Title: What Constitutes a Good Death?

Perceptions of the public and professionals working within generalised and specialised palliative care services in the South East of Ireland.

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DEDICATION

Firstly, I would like to dedicate this research to Joe. For all the humanity and wisdom, you bestowed. Although you are sadly missed, we were truly blessed to have known you. Secondly, I would like to dedicate this research to Shannon and Kayleigh. I hope you both aspire to what you want to be in life and realise the endless possibilities that education can bring. You are both now and always will be my proudest accomplishments. Thirdly, dedication goes to all health and social care professionals within generalised and specialised palliative care services. I hope this study in some way gives recognition of the tirelessness, compassion, empathy and warmth you provide each day. Finally, I dedicate this study to individuals suffering from chronic or terminal illness. In the words of Cicely Saunders, I hope this study conveys:

> *'You matter because you are you and matter to the end of your life'*
>
> (Saunders 2014, p. xxiii).

ABSTRACT

Death is universal, making end of life care (EOLC) crucial for all (Cipolletta & Oprandi, 2014). Health and social care professionals are faced with a monumental task more so than any other profession, as they may only have one chance to get care right for the terminally ill and their family/loved ones (Irish Hospice Foundation (IHF), 2017). Therefore, a fundamental line of inquiry is, what constitutes adequate EOLC and where can possible improvements be made? (Meier et al., 2016). Thus, this research centres upon the concept of a 'good death' (GD). Minimal international studies and none to date in Ireland have explored this component from both public and professional viewpoints (McLoughlin, 2017; Meier et al., 2016). Thus, it is unknown if current palliative and EOLC service delivery reflects public expectation. Recent legislative developments in Ireland, namely the Assisted Decision Making (Capacity) Act (2015), have further prioritised the need for individual preferences in EOLC (House of Oireachtas, 2019). Correspondingly, this research is a timely investigation into both public and professional perceptions of the meaning of a GD. A qualitative methodological approach involving the use of in-depth, semi-structured interviews was adopted. Findings revealed consensus among the public and generalised professionals on their views of a GD, while specialised professionals had some divergent ideals on this topic. Five main findings of a GD were also uncovered; (1) Pain, (2) Family, (3) Control, (4) Maintaining Personhood, (5) Independence. Independence is a newly emerging finding on what constitutes a GD in Ireland. Thus, this study provides new insight on public perceptions of a GD in Ireland and extends previous national and international research. Results further provided an evaluation of current palliative care supports and services to obtain a GD. Key challenges hindering the accomplishment of a GD were; (1) Resource issues, (2) Lack of public awareness of EOLC services, initiatives and resource issues (3) Media influence, (4) Lack of supports for family, loved ones, informal caregiver(s) and professionals (5) Professional challenges. Key conclusions include; (1) A GD may be impossible to define, (2) Current unmet needs in palliative care means a GD may be largely unattainable, (3) Lack of professional training, (4) Many resource issues remain in palliative care in the southeast of Ireland, (5) Accessibility and availability of financial supports is problematic, (6) Decision-making initiatives cause confusion and professional fears on safeguarding individuals in their care. This study recommends; (1) Heightened efforts by government and policy makers to reduce identified resource issues, (2) Increased public awareness campaigns, (3) Accurate education to the public, (4) Enhanced prior and post bereavement supports for family/loved ones, (5) Heightened supports for professionals, (6) Training for informal caregivers, (7) Committed provision of supervision, (8) Training across all palliative care services.

ABBREVATIONS

AHD	**Advanced Healthcare Directives**
AIIHPC	**All Ireland Institute of Hospice and Palliative Care**
BPSS	**Bio, Psycho, Social and Spiritual**
BPSSM	**The Bio-Psycho-Social-Spiritual Model of palliative care**
CIC	**Citizens Information Centre**
CPD	**Continuous Professional Development**
CSO	**Central Statistics Office**
DPP	**Death Preparation and Planning**
DSS	**Decision Support Services**
EOL	**End of life**
EOLC	**End of Life Care**
GD	**Good Death**
GP(s)	**General Practitioners**
H*F*HP	**Hospice Friendly Hospital Programme**
HSE	**Health Service Executive**
IASP	**International Association for the Study of Pain**
ICS	**Irish Cancer Society**
IHF	**Irish Hospice Foundation**
IHI	**Individual Health Identifiers**
LPI	**Life Prolonging Interventions**
NACR	**National Advisory Committee Report**
NCPC	**The National Council Palliative Care**
POC	**Place of Care**
PS	**Pilot Study**
QOC	**Quality of Care**
QOD	**Quality of Death**
QOL	**Quality of Life**
RO	**Research Objective**
IHI	**Individual Health Identifiers**

GLOSSARY OF KEY TERMS

- **Palliative care** is an approach which emphasises improving the quality of life (QOL) of individuals with a chronic and or terminal illness and his/her family/ loved ones by providing physical, psychosocial and spiritual relief from suffering through early identification and pain management. This approach is not limited to the terminally ill as it may also be provided during curative treatments and follow-ups. Palliative care encompasses elements of hospice and EOLC (Krau, 2016).

- **Hospice care** begins when treatment of an illness is no longer viable and focuses on providing comfort care rather than curative approaches (Krau, 2016). Hospice care provides care, support and pain management to an individual suffering from an intractable illness nearing his/her death (6-month time frame). Both hospice and palliative care provide a holistic approach focusing upon addressing the bio-psycho-social and spiritual needs of the terminal ill and their family/caregivers (American Academy of Hospice & Palliative Medicine, 2017).

- **EOLC** is regarded as continuum rather than a specific aspect of care. It encapsulates all aspects of care provided to the terminally ill from the onset of illness to the final hours of life (IHF, 2019). Hospice and EOLC are elements of palliative care. They provide care, support and pain management to individuals nearing EOL, although difficult to predict, typically within the last year to 6 months of life (American Academy of Hospice & Palliative Medicine, 2017).

- **Euthanasia** entails the administration of lethal medications to an individual with merciful intent upon his/her request (Rudbruch et al., 2016).

- **Self-Determination** is a core principle of social work and social care practice which encourages and acknowledges a service user’s expression of wishes, goals and aspirations (Irish Association of Social Workers, 2019).

- **Autonomy** involves respect for individual choice and decision making (Irish Association of Social Workers, 2019).

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CHAPTER ONE

INTRODUCTION

CHAPTER ONE INTRODUCTION

Title: “What constitutes a good death: Perceptions of the public and
professionals working within generalised and specialised palliative care services
in the South East of Ireland.”

1.1 Introduction

Death is both a universal and inevitable human process, yet remains a largely unspoken topic (Meier et al., 2016; IHF, 2016; Cipolletta & Oprandi, 2014). Advancements in medicine have altered illness trajectories meaning individuals are unlikely to experience a quick and painless death (Kane, 2015; Scarre, 2012). Instead, death may occur after lengthy deterioration from comorbidity issues associated with chronic and terminal illnesses. Approximately, 28,000 individuals die annually in Ireland and a further 28,000 at least are bereaved (IHF, 2018). Health and social care professionals are faced with a monumental task more so than any other profession as they may only have one chance to get care right for an individual and his or her family/loved ones (IHF, 2013). Establishing individual EOLC preferences, needs and desires is fundamental. Therefore, ascertaining what constitutes a GD is of pivotal concern.

1.2 Background and Current Context of a GD Internationally

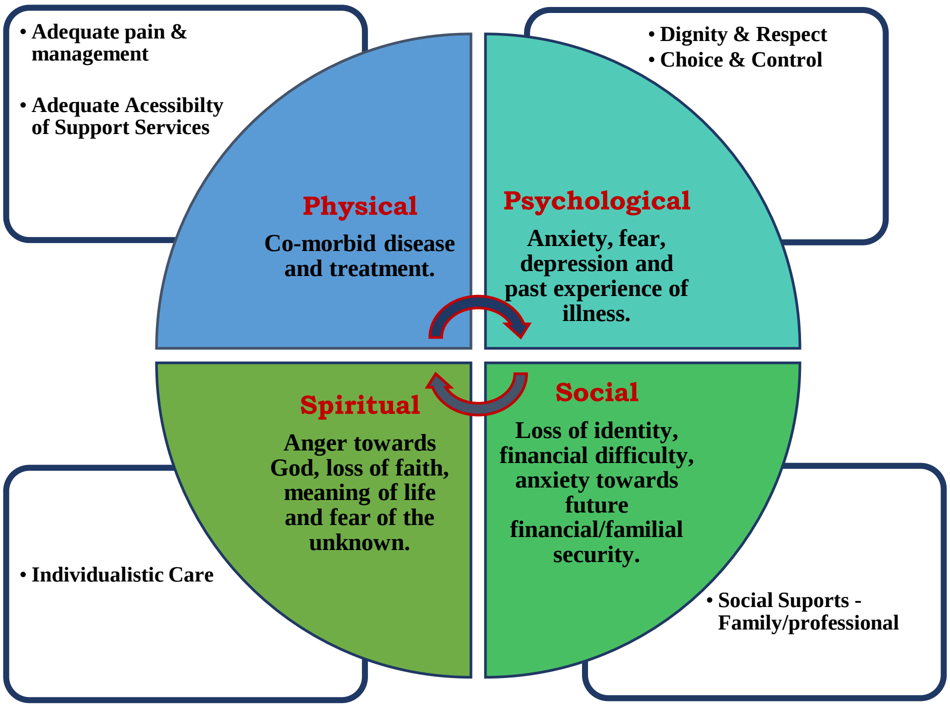
Though ‘Ars Moriendi’, or the art of dying well may be centuries old (Kelly, 2012), the concept of a GD is largely attributed to ideologies of Dame Cicely Saunders, founder of the modern hospice movement (Meier et al., 2016; Scarre, 2012). Hospice care (***glossary***) originated in the 4th century to cater for the needs of the terminally ill. Although welcomed, this led to considerable shifts on death attitudes and the ‘invisibility of death’ (Philippe Ariés, 1974 cited in Aramesh, 2016, p.2). Correspondingly, by the 1800s hospices became synopsis with death and dying and were coined, ‘the home of incurables’ (Department of Health & Children, 2013). Complaints regarding the medicalisation of care of the terminally ill also began to surface in the 1960s, concerning the excessive use of curative treatments greatly diminishing quality of life (QOL) and individual choice for those nearing end of life (EOL) (Mak, 2014). Saunders recognition of these issues led to the emergence of the modern hospice care movement in 1967, with the establishment of St. Christopher’s Hospice in London (Department of Health & Children, 2013). Saunders revolutionised a modern philosophy of comfort care rather than curative approaches.

In the following decade hospice care expanded across western and later non-western countries (Mak, 2014; The Department of Health & Children, 2014). It further evolved in Canada in 1975 to include palliative care (***glossary)*** introduced by Dr. Balfour Mount, expanding care to those also suffering from chronic conditions (Mak, 2014). In contemporary society, both hospice and palliative care work in tandem with an overarching aim to provide a GD for all (Morris et al., 2017). Empirical research on what comprises a GD is relatively new beginning only two decades ago (Meier et al., 2016). Consequently, various perspectives have evolved. For instance, sociological and anthological literature discuss it in terms of 'dying well' while medical, legal and philosophical literature frequently associate a GD with debates on euthanasia (***glossary***) (Mak, 2014). Although it may be defined as one that is free from pain and suffering, depicting individual preferences and consistent with cultural, clinical and ethical standards, this remains unverifiable owing to the subjectivity of individual interpretation and diversity of culture, social norms and religion (Hold, 2017; Meier et al., 2016). Therefore, many conclude this topic is conceptualised rather than conclusively defined (Cipolletta & Oprandi, 2014; Scarre, 2013; Kelly, 2012). Despite weighted literature, many attest further investigation of this concept is needed as it remains inadequately defined and understood thus, is difficult to implement in practice (Meier et al., 2016; Hutter et al., 2015; Mak, 2014; Kennedy et al., 2014). Therefore, this study aims to gain a comprehensive understanding of this concept in an Irish context.

1.3 Theoretical Framework of the Research Enquiry

To actualise a GD, a holistic approach is needed to encapsulate the entirety of the individual (Hold, 2017). Holism (Carl Rogers 1905-1987 cited in Freeman, 2015, p.154) centres on the premise of a collective whole of interconnecting, correlating and inseparable entities. This is reflected in Saunders (1967, cited in Cooper, 2016, p. 121) 'total pain' approach in palliative care and the subsequent Bio-Psycho-Social-Spiritual Model (BPSSM) (Engel 1977, cited in Wachholt et al., 2016, p.3) whereby physical, psychological, social and spiritual elements are viewed as collective contributors of pain all of which need addressing for an individual to receive effective palliative care (*Figure 1*) (Hackett, 2017). Holism also concerns human perceptions of experiences and emotions. For this reason, it is also important to investigate the concept of a GD from this viewpoint, as all human life is lived through interconnecting entities such as experiences, culture, socialisation, social norms and religion (Environment & Ecology, 2019; Hjelm et al., 2005 cited in Cithanbaum, 2017, p.105).

Figure 1: **Holistic Approach and The BPSSM in Palliative Care**



Adapted from Digitális Tankönyvtar, (2019).

In doing so, this study will respect the unique truth of individual perceptions of a GD considered by each participant.

1.4 Context of Current Palliative Care Policy Development in Ireland

Spearheaded by the Sisters of Charity, hospice and palliative care began in Ireland between the 1970s and 1980s with the establishment of Our Lady’s Hospice in Dublin in 1979 and the Marymount Hospice in Cork in 1984 (Trinity College Dublin 2010; Goebel et al., 2009). The Milford Care Centre emerged in Limerick in the 1980s to provide specialised palliative care services (Trinity College Dublin, 2010). Once palliative care became a medical speciality in 1995, further developments emerged through Government responses with the opening of an additional hospice in Raheny in Dublin, Galway, Donegal Hospice and the North West (***Appendix A***) (McCarron et al., 2010). Government policies evolved namely, the ‘National Health Strategy’ which aimed to provide structured palliative care to enhance quality of care for individuals and their families/loved ones (Department of Health, 1994).

In 1996, the ‘National Strategy for Cancer Services in Ireland’ was implemented focusing on person-centred care for cancer patients and flexibility in place of care where appropriate, through the provision of specialised palliative care services (Department of Health, 1996). Yet, these aims were unattainable as there remained no strategy to implement palliative care locally/nationally (Cithambara, 2017). In response to this deficiency the National Advisory Committee on Palliative Care was established in 1999, which commissioned the ‘National Advisory Committee Report’ (NACR) in 2001, detailing recommendations for the structure of service delivery, funding, bereavement services and palliative care training and education (Department of Health & Children, 2001). Marking the beginning of generalised and specialised palliative care services, it asserted palliative care should be devised into three levels of differing skillsets, as not all individuals would need specialist palliative care (IHF, 2013) (*Table 1*). In efforts to reduce inequalities recognised by the NACR, (2001) and incorporate palliative care for all, not just cancer patients the ‘Quality and Fairness – A Health System for You’ policy was introduced, recommending each health board conduct regional assessments of specialised palliative care (Department of Health & Children, 2014). Thereafter, this and the NACR, (2001) became national policy for the provision of palliative care in Ireland and health boards were replaced with Community Healthcare Organisations (CHO) (*Table 2*) (The Palliative Hub, 2019).

Table 1: Levels of Palliative Care in Ireland

Level	**Palliative Care Approach**	**Implementation**
Level 1	Palliative Care Approach	Application and engagement of palliative care principles by all health care professionals (HSE, 2014).
Level 2	General Palliative Care Approach	This is the intermediate level of expertise, where a group of patients and families 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 (Department of Children & Health, 2014).
Level 3	Specialist Palliative Care Approach	This is the territory of palliative care service; whose core activity is to provide palliative care service. These professionals are specially equipped with knowledge and expertise to provide palliative care for people with complex needs. Specialised professional provides direction of care to generalised professionals (McVeigh et al., 2018).

Current HSE structures of palliative care provision are situated within the Primary Care Division collaborating across hospital groups and nine CHOs. They cover primary care, social care and health and well-being care (HSE, 2017).

Table 2: Structure of CHOs in Ireland	
CHO Area 1	Includes the five counties of Donegal, Sligo, Leitrim, West Cavan, Cavan and Monaghan
CHO Area 2	**Community Healthcare West** Galway, Roscommon and Mayo
CHO Area 3	**Mid-West Community Healthcare** Clare, Limerick, North Tipperary and East Limerick
CHO Area 4	**Cork Kerry Community Healthcare** Kerry, North Cork, North of the Lee, South of the Lee and West Cork
CHO Area 5	**South East Community Healthcare** Tipperary South, Carlow, Kilkenny, Waterford, Wexford
CHO Area 6	**Community Healthcare East** Wicklow, Dun Laoghaire, Dublin South East
CHO Area 7	**Community Healthcare Dublin South, Kildare and West Wicklow** Kildare, West Wicklow, Dublin West, Dublin South City and Dublin South West
CHO Area 8	**Midlands Louth Meath Healthcare** Laois, Offaly, Longford, WestMeath, Louth and Meath
CHO Area 9	**Dublin North City and County Healthcare** Dublin North, Dublin North Central and Dublin North West (HSE, 2017).

Furthermore, several key reports have also been instrumental in palliative care provision in Ireland. O’ Shea et al.’s, (2008), study into EOLC for residents in eldercare residential services led to the establishment of the first ‘National Quality Standards for Residential Care Settings for Older People in Ireland’ devised and monitored by the National Information and Equality Authority (HIQA) in 2009. The HSE and the Irish Hospice Foundation (IHF), (2008) ‘Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks’ reported the importance of assisting both malignant and non-malignant diseases such as Dementia, Pulmonary Heart Disease and Chronic Obstructive Pulmonary Disease. This aimed to enhance a palliative care approach for all regardless of illness or disease. In efforts to incorporate a holistic, person-centred focus across the health system the HSE, implemented the ‘National Strategy for Service User Involvement in the Irish Health Service’(2008-2013). This aimed to introduce a user-led focus in healthcare by encouraging individuals to become ‘experts in their own care needs.’ Thereafter in 2010, the IHF created the ‘Hospice Friendly Hospital Programme’ (H*f*HP) to improve the culture of palliative care in hospitals. Through public feedback ascertained from the ‘Forum on End of Life (2009-2010), the IHF launched the ‘Think Ahead’ Programme in 2009, providing a public platform on EOLC planning circulating over 40,000 forms to date (O’Shea et al., 2014).

The enactment of the Assisted Decision-Making (Capacity) Act, (2015), which places individual preferences concerning medical treatment/care on a statutory footing, stipulated within advanced healthcare directives (AHD) further enhanced advanced EOLC planning (The Irish Law Society, 2016). More recent initiatives namely, the 'Your Say Your Service; The Management of Service User Feedback for Comments and Complaints Policy' was introduced in 2017, to meet international best practice standards in quality care giving families and individuals enhanced holistic care (HSE, 2017). However, despite these developments, recommendations made by the NACR, (2001) have yet to be realised and disparities across the country remain particularly in the Southeast and Midland with no out-of-hours services, deficiencies in staffing levels, and no dedicated inpatient specialist palliative care beds for these entire regions (National Clinical Programme for Palliative Care, 2019).

1.5 Justification for this Study

The universality of death means EOLC is a distinct possibility that many of us may or have yet to face (Kelly, 2014; Cipolletta & Oprandi, 2014). This makes EOLC a critical issue for all (Dalal & Bruer, 2017). Advancements in medicine, technology, sanitation, housing, nutrition and substantial research into health and disease prevention have significantly increased life expectancies: males 78.4 years/females 82.8 years compared to 1926 figures of males 57.4 years/females 57.9 years (Kelly, 2014, p. 36; Central Statistics Office, 2018). Although welcomed, this amplifies the need for effective EOLC as research attests prevalence rates of chronic illness also increases with age (Scarre, 2012; Kane et al., 2017). As Ireland has one of the fastest ageing population in Europe, especially among 70 to 80-year olds, EOLC needs here are considerable (Kane et al., 2017). While medical expenditure should come secondary to human issues, it must also be considered. Annually, 80% of deaths in Ireland are from conditions considered to have palliative care needs at an estimated annual cost of €1.3 million. Future healthcare fiscal projections report this expenditure may be unsustainable. Thus, the need to implement cost effective initiatives is a priority (Kane et al., 2017; The IHF, 2013). While death may occur at any stage throughout the lifespan, future care projections stipulate by 2021, 30% of those aged 65 years and over will be living alone therefore, formal caregiving will be of pivotal concern for this client group (Kane et al., 2017). As a lack of community and familial support networks are indicators of institutionalised and or hospital deaths, early intervention, which is one of the remits of palliative care, is of utmost concern.

