hospice care and also I hope the same level of care should be given to the people with intellectual disabilities when they approach death.(Adam)</p>	<p>Providing the same care as everybody else</p>			
<p>Medical care and other general care such as physical care, keeping them comfort, meeting all their needs are much important at the end of life of people with intellectual disabilities I assume this makes final journey be</p>	<p>Making comfort</p>			

peaceful as possible for the individual. (Adam)				
I think they have the same needs as everybody else and they are more susceptible to Dementia and Alzheimers and I know many cases because I engage with prosper fugal. This is very common among people with intellectual disabilities and they have early aging. (Eimer)	Having same needs as everybody else			
sick people needs other people check on them all the time 24hours a day they have to check on them to see how they get on (Conor)	Requiring constant attention/supervision		<b>Surrendering Independence</b>	
Specially handicapped people need	Requiring close attention by nurses	<b>Vigilant Monitoring</b>		

nurses to stay with them to look after the sick and dying people. (Conor)				
When you know somebody is sick dying leaving them alone and the doctor and nurse will look after them and help them.(Ciara)	Need of professional support			
Giving them a good care. To make sure that they get their medicine, food, plenty of fluids and get may be if doctor examine that person (Katie)	Ensure getting foods and fluids			
Look after them. Put them in a hospital and make sure they get all treatment that they needed.(Katie)	Ensure getting treatment			
Regular attention	Giving constant			

<p>should be given to these people. That will be very very important. I suppose, myself if I will be bed ridden these are the things I will be looking for. (Lauren)</p>	<p>attention</p>			
<p>These people can't express and unable to look after themselves. Regular attention should be given to these people. That will be very very important. (Michael)</p>	<p>Giving regular attention</p>			
<p>Talk to them you know what I mean we have to talk to them and let them know that we are here for them. If they very sick give them tablets you know... if they are dying nothing more we can do. Talk to them, (Ciara)</p>	<p>Talking to people</p>			

<p>People should stay with him speak to him. Sit with him You know. The people come to him. (Ciara)</p>	<p>Speaking to people</p>			
<p>Listen to them and we have to do what ever they ask for them (Ciara)</p>	<p>Listening to them</p>	<p>Maintaining Communication</p>		
<p>Nothing we can do much if he is going to die. Really we can talk to him.(Ciara)</p>	<p>Talking to people</p>			
<p>Speak to them you know.. speaking make them easy and happy (Katie)</p>	<p>Speaking to them</p>			
<p>People should be in peace and happy at their last days of people. We have to look after the well. You know what I mean. We</p>	<p>Making happy at the time of dying</p>			

<p>have to talking to them I think taking makes the person happy and sit with them you know. Staffs are wonderful to the dying people you know. I think everybody has to do their own parts.(Rachel)</p>				
<p>Somebody have to stay with dying people, sit with them speak with them. If possible people can stay with them some more time (Conor)</p>	<p>Accompanying with them</p>			
<p>Talk to them sits with them. Giving them reassurance you know, the dying people are poor they want us be with them (Sarah)</p>	<p>Being with them</p>		<p>Social Connectedness</p>	
<p>Sit with him You know. The people come to him and stay</p>	<p>Sitting with him</p>	<p>Meaningful Companionship</p>		

with him (Ciara)				
Talk to the people who are sick and dying. Stay with them. (Sarah)	Staying with them			
Talking to them, being with them, holding their hands. Visit from their own people like parents, uncle and friends. (Sarah)	Holding their hands			
Being with dying people is very important, this gives them hope and assurance (Katie)	Being with dying people			
If the people are really sick, the doctors and nurses should be there all the time and make them to realise that they are going to the other world and the gate is being ready to open. Their	Being with dying people			

<p>parents and friends stand beside their beds. (Lauren)</p>				
<p>The support is to stay with them help them and looked after them. If someone is dying, you need to stay with them, sit with them and hold their hands because sometimes they can't talk. So we have to let them know we are here to look after them. (Lauren)</p>	<p>Staying with dying people</p>			
<p>They need to be there all the way through and the person who is dying need lot of support and care. (Rebecca)</p>	<p>Being present with dying people</p>			
<p>Be with dying people, give them whatever they want. In and out all the time with them. (Rebecca)</p>	<p>Constant presence with dying people</p>			