While the HSE has implemented recent policy developments to reduce gaps and enhance early intervention in palliative care service delivery in Ireland namely, the ‘Palliative Care Development Framework (2017-2019)’ and the ‘Adult Palliative Care Model of Care, (2019)’, they remain very much in infancy stages and are subject to the availability of resources (HSE, 2017;2019).

1.6 Research Gaps

Although research into palliative care and the concept of a GD has gained momentum, significant gaps remain: Firstly, although many international studies have examined perceptions of a GD from the view of the terminally ill, recently bereaved, caregivers and EOLC professionals (Tenzek & Depner, 2017; Vrinten, & Wardle, 2016), few have explored public opinion on the matter despite many calling for reform (The National Council for Palliative Care, 2016; Meier et al., 2016; Vrinten & Wardle, 2016; Cipolletta & Oprandi, 2014; Scarre, 2013). Studies involving the public on death and dying matters and what may matter most if faced with a terminal illness, have increased in Ireland yet, they remain minimal in comparison to international scope and none to date has explicitly focused on the concept of a GD (McLoughlin, 2017; Weafer 20014-2004; McCarthy et al., 2009). There is also a scarcity of available international literature incorporating both public and professional perceptions on the concept of a GD and an absence of such in Ireland (Meier et al., 2016; Vrinten & Wardle, 2016). Therefore, it is largely unknown if professional ideologies of a GD reflect public opinion. Secondly, professional explorations of a GD and death and dying matters nationally and internationally have largely concentrated on generalist and or specialist professional domains (Butler, 2017; Banerjee et al., 2016; Mistry et al., 2015; Quinlan & O’ Neill, 2013; O’Shea et al., 2008). However, few have incorporated both sectors viewpoints collectively on the matter (Mistry et al., 2015). Thirdly, research reports increased public interest on death and dying matters in Ireland (McLoughlin, 2017; Weafer, 2004; 2014). Furthermore, studies show the public believe preferences in EOLC should be ascertained before a terminal diagnosis or medical crisis when individuals are healthy and capable of expressing them (Carr & Luth, 2017; National Council for Palliative Care, 2012). Hence, it is crucial to elicit public opinion on death and dying matters for without public consultation how can principles of hospice and palliative care be fully realised and implemented and how can acquisitions towards a GD be achieved?

Through the inclusion of the public, generalist and specialist professionals, this study aims to add to international literature and bridge these gaps in current national literature by providing a comprehensive public and professional insight on parameters of a GD.

1.7 Study Aim

The aim of this study is to explore public and professional perceptions on what it means to have a GD and to ascertain if professional ideals of a GD reflect public expectations.

1.7.1 Research Objectives

1. What constitutes a GD from the view(s) of public and professionals working within generalised and specialised palliative care services in the Southeast of Ireland?
2. How are individuals, their families/loved ones currently supported to achieve a GD in the Southeast of Ireland?
3. What issues may impact upon individual opportunities to experience a GD in Ireland?

1.8 Relevance to Health and Social Care

This research has the potential to contribute to health and social care sectors. It will enhance professional awareness into social expectations on dying well which may uncover further suggestions on holistic approaches in palliative care (Carl Rogers 1905-1987, cited in Corey, 2017, p. 163) and in achieving a GD for all. It also provides a platform for the public to voice their opinions on the matter. By seeking open dialogue, it also has the potential to reduce negative views and societal barriers towards death and dying. Gaining professional perceptions will also provide invaluable insight into how service delivery is implemented and where improvements could be made (Campbell et al., 2016). It will bridge gaps in existing national and international literature and add to the body of knowledge within health and social care domains.

1.9 The Researcher’s Experience and Aptness for The Study Inquiry

Interest for this research was initially sparked by placement within an eldercare service for older adults with intellectual disabilities conducted in 2015 as part of undergraduate studies in Professional Social Care, where existential suffering was encountered. Søren Kierkegaard (1813-1855 cited in Sharf, 2016, p.164) concept of existential suffering depicts how an individual may view life as ‘meaningless’ which has been associated with depression and desires to hasten one’s death (Ost & Mullock, 2011). Jerant et al., (2004) attests it is a recurring phenomenon within social care services especially community care, eldercare and disability domains. Consequently, contemplations of the possible implications of the Dignity with Dying Bill, (2015), which seeks to give the terminally ill the sole or assisted means to hasten one’s death, from a professional social care perspective evolved (House of the Oireacthas, 2016). This led to an undergraduate research dissertation on the topic of assisted dying entitled, ‘The Dignity with Dying Bill, (2015): A social care perspective.’ Thereafter, the researcher possessed insight in the area of generalist palliative care having worked as a healthcare assistant (HCA) in an eldercare residential care service. Given my professional credentials namely, a Bachelor of Arts Honours Degree in Professional Social Care, part of my role in this service involved conducting EOLC planning with all 36 residents. Engagements with this and experiencing the deaths of three residents throughout my time there heightened the need for holistic care and to establish individual preferences at this stage of life for both the terminally ill and their families/loved ones. It also increased my admiration for professionals working in the area of EOLC. My undergraduate thesis and my professional experiences within eldercare residential care subsequently led to an interest in investigating what constitutes a GD from both public and professional viewpoints. My intention for this research is to explore if disparities between these groups on this topic are evident and if so, how can they be reduced in order to depict public expectation on what may constitute dying well. It also seeks to heighten the profile of palliative care and heighten public awareness on the importance of EOLC planning in advance for all. It was further hypothesised that data gained from this study would:

1. Identify challenges in palliative care in Ireland.
2. Uncover and help define what it means to have a GD in the 21st century in an Irish context.

Having previously conducted research in the area of death and dying involving 15 professionals in various social care settings, I was confident in my ability to undertake and complete this research.

1.10 Thesis Structure

This study is a holistic exploration into participants' perceptions of a GD. This thesis is structured as follows.

Chapter Two provides an overview of existing research on the concept of a GD both nationally and internationally highlighting gaps, the relevance and need for this study.

Chapter Three details the appropriateness of the methodological approach, the theoretical underpinnings and the subsequent research method and instruments incorporated in this study. It describes the participant cohorts involved, the sampling method, process and procedures utilised in data collection. Ethical considerations employed and the robustness of this study are also deliberated.

Chapter Four thematically presents the findings and analysis of the data obtained. In doing so, it analyses the findings of this study with existing literature showing similarities and discrepancies between them. Findings uncovered new insight on perceived characteristics of a GD in an Irish context.

Chapter Five draws conclusions on the findings ascertained from this study. It also provides recommendations for practice, policy and public initiatives and possible further avenues of research.

1.11 Conclusion

This chapter outlines an extensive overview of the research topic. Given the scarcity of available research on the concept of a GD in Ireland, both a national and international background is included to provide the reader with a comprehensive insight of this topic. How we care for the dying reflects the very humanity of our society thus, all should be involved in the discussion (IHF, 2013). By encouraging a more open culture on death through empowering the public and professionals collectively to have these conversations we can provide a future whereby a GD is obtained (University of Glasgow, 2014).

CHAPTER TWO

LITERATURE REVIEW

CHAPTER TWO LITERATURE REVIEW

2.1 Introduction.

This chapter aims to provide a comprehensive report on how the literature review was conducted. It begins by exploring the concept of a GD from the view of the public. It then discusses components considered important in achieving a GD according to allied professionals working within diverse care settings and describes commonalities and disparities in these views across diverse stakeholders. Thereafter, it details a thematic analysis of current national/international literature on predominant quality indicators of a GD as perceived by both groups. Finally, barriers within these themes proposed by both the public and professionals will also be considered.

2.2 Refining the Search

The secondary research was conducted using the Google Scholar search engine and the Institute of Technology Carlow online library databases such as PubMed, Researchgate, Oxford Academic, Taylor and Francis Online, Wiley Online Library, the British Association of Social Workers and the British Medical Journal. This investigation focused on attitudes towards death and dying from the perception of both the public and professionals working within palliative care, hospice and EOLC domains ranging from 2004 to 2019. Terms utilised within the search were ‘a good death’, ‘peaceful dying’, ‘successful dying’, ‘quality of death and dying’, ‘dying well’, ‘quality in dying’, ‘quality indicators in palliative, hospice and EOLC’, ‘EOLC impacts on the dying process’, ‘preferences in palliative, hospice and EOLC’ and ‘public and professional attitudes, perceptions, opinions and views towards death, dying and a good death’. *Table 3* provides a breakdown of the sources included in this review.

Table 3: Breakdown of Sources Included in the Literature Review

Document Type	Number
Secondary reviews	5
Irish studies involving the public	3
International studies involving the public	18
Irish studies in professional domains in EOLC	3
International studies in professional domains in EOLC	86
Total number of articles included in the reviewed	**115**
Reports and Websites of interest in Ireland	20
Total number of sources	**135**

2.3 Current Public Perceptions of a GD in Ireland

A small number of studies in Ireland have uncovered perceived characteristics of a GD, the most substantiated are to be surrounded by loved ones, free from pain and being treated with dignity and respect. Although not explicitly focused on the concept of a GD, John Weafer's (2004) investigation of public perceptions on death, dying and bereavement was the first to elicit such findings. Weafer conducted a similar study in 2014 on behalf of the Irish Hospice Foundation (IHF). Both studies revealed the public perceived being surrounded by loved ones and being pain-free pain as the top two defining components of a GD if terminally ill. Yet, findings in his 2014 study showed the emphasis on pain had heightened, making it the leading aspiration in achieving a GD compared to 2004, where being surrounded by family was rated highest. Avoiding pain and suffering are prominent hallmarks of a GD according to international literature involving the public (Milnes et al., 2016; Meier et al., 2016; National Council for Palliative Care, 2016; Joarder et al., 2014). Other elements of a GD portrayed in Weafer's (2004; 2014) studies (*Table 4*) are evident in international literature yet, they are given higher priority. For instance, retaining dignity and independence were considered the second leading parameters of QOL in EOLC according to the public and patients attending an advanced care planning clinic in Australia (Milnes et al., 2016). However, no mention was given to independence in Weafer's (2014; 2004) studies and dignity was given less prominence (*Table 4*).

Table 4: Characteristics Revealed by Weafer's (2004; 2014) Investigations	
WEAFER 2004 - most important things about the care available to you if dying or terminally ill	
1. Surrounded by loved ones	**68%**
2. Free from pain	**55%**
3. Conscious and able to communicate	**35%**
4. Remain in own home	**34%**
5. Readily available medical supports	**32%**
6. Spiritual supports	**19%**
7. Privacy	**11%**
WEAFER 2014 - If you had a terminal illness, which of the following would be the most important to you regarding how you spend your final days? Not specifically asked about a GD	
1. Free from pain	**70%**
2. Surrounded by loved ones	**82%**
3. Privacy and Dignity	**46%**
4. Remain in familiar, peaceful and calm environments	**42%**
5. Medical personnel on standby in the event of an emergency	**41%**
6. Competent caregiver supports	**34%**
7. Having cultural, religious and spiritual needs addressed	**29%**
8. Accessibility to supports concerning fiscal and or legal affairs	**25%**
9. Surrounded by pets	**23%**
10. Maintaining personal belongs	**23%**
11. Feeling control over one's care and treatment	**21%**
12. Being surrounded by individuals in similar situations for comfort and support	**15%**

Weafer’s lack of rationale behind GD attributes means it is unknown why dignity was considered an element of a GD and why it was prioritised less than other characteristics. Hong et al.,’s (2016) qualitative investigation of bereaved caregivers of terminally ill individuals in America, showed further disparities. Like Weafer (2004-2014), they found being surrounded by loved ones when nearing one’s death is a leading ingredient of a GD. Yet, contrastingly having the opportunity to settle disputes and say goodbye to loved ones were considered the second and third most essential qualities. Further differences are evident in countries such as, Belgium and the Netherlands where a GD is largely in accordance with assisted dying, a practice entailing the deliberate hastening of one’s death through self or assisted administration of lethal medications (Gypels et al, 2012). The fact that euthanasia practices are legalised in both countries and offered as an optional intervention in EOLC may have led to this result (Gypsel, et al., 2012). Evidently, cross-country variations of a GD are apparent, verifying the claim in chapter one that death attitudes are largely socially constructed representations of our culture, societal norms and values (Galbin, 2014; McCarthy et al., 2010). While Weafer’s (2004; 2014) studies uncovered insight into public perceptions on death and dying on a large scale with his 2004 study involving 1,000 participants and his 2014 study comprising 985 respondents, there were limitations. Firstly, both utilised a quantitative approach leaving no room for participants’ rationale for answers. Secondly, Weafer’s (2004; 2014) use of a nine-point, categorical scale, taken directly from a Scottish survey conducted by Wallace, (2003) to measure what may be important to the public if faced with a terminal illness may not be transferable. While Scottish based palliative care research has assisted in enhancements in EOLC and continues to be of academic interest internationally (Finucane et al., 2018), the selections put forth in this question, displayed in *Table 5* may not adequately reflect socio-cultural undertones in an Irish context. Even though the options of ‘I don’t know,’ and ‘other’ were included, the remaining seven categorical options may have led participants to answer in a certain way. Consequently, bias may have occurred resulting in findings obtained not truly representing participants’ opinion(s) (The Victorian Quality Council, 2008).

Table 5: Weafers (2014) Question Posed Revealed Characteristics of a GD
Question Posed in Weafer's (2014) study
What three things would you consider to be most important about the care available to you if you were dying or in the last stages of a terminal illness?
1. To be free from pain.
2. To be conscious and able to communicate
3. To be surrounded by people I love
4. To be at home
5. To have medical and nursing support readily available
6. To have spiritual support available
7. To be in a private space
8. Other
9. Don't know

McCarthy et al.,'s (2009) study which sought to elicit public views on death and dying issues in Ireland, provided a qualitative lens on this topic. Some participants in their study described a GD light-heartedly as 'having a model in one hand and a pint of Guinness in the other'. This resonates with Ryan's (2016), review on death and the Irish whereby he concludes humour is commonly used when discussing the topic of death. Others attributed it to 'dying peacefully in one's sleep', 'dying in old age according to the natural life cycle' or 'when one no longer has dependent children'. All three quotes reveal common characteristics of a GD; being aware, dying after a long life and beneficence for those left behind (Meier et al., 2016; California Healthcare Foundation, 2012). Some also paralleled Weafer's (2004; 2014) findings, associating a GD with having the time to say goodbye to loved ones, being in control, pain-free and having adequate medical supports. More recent public notions of a GD in Ireland were put forth in a national charter on death, dying and bereavement conducted by McLoughlin, (2017) on behalf of the IHF in 2016. This study indicated a shift in public views from Weafer's (2004; 2014) studies on elements considered important to achieve a GD. In asking the public in Ireland what they perceived each person deserves in order to have a GD the following themes displayed in *Table 6* emerged.

Table 6: McLoughlin's (2017) Themes of a GD	
Themes Revealed	
1. Dignity	**6.** Comfort
2. Pain Control	**7.** Wishes respected
3. Respect	**8.** Love
4. Care	**9.** Peace
5. Family	**10.** Support

McLoughlin's (2017) study is an important step forward in Ireland. She accessed 2,563 respondents, making it the largest known public survey conducted in Ireland to date in relation to death, dying and bereavement matters (McLoughlin, 2017).

It implies a public willingness to engage in conversations on death and dying. Yet, as this study is still in the process of rigorous dissection, the consensus of GD components across the study population is currently unknown.

2.4 Current Perceptions of a GD According to Allied EOLC Professionals

In professional terms a GD signifies, quality of care (QOC) at EOL, quality of life (QOL) in EOLC and quality of death (QOD) (Dempsey et al., 2015; Lueng, et al., 2009). For professionals, a GD represents the very essence of palliative care and encompasses the integration of pain and symptom management, preparation for death, life completion, dignity and respect, having social supports and being at peace (Meier et al, 2016; The NCPC, 2016; Dempsey et al., 2015; Callahan-Lesher, 2010; Barazzetti et al., 2010). This understanding has evolved from perceived quality indicators of effective EOLC from the view of the terminally ill, family members, the bereaved and informal caregivers throughout existing national and international literature; all of which have informed policies, frameworks and developments in EOLC (Meier et al., 2016; Mistry et al., 2015; The Office of the Ombudsman, 2014; Weafer et al., 2014; Broom, 2013). Given the breadth and scope of various quality indicators of effective EOLC, some studies have predominately focused on individual themes of a GD (Louchka et al., 2014; Quinlan & O'Neill, 2009). For instance, Quinlan and O'Neill, (2009) examined patient autonomy, a concept which respects individual choice and decision-making processes (Irish Association of Social Workers, 2019), from the perspective of practitioners managing EOL experiences in hospitals throughout Ireland. The following features were considered fundamental for patients in this setting to obtain a GD;

1. Patient autonomy - having choices respected and acted upon.
2. Having access to all the resources and supports available.
3. Having family and professional supports.
4. Managing pain and symptom control (Quinlan & O'Neill, 2009).

While Quinlan and O'Neill's (2009) longitudinal study provided substantial qualitative results, utilising narrative descriptions (102 written submissions), focus groups (104 participants) and interviews (57 interviewees) they focused solely upon the concept of autonomy and involved professional views within hospitals only. Therefore, it is unknown if these themes resonate with the public, professionals working within differing generalised palliative care settings or specialised professionals. Yet, death is everyone's business, thus all must be incorporated in EOLC discussions.

Furthermore, it is essential to obtain all healthcare and other services' viewpoints on the matter in order to fully cater for and address individual EOLC needs and preferences (IHF, 2017). Therefore, my research aims to explore the concept of a GD in both professional and public domains to ascertain whether a consensus on this topic exists in Ireland. It will also capture a broader professional insight on this topic. Other Irish studies exploring positive factors in EOLC have shown one prevalent theme, that of supportive relationships. Findings proposed by Butler, (2017) and O'Shea et al.,'s (2008) investigations of EOLC in long-stay residential settings for older individuals found relationships between the resident, the family and staff were key to having a GD (Butler, 2017; O'Shea et al., 2008). Unlike research conducted in Ireland, international research has sought to investigate a GD in its entirety from multiple viewpoints. Consequently, numerous authors agree commonalities exist between all stakeholders, yet discrepancies in perceptions are also apparent (Meier et al., 2016; O'Shea et al., 2008). Meier et al.,'s (2016), study portrayed evidence of this in their evaluation of international research, involving 12 countries, on the concept of a GD according to healthcare providers, terminally ill individuals and bereaved family members. Themes of life completion and relationships with professionals were given less importance by healthcare providers than bereaved family members of the terminally ill. Additionally, the theme of QOL showed marked differences in its level of importance between these groups with healthcare providers valuing it at only 22%, patients at 35% and bereaved family members at 70%.

As was discussed in chapter one, the main tenet of palliative care is to diminish pain and suffering while also maintaining and enhancing the QOL of a terminally ill individual and his/her family. Added to this, Mistry et al.,'s (2015) Canadian study exploring what matters most in EOLC from the view of allied professionals in community palliative care services, found this heterogeneity exists even among professionals. Their findings implied nurses prioritised including and supporting the family in an individuals' EOLC more so than any other professional group. The authors suggested this may be due to nurses spending more time with patients and families than other healthcare professionals which may lead to enhanced relationships. This increased exposure to both the patient and family may give nurses a deeper appreciation of, and value for the family of the terminally ill. Yet, as Milner et al.,'s (2015) study did not investigate why this finding occurred, their reasoning put forth cannot be confirmed.

Both studies clearly show GD indicators among various groups can differ significantly in terms of their weight and frequency. A limitation of these studies which Meier et al., (2016) acknowledged, is the lack of inclusion of public opinion. Therefore, it is unknown if any or all stakeholders' opinions included in this study correlate or conflict with public ideology in these countries. Briefly mentioned earlier in ***section 1.6 Research Gaps***, this is also the case in Ireland where no known study to date has investigated the views of the public and professionals on quality indicators of effective EOLC. This is despite international studies revealing mutual ideologies on death and dying matters from perceptions of the public and terminally ill individuals, making public inquiries into this topic just as valuable as terminally ill individuals' insight (Milnes et al., 2015; Nozario & Dousti, 2013). Evidence shows the public believe discussions on EOLC should happen before a terminal diagnosis when an individual is healthy and capable of decision-making (National Council for Palliative Care, 2012). Nozario and Dousti, (2013) contend death attitudes are shaped before the onset of an incurable illness. Ascertaining these attitudes and promoting improved ideologies on the topic of death and dying of healthy individuals assists healthcare professionals in diminishing vulnerability experienced by the terminally ill and their families/caregivers. Societal perspectives on death and dying matters cannot be underestimated as public insight helps to ensure EOLC reflects a general consensus on what matters most at the EOL (Scottish Government, 2010). Resultantly, it is apparent that research is needed to establish if public opinion(s) on what matters most in EOLC correlates with professional opinion.

Thematic Analysis

2.5 Most Common Themes of a GD Nationally and Internationally

Analysis of national and international research revealed three main recurring themes of importance considered essential to assist in the facilitation of a GD on both an individual and professional level;

1. Choice and Control.
2. Sources of Support.
3. Maintaining Personhood (Meier et al., 2016; Weafer, 2014).

2.6 Choice and Control

A common national and international element considered essential in achieving a GD is having choice and control over one's fate. Many characteristics are involved in this theme. The most commonly cited are death preparation and planning, saying goodbye to loved ones, choice on place of care and receiving care in accordance with individual preferences.

2.6.1 Death Preparation and Planning

For many, Death Preparation and Planning (DPP) involves having the opportunity to put one's affairs in order and state medical treatment preferences (Jasemi et al., 2017; Rainford et al., 2016; Meier et al., 2016: The Office of the Ombudsman, 2014). Planning for one's death has huge significance in the quality of EOLC an individual receives and should not be limited to the terminally ill (The National Advisory Committee of Palliative Care 2016; Nici & ZuWallack, 2014; Sallnow et al., 2012). On an individual level, DPP provides a future sense of control, especially if an individual becomes cognitively impaired (Sallnow et al., 2012). It is also fundamental prior to a medical crisis or terminal diagnosis as it informs EOLC, helping to ensure service provision meets individual needs and choices. Undoubtedly, DPP is a vital component from a professional viewpoint as it increases a holistic, person-centred approach (Mistry et al., 2015). This person-centred focus was strongly emphasised in Mistry et al.,'s (2015) Canadian study of allied professionals' perspectives into what matters most in EOLC. 51% (n=107) of their participant sample reiterated the most fundamental aspect of EOLC is meeting the needs, wants and desires of the patient (Mistry et al., 2015). However, it seems this view may not be shared by the public as current research in Ireland alone portrays a public reluctance to make provisions for the eventuality of death (O'Shea et al., 2018; Weafer, 2014; McCarthy et al., 2009). While this lack of public engagement with DPP is acknowledged, authors affirm the drafting of a will, making funeral arrangements and organ donations are the most common measures taken by the public in Ireland (Weafer, 2014; McCarthy, 2013; McCarthy et al., 2009). For example, while research demonstrates females (60%) tend to be more proactive in this regard than their male counterparts (53%), three in ten adults have made a will in Ireland (O'Shea et al., 2014; IHF, 2017).

Noteworthy, these planning arrangements tend to reflect beneficence for others rather than for oneself which is a common trend throughout Irish literature (Weafer, 2014; McCarthy et al., 2009). This contradicts findings from a national survey conducted by the Forum on End of Life in 2009, highlighting public desires for the implementation of some form of initiative which would enable the recording of care preferences should future capacity to do so be compromised. Thus, implying DPP was considered important by the public (Weafer et al., 2016). The Irish Hospice Foundation ‘Think Ahead’ programme and the introduction of AHDs discussed earlier in chapter one, were implemented as remedies. Yet, there are issues concerning the accessibility, evaluation, recording and monitoring of these initiatives (Sharp et al., 2018). Presently, editable, downloadable ‘Think Ahead’ forms are available electronically from the IHF website. However, the latest CSO, (2017) figures on internet accessibility and usage in Ireland show although an estimated 89% of households currently have access to the internet, 43% lack the necessary skillset to use it. Therefore, it could be construed that this percentage is indirectly excluded from availing of this option (CSO, 2017).

Alternatively, a hard copy of this form may be obtained upon request via local Citizens Information Centres (CIC) throughout the country and advice on how to fill in the form can be sought from general practitioners (GP) (CIC, 2018; IHF, 2017; O’Shea et al., 2014). However, Sharp et al.,’s (2018) study of 21 GPs attitudes to conversations on advanced care planning with frail and older individuals with non-terminal conditions in the UK, found some GPs recounted difficulties experienced in the documentation of advanced care plans and AHDs, deeming these forms restrictive, more akin to a ‘tick-box exercise’, non-user-friendly and largely inaccessible to patients bringing the principle of person-centredness into question. Although only in infancy stages in Ireland, AHDs are also not widely accessible, recorded or monitored. Regardless of these issues, Weafer, (2014) concluded 73% of the public had taken no action in the documentation of an AHD (Weafer, 2014). This lack of public uptake in AHDs is noted internationally. Research shows just 5% of the public in the UK (British Social Attitudes, 2012) and 6% in Australia (Palliative Care Australia, 2018) had drafted an AHD. While Weafer, (2014) did not explore what may hinder EOLC planning, he did uncover some respondents, aged from 55 years onwards were more likely to have drafted an AHD compared to 87% of those aged 18-24 years who had taken no action in this regard.

This implies that older individuals are more likely to have given their death serious consideration or taken some form of EOLC planning in comparison to younger cohorts. This assumption on age differentials is shared by other researchers in the area of death and dying in Ireland, who also assert older individuals seem to be more open to aspects of DPP (McCarthy et al., 2009). One reason for the low uptake of AHDs in an Irish context was proposed by McCarthy et al., (2009). All 16 participants involved in their study, reported they were confused on the meaning of an AHD, a concept which seeks to enable competent individuals to express care and treatment preferences in the event the loss the capacity to do so in the future (House of Oireachtas, 2019). After providing a definition of this term to participants in this study and thereafter again asking for their opinion of them, some felt they were a good idea, while others worried about reconsiderations after the drafting of such a document. The most significant reason for a public lack of DPP in the UK centres on the belief that 'death feels a long way off' (NatGen, 2013). This suggests that respondents felt they would have adequate time and sufficient future capacity to plan for such matters**.** Further deficiencies in DPP among the public is portrayed in America and Japan, where the execution of a will alone is considered a rarity (Prince-Paul & DiFranco, 2016; Kissane et al., 2015). Being unaware of one's death is a cultural norm in Japan. This may directly halt DPP as individuals may not want to be informed of a terminal diagnosis (Kissane et al., 2015).

Whereas, according to Prince-Paul and DiFranco, (2016) the American public tend not to identify the importance of DPP until after a medical crisis has occurred. However, in such scenarios, anxiety, fear and uncertainty may cloud logic and reasoning behind decisions made. The worst conceivable time to deal with these delicate decisions and EOLC planning is when diagnosed or suffering from a terminal illness (Huenchuan, 2017; Carr & Luth, 2017; Prince-Paul, 2015). Advance planning alleviates this upheaval and worry and promotion of such should be of the utmost importance (Huenchuen, 2017). Religious inclinations are also a predominant element impacting on an individual's readiness to make provisions for one's death throughout current literature (McCarthy et al., 2009; Lueng et al., 2009). While some authors associate religious teachings, as a contributor to death anxiety, for example, punishment in the afterlife (Dezutter et al., 2009), others affirm that religious devotion and beliefs positively relate to perceptions on death preparation, instilling a sense of acceptance and life completion (Lueng et al., 2009).

Therefore, this aspect must also be considered in the exploration of a GD. There are also professional challenges in meeting this component, particularly regarding communication. Research reports a professional reluctance to have these conversations both pre and post terminal diagnosis as they are deemed difficult to instigate and it is feared they may incur a loss of hope for the individual (Lewis, 2013 cited in Cithambaram, 2017, p. 15; Almack et al., 2012). White et al.,'s (2013) secondary analysis of literature, exploring healthcare professionals' views on dying in intensive care units, proposed professionals may postpone such discussions until the later stages of illness. Again, this is problematic as disease and co-morbidity issues may compromise cognition and capacity (White et al., 2013). Sharp et al., (2018) further contend they cause patient and family distress and feelings of guilt on utilising healthcare resources. They imply patient's willingness to engage in such discussions is also problematic due to 'individualism' as some would welcome this while others would refuse to engage in such conversations. For those that do converse on such matters, it is said to incur a sense of peace, relief and security for both the individual and his/her family/loved ones (Sharp et al., 2018). Yet, even when patients undertake necessary DPP arrangements, problems reflected in McCarthy et al.,'s (2009) study may arise concerning last-minute desires to alter previously recorded decisions and preferences, leaving professionals ill-prepared to enact updated wishes (Sharp et al., 2018). A further issue heightening the need for DPP is raised by some authors who state while a shift to a holistic model of care has and continues to evolve since the emergence of the hospice movement, some professionals still use the outdated, traditional medical model of care focusing solely on curative approaches. Thus, documenting aspects regarding individual preferences on medical treatments is important for patients to receive person-centred care and for professionals to provide it (Jersemi et al., 2017; Rome et al., 2011).

2.6.2 Place of Care

A further aspect of this theme on choice and control, is a desire to have control over one's place of care (POC). Home is regarded as the most desired public preference in POC if nearing EOL both nationally and internationally (The Choice in End of Life Care Programme Board, 2015; Joint Committee on Health & Children, 2014; Palliative Care Australia, 2014, McKeown, 2014; Weafer 2014; Gomes et al., 2013). Professionals also acknowledge enabling and supporting an individual to die at home corresponds to high-quality EOLC (De Roo et al., 2014).

Yet, of the estimated 28,000 individuals who die in Ireland annually, only one in four do so in their own home (The Irish Hospice Foundation, 2017). Instead, over 70% of individuals die outside their home. Approximately 22% die in residential care or other long-stay settings and 48% die in hospital settings where privacy, space and maintaining patient autonomy (***glossary***) and dignity are challenging (IHF, 2019; Pollock, 2015; Centre for Ageing Research & Development in Ireland, 2014; Quinlan & O'Neill, 2009). There are cultural variations to this preference. In Ireland, home is linked to familiarity, comfort, safety and accessibility to loved one's (McKeown, 2014). Whereas in China, it correlates to a cultural belief that the deceased's spirit will rest in peace. To do otherwise is believed to bring misfortune to the deceased in afterlife (Kao et al., 2018). Cross-cultural variations in POC are also evident in Ireland among minority groups such as the travelling community who view dying at home with apprehension as the deceased's belongings are said to bring bad luck to the bereaved. Common rituals shared by Apachè Indian tribes entail the deliberate incineration of a deceased member's belongings and place of residence in efforts to reduce bad omens (Elder et al., 2009; Quinlan, 2009). While this tradition may have dissipated in more contemporary times due to settlement and economics, a deceased's member of the traveller community trailer is still disposed of in accordance with these beliefs (McQuinlan, 2013). Although the travelling community view hospital and homecare supports as important resources, they report issues with both services (McQuinlan, 2013). Homecare is deemed inappropriate by this client group due to the overwhelming sense of sadness a death incurs for the family: while hospital settings are considered problematic due to perceived discrimination and an inability to cater for the collective nature of the travelling community. One hundred family members or more may rally around a member approaching death for comfort and support. However, such crowds can be intimidating and cannot be accommodated in such settings (McQuinlan, 2013). The travelling community also display aversion to inpatient hospice care as it signifies a loss of hope, a concept they cannot live without. Notably, hospice settings may be best equipped to accommodate this client group, yet inadequate knowledge of this service halts them availing of such services. This is concerning as members of the travelling community report higher instances of chronic illness than most of the public in Ireland (McQuinlan, 2013). Disease type may predict preferences in POC.

For example, Kissane et al., (2015) utilised hypothetical situations in their Japanese quantitative study involving 969 public respondents, to test the widely held assumption on home as the preferred POC. Using three case examples namely, cancer, dementia and cardiac failure, they discovered findings to the contrary. When asked the public preferred POC if suffering from cancer, 39% stated home as their chosen POC, while 49% indicated a hospital setting. For cardiac failure, 53% of respondents implied favouring a hospital environment, while 22% reported a desire to remain at home. For dementia care more weight was given to a residential care setting than either a hospital or home environment. Yet, while it may be construed from this study that disease type is an influential factor, Kissane et al.,'s (2015) quantitative approach did not establish why this may be the case. Therefore, this study will ask the public what preferences they may have on POC if terminally ill and why this location is considered important to them. Other research infers further inconsistencies regarding home as the most preferred POC if suffering from a terminal illness. Arnold et al.'s, (2015) review of 1,127 patients' case notes on POC in the UK found gender differences, age, life stage, prior death related-experiences, exposure to EOLC services and not wanting to become a burden on family/loved ones were all deemed to incur negative views on dying at home (Weafer, 2014; Gysels et al., 2012; Cox et al., 2012). Any of these factors could be shared among the public. Divergent views on this topic among the public and professionals is apparent throughout international literature. Gysels et al.,'s (2012) review of literature on EOLC and culture in Germany, Italy, the Netherlands, Norway, Belgium, Portugal and Spain showed professionals placed greater emphasis on home as the preferred location of care compared to the public. Therefore, how congruent or dispersed are public and professional views on what matters most in EOLC in Ireland? This is relevant to establish whether current EOLC service delivery reflects or contradicts societal expectations.

2.6.3 Saying Goodbye to Loved Ones

Having the opportunity to say goodbye to loved ones is also a defining component in maintaining choice and control (Kinghorn & Coast, 2018; Otani et al., 2017; Weafer, 2014; MacMurray, 2011; McCarthy et al., 2009). While it is not surprising there are strong desires to say goodbye to significant others, notably the definition of 'family' and or 'loved ones' may have diverse individualistic meanings. Weafer, (2004-2014) discovered that 23% of public respondents stated they would like to be surrounded by their pets if nearing EOL.

Thus, implying for some a pet may be held in similar regard to family members/loved ones. Affirming this claim, research indicates Ireland is a pet-friendly nation with 61% of households possessing a dog or cat and 91% regarding both as a member of the family (Pet Sitters Ireland, 2018). For many, saying goodbye to loved ones instils a sense of life completion, facilitates conflict resolution and rebuilds fractured relationships, all of which instils a sense of peace, comfort and closure for those approaching death (Cancer Council, 2017). Hong et al, (2016) further states having this discussion diminishes the burden of guilt of leaving loved ones behind. However, for some saying goodbye may be an extremely difficult task to undertake, therefore, professional assistance is often required. Memory boxes, memoirs, an emotional will, letters and audio and/or visual messages are common activities encouraged and supported by professionals to assist individuals in final farewells **(**Cancer Council, 2017). As death draws nearer palliative care professionals are instrumental in alleviating the burden of care commonly experienced by families and caregivers of the terminally ill. They also assist in maintaining and strengthening these relationships in efforts to enable an individual to reach a peaceful transition towards death (Rome et al., 2011). Having the opportunity to say goodbye to loved ones enables those left behind to begin an anticipatory grief process, giving them time to gradually come to terms with the loss even before their loved one has died. Similar to the terminally ill, this conversation gives significant others closure, the opportunity to complete unfinished business and provides a sense of peace in knowing that they did all they could for their loved one (National Cancer Institute US, 2017). Correspondingly, this study will ask all participants what they consider as the most important supports to achieve a GD to ascertain if having the opportunity to say goodbye to loved ones is prioritised in an Irish context.

2.7 Sources of Support

Another parameter acknowledged as an element of a GD is the topic of formal and informal support networks. Navigating through a terminal illness is not an isolated journey, rather it is one accompanied by family, loved ones, friends, and professionals (Keeley, 2017).

2.7.1 Family Support

The desire to be surrounded by family/loved ones when nearing one's death is a frequently cited cross-cultural theme throughout national and international literature, confirming the importance of supportive relationships and continuing bonds (Samerchua et al., 2016; Meier et al., 2016; Weafer, 2014; McCarthy et al., 2009). Family and social support networks are a critical component for the terminally ill in providing emotional support, life validation, incurring a sense of belonging, purpose and worth and assisting with difficult decision-making processes regarding care preferences (Hong et al., 2016; Ko et al., 2015; Zaider & Kissane, 2009). While this desire resonates with 82% of the general population in Ireland, international research depicts divergent views (Weafer, 2014). In Sweden for example, 513 public visitors to a museum exhibition entitled 'Room for Death' from 46 countries, were asked by Lindqvist et al., (2015) for narratives on their perceptions regarding preferences of place and surroundings if they were dying. In common with Irish literature (Weafer, 2004; 2014), a wish to be surrounded by loved ones was recounted by some participants, yet other descriptions entailed what Lindqvist et al., (2015) terms as the 'lone death' scenario, whereby one dies in solitude. Although minimal explanations were given for this preference, they unintentionally or deliberately centred on not having familial supports for some or out of a need to shelter loved ones from sadness for others.

Presenting additional rationale, Hong et al., (2016) further state many terminally ill individuals deliberately choose to spend minimal time with significant others in efforts to reduce a perceived burden of care or to increase pain management options, preferring instead to gain greater support from professionals often outside the home environment. This study clearly shows while the presence of significant others when nearing one's death is deemed symbolic of a GD, this is not always the case as isolation for some may be just as crucial. In addition to individual needs, supports for the family of a terminally ill person is also acknowledged as a recurring GD theme throughout existing national and international literature (Kim & Yi, 2015; Girgis et al., 2013; IHF, 2013, Park et al., 2010). In a recent systematic review of literature involving 29 articles in Australia on informal caregiver needs in assisting a loved one in their cancer care, Lambert et al., (2012) outlined how informal caregivers, mainly family members and or partners, also possess unique physical, social and psychological needs. They revealed how informal caregivers see themselves as equally 'battling the illness' and facing multiple knock-on effects of such throughout the illness.

However, they showed informal caregivers experience many unmet needs, especially regarding financial, social, physical and psychological supports. This not alone adversely impacts upon the informal caregiver (s) QOL, but also on the terminally ill individual, diminishing QOL, psychological and social well-being. Supports for families both pre and post-death were considered important by the public in Irish literature, with Weafer, (2014), McCarthy et al., (2009) and McLoughlin, (2017) all highlighting a public desire for family, significant others and even pets, in some cases, to be supported and looked after in the event of their death. In agreement, many authors describe the dyad of patient and family as the pillar of palliative care (Hattrori & Ishida, 2012, cited in Estebsari et al., 2017, p. 4; Borimnejad et al., 2014; The IHF, 2013; Broom et al., 2013; Wilder et al., 2008). Owing to the significance of supports for informal caregivers, this research will explore if and how this client group are implemented into the care trajectory to establish the perceived effectiveness of support structures for family/loved ones of the terminally ill.

2.7.2 Professional Support

According to the IHF, (2013) international literature suggests that professional support leads to enhanced QOL for the terminally ill by delivering increased effectiveness in symptom control, emotional support for both the individual and their loved ones and longevity of life. In Ireland, survey findings from the 2016 Irish Charter on Death and Dying report revealed the public view the following as important professional supports if terminally ill or nearing EOL;

1. To be supported in decision-making.
2. To be provided with adequate pain management.
3. To be cared for in a place of ones choosing with professional supports on standby.
4. To be treated individually, with dignity and respect maintained both pre and post-death.
5. To be supported to cope with a terminal diagnosis and any perceived stressors or worries that may unfold (IHF, 2013).