<p>Say you think the person is going to die, I am not saying they are dying. If somebody is dying in the house like failte or anywhere in the world, the good care is, you stay with them, the persons you are working with they want to stay with them (Conor)</p>	<p>Staying with dying people</p>			
<p>If the person living in the home they have a family to support them, their own parents and family members with them. But people who stay in the mental hospital, they have staff with them; they have other people living in the house with them. So anybody needs people with them all the time. (Conor)</p>	<p>Being in company</p>			

<p>People should spend time with dying people and stay with them. Be with them and holding their hands will give lots of message to them even they don't speak to them.(Emma)</p>	<p>Needing a physical touch</p>			<p>Holism</p>
<p>Let the family should stay with their friends and parents. (Sean)</p>	<p>Staying with friends and family</p>			
<p>I think facilitating their needs whatever arises during that time is much important may be medical or psychological you know everything that surrounds at the end of life and everything that makes it as peaceful..(Adam)</p>	<p>Making life peaceful at the end of life</p>			
<p>. I think if some body going to die we have to talk to them and holding their</p>	<p>Letting the dying people know we are there for them</p>			

<p>hands and tell them that we are here for them. Be there with them. People should be in separate room, friends, family and staff can go in and out and it gives privacy and comfort. Be with them and talk to them.(Rachel)</p>				
<p>Pray for the dying people and be with them (Michael)</p>	<p>Saying prayers for dying people</p>			
<p>Bring them to the hospital and probably they will be alright, but what we can do is pray for them and they will die. Just we can do is pray for him and care for him.(Ciara)</p>	<p>Praying for dying people</p>			
<p>Talk to them you know what I mean we have to pray for them if he dies and pray for them. (Ciara)</p>	<p>Giving prayers</p>	<p>Suggesting Solace</p>		

<p>Talk to them sits with them. Saying prayers for them, it helps to give them a inner peace (Sarah)</p>	<p>Saying prayers</p>			
<p>It is very sad is not it. We have to look after them. I feel very sad for them. Pray over them (Katie)</p>	<p>Praying over</p>		<p>Religious Reconciliation</p>	
<p>say the prayers over the dying people, it is very go the sick people you know we all have to do this (Conor)</p>	<p>Saying Prayers</p>			
<p>They should get all spiritual care as any other people for example my sister loves to go to mass on every Sunday, so I expect the same thing happen even if she become sick and ill. If she cannot so and attend the</p>	<p>Praying for sick people</p>			

<p>mass I expect some to come and visit her and pray for her, like voluntary group go and pray for sick and dying people. (Nicole)</p>				
<p>Bring priest in and ask the priest to bless the dying person it may make the sick people happy and peace. Let me think..... the person should get anointed. Priest should come and bless the person. (Katie)</p>	<p>Blessing the dying people</p>	<p>Seeking Blessings</p>		
<p>Doctor or nurse should contact the priest and the priest come in and bless the dying person that make him comfort and peace (Conor)</p>	<p>Blessing makes peace</p>			
<p>Any person is dying the priest is always coming with you. They stays with person</p>	<p>Blessing the dying person</p>			

<p>who dies and bless him all the ways through and talk to him (Conor)</p>				
<p>then the dying person and the family members must be blessed and say prayers by priest or somebody in line with their religious faith (Michael)</p>	<p>Blessing by priest</p>			
<p>Also I think their spiritual needs are important to be met, he goes to mass every week but I don't know how religious he is? He goes to Saturday night. The service should call somebody to provide some kind of religious stuff. Certainly somebody has to talk to him. Definitely he cannot make any decision at the time of dying but the people who nurse him at that</p>	<p>Meeting spiritual needs</p>			

time should able to make decide what is good for him.(Eimer)				
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