A full report on this charter by McLoughlin, (2017), outlined how many participants relayed they were averse to family involvement in their direct care needs if terminally ill Therefore, it could be construed that the public in Ireland contend formal supports should be more involved in EOLC than informal support networks. Irish literature reflects public perceptions on professional supports in terms of both biological and psychosocial care needs, as the previous points taken from the 2016 report clearly demonstrates, with physiological pain, dignity, individualism, autonomy, self-determination (***glossary***) and respect, all hallmarks of the BPSSM of palliative care encapsulated within perceptions outlined (IHF, 2013). International literature involving professionals show similar results (Bormneiad et al., 2014; Ko et al., 2015; Kirby et al., 2013). However, some authors (Salehe & Njine, 2016; Borimnejad et al., 2014; Kirby et al., 2013) provide additional supportive elements, namely, the importance of the patient-professional relationship, trust, empathy and emancipation. They state the aforementioned enables the development of reciprocal relationships between both the terminally ill individual and the professional. For instance, in Borimnejad et al.,'s (2014) qualitative study exploring 10 nurses' experiences in EOLC in Iran, trust alone was found to instil effective patient-nurse relationships. Within this trusting relationship, nurses were considered an extension of family or friends, thereby facilitating a holistic approach to care and assisting in anticipating patient and family needs. Other western research in this area support these findings (Kirby et al., 2013). Yet, in absence of a comparative study involving both the public and professionals, the level of significance given to each element described above by both groups is currently unknown. This leads to question, 'Is there differences in the level of significance of these elements among both groups and if so why?

Palliative and EOLC are physically and emotionally taxing professional domains (Kamal et al., 2016). Many challenges identified as risk factors for stress encountered by allied professionals in EOLC are evident throughout existing literature. The most commonly cited are the emotional and physical demands of caring for individuals with complex needs and families/loved ones, inadequate training, conflicts among all stakeholder from patients, families, professionals within and across service settings, and difficulties with prognostication and disease trajectories (Pelon, 2017; Kamal et al., 2016; Davis et al., 2014). Several authors imply stress is a prominent feature in palliative care.

Many verify the exposure of allied professionals to multiple stressors and the nature of the work can lead to negative effects such as burnout and compassion fatigue (Odhiambo & Rutto, 2018; Plen, 2017; Kamal et al., 2016; Davis et al., 2014, Beckstrand, 2012). Despite these numerous professional obstacles outlined, Mills et al.'s, (2017) systematic review of 38 articles in Australia exploring allied palliative care professionals' compassion and care towards themselves and patients, found professionals deemed their role provided an overwhelming sense of meaningfulness leading to professional and personal satisfaction. Both factors shield against occupational-related stressors diminishing the occurrence of emotional fatigue and burnout.

2.8 Maintaining Personhood

According to Kitwood, (1998, cited in Fazio et al., 2018, p. S11) personhood, which he terms 'selfhood', encapsulates psycho-social elements of human beings and is a core component of person-centred care (Kitwood, 1998 cited in). It depicts the uniqueness of human beings entailing individual belief systems, values, culture and identity, thus holistically viewing the whole being of an individual rather than any illness he/she may be suffering from (Fazio et al., 2018; Chochinov et al., 2015). Personhood is established through strong relationships that give an individual a sense of purpose, belonging and connectedness. Through this approach individual's social identity remains intact and their psycho-social needs are incorporated (Marhardt & Spira 2013). Throughout international literature, personhood is linked to being treated with respect and maintaining normalcy, dignity and independence. For instance, Fitchett et al.,'s (2015) review of literature on dignity therapy in America found maintaining normalcy after a terminal diagnosis is instrumental in maintaining personhood.

2.8.1 Dignity and Respect

The public tend to discuss personhood in terms of maintaining dignity and being respected (Butler, 2017; Weafer, 2014, Scottish Government, 2010). This was evident in Weafer's, (2014) study whereby 46% of the population rated dignity significantly. In McLoughlin's, (2017) research, being pain-free, aware of one's death, respected as a person, possessing capacity to choose and having choices respected, having the option of euthanasia practices and accessibility of adequate professional supports were all described as elements in maintaining dignity and personhood.

In McCarthy et al.,’s (2009) study these components also meant having the ability to make individual decisions and being fully informed and aware. In the UK, the public associated dignity with having respectful caring support (National Council for Palliative Care, 2016). Whereas, in Yun et al.,’s (2018) exploration of public, professional and patient attitudes towards EOLC interventions in Korea, these elements were linked to having adequate pain management. Kennedy’s, (2015) review of literature on dignity in EOLC provided further characteristics of a GD namely, communication and empowerment. Communication was deemed to assist in preserving dignity by giving and receiving information and having choice and control, while empowerment involves maintaining and enhancing self-esteem and worth.

2.8.2 Independence

No mention of independence is made in national literature (McLoughlin, 2017; Weafer, 2014) yet although minimally, it is cited by international authors mainly in terms of one’s ability to maintain self-care and to be pain-free (Hartogh, 2017). While for others it relates to maintaining cognitive and physical functioning if terminally ill (Balducci, 2012). As illness progresses a loss of independence may evolve. Those who consider this element significantly will need support to grieve this loss (Cancer Care Victoria, 2019).

2.9 Challenges Hampering Individual Opportunities for a GD

Many challenges hamper individual opportunities to accomplish a GD. The most cited obstacles depicted throughout national and international are herein discussed.

2.9.1 Resource Issues

Resource issues are a recurring feature in palliative and hospice care, especially urban and rural provinces (Githaiga & Swartz, 2017; Nasrullah, 2017; IHF, 2013). Ireland is similar in this regard, portraying substantial resource limitations, the most notably of such involve the uneven distribution of service delivery throughout the country, first acknowledged nationally by the NACR, (2001) (NCPC, 2011). The southeast region of the country reports the greatest discrepancies in this regard, where there remains no inpatient hospice setting, minimal palliative care in-patient beds in hospitals throughout the region and staff shortages. There is also no medical social worker currently available within this region (NPCC, 2014).

2.9.2 Impact of Resource Issues on Informal Caregivers

According to the latest CSO figures 195, 263 individuals are identified as providing unpaid caregiving in Ireland representing a 4.4% increase from previous 2011 figures of 187,112 (CSO, 2018). Primary informal caregivers of the chronic or terminally ill are predominantly female family members or friends (60.5%) aged between 35 and 64 years. A spouse, parent and/or adult child may also adopt a caregiving role (Hanley & Sheerin, 2017). While research shows cultural norms, gender roles, familial belief systems and/or a personal onus (Pharr et al., 2014) as reasoning for adopting a primary informal caregiving role, resource issues may also increase the likelihood of this (Otis-Green & Juarez, 2012). Yet, the under-resourced structures of professional supports for this client group mean their needs are often unintentionally overlooked (Nasrullah, 2017). Research suggests that informal caregivers are at an increased risk of developing adverse health effects such as chronic stress due to caregiving responsibilities and emotional fatigue necessitating the inclusion of this group into the care trajectory (Morris et al., 2015; Borimnejad et al., 2014; Hattrori & Ishida, 2012, cited in Estebsari et al., 2017, p. 4; The IHF, 2013; Wilder et al., 2008). The lack of supports for this client group also adversely impacts the terminally ill, diminishing their QOL, psychological and social well-being (Lambert et al., 2012).

2.9.3 Impacts of Resource Issues on Formal Supports

Two prominent challenges coinciding with resource issues experienced by professionals, depicted in national and international literature, are that of environmental issues and time constraints (Vlug et al., 2013, Quinlain & O’Neill, 2013). Vlug et al.,’s (2013) study uncovered impacts of both these elements in their investigation of residents dignity in EOLC in the Netherlands involving 28 nursing home care staff. They found preserving dignity in this environment is difficult (Vlug et al., 2013). Lack of privacy, space and personal belongings in this setting meant many violations may unintentionally occur (Vlug et al., 2013). Many participants described how time constraints resulted in ethical dilemmas and feelings of guilt as it hampered time spent with residents. Staff shortages were said to lead to unmet hygiene needs of residents for prolonged periods. An Irish report conducted by McKeown, (2014) mirrored these obstacles in hospital environments. Further Irish research conducted by Quinlan & O’Neill, (2013) concluded neglect of patient autonomy in hospitals contradicting principles of holistic palliative care (Quinlan & O’Neill, 2013).

They also determined religious supports were lacking due to resource issues in hospitals. Underfunding means only two pastoral care workers may be caring for entire hospital populations currently in Ireland. Even though Ireland is considered an ethnically diverse nation, this implies disregard for religious diversity. They claim when a patient is nearing death in Irish hospitals a priest is routinely called by an individual's bedside, whether requested or not (Quinlan & O'Neill, 2013; McCarthy, 2013). Cultural norms of collectivism are also not fully catered for or understood among professionals in hospitals (Quinlan & O'Neill, 2013).

2.10 Issues Concerning POC

Numerous challenges impacting upon a terminally ill individuals' ability to remain within the home environment are apparent throughout current literature. Inconsistencies in community and informal support networks, fiscal constraints associated with modifications and equipment necessary for a terminally ill individual to remain at home, poor infrastructure and lack of professional resources are the most recurring obstacles (McKeown, 2014; Centre for Ageing Research and Development in Ireland, 2014). Facilitating this desire incurs conflicting ethical dilemmas for professionals of providing holistic care in accordance with individual wishes and maintaining patient safety, which inevitably may override the latter (Cipolletta & Oprandi, 2014). For 'what is desirable is not always possible' (Taylor, 2008). This hampers professionals' ability to provide this constituent of a GD and holistic care in accordance with individual wishes. Consequently, dying at home for many continues to be an aspiration (McKeown, 2014).

2.11 Challenges with Informal Supports

Added to resource issues, research highlights that families and friends may incur a paradox of sorts for allied professionals in EOLC (Odhiambo & Rutto, 2018). On the one hand, families/loved ones enhance QOL and QOC for the terminally ill by being present and maintaining normality (Wolfenberger, 1974 cited in Mallet & Runswick-Cover, 2014, p.21) for the terminally ill attempting to make their situation bearable (Davies, 2014; Beckstrand, 2012). Alternatively, they may become demanding, unrealistic and difficult, even withholding information critical for the care of the individual which negatively impacts on the patient-family-professional relationship (Odhiambo & Rutto, 2018). This may be due to an inability to accept their loved one is dying (Nasrullah, 2017) which again highlights the need for pre-bereavement supports for this client group.

2.12 Socio-Cultural Aspects

Culture has fundamental importance when considering the formation of attitudes towards death, illness and individual EOL decisions as it undoubtedly shapes these views (Richardson, 2014). It is within society that we learn about and experience death which shapes our views, how we express grief and how we come to accept or deny death (McCarthy et al., 2010). Our attitudes and belief systems become socially constructed representations of our culture, societal norms, familial values and religious beliefs and traditions (Galbin, 2014; McCarthy et al., 2010). Research conveys the influence culture plays on death and dying attitudes; therefore, it must be considered when exploring perceptions of a GD (Gire, 2014; Galbin, 2014; McCarthy et al., 2010).

2.12.1 Discourse on Death and Dying Matters

Prominent thinkers in the area of death and dying related matters have long proposed there exists a sense of fear and helplessness concerning human mortality (Becker, 1974, p.10) which has attributed to a death-denying culture on the topic death (Kubler-Ross, 1997, p.29). This is evident in contemporary society as death remains a social taboo on a global scale (The National Council of Palliative Care, 2016; Gire, 2014, Weafer, 2014; McCarthy et al., 2013; Bloomer et al., 2010). Consequently, conversations on death and dying are often avoided by both professionals and individuals (Weafer, 2014: Bloomer et al., 2010; McCarthy et al., 2009). McCarthy et al.,'s (2009) study findings suggests there can be a sense of awkwardness around discussions on death and dying in Ireland. These topics can be viewed as morbid or superstitiously unlucky in some way. In her recent book detailing a collection of her professional memoirs, English palliative care physician, Dr. Kathryn Mannix (2016), states this awkwardness is due to the medicalisation and institutionalisation of death, which resonates with influential historian on death attitudes, Philip Ariés (1974), concept of the *forbidden or invisible death*. He asserts modernity has transformed death from a predictable, communal event predominantly occurring at home, to a fearful, unpredictable, unwanted, and isolating incident (Aramesh, 2016, p.4). Mannix further implies, because we lack familiarity with death and all that it entails, the topic has been replaced by euphemisms such as, 'passed away', 'drifted away' and 'no longer with us'. While some view the use of such metaphors is to convey the death of an individual in less explicit terms (Despelder, 2008), others contend this vocabulary suggests a lack of openness and negativity towards death (Demjén et al., 2016).

Weafer et al.,'s (2009) study further affirmed these claims in an Irish context. Utilising an Omnibus survey, its original population sample of 1,046 dwindled to 667 once participants fully understood the nature of the topic. While reasons to decline were not stated, the authors maintained this was not due to time constraints, as many of these participants subsequently answered other sections on the survey. Hence, although it cannot be validated, they determined it may have been the nature of the topic under investigation that deterred participation in this section. Likewise, research in the UK confirms two-thirds of the population are uncomfortable discussing death and dying matters even though it is considered less of a taboo topic in comparison to twenty years ago (National Council for Palliative Care, 2012). This lack of open discourse on death has serious implications for both an individual and society and in aspiring for a GD. It may potentially lead to past or future related regret(s) such as feeling one's life was unfulfilled in some way or that future aspirations will not be achieved, meaning many individuals may approach their EOL with unresolved death anxiety (Tomer et al., 2007, p. 318). Additionally, individuals are less prepared for their own death or that of a loved one. Consequently, many do not make plans or stipulate future care preferences in the event of a terminal illness, therefore many individuals may not acquire the kind of death they wish. Additionally, financial and legal implications of disease and death are not contemplated increasing distress experienced by a decedent's family/loved ones (Scottish Government, 2010).

2.12.2 Changes in Family Structures

At a societal level, individuals and communities are less prepared for the impact of grief or to provide support to the bereaved. Family structures have become disparate with many members no longer living in close proximity and both genders routinely working outside the home. Consequently, care is largely provided by professionals as many families may lack the time, knowledge and skill to provide such care (Scottish Government, 2010). This has led to a perceived assumption and expectation by younger generations that care of the terminally ill should rest solely within professional domains (Scottish Government, 2010). Lack of familial support networks further impacts upon an individual's ability to remain in the home and places increased pressure on already under-resourced, over-stretched palliative, hospice and EOLC services.

This adds to the institutionalisation of death, hinders community involvement and supports and further removes death and the dying from the normalcy of everyday life (Scottish Government, 2010).

Life expectancy increases will heighten the demand for EOLC service delivery (Jack, 2015). Future EOLC care needs to incorporate both formal and informal caregiving to fully address the needs of the terminally ill (Jack, 2015; Scottish Government, 2010). Yet, this may be unattainable at present as evidence suggests families and communities may be ill-equipped to take on such responsibilities (Scottish Government, 2010). More recent research in Ireland (Weafer, 2014) reports 85% of the public state they feel comfortable talking about death and dying related topics. Death Café conversations are gaining momentum in Ireland, with 29 events listed in 2018 alone and over 3,000 events held within 33 countries to date (Death Cafès Ireland, 2018;). Hosted by prominent national, voluntary organisations and members of the public, to promote dialogue, guidance and diminish fear and societal barriers, in a relaxed environment, they have received an overwhelmingly positive response from the public (IHF, 2017). However, this perceived public openness on death has not developed into practice given the lack of public uptake on DPP in Ireland (Weafer, 2014).

2.13 Professional Discourse on Death and Dying Matters

Irrespective of public or professional exploration, social and cultural mechanisms underlie interpretations of death (Brussel & Carpenter, 2014). Therefore, mirroring public contention, professionals' personal and cultural views on death and dying may impact their professional ability to engage in such discussions (Benerjee et al., 2016). Additionally, living and working within a death-denying culture makes it extremely difficult for professionals to engage in open and honest communication on death and dying (Scottish Government, 2010). In practice, the main identified problem areas undermining the efficacy of communication are, censored information and truth-telling, both of which impact on the disclosure of a terminal diagnosis (Punjani, 2013; Bequiri et al., 2012). Research shows family members may ask professionals to conceal information from their terminally ill loved ones in efforts to shield them from their condition, leading to collusion and censored communication (Weafer, 2014; Punjani, 2013). Many authors state truth-telling raises ethical dilemmas for professionals of potentially causing harm to individuals if complete disclosure of a terminal diagnosis is given (Sarafis et al., 2014; Quinlan & O'Neill, 2013; Almack et al., 2012; Bloomer et al., 2010). Therefore, similar to censored information, half-truths may be given as some professionals believe to do otherwise may diminish hope for the terminally ill or they may not have the ability to cope with this information (Punjani, 2013).

Many national and international authors convey other numerous challenges encountered by professionals (Pendleton & Krohon, 2018; Office of the Ombudsman, 2014; Sarafis et al., 2014; Quinlan & O'Neill, 2013; Beqiri et al., 2012; Zafedi, 2011**).** Banerjee et al.,'s (2016), American study, which sought to elicit communication challenges in EOLC from the view of 120 oncology nurses highlighted many of these challenges. Utilising a qualitative survey, the main issues uncovered were dialectic tensions, conversations on palliative care and EOLC goals and characteristics of the patient and family. Dialectic tensions detailed the balance of attachment versus detachment between the nurse-patient relationships**.** Some nurses described this may lead to transference resulting in an inability to relinquish emotions when conversing on EOLC discussions with patients. A second tension recounted focused on balancing informing the patient and family or withholding information. Several nurses conveyed situations where a physician's personal unease in introducing EOLC discussions left them carrying the burden of bad news prior to patient-family disclosure. This is concerning as research suggests physicians are the main communicators of a terminal diagnosis (Nwodoh et al., 2018).

In addition to Benerjee et al.,'s (2016) study, some authors imply physicians can be unrealistic about prognosis and available treatment options (Pendleton & Krohon, 2018). The emphasis is shifting from curative to individualised, person-centred care (Cithambaram, 2017), yet some physicians may hold an outdated perspective on terminal illness, viewing it as a failing of medical practice (Pendleton & Krohon, 2018). This contradicts policies and initiatives promoting individuals to become experts in their care (McCarthy et al., 2009). Furthermore, how can an individual make fully informed decisions on care needs without adequate information? Achieving other characteristics of a GD such as having the opportunity to say goodbye to loved ones, putting one's affairs in order and spending precious time with significant others is also questionable. For how can one accomplish these tasks if he/she is unaware of his/her impending death? Regarding conversations on palliative and EOLC goals, Banerjee et al., (2016) uncovered three main obstacles. Firstly, nurses found patient-family emotions problematic, especially when transitioning from palliative care to EOLC. Secondly, they described a challenge recognised in Irish literature (Weafer, 2014), where patient expectations and their willingness to engage in EOLC conversations impacted upon communication flow. Thirdly, questions on EOLC goals and what to expect when nearing EOL were considered difficult to answer by some nurses.

Nurses described how patients or family members routinely ask ‘when’ and ‘how’ questions on the dying process. They point out that concepts such as ‘the body shutting down’ are both challenging to explain and comprehend. Characteristics of the patient and family, such as dealing with pediatric patients, young patients with dependent children, the family’s inability to let go and differing cultural belief systems were all said to impact on nurses’ caregiving role and communication (Benerjee et al., 2016). Other obstacles impacting on effective dialogue, which Benerjee et al.,’s (2016) study did not consider are language barriers and the patient’s condition (Marie Curie, 2018). While the withholding of full disclosure is not due to malicious intent, it opposes palliative care principles and aspects considered important for a GD by both the public and the terminally ill (HSE, 2019). In Ireland, 88% of the population want to be informed of a terminal diagnosis (Weafer, 2009). Recent international literature shows comparable results. Lee and Hawkins, (2017) examination of palliative care professional disclosure practises and priorities among family members (30), terminally ill patients (6), palliative care professionals (37) and members the public (42) in Singapore found 97.6% of their public cohort favoured disclosure. In a similar study in Albania consisting of one hundred and fifty cancer patients, family members and members of the public, 70% of the public supported disclosure of a terminal diagnosis (Beqiri et al., 2012). While truth-telling is believed to be common practice in western societies, with approximately 80% to 90% of patients said to be given explicit truths on diagnosis and prognosis, in comparison to non-western countries portraying estimations of between 0% to 50%, the research outlined clearly disputes this (Punjani, 2013; Zahedi, 2011).

2.14 Negative Media Influences

The media also influence public attitudes towards death and dying. Williamson et al., (2011) imply the media often provide misrepresentations of illness and disease, thus misinforming the public. Their comparison of media reports to that of statistical data on the leading causes of death through illness and disease over a 12-month period found media misrepresentations in the UK. For instance, the most common causes of death related to illness or disease reported in the media were; 1. Pneumonia/flu 2. Prostate cancer 3. Dementia 4. Breast cancer. Whereas the actual leading causes of death through illness or disease statistically recorded at that time were; 1. Heart disease 2. Cerebrovascular Disease 3. Pneumonia/Flu (Office of National Statistics 2009, cited in Williamson et al., 2011, p. 6).

Williamson et al., (2011) suggests the significance given to Flu/Pneumonia was the highly publicised Swine Flu epidemic within that period. They also found media has a significant impact on public perceptions of illness and disease which may affect one's readiness to seek medical attention or increase concerns regarding certain illnesses/disease. Quinlan's (2009) exploration of media influences on public attitudes on death, dying and illness in Ireland contends the media commonly inadvertently present palliative and EOLC negatively highlighting failings in care. While these reports are fundamental, positive media reportage is rare (Quinlan, 2009). Technological advances have provided instant access to media and information sharing to a wider public audience (Florea & Rabatel, 2011). Past crises and their reportage by the media make it difficult to alter public perceptions if this is the only representations they have of these events (Biasini & Mergier, 2016).

2.15 Less Frequently Cited Challenges

Other challenges are also depicted throughout literature yet are given less frequency concerning the concept of a GD and EOLC than the previous six themes discussed. Therefore, they are all grouped under theme seven. Jasemi et al.,'s (2017) secondary analysis of 44 articles involving 16 Western and non-western countries found other barriers experienced by professionals in EOLC.

1. Deficiencies in professional/patient relationships.
2. Incomplete record keeping.
3. Lack of supervision.
4. Issues in managerial structures and efficacy.
5. Numerous restricted resources.
6. Staff motivation.
7. Knowledge gaps.
8. Lack of education (Jasemi et al., 2017).

2.15.1 Patient-Professional Relationships

Poor patient/professional relationships hamper conversation flow impacting upon choice and individual ability(ies) to make DPP. Poor communication within multidisciplinary teams may decrease professional relationships, motivation, autonomy and worth and acquisitions towards the BPSSM of care, as undoubtedly some elements within the model may be overlooked resulting in unmet needs (Office of the Ombudsman, 2014; Almack, 2012; Fong et al., 2010).

2.15.2 Lack of Supervision

Jasemi et al., (2017) suggests there is a lack of supervision for professionals in EOLC. Inadequate supervision reduces patient safety and may lead to professional burnout and compassion fatigue (Tomlinson, 2015; Edmonds et al., 2015). Poor management is said to be demotivating and frustrating for staff and may also lead to patient neglect (Reader & Gillespie, 2013).

2.15.3 Lack of Professional Training and Education

Lack of professional education is a recurring problem voiced by many national and international authors (Croxon et al., 2017; Lee & Hawkins, 2015). In Lee and Hawkins, (2016) study, discussed earlier, findings implied clinical professionals felt unskilled in empathetically communicating prognosis and diagnosis. An Australian study of recently graduated nurses' experiences in palliative care mirrored these findings while adding the undergraduate curriculum did not prepare them for palliative care practice (Croxan et al., 2017). Nielsen and Glasdam, (2013) imply this is evident across many professional domains leaving formal caregivers incapable of maintaining professional boundaries and again vulnerable to emotional fatigue. Croxon et al., (2017) noted minimal practical caring experience was also problematic showing the need for practical training experience in combination with educational attainment. Anstey et al.'s, (2016) thematic review of 21 studies investigating education and training of nursing home staff in Wales highlighted direct care is mainly provided by unqualified support workers supervised by qualified, experienced clinical professionals which have been linked to a high turnover of staff. This begs to question: what practical and theoretical education is available in the sector in Ireland and how effective is it for professionals in service delivery?

2.15.4 Lack of Public Awareness on Aspect of EOLC

Mcllfatrick et al.,'s (2014) survey involving 3,557 members of the public further showed a lack of awareness and confusion on hospice, palliative and EOLC. Participants in McCarthy et al.'s (2009) study paralleled these findings while also showing the public confused the withholding and or withdrawing of life sustaining medical treatments such as artificial nutrition hydration with euthanasia practices. Yet, are the public more informed since McCarthy et al.,'s (2009) exploration, or does confusion still remain and if so, why?

2.16 Conclusion

Literature outlined choice and control, sources of support and maintaining personhood as the predominant themes encapsulating many characteristics of a GD. Various challenges to all these elements were discussed highlighting difficulties experienced by the terminally ill, their families/loved ones and professionals in EOLC.

Even though Ireland ranks fourth on the latest 2015 quality of death index, further improvements in EOL care are clearly needed (The Economist Intelligence Unit, 2015). Gaps in existing literature were evident concerning perceptions on current service delivery, supports for families/loved ones and professionals, awareness of palliative and EOLC services, DPP initiatives and their lack of public uptake, aspects on individual autonomy, difficulties encountered by professionals regarding family members of the terminally ill and what are perceived challenges in EOLC. These aspects show the need for this research in an Irish context to minimise gaps, gain a deeper understanding of a GD and to further explore themes identified (Meier et al., 2016). Although the themes outlined are not all inclusive, they provide plausibility for this research and rationale for the line of questioning posed. Though the studies discussed note factors of significance from the view of professionals, the public, the bereaved, family members and the terminally ill, they did not prospectively determine the most significant factors a GD in palliative and EOLC (Zhang et al., 2012). By establishing the strongest set of quality predictors of a GD from both the view of the public and generalised and specialised professionals, the findings from this research will reveal if consensus on the meaning of a GD exists between these groups in Ireland. This will assist in future palliative care practice by providing a concrete, united, focus on what matters most for all. This research will do this by capturing, for the first time in Ireland, the views of all three stakeholders.

CHAPTER THREE

METHODOLOGY

CHAPTER THREE METHODOLOGY

3.1 Introduction

This chapter firstly discusses philosophical and theoretical underpinnings and how they link to the overall methodological strategy employed. Thereafter, it outlines the suitability of the methodological approach adopted in answering the main aim of this study which seeks to explore public and professional perceptions of a GD. It then describes the participants, the population size, the sampling selection and method utilised. Data collection methods, analysis and processing are also explored. Finally, validity, reliability and ethical considerations are deliberated.

3.2 Philosophical and Theoretical Viewpoint of the Researcher

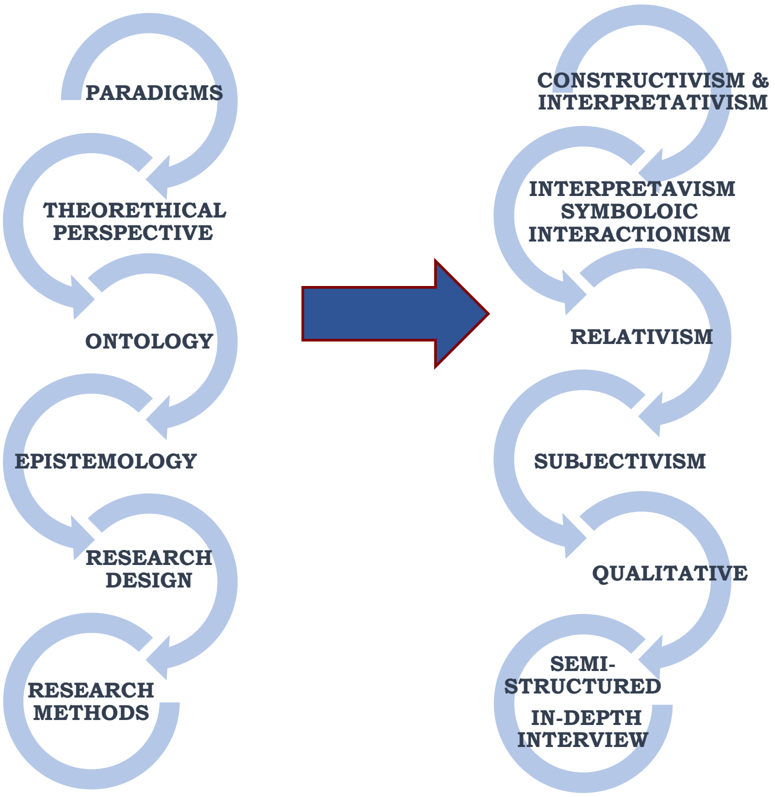
The research philosophy entails the source, nature and development of knowledge informing all research decisions from conception to completion (Research Methodology, 2019). All research questions correlate to philosophical ideals guided by certain rules coined paradigms, entailing the theoretical characteristics of the research undertaken (Taylor, 2017). They contain ontological belief systems regarding the reality of the world. What is known about this reality is defined as epistemology (Rider, 2016). Commonly utilised in qualitative research, the philosophical orientation of this study lies within constructivist and interpretivist paradigms. Constructivism states knowledge is socially constructed through individuals' lived realities, whereas interpretivism concerns individual interpretations of a particular phenomenon (Ritchie et al., 2013). Their ontological and epistemological viewpoints are that of relativism and subjectivism maintaining knowledge is subjective, individualistic and does not exist independent of the knower (Howe, 2011). Interpretivism is influenced by numerous theoretical positions namely, phenomenology, hermeneutics, ethnomethodology and symbolic interactionism (Mack, 2010). While all are important, the main theoretical perspective underpinning this study is that of symbolic interactionism (Mead, 1934 and Blumer, 1969 cited in Wright & Losekoot, 2012, p. 418) which encompasses;

1. The meaning individuals attribute to a concept/idea.
2. How these meanings originate and develop through social interactions.
3. How they alter through interpretation (Ritchie et al., 2013; Wright & Losekoot, 2012).

The philosophical approaches coupled with this theoretical perspective seamlessly align with the main aim of study as they strive to investigate environmental, social and cultural interaction, and historical underpinnings of participant's lives to gain an understanding of how a concept is interpreted and why (Scotland, 2012). These approaches are further rationalised as it is the diversity of individual socially constructed interpretations and experiences of bereavement that will predominately lead to perceptions of what it means to have a GD (Tenzek & Depner, 2017). It is theorised that Mead's (1934 cited in Wright & Losekoot, 2012, p. 418) philosophy and the paradigms outlined will provide symbolic meaning into how participants' social interactions and their environment shape and modify their meaning of a GD.

3.3 Research Design

Figure 2: Methodological Strategy, Design and Method



(Devised by the researcher, 2018)

Informed by constructivist and interpretivist paradigms, a relativist ontology and subjectivist epistemology, this study utilised a qualitative methodological strategy, which subsequently led to a qualitative research design.

3.3.1 Rationale of Research Design

This design approach was chosen due to its capability to address the research question prioritising individual experiences, interpretations and perceptions over measurements and predictions as would be the case in quantitative methodologies (Kumar, 2014). A quantitative approach negates from the purpose of this study because it emphasises cause and effect relationships and numeric testing which would result in general descriptors on opinions of a GD (Pathak et al., 2013). The previous chapters showed the necessity to increase research in palliative care coinciding with current and future palliative care projections, legislative developments on person-centred, holistic care and public and professional desires to promote discourse on death and dying matters (Vrinten & Wardle, 2016; Cipolletta & Oprandi, 2014; Scarre, 2013). As the overall aim of this study is to ascertain public and professional perceptions of a GD, a qualitative methodological approach was deemed the most appropriate to employ as it seeks to give meaning to individual feelings, attitudes, values, beliefs and perceptions on a particular phenomenon (Kumar, 2014). Studies discussed in the literature review mainly contained quantitative approaches (Weafer 2014; National Council of Palliative Care, 2016) ascertaining the magnitude and variance of perceptions of a GD, yet failing to uncover the meaning behind them. Concerning qualitative studies reviewed, some utilised a focus group method, involved singular participant cohorts and many of the research findings showed underrepresentation's of participant profiles, all of which may have led to biased results (McLoughlin, 2017; McCarthy et al., 2009). **Appendix B** provides a matrix on Irish literature showing these deductions made. To reduce these obstacles, this study conducted 24 interviews involving public and professional groups encapsulating an extensive age range of 18 to 80 years. The interest of this research is to explore public and professional perceptions, belief systems and meanings attributed to a GD to:

1. Inform and enhance palliative care service delivery, policies and practice guidelines.
2. Increase research in the area of palliative care.
3. Incorporate both public and professional perceptions of a GD to give voice to all and ascertain if service delivery reflects public expectations on what it means to have a GD.

3.4 Research Method

This study utilised a qualitative semi-structured, in-depth interviewing technique. This method appropriately aligned with the aim of the study by providing rich, deep descriptors on participants' perceptions of a GD and understanding on what and how these opinions were formed.

3.4.1 Rationale for the Study Instrument

In depth, semi-structured interviews provide direction in the research process by using a predetermined questioning guide correlating to the research question, while offering plenty of scope for participants to discuss matters they feel of significance (Morris, 2015). Given that death and dying have long been thought of as sensitive topics to research (Woodby et al., 2011; Liamputtong, 2007, cited in Johnson, 2011), this was deemed the most appropriate method to incorporate (Trochim et al., 2015). It also eliminates the weaknesses of the other methods mentioned such as, the possibility of bias occurring through group conformity and missed data from body language ques in surveys (Morris et al., 2015).

3.4.2 Formulating the Interview Questions

The line of questioning in the interviews (**Appendices C & D***)* were based on the aims and objectives of this study formulated through dissection of existing themes, knowledge and gaps ascertained in current literature (Bruan et al., 2017). Consequently, the interview questions were designed to ascertain perceptions of a GD and explore what may have influenced these views, how individuals and their informal support networks are currently supported to have a GD and what possible challenge, if any may impede individual opportunities to obtain a GD. **Appendices E** and **F** show the alignment of the interview questions to the aims and objectives of this study.

3.4.3 Pre-testing the Research Design and Interview Questions

Two pilot studies were conducted within the early stages of this research project (**Appendix G**) to pre-test the research design and interview questions (**Appendices C & D**). They involved two participants with over 20 years professional experience in social work and/or social care who had worked in EOLC services. The first pilot study confirmed the appropriateness of the research design.

While analysis of findings from the second pilot study highlighted where minor modifications and some retractions needed to be made to interview questions. Question 16 addressed to the public and question 18 to professionals (*Table 7*) may cause confusion concerning distinctions between religion and spirituality as one of the pilot study participants grouped religion and spirituality together.

Table 7: Changes Made to Interview Questions After Analysis of PS2

<table>
<tr><th>Original Q16/Q18.</th><th>Q16/18. After Modification</th></tr>
<tr><td>Do you believe people are currently supported;
a) Socially,
b) Psychologically,
c) Financially,
d) Religiously,
e) Spiritually,
to have a good death?</td><td>Do you believe people are currently supported in the following areas below to have a good death?
a) Socially
b) Psychologically
c) Financially
Before moving on to the next two components participants were asked if they saw a distinction between spirituality and religion. Those that did not were provided with the following definitions.
d) Religiously - Religion is a set of behavioural manifestations connected to religious beliefs, values and social relationships that unit a common faith" (Canda & Furman, 2010, cited in Becker et al., 2015, p.105).
e) Spiritually – is described as the way in which an individual seeks and expresses meaning and purpose in one's life (Puchalski et al., cited in Becker et al., p.106).</td></tr>
<tr><th colspan="2">Original Q26.</th></tr>
<tr><td colspan="2">Q26. An Advance Healthcare Directive (AHD) is defined as a statement made by an individual with capacity (the ability to make and understand information and make decisions) detailing his/her will and preferences about medical treatments that may arise in the future at a time when he/she no longer has the capacity and so cannot make decisions (The Irish Hospice Foundation, 2019).
a) Were you aware of an AHD?
b) What is your opinion of an AHD?</td></tr>
<tr><th colspan="2">Q26. After Modification</th></tr>
<tr><td colspan="2">An Advance Healthcare Directive (AHD) is defined as a statement made by an individual with capacity (the ability to make and understand information and make decisions) detailing his/her will and preferences about medical treatments that may arise in the future at a time when he/she no longer has the capacity and so cannot make decisions (The Irish Hospice Foundation, 2019).
(a) Were you aware of an AHD?
(b) What is your opinion of an AHD?
(c) Would you see a value in drafting an AHD?</td></tr>
<tr><th colspan="2">Questions Retracked</th></tr>
<tr><td colspan="2">QX1.Who do you believe has the authority to make decisions about commencing medical treatment if an individual was in the final stages of the dying process? You may pick more than one answer.
a) The individual,
b) Physicians,
c) The individual's family/caregiver or next of kin?</td></tr>
<tr><td colspan="2">QX2 Who do you believe has the authority to make decisions about commencing medical treatment if an individual was in a coma? You may pick more than one answer.
a) The individual
b) Physicians
c) The individual's family/caregiver or next of kin?</td></tr>
</table>

As both are recurrent themes depicted throughout current literature, it was important to segregate the two to ensure full clarification for participants and that both elements would be discussed independently so as not to result in blurred findings. To eliminate these issues, before probing participants about spiritual and religious supports they were asked if they knew distinctions between the two. Those who were unaware of their distinctions were provided with a definition of each by the researcher. A further two questions labelled as **QX1** and **QX2** in *Table 7* were removed from the interview list because they were deemed irrelevant as an individual receiving EOLC would have long established medical treatment. Therefore, both were retracted from the interview questioning. Both pilot studies were instrumental in this study. This process of refinement, retraction, modification and addition (Leavy, 2018) enhanced the overall methodological approach, flow, and consistency of the interview questions.

3.5 Study Population and Participant Sample

Sampling in research involves carefully selecting a portion of the population target that meet the needs of the research enquiry (Kumar, 2014). A sampling plan is required from the onset of a research project, as flaws in the sample selection will lead to selection bias seriously undermining the reliability and credibility of the study findings (Mesa et al., 2016). Members of the public and professionals working within generalised and specialised palliative care services were the target population for this study because public and professional perspectives of a GD was the study focus. Predetermined inclusion criteria for the selection of participants was established at the onset based on the aim of this study, to explore public and professional perspectives on the concept of a GD. These included:

1. Members of the public over the age of 18 years involved in a club, group or society. This was an ethical requirement by the HSE to enhance safeguards for both the researcher and this participant cohort.
2. Professionals over the age of 18 years working within generalised palliative care services in the southeast region of Ireland.
3. Specialised palliative care professionals working in specialist palliative care roles within the southeast region of Ireland.

Incorporating public, generalist and specialist palliative care professional viewpoints collectively aimed to provide a comprehensive investigation of GD ideals, to bridge gaps in current literature and to ascertain if professional ideals of a GD reflect public expectations of what it may mean to have a GD. The rationale for limiting the scope of this study to the Southeast of Ireland was due to ethical approval considerations. Outlined earlier in chapter one, nine CHOs deliver the provision of palliative care services in Ireland (HSE, 2017). Conducting research nationally involving generalist and specialist palliative care services and professionals would require seeking and gaining approval from each of the nine CHOs ethical review boards. The short time frame of this study could not possibly accommodate for this lengthy process, thus accounting for the study location.

3.5.1 Purposeful Sampling

A purposeful sampling method was utilised in the selection of participants. This involves the researcher determining and then selecting the most appropriate sample that will answer the research aims and objectives (Palinkas et al., 2015).

3.5.2 Sample Recruitment

A list of potential participants from both public and professional domains meeting the inclusion criteria was compiled (*Table 8*). Each reference was contacted via email and or telephone and invited to partake in this study.

Table 8: Sample of Compiled List of Possible Participants		
Potential Generalist & Specialist Professional Participants Contacted		
Service Setting	**County**	**Number Contacted**
Eldercare Residential Care	Carlow	11
	Kilkenny	13
	Wexford	17
	Waterford	12
	Tipperary South	25
Primary Care	Carlow	12
	Kilkenny	25
	Wexford	20
	Waterford	25
	Tipperary South	24
Palliative & Hospice Homecare	Carlow	5
	Kilkenny	4
	Wexford	4
	Waterford	4
	Tipperary South	5
Acute & General Hospital	Carlow	1
	Kilkenny	2
	Wexford	3
	Waterford	2
	Tipperary South	4
General Practitioners	Kilkenny	55
	Wexford	55
	Waterford	55
	Tipperary South	55
	Carlow	55
Potential Participants from the Public Contacted		
Various clubs, groups and societies contacted	Carlow	50
	Kilkenny	50
	Wexford	50
	Waterford	50
	Tipperary South	50

A flyer (**Appendix H**) outlining this study was also advertised in shopping centres and convenience stores in some southeast counties to attract public interest and possible participation. Founders or managers of public groups, clubs and societies were also contacted via social media forums and invited to participate in this study. Manages of services were also contacted. Through these approaches a list of participants from all three groups emerged.

3.5.3 Sample Size

In total 24 individuals came forward and participated in this study. *Table 9* below provides a summary of all involved corresponding with their respective group which were colour coded to highlight the differing cohorts. A total of 23 participants lived and/or worked in the Southeast region of Ireland. A further professional participant from the Mid-Eastern region of Ireland also came forward and expressed interest in becoming a participant in this study. As this participant worked outside the remit of the HSE region his participation was deemed appropriate.

Table 9: Summary of All Participants

Group Name	Participant Cohort	Participant Number
Group A **The Public**	Members of the Public	**10**
Group B **Generalised Professionals**	Professionals working within Generalised Palliative Care Services	**9**
Group C **Specialised Professionals**	Professionals working within Specialised Palliative Care Services	**5**
	Overall Study Population	**24**

3.6 Data Collection

Interviews were pre-arranged with all participants; the location of interviews were in local restaurants, cafés, in the Institute of Technology, Wexford Campus or by telephone and lasted between 30 to 60 minutes. A total of 20 interviews, were conducted face-to-face in neutral locations (**Appendix I**) while the remaining 4 were conducted by telephone on participant's request. Interviews occurred between June to November 2018. All members of the public were asked the same 37 questions (**Appendix C**) whereas, generalised and specialised professionals were queried on a total of 30 identical questions (**Appendix D**). A full response rate was obtained from all 24 participants (**Appendix I**). All interview sessions were recorded using mobile voice recording software.

3.7 Data Analysis

Embedded within the interpretivist and construction tradition, deductive and inductive thematic analysis was utilised in the data analysis phase (Braun & Clarke, 2006). Deductive analysis involves using pre-existing codes evident in current and previous literature on the research question as a starting point for encoding data obtained.

Whereas, inductive reasoning evolves when codes not evident in existing research emerge (Armat, 2018). Aligning with the literature review the predetermined themes used for deductive analysis in this study were;

1. Choice and Control.
2. Sources of Supports.
3. Maintaining Personhood.
4. Perceived Public and Professional Challenges.

All findings obtained which did not align with the literature review were categorised as inductive, newly emerging themes on what constitutes a GD. NVivo Pro 12, was employed to assist in the management of the magnitude of data obtained and effectively enhanced the alignment of the data analysis across the three participant cohorts. All transcripts were analysed using steps consistent with Colaizzi's (1978 cited in Alemneh et al., 2017, p.149) phenomenological data analysis model. Firstly, interviews were transcribed verbatim and initial notes made. Secondly, all transcripts were read multiple times with further notes added. Thereafter, significant statements mirroring the literature were explored, organised thematically using NVivo Pro 12 again for efficacy and cross checked for discrepancies. Some themes correlated with subthemes as they were discussed in the same context. Employing NVivo Pro 12, main themes were grouped into parent codes, while subthemes were placed into secondary nodes. Again, all transcripts were checked to ensure no data was missed. A participant coding system was also developed to distinguish between the three participant cohorts and to ensure each participant was given equal weight in this study. *Table 10* below provides an example of this.

Table 10: Sample Coding System

THE PUBLIC	
Participant	**Coding System**
Participant C **Public** **PPC**	**PPC, (F), (I), (AB 59-69)** **Female (F)** **Irish (I)** **Age bracket (AB 59-69)**
SPECIALISED PROFESSIONALS	
Participant	**Coding System**
Participant E **Specialised** **SPE**	**SPE, (F), (I), (AB 48-58)** **Female (F)** **Irish (I)** **Age bracket (AB 48-58)**

(**Appendix J** *provides a full version of this coding system*)

Finally, preliminarily findings were shared between the researcher and supervisors and scrutinised to ensure unbiased interpretations of results.

3.8 Validity and Reliability

Validity entails the suitability of the research design and instrument incorporated in answering the research investigation and reliability concerns how reliable the data obtained can be from that instrument (Mohaian, 2017). Utilising a qualitative approach is deemed the most appropriate for this study because gaining deep understanding into public and professionals' perceptions of GD is its main purpose. Consequently, the philosophical and theoretical undertones, research design, instrument and data analysis techniques utilised increased the validity and reliability of this study given their appropriateness to address the study aims and objectives. Semi-structured interviews allowed participants the freedom to express a natural response in an informal and relaxed atmosphere (Rwegoshora, 2014). All participants were asked the same set of open-ended questions to allow for consistency and to prevent participants being misled ensuring reliability of data findings (Alsehenqeeti, 2014).

3.9 Triangulation

Triangulation is a research strategy using multiple sources of data, which increases the validity, reliability, credibility and transferability of the findings (Moon, 2018). This is fundamental for the validity and reliability of a constructivist and interpretivist inquiry, which assumes reality is subjective and that multiple realities exist (McManus et al., 2017). *Tables 11*, *12* and *13* show the diversity among participants involved in this study which incurred triangulated results, thus increasing validity and reliability of this study.

Table 11: Variations Among Specialised Professionals

Gender	Age	Service Setting	Job Title	Experience
Hospital Setting **2**				
Female 1	***48-58*** ***1***	Palliative Care	Consultant in Palliative Medicine	28 years 1
Male 1	***37-47*** ***1***		Clinical Nurse Specialist In Palliative Care	5 years 1
Community Palliative & Hospice Homecare **3**				
Female 3	***37-47*** ***3***	Palliative /Hospice Homecare 3	Clinical Nurse Specialist in Palliative Care	4 years 1
			Clinical Nurse Specialist in Palliative Care	15 years 1
			Clinical Nurse Manager	25 years 1

Table 12: Variations Among the Public

Gender	Age	Occupation	Group Affiliation	Educational Attainment	Religious Belief
Male 5	***37-47*** ***4***	Events Technician	GAA Club 3	Leaving Cert 4	Catholic – practicing 4
		Student Farm Assistant			
		Housewife			
		Retired	Drama Group 2		
Female 5	***59-69*** ***2***	Property Valuer		Masters Level 2	Catholic Non-Practicing 2
		Engineer	Book Club 1		
	18-25 ***1***	Outreach Worker	Immigrant Group 1	Junior Cert & Diploma in Business 1	Catholic- Loosely practicing 2
	48-58 ***1***	Social Care Worker	Relay for Life 1	Ordinary Degree 1	
	70-80 ***1***	Farmer	Community Committee Group 1	Honours Degree 1	Atheist 1
	26-36 ***1***	Butcher	Liberal Studies Group 1	PhD 1	Pantheism 1

Table 13: **Variations Among Generalised Professionals**

Gender	Age	Service Setting	Job Title	Education	Experience
General Hospital Setting **1**					
Female 1	***37-47*** ***1***	Hospital Setting	Outreach Officer H*f*H Programme	Masters Level	19 years 1
Eldercare Residential Care Setting **3**					
Female 3	***59-69*** ***1***	Eldercare Residential Setting with Hospice Unit 2	Nurse 2	Conventional Nursing Training	15 years 1
	18-25 ***1***			Honours Degree	1 year 1
	37-47 ***1***	Eldercare Residential Setting without Hospice Unit 1	Healthcare Assistant 1	Honours Degree & Higher Diplomas 1	6 years 1
Community Homecare **3**					
Female 4	***59-69*** ***1***	Community Homecare 3	Healthcare Assistant 3	FETAC Level 5 3	20 years 1
	37-47 ***1***				5 years 1
	48-58 ***1***				8 years 1
	18-25 ***1***	Youth Residential Setting 1	Youth Worker 1	Honours Degree 1	1 year 1
Male 1	***48-58*** ***1***	Community Pastoral Care 1	Catholic Priest 1	PhD 1	19 years 1

3.10 Eliminating Researcher Bias

Important to recognise from the onset of a qualitative inquiry, the researcher may unintentionally incur bias of the findings (Galgas, 2017). The use of Colaizzi's (1978 cited in Alemneh et al., 2017, p.149) model instills reflections of the researchers' opinion/attitude enabling him/her to recognise potential impacting bias, thus eliminating them increasing the reliability and validity of the research findings (Shosha, 2010). Fully engaging in regular supervision meetings and employing self-reflection (Kolbs 1976, cited in, Makewa et al., 2019) through the use of a reflective dairy throughout the research process were further strategies that reduced this occurrence. Using NVivo software further enhanced the reliability of this study findings.

3.11 Ethical Considerations

This study underwent a lengthy and intense ethical review process requiring an oral proposal of this study to an 11-panel member within HSE South East Research Ethics Committee (**Appendix K**). Ethical approval was also sought by the Institute of Technology Carlow (**Appendix L**) and subsequently granted by both organisations in May 2018. Respect for participant's dignity, gaining voluntary informed consent, upholding confidentiality and beneficence for participants were of the utmost importance and guiding principles from commencement to completion. All participants were treated fairly, sensitively, with dignity and respect and without prejudice. Data encodings were conducted in a non-biased manner to retain participants' true opinions, attitudes, and perceptions. Initially, information sheets (**Appendix M**) and flyers (**Appendix H**) were distributed, via email or manually to all participants, outlining in appropriate language the aim, research methods and contribution of this research to ensure participants fully understood the nature of the research topic and what their participation involved. All consent forms (**Appendix N**) were signed by participants prior to the commencement of an interview. All participants were made aware of their right to withdraw at any stage. Subject to the Data Protection Act, (1998-2014) and the Freedom of Information Act, (2014), all participants were asked if they would like to be supplied with a summary of the study findings (Government of Ireland 2014a, 2014b). Forwarding contact details of all who expressed an interest in obtaining the findings (16) were recorded and upon completion of the study findings were supplied with a summarised version of such via email or personal delivery (**Appendix O**).

Confidentiality was upheld by anonymising both names and distinguishing features and all participants were given pseudo names such as ***'Participant A'***. Further precautions applied to professionals as all distinguishing features of the services they worked in were also purposefully omitted. Death and dying are deemed difficult areas to research as they are considered intimate and emotional topics (Johnson, 2011). Although there was a view that the risk of the interview was no greater to participants than what they would encounter in their daily lives the researcher was mindful not to be cause any discomfort to them ethically. This study adopted the following strategies to diminish this risk in so far as possible:

1. Utilising a semi-structured interview research design allowed participants to freely express their views in a non-judgemental manner.
2. All participants were asked on three separate occasions, prior to an interview session if they felt comfortable proceeding.
3. All participants were debriefed after each interview and offered low-cost counselling support service contact details within their geographic locality (**Appendix P**).
4. All participants were given a copy of the line of questioning prior to the interview and informed if they became upset, interviews would pause or stop completely, depending on their wishes.
5. A pilot study was also conducted prior to the commencement of this research to enhance safeguards for participants and to pre-test the line of questioning (Leon et al., 2011).

3.12 Conclusion

This chapter outlined the methodology and its appropriateness to the research. A qualitative approach was taken because it aligns with the aims of this study which seeks to gain public and professional perceptions of a GD. A total of 24 participants participated in this study. This sample was chosen as they meet the inclusion criteria. In-depth, semi structured interviews were conducted again for their appropriateness to the research aims and objectives. Ethical principles were upheld throughout, and validity and reliability maintained by the consistency in the interviews and triangulation of data.

CHAPTER FOUR

FINDINGS

AND

ANALYSIS

CHAPTER FOUR FINDINGS AND ANALYSIS

4.1 Introduction

This chapter outlines the findings and analysis of the data obtained. Findings are thematically analysed and presented through tables, charts (some of which are contained with the Appendices) and participants' verbatim responses to the interview questions corresponding with the research objectives (RO).

4.2 Research Objectives

The aim of this study was to ascertain:

1. What constitutes a GD from the view(s) of public and professionals.
2. How are individuals, their families and loved ones currently supported to achieve a GD in Ireland.
3. What issues impact upon individual opportunities to experience a GD in Ireland.

4.3 Participant Profiles

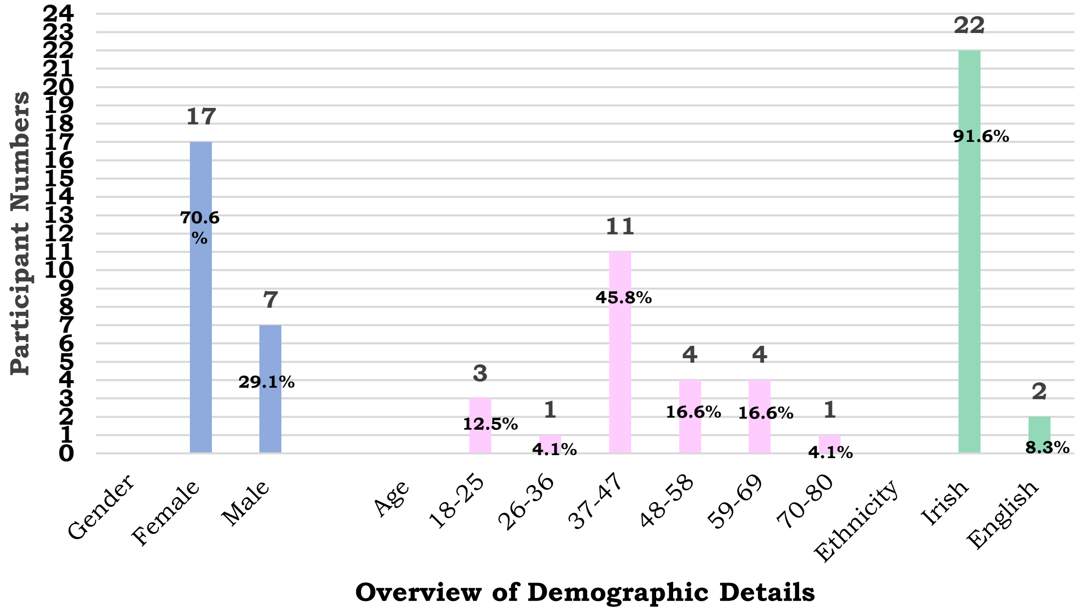
A total of 24 participants, from three distinct cohorts engaged in this research (*Table 14*).

Table 14: Summary of Participants

Group Name	**Participant Cohort**	**Participants Number per group**
Group A The Public	Members of the Public	**10**
Group B Generalised Professionals	Professionals working within Generalised Palliative Care Services	**9**
Group C Specialised Professionals	Professionals working within Specialised Palliative Care Services	**5**
	Overall Study Population	**24**

Each participant profile is supplied in **Appendix Q**. However, a collective summary across all groups shows most participants (70% n=17) were females, 91 % (n=21) catagorised themselves as Irish and the largest age range at 45% (n=10) was 37-47 year olds. *Figure 1* below displays participant profile.

Figure 3: Total Population Participant Profile



An equal distribution of gender was obtained from the public in contrast to earlier studies in Ireland (Weafer, 2014; McCarthy et al., 2009). However, generalised professionals (8 females (88.8%)1 male (11.1%) and specialised professionals were predominately female (4 females (80%)/1 male (20%). This result mirrors the predominance of females in health and social care professions (The World Health Organisation, 2018; The Department of Health, 2017).

4.4 Research Findings

Given the number of findings obtained, they are presented and discussed under each of the research objectives (RO).

4.4.1 Findings from RO1: What Constitutes a GD

4.4.2 Finding One from RO1: Perceived Characteristics of a GD

Question 8 (**Appendix C**) posed to the public and question 10 (**Appendix D**) directed to professionals, sought participants' opinions on what constituted a GD. *Figure 4* on the proceeding page shows the most frequent used words by all groups to describe a GD.

Figure 4: **Most Frequent Used Words by All Participant Groups to Describe a GD**


GROUP A: The Public

GROUP B: Generalised Professionals

GROUP C: Specialised Professionals

A total of 76 characteristics of a GD (**Appendix R**) summarised below in *Table 15* were found. A full breakdown of all characteristics, according to each group is presented in **Appendix S**.

<table>
<tr><th colspan="2">Table 15: Total Summary of GD Characteristics Across All Groups</th></tr>
<tr><th>Participant Group</th><th>Number of Characteristics Obtained</th></tr>
<tr><td>1. The Public</td><td>24</td></tr>
<tr><td>2. Generalised Professionals</td><td>31</td></tr>
<tr><td>3. Specialised Professionals</td><td>21</td></tr>
<tr><td>Overall Total</td><td>76</td></tr>
</table>

This finding is notable, as it is the first known study in Ireland to reveal detailed characteristics of a GD from both public and professionals (Weafer, 2014; Meier et al., 2018). Similar to the literature (Meier et al., 2016; Weafer, 2014), these characteristics of a GD are both fluid and diverse. Demonstrated in *Figure 4*, public and generalised professionals believed the most important element of a GD was to be pain free. However, specialised professionals considered both family and professional supports the most important element. A tabulated summary of all similarities and discrepancies among the groups are supplied in **Appendices T** and **U.** *Table 16* details a total of 33 separate characteristics uncovered.

<table>
<tr><th colspan="4">Table 16: Breakdown of Characteristics of a GD</th></tr>
<tr><th>All Groups</th><th>Other Characteristics Shared Among the Public and Generalised Professionals</th><th rowspan="2">No Other Shared Characteristics Among the Public and Specialised Professionals</th><th>Other Shared Characteristics Among Professionals</th></tr>
<tr><td>1. Pain Free
2. Choice & Control
3. Surrounded by loved Ones
4. Person-Centred
5. Pain/Symptom Control
6. Support for Family
7. Planning & Preparation
8. Aware/informed
9. Respect
10. Dignity
11. Family support</td><td>1. At Home
2. Acceptance of Death
3. Quickly
4. Unaware
5. Natural Cause
6. Without Fear</td><td>1. Support for Family
2. Support for Individual
3. Professionals Support
4. Total Pain Approach
5. Support for Professionals</td></tr>
<tr><th colspan="2">Stand Alone Characteristics Below</th><th colspan="2">Total of Above Characteristics: 22</th></tr>
<tr><td colspan="2">1. No Regrets
2. Sudden
3. Love
4. Without Dependents
5. Private Time with Loved Ones
6. Facilitate Enjoyment through Meaningful Activities where Possible</td><td colspan="2">7. In a Place of One’s Choosing
8. Effective Multidisciplinary Team Involvement
9. Open Transparency Between the Individual & Family
10. Without Suffering of Any Kind
11. Preferences Reviewed</td></tr>
<tr><th colspan="4">Total Characteristics Uncovered: 33</th></tr>
</table>

4.4.3 Thematic Analysis from RO1

Through analysis of all 76 GD characteristics, a further five thematic findings emerged:

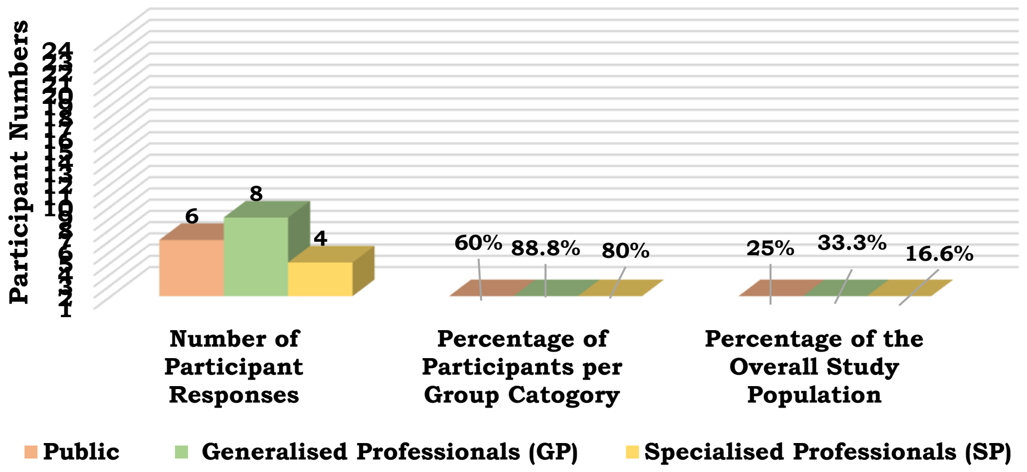
1. Pain.
2. Family/feeling accompanied.
3. Control.
4. Maintaining personhood.
5. Independence.

4.5 Finding Two from RO2: Pain

Figure 5: Most frequent used words by participants to describe Pain.

The majority (75% n=18) of participants stated pain elimination, in all its formats, as significant for a GD. However, total pain elimination was not seen as essential by specialised professionals as a requisite for a GD. 75% (n=18) of participants in this study prioritised a need to be pain-free in order to gain what they considered a GD (*Figure 5*).

Figure 6: Pain



Coinciding with McLoughlin's (2017) study, the public stated being pain free was essential for a GD. This contrasted with Irish (Weafer, 2014) and UK literature (NCPC, 2016) attributing lower significance to pain. While McLoughlin, (2017) did not provide rationale for this finding, a possible explanation for the increased emphasis on pain in this study, may arise from the proposed Dignity with Dying Bill, (2015) in Ireland. This Bill has brought the euthanasia (***glossary***) debate and perceived challenges if faced with a terminal illness to the fore. This has led to the need to avoid perceived suffering which has been a prime motivator for request(s) for and the enactment of such legislation (Rujis et al., 2014). Consequently, pain when nearing one's death may indeed be more widely acknowledged and of significance in contemporary Irish society:

> '…[I] Like, say if you're in stage 4 of cancer …you already know it's going to be terminal, you just have to live it out and just let it take you as it does … I'd rather not go through that pain and maybe just like bite the bullet early.'

[**Participant H**]

Another factor is increased longevity, improved illness trajectories and life expectancy rates, outlined in chapter one, meaning more individuals are living with chronic/terminal illnesses (Moşoiu, 2014). Consequently, these increases have provided exposure to the challenges faced through terminal illness which may account for public participants' perception on pain and suffering endured, heightening the importance of eliminating such at the EOL.

4.5.1 A Desire to be Pain-free

While pain was recounted by a substantial portion of all participants, most of the public referred to it in broad general terms:

> 'It's a hard one to describe but, I would probably say…not be in pain…and, I think a GD, yeah to be free from pain.'
>
> [**Participant L**]

Similarly, ***Participants C, M, O,*** and ***W*** also regarded a GD as '*something that is pain-free'*. This finding parallels previous national and international studies (Milnes et al., 2016; Meier et al., 2016; The National Council of Palliative Care, 2016; Joarder et al., 2014; Weafer 2014, 2004) showing a desire to be pain-free.

4.5.2 Without Suffering of Any Kind

Many (42.8% n=6) professionals considered being pain-free as a crucial component of a GD. However, unlike most of the public, some professionals elaborated on pain. ***Participants J, E*** and **I** recounted how being pain-free meant being free of pain, difficult symptoms and emotional distress:

> 'I suppose for me, a good death is certainly comfort and that's comfort from a symptom and physical point of view, that's physical symptoms and a psychological point of view.'
>
> **[Participant I]**

These responses clearly demonstrate the theoretical perspectives underpinning this research namely, the BPSSM. Outlined in previous chapters, these theoretical components highlight the multifaceted dimensions of pain, stressing the importance of adopting a total pain, person-centred, holistic approach to care.

4.5.3 Pain and Symptom Management

Pain and symptoms management were also pertinent for some participants when nearing death. ***Participants A*** and ***B,*** reiterated a professional onus to ensure symptoms are being managed well and that individuals receive whatever pain relief possible:

> '…symptom free, within the bounds of possibility.'
>
> **[Participant K]**

Providing a public insight, one participant wanted:

> ‘As much medication as possible to maintain humour…not to be in despair.’
>
> **[Participant C]**

Adequate pain and symptom management were recurrent attributes of a GD throughout current national and international literature (McLoughlin, 2017; Meier et al., 2016; The NCPC, 2016; Weafer, 2014; Callahan-Lesher, 2010; Barazzetti et al., 2010; McCarthy et al., 2009). However, although 16.6% (n=4) professionals discussed these characteristics, it was not a priority for the public. For instance, in Weafer’s, (2014) study, 70% of the public referred to the importance of pain and symptom management. Whereas, in this study only one member of the public (10%), namely ***Participant C*** mentioned these attributes. A possible explanation for her response mirroring that of professionals, may be due to her degree in Applied Social Studies. This knowledge may have made her more acutely aware of the broader dimensions of pain than her fellow public participants.

4.5.4 Fear of Pain

Fear and uncertainty were also discussed in relation to pain:

> ‘I’ve a horror of dying in pain.’
>
> **[Participant C]**

> ‘…people are not afraid of dying, they are afraid of how they get there.’
>
> [**Participant V**]

Another participant also reiterated the importance of eliminating fear:

> ‘…a good death I suppose is…being without fear.’
>
> **[Participant L**]

These findings explicitly argue that eliminating fear is also pivotal in achieving a GD. This study parallels fears discussed by Cortês et al., (2017) who determined cancer patients fear unbearable pain more than dying itself. They further implied this fear may potentially manifest in death anxiety which both ***Participant C*** and ***V’s*** responses suggest. It also resembles McLoughlin’s (2017) study in Ireland who found a public need to be supported to manage any fear or distress when receiving EOLC.

While McLoughlin, (2017) did find fear in relation to pain, it was not explicitly associated with GD ideals. Instead fears in relation to one's death in an Irish context have until now mainly revolved around suffering from illnesses such as dementia, resulting in diminished dignity, choice and control (McCarthy et al., 2009). All three (12.5%) participants who discussed fear in this study were females in the 59-69 age bracket. This age range correlates with Weafer's (2014) findings, suggesting middle-aged and older individuals are more likely to seriously consider their EOLC. While the gender differential is consistent with Skulason et al.,'s (2014) longitudinal study into death discussion among patients receiving palliative care in Iceland, they concluded females were more comfortable expressing emotions concerning one's death than males. Given the responses from ***Participant C*** and ***V*** and the absence of such from male participants, this study supports Skulason et al.,'s (2014) findings. Similar to Weafer, (2014) and Skulason et al., (2014), this finding also suggests age and gender may impact perceptions of GD ideals. In summary, a total of 18 (42.8%) of participants indicated pain as the most relevant feature of a GD, whilst six (25%) did not mention pain as an element. Pain was interpreted and discussed in diverse contexts highlighting its interconnecting characteristics of a GD namely:

1. A desire to be pain-free.
2. To be without suffering of any kind.
3. To have adequate pain management and symptom control.
4. Any death anxiety in relation to pain is addressed.

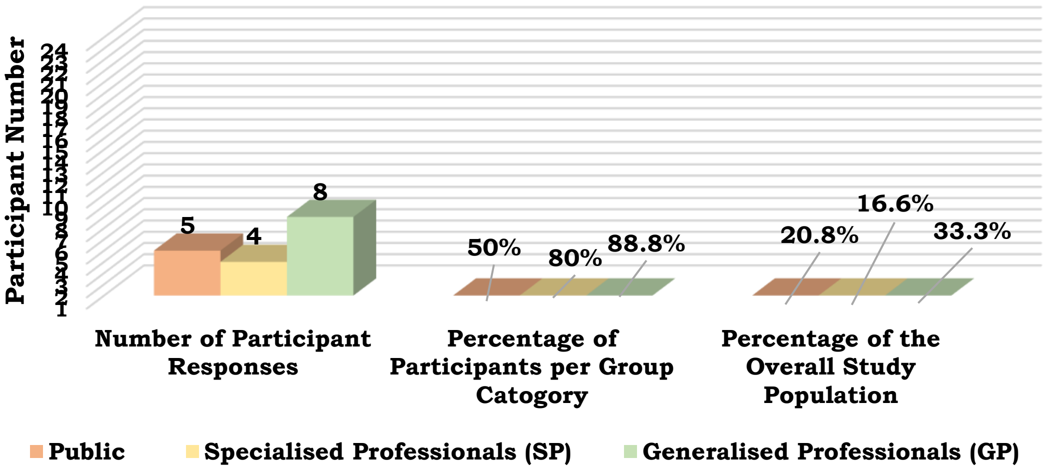
The results of this finding demonstrate similarities on perceptions of a GD among the public and generalised professionals with both groups maintaining being pain-free as the defining component of a GD. Specialised professionals considered being pain-free less significantly with only two (40%) in this group referring to it. This may correspond with their role in managing pain and symptoms. Specialised professionals may better appreciate that pain may be managed, yet never eliminated (Baillie et al., 2018). Both generalised and specialised professionals affirmed adequate symptom and pain management were imperative for a GD. Specialised professionals emphasised the importance of a total pain approach to care more than generalised professionals. This could imply a possible lack of palliative and EOLC training among this cohort. However, both professional groups reported adopting this theoretical stance and the BPSSM as a strong indicator of achieving a GD.

4.6 Finding Three from RO1: Family/Feeling Accompanied

Figure 7: Most frequently used words to describe Family

The second parameter of a GD centred on the importance of having family support. Seventeen participants (71.1%) (*Figure 8)* spoke of the importance of family to varying degrees for an individual approaching EOL.

Figure 8: Family/Feeling Accompanied



4.6.1 Surrounded by family/loved ones

Ten participants (41.6%) expressed a desire to be surrounded by loved ones if in the final stages of life; five (50%) members of the public, four (44.4%) generalised professionals and two (40%) specialised professionals. For the public who discussed this attribute, loved ones meant, *having family around.*'[1]

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[1] **PPW (M), (I), (AB 26-36)**

Some professionals suggested that support from other sources could be more important than family. Other sources of accompaniment may also be favoured as much or more than family. For instance, when asked what in her opinion are the most important factors that help an individual gain a GD P***articipant F*** stated:

> **'**People around them and people who matter to them around them which isn't always in all cases relatives and that. It may be a priest or a religious minister if religion is important to them or it may be someone close to them.'

This diversity on the meaning of 'significant others' is recognised throughout national and international literature (Otani et al., 2017; Weafer, 2014). Specifically, in Ireland, Weafer, (2014) found 23% of his participants expressed a desire to be accompanied by a pet in the final stages of life.

4.6.2 Accompaniment

Three (21.4%) professionals believed companionship of any kind is a crucial component:

> '…a sense of accompaniment' [*is*] …the heart of the matter.'
>
> **[Participant B]**

> 'We'd all like to think that we'd have someone with us when we are dying.'
>
> [**Participant G**]

Three (12.5%) professionals also relayed how in practice this is not always the case:

> '…surrounded by people, preferably people that you know, [but]…it can't always be that way.'
>
> [**Participant G**]

Further expressions of this view were made by ***Participants K*** and ***F*,** both stressing those approaching death should be '*surrounded by people that they want to be around them'*[2] and to have *'people who matter to them around them'*[3]. Although, these participants did not divulge why they believed some individuals may lack adequate supports, Lindqvist et al.,'s (2015) concept of the 'lone death' suggests this may be unintentionally due to an individual having minimal familial relationships and supports or intentionally, to minimise the impact of their death on loved ones.

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[2] **SPK (F), (I), (AB 37-47)**

[3] **GPF, (F), (I), (AB 59-69)**

Others imply the family/loved ones may be the cause of this occurrence as some members may not want to be present when a loved one is actively dying (Pallimed, 2014).

4.6.3 Not Alone

Affirming the importance of a sense of accompaniment, two (22.2%) generalised professionals and one (10%) member of the public also echoed not being alone as a fundamental component of a GD:

> '…I think that...I would go back to the whole idea of accompaniment that people feel that they are not on their own. That's really the heart of the matter. And that can apply to any of life's crises. People don't want to be isolated full stop and they certainly don't want to be isolated around their death. The biggest challenge in their life is their death. So, I think the single most important thing is that there are people there with them.'
>
> **[Participant B]**

Further developing this point:

> 'You would even know by them **[referring to residents in eldercare service she currently works in as a HCA]** that they are a lot more comfortable when they have people around them. You'd even see some people that don't have families or whatever, you know, they'd be asking carers, 'Can you just stay with me?
> You know that kind of thing. They obviously don't want to be alone.'
>
> **[Participant G]**

Whereas, public comment, although minimal in comparison to professional, came from one participant:

> '…I'd hate to die alone.' **[Participant C]**

These responses display a preference for individuals in EOL to have companionship. However, specialised professionals did not mention these aspects. Perhaps they assume from their professional experience accompaniment of some kind whether it be from family or professionals would be catered for thus accounting for their lack of discussion on this topic. Mile's (2015) point may help explain the minimal public discourse on these matters. She suggests there is a common, misinformed, assumption that family want to be present when a loved one is actively dying (Pallimed, 2014). The majority of the public in this study may be of this assumption.

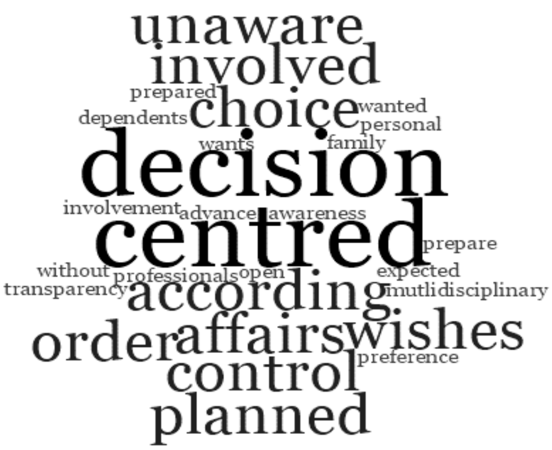
Clearly, from the findings outlined, both the public and professionals (71.1% n=17) consider the presence of family significant. Similar to finding two (***section 4.5 Pain***), family was discussed and conceptualised in varying ways:

1. Surrounded by family/loved ones.
2. Accompaniment.
3. Not alone.

The elements discussed under this finding are commonly sighted indicators of a GD both nationally and internationally. All three participant groups emphasised the importance of terminally ill individuals having family/loved ones present when nearing one’s death. Yet, for specialised professionals, family support was the leading attribute of a GD compared to generalised professionals and the public who assigned being pain-free as the overarching tenet of a GD. Specialised professionals favoured family support above all else in aspirations towards a GD.

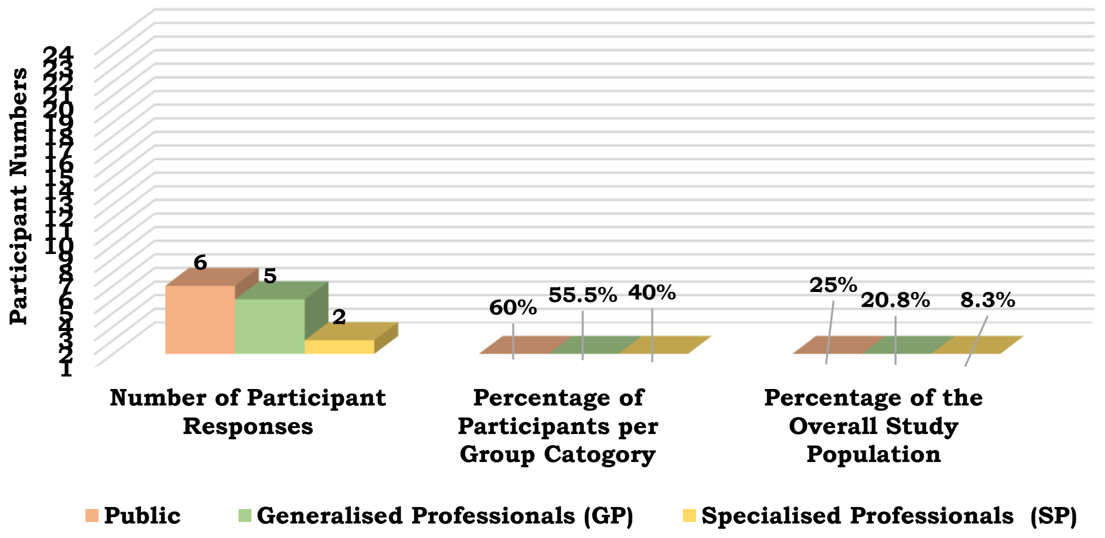
4.7 Finding Four from RO1: Control

Figure 9: Most frequently used words to describe Control



Thirteen (54.1%) participants discussed the importance of control in achieving a GD (*Figure 10*). Generalised professionals and the public showed marginal differences (4.2% n=1) on control while specialised professionals’ ranking showed a 12.5% (n= 3) difference. This reflects the importance of this aspect in existing literature (Ahmed, 2017; Zamanzadeh et al., 2015; Office of the Ombudsman, 2014; The Irish Hospice Foundation, 2013; McCarthy et al., 2009; Quinlan & O’Neill, 2009). Having control over the circumstances of one’s death was deemed a fundamental component of a GD in this study.

Figure 10: Control



4.7.1 Aware and Informed

Four (40%) members of the public determined having choice as the catalyst for controlling one’s fate if terminally ill:

> ‘I would hope to have… an awareness of the process as one would experience it.’
>
> **[Participant L]**

Two (20%) public participants, ***Participant H*** and ***P*** further associated control with *‘dignity’* both stating how this concept enabled an individual to maintain the ability to choose. From a professional perspective:

> ‘…individuals should be informed in decision-making so they can be involved in the process.’
>
> **[Participant K]**

Another professional highlighted in practice, it is crucial for individuals to have an awareness of their condition:

> ‘So, for me a GD is about… knowing in advance.’
>
> **[Participant A]**

Three (21.4%) professionals repeatedly disclosed the importance of being informed and aware as a prerequisite of a GD:

> '…where the patient or the client is prepared, fully aware and informed.'
>
> **[Participant T]**

> '…time to think about death.'
>
> **[Participant F]**

These responses highlight how ensuring individuals are adequately informed of their condition and prospective care needs, are vital from a professional viewpoint in order to ascertain individual wishes and are crucial if the terminally ill are to have control:

> '…you can only plan if you know what a person wants.'
>
> **[Participant A]**

These responses show, similar to the literature (Lee & Hawkins, 2017; Punjani, 2013; Beqiri et al., 2012; Zahedi, 2011; Weafer, 2009), both a public and professional eagerness to be informed and aware of a terminal diagnosis and the need for an effective partnership approach between those receiving care and those providing it. From a professional viewpoint, they show a committed focus to principle two of the HSE person-centred care practice guidelines. That of enabling individuals to become partners in their care needs by ensuring they are supported to make informed decisions (McCormack & McCance, 2017). Consequently, professionals are duty bound to ensure individuals are fully aware and informed in order to make necessary preparations regarding care preferences (HSE, 2019). Monitoring of these aspects would be an essential requisite in achieving a GD.

4.7.2 Person-Centred, Holistic Care

Five (20.8%) participants spoke of the importance of person-centredness. When asked, what in her opinion are the most important factors that help an individual gain a GD, a public participant said:

> 'I would say respect very much…. Person-centred to use the big important phrase in the business of looking after people. Absolutely what the person would want. If I wanted the bloody curtains closed day and night, that's what would be done for me… If I wanted brandy at 3 o'clock in the morning, that's what would be brought to me.'
>
> **[Participant C]**

Responses from professionals demonstrated core principles in person-centred care and agreement from the public:

> '…what the person wants is what goes.'
>
> **[Participant A]**

> 'That it's the client's decision. Everything is what they wanted down to the music in the room, who's holding their hand, who's taking care of them.'
>
> **[Participant X]**

Additionally, ***Participant B*** argued that the individual should be '*looked after as human beings.'* Again, these responses display the theoretical underpinnings and guidelines of a person-centred (Rogers, 1973, cited in Freeman, 2015, p.154), holistic care contending the overall health and well-being of the individual is the main focus of care, not whatever illness they are suffering from (McCormack & McCance, 2017). Participants responses in this study portray a professional commitment to a longstanding goal of health and social care services to assist service users to become the driving force in their own care, by being afforded choice and control (HSE, 2018). Yet, public responses obtained from question 29 (*Table 17*) shows 50% (n=5) believe individuals do not have choice and control and a further 40% (n=4) perceive individual do '*but only to a certain extent'*[4]. ***Participant O, N, M*** and ***C*** all inferred cognitive capacity may be a leading barrier. While ***Participant P, M, D*** and ***H*** proclaimed one's assertion of choice and control are limited in this country *'because we do not have the option here to end life* '[5]. This finding was evident in McLoughlin's, (2017) study which found some of the public perceive the current legal standing on euthanasia practices in Ireland, limits individual choice if terminally ill. Thus, this implies some perceive the only way to retain choice and control is to have the option of hastening one's death as there is a perception these elements may be compromised is terminally ill.

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[4] **PPM, (F), (B), (AB 37-47)**

[5] **PPH, (M), (I) (AB 18-25)**

Table 17: Public Perceptions on Individual Choice & Control

Q29. Do you think people nearing death have choice and control over their care?

Participant Name	Yes	No	Variable	Rationale (*Direct Quotes*)
Participant C		✓	✓	Depends on nature of disease.
Participant D		✓		A medical practitioner would make that choice for you.
Participant H	✓			I think that, I have only ever seen it like in films and stuff like that where they have said…if they're on life support or… I know they can have a 'do not resuscitate'…but you don't actually get to choose when you die.
Participant L		✓		No rationale given.
Participant M	✓			Yes, to a certain extent if they have still got their facilities. But, the later they go… then the care is taken away from them. That decision isn't made by them anymore. It's made by close family or the next of kin. No, because people that are dying of cancer…they should be given the choice if they want euthanasia.
Participant N	✓			No, I suppose they don't…in a lot of cases they are incapacitated, and they are not really in a position to express their choices or wishes.
Participant O		✓		Again, it depends on if they have capacity or whether they can voice their opinions.
Participant P		✓		Nope, because we don't have the option here to end life…again it's down to the ethics that you have to practice under as a medical professional. So, it could be something that could be addressed, and it will come down eventually in my opinion to people's personal ethics.
Participant Q		✓		Sure, it depends on their circumstances. Some people do, and some people don't.
Participant W			✓	I don't know.

4.7.3 Death Preparation and Planning (DPP)

All professionals (58.3%, n=14) in this study valued the importance of DPP in ensuring a GD, mirroring current literature (The National Advisory Committee of Palliative Care 2016; Nici & ZuWallack, 2014; Sallnow et al., 2012). Yet, Rainford et al., (2016), Meier et al., (2016) and Weafer, (2014) show the public may not be of the same opinion. Research in Ireland alone portrays a public reluctance to make provisions for the eventuality of one's death (O'Shea et al., 2018; Weafer, 2014; Quinlain & O'Neill, 2009; McCarthy et al., 2009).

Owing to the significance of DPP and the apparent lack of public uptake reported throughout existing literature, this research probed the public further on this to ascertain the current value placed on DPP in an Irish context. Questions 26 to 30 exhibited below in *Table 18* specifically addressed these aspects.

Table 18: Questions on DPP

Q26. Ascertain if DPP is important and level of awareness on current initiates in palliative, hospice and EOLC.	**An Advance Healthcare Directive (AHD) is defined as a statement made by an individual with capacity (the ability to make and understand information and make decisions) detailing his/her wishes and preferences about medical treatments that may arise in the future at a time when he/she no longer has the capacity and so cannot make decisions (The Irish Hospice Foundation, 2016).** **(a) Are you aware of AHD?** **(b) What is your opinion of it?** **(c) Do you see a value in drafting an advanced healthcare directive?**
Q27.	**Do you think it is important to plan for one's death?**
Q28.	**Do you think people express their wants, needs and desires regarding their care when in the final stages of life?**
Q29.	**Do you think people nearing death have choice and control over their care?**
Q30.	**Have you ever discussed any of the following with anyone?** **1. Funeral arrangements.** **2. Where you would like to die.** **3. If you have a living will.** **4. Things you would like to do before you die.**

Firstly, responses to question 26 (*Table 18*) demonstrated minimal public knowledge of AHDs. Public responses obtained from question 27 maintained all ten (100%) participants perceived DPP as significant. Yet, this result contrasted with previous findings obtained from question 26(c) *(Table 19)* whereby only seven out of ten (70%) participants stated they saw a value in drafting an advanced healthcare directive. This discrepancy possibly was prompted by the discussion evoked in question 26.

Table 19: Responses on DPP			
Q26(c). Do you think it is important to plan for one's death?			
Participant Name	**Yes**	**No**	**Depends**
Participant C	✓		
Participant D		✓	✓ - only if diagnosed with a terminal condition
Participant H	✓		
Participant L	✓		
Participant M		✓	✓- only if diagnosed with a terminal condition
Participant N	✓		
Participant O	✓		
Participant P		✓	✓- only if diagnosed with a terminal condition
Participant Q	✓		
Participant W	✓		

Three (30%) participants maintained they would only consider undertaking DPP initiatives if faced with a terminal illness:

> 'Nobody wants to think about becoming terminally ill until it actually happens.'
>
> [**Participant M**]

This ideology parallels American (Prince-Paul & DiFranco, 2016) and UK (NatGen, 2013) research, showing the main reason for avoiding DPP rests with a belief that death is too far removed from everyday life. Additionally, one participant suggests age and only older individuals contemplate their mortality:

> 'I think that the final departure burdens the family, because it is very, quite expensive to die. I don't plan on doing it [***dying***] for quite a while. So, if I was diagnosed with a terminal illness or I understood my finality was coming then I would make decisions regarding the finances of that. But until I become a little older or that happens, I will probably not make that choice.'
>
> **[Participant D]**

This mirrors McCarthy et al.,'s (2009) study, whereby some participants associated a GD as one where an individual dies 'according to the natural life cycle' thus implying in old age. Again, this demonstrates a lack of public attention to DPP.

This study is similar to Weafer's (2014) showing the public do not make provisions for what they would like to happen if terminally ill or post-death. Furthermore, ***Participant D's*** response implies he would only consider making arrangements in relation to finances to alleviate financial pressures on family after his death. Another participant stated:

> 'It would be very important for me to have my affairs in order...because I have a dependent relative…so it would be really important to me that while I was hale and hearty that I had made sure that he was protected in terms of property and care. And there would be causes, you know, that I would be very interested in advancing if I did have a few bob. That would be very important to me that that's done.'
>
> **[Participant C]**

These two comments from the public demonstrate the prioritising of others needs over their own if terminally ill. This beneficence for others rather than for oneself was also evident in Weafer's, (2014) study. He found actions undertaken regarding DPP were mainly associated with making things easier for the bereaved such as the drafting of a will and funeral arrangements more than expressing personal preferences on EOLC. This study similarly found (**Appendix C-Q30***)* 80% (n=8) of the public had discussed funeral arrangements and 40% (n=4) described details of a will with a significant other. Yet, this may potentially hinder individuals' true expressions on EOLC preferences. Some of the public (40% n=4) in this study also assume individuals do not make their care preferences known if terminally ill despite the emphasis in their responses on control (*Table 20*).

Table 20: Public views on individual preferences regarding care

Q28. Do you think people express their wants needs and desires regarding their care when in the final stages of life?

Participant Name	Yes	No	Somewhat Improving	Don't Know
Participant C		✓		
Participant D			✓	
Participant H				✓
Participant L		✓		
Participant M		✓		
Participant N		✓		
Participant O	✓			
Participant P	✓			
Participant Q	✓			
Participant W			✓	

Likewise, nine (64.2%) professionals acknowledged this is the case in practice. While the remaining five (35.7%) stated in their experience, only a small minority engage in DPP when terminally ill. The most substantiated reason put forth by public participants (40% n=4) for a lack of public engagement with DPP was due to socio-cultural factors of death avoidance which will be discussed in ***section 4.17.2 Lack of Public Discourse***. Overlapping with the finding on pain, some professionals also implied gender and age may be influential factors for engaging in DPP. Again, correlating with Weafer 's (2014) findings, ***Participant E*** stated in practice older individuals seem to be more at ease conversing about death. A response from a HCA in eldercare residential care, indicated older men tend to be more open in this regard:

> 'Some people would discuss it more …in the nursing home men seem to talk about it more than women would…when you'd be asking men about their wishes or anything, they seem to be a lot more open in talking about it and like they'd be more detailed. Whereas, if you talk to women about it, they kind of just brush it off like their just like, 'ah yeah sure whatever I don't really care what happens when I'm gone, I'm gone'…… Whereas men they seem to have a lot more of an opinion on it.'
>
> **[Participant G]**

However, this finding refutes current Irish research showing female members of the public are dissatisfied with current levels of death and dying conversations thus implying they would favour more discourse on these matters (Weafer, 2014). It would seem from ***Participant G's*** comment, in practice females may be the hardest client group to elicit conversations on death and dying.

In summary, control was discussed and conceptualised in varying ways:

1. Choice and control.
2. Person-centred care.
3. DPP.
4. Informed and aware.

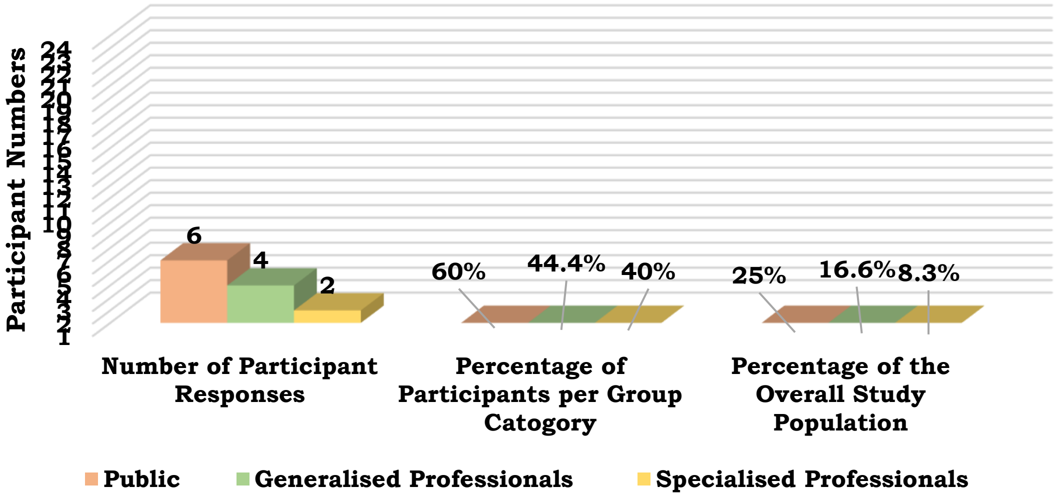
The most important aspect of control discussed was DPPs by both generalised and specialised professionals. This is fundamental prior to a medical crisis or terminal diagnosis as it informs EOLC, increasing the likelihood of a holistic, person-centred approach. This aspect was prioritised by the public however they assumed individuals receiving palliative care do not have choice and control.

4.8 Finding Five from RO1: Maintaining Personhood

Figure 11: Most frequently used words to describe Maintaining Personhood

As was discussed in the literature review, personhood commonly referred to as identity (Kitwood, 1997 cited in Smebye & Kirkevold, 2013, p.2) depicts the essence of humanity encapsulating psycho-social, thus is a fundamental component of person-centred care (Kitwood, 1998, cited in Fazio et al., 2018, p. S11). Maintaining personhood, often referred to as identity, emerged as a fourth finding. It was discussed by 12 (50% n=12) participants in relation to having a sense of peace with oneself when nearing death, preserving dignity and being treated with respect both pre and post-death (*Figure 12*).

Figure 12: Maintaining Personhood



4.8.1 At Peace

Four members of the public (40% n=4) associated being at peace with having a sense of life completion:

> ‘The feeling in themselves that they have completed what they wanted to complete. So, it could be something like having children that could be someone’s goal in life. Or somebody else’s goal could be climbing a mountain and not having any children and living…that you’re happy that you have done everything that you could have done in your life.’

[Participant D]

Another participant:

> ‘I think where there’s no regrets, no bitterness or anger… I think they are factors that help the person in the letting go. That they’ve lived a good life and they are moving on and I think …I suppose you know, that the person would have some trust in the process, the process of death itself. You know, that we are leaving the world, we don’t know where to …that we can trust that, that is ok.’

[Participant L]

Finding peace when nearing death increases self-worth and identity (Ho et al., 2013). Nine (37.5%) participants spoke of the necessity of reaching a tranquil state. This was the most substantiated characteristic in maintaining personhood. Throughout literature, finding peace is embedded within philosophical origins of existentialism, spirituality and/or religiosity (Ho et al., 2013). Of note, no member of the public expressed religious inclinations when discussing this attribute. Rather existentialism and spirituality, whereby one seeks meaning in one’s life were prioritised. Ho et al.,’s (2013) exploration of dignity according to 16 terminally ill patients in Hong Kong, found a sense of peace for many correlated to spirituality. This was evident in this study showing Ireland has witnessed a marked decline in religious beliefs (CSO, 2018). Although generativity was not evident in this study, an element of being at peace was leaving something behind:

> ‘We all want to be remembered…and remembered in a good way.’

[Participant D]

Ho et al., (2013) coined this ‘moral transcendence’ – the concept of leaving something of value behind. Meier et al., (2016) found that life completion was particularly important for the bereaved and family but less so for professionals.

However, this study contradicts Meier et al.,'s (2016) as five (35.7%) professionals and four (40%) members of the public valued this component. Current literature highlights the merits of saying goodbye to loved ones in achieving a peaceful death (Meier et al., 2016; Weafer, 2014). The importance of making peace with others was expressed:

> 'Made their peace with those around them, the ones they love.'
>
> **[Participant F]**

4.8.2 Dignity

Professionals widely acknowledge a key indicator of quality palliative care is maintaining patient dignity (Vlug et al., 2013; Quinlan & O'Neill, 2013). This was also evident in this study with four (28.5%) professionals, two (22.2%) from generalist and two (40%) specialist domains emphasised dying with dignity. However, only two (20%) female members of the public discussed this aspect:

> 'Immediately after death, well obviously you would hope that your body would be treated with the dignity that the human body deserves.'
>
> **[Participant C]**

> 'Having dignity when you die…having choice.'
>
> **[Participant P]**

This is somewhat inconsistent with current Irish research showing 46% of the public prioritise maintaining dignity if at EOL (Weafer, 2014). However, the public in this study rated it at a marginally lower 20% (n=2). Consequently, this finding suggests dignity may be given less prominence by the public than previously reported in Ireland. It further refuted Milnes et al.,'s (2017) Australian study, into public and patient perceptions of QOL in EOLC whereby dignity was identified as the second leading characteristic of a GD. However, there were similarities between this study and that of Milnes et al.,'s (2017) concerning gender differentials with both revealing females rated dignity significantly higher than their male counterparts. No male members of the public mentioned dignity. The findings did concur with Vlug et al., (2012) with professionals citing dignity as a key principle in palliative care.

Evident from the findings, both the public and professionals agree the key elements of maintaining personhood are associated with dignity, respect, being at peace, finding a purpose to one's life and reconciliation, all of which are recurrent themes in international literature (McCaffery et al., 2016; Meier et al., 2016; The NCPC, 2016; Callahan-Lesher, 2010; Barazzetti et al., 2010).

Public comments made equally by both males and females on finding peace, suggest many would reflect upon and seek meaning in their lives if nearing EOL. This suggests they may utilise spirituality to achieve peace if nearing death rather than gaining solace from religious devotion which was considered important by the public in Weafer's, (2014) study.

4.9 Finding Six from RO1: Independence

A new finding, not expressed throughout current national literature emerged from two (20%) male members of the public, namely maintaining independence, which may explain their lack of discussion on dignity as they may see both as interchangeable components. One participant saw independence as being cognitively aware and competent:

> **'…** I suppose to have all your faculties and to be independent.'
>
> **[Participant N]**

He further suggested this component is especially important to him because he has seen:

> '…people that can't care for themselves being dependent…very dependent on others.'
>
> [**Participant N**]

Again, arising from personal experience another said:

> 'I had made up my mind very quickly…when I was after having a stroke that from the minute I got out of intensive care, that I was going to try to get back as quickly as possible because I had seen people that didn't put in the effort straight away and suffered for it'…I'd known the minute they **[referring to healthcare personnel]** dropped me in the ward, they said they were going to send nurses to give me a hand to get into the shower. I made sure that I got into the shower and got my clothes on me before they came [sic]. The next thing they wanted to [sic] do, they wanted to bring a wheelchair to bring me down to the rehab place, but I said; No, I'm walking. They didn't like it …but I had to try and get back everything I could.'
>
> [**Participant Q**]

Participant N and ***Q*** spoke of the importance of maintaining and being supported to remain independent in order to accomplish GD. Undoubtedly, as a terminal illness progresses a loss of physical and/or cognitive functioning may occur (Rodríguez-Prat, et al., 2016) which both ***Participant N*** and ***Q*** perceived as an imminent threat.

Male hegemonic masculinity prescribes males as strong and dependable (Gordon et al., 2013) which may somewhat explain ***participant N*** and ***Q's*** focus on independence, yet it does not account for the lack of discussion by other male participants from the public. Rodríguez-Prat, et al.,'s (2016) systematic review of twenty-one international studies recording experiences of over 400 terminally ill participants, may provide an explanation. They found higher status terminally ill individuals prioritised their independence. ***Participant N*** and ***Q*** both were self-employed and the only male members of the public with either dependent or non-dependent children at the time of this study. Fatherhood coupled with their independent professional status and male social norms of valuing strength and independence, may have contributed to this finding. Therefore, it could be interpreted the rationale for the significance they attached to independence is culturally specific and family orientated.

4.10 Findings from RO2: Exploration of Supports to Obtain a GD

The literature affirmed the relevance of both formal and informal support (Weafer, 2014; Ko et al., 2015). Therefore, this study sought to explore public and professional perceptions of current supports and their effectiveness/ineffectiveness in generalist and specialist palliative care. Firstly, components of the bio-psycho-social-spiritual model were explored in order of their perceived effectiveness. Secondly, it explored support factors for both formal and informal caregivers. Finally, perceptions of service delivery within various settings were revealed. In doing so this study investigated how individuals, their families/loved ones are currently supported to achieve a GD.

4.11 Finding One from RO2: Perceived Effective Components of the BPSSM

4.11.1 Religious Supports

For some, religion provides a sense of peace if terminally ill, thus implying the significance of this support in palliative care (Lueng et al., 2009):

> '…I think there is a lot of people turn to it in their hour of need and I see it in practice everyday…I see all these people who gain acceptance and like how would you gain acceptance with the fact that you're dying only that it comes from, comes from something. I don't know what it is, but people gain that, the majority of them do and I think there is a good bit of support there.'

[Participant K]

Lueng et al., (2009) argued its significance. A total of 70.8% (n=17) of the overall study population perceived religious supports to be effective in current services (*Table 21*). However, while seven (70%) members of the public viewed religious supports as effective, five (50%) stated this was inferred from their knowledge of the Catholic tradition.

Table 21: Perceived Effective Components of the BPSSM

1. Religiously - Majority View Pertaining to Each Group		
Public	Yes n=7 (70%) **H, D, M, N, O, Q & W**	Percentage of Study Population 17 Yes = 70.8%
Generalised Professionals	Yes n=7 (77.7%) **A, B, F, G, J, X & U**	
Specialised Professionals	Yes n=3 (60%) **E, S & K**	
2. Socially - Majority View Pertaining to Each Group		
Public	Yes n=4 (40%) - supported socially by family **L, M, N, Q, W, O &P**	Percentage of Study Population 9 Yes = 37.5% Supported socially by family =29.1%
Generalised Professionals	Yes n=3 (33.3%) – Supported socially by family **J, U & X** Yes n=2 (22.2%) socially supported by professionals **J, G & R**	
Specialised Professionals	No n=3 (60%) **E, T & K**	3 No = 12.5 % total population 3 No= 60% of participant group
3. Spiritually - Majority View Pertaining to Each Group		
Public	Yes n=4 (80%) **N, Q, P & W**	Percentage of Study Population 8 Yes = 33.3% 3 No = 12.5%
Generalised Professionals	Yes n=4 (80%) **B, G, J & X**	
Specialised Professionals	No n=3 (60%) **E, T & I**	

(***Appendix V*** *for full breakdown of the BPSSM Across all Groups)*

Participants' comments demonstrate a lack of awareness as to whether other religions would receive the same standard of support:

> '...I can only speak…as [a]Catholic…and yeah there is always help there from the religious orders if you need it. I don't know with regard to any other religion.'
>
> [**Participant N**]

> 'I wouldn't know enough about the multiplicity of religions that are now in Ireland to know how they deal…I've no idea how our Muslim population or the like would face death and support their communities.'
>
> [**Participant C**]

Correspondingly, some professionals cited the multifaceted nature of current religious supports in practice:

> 'Yeah, we would be hot on the religion here, like you know and not just on the Roman Catholic...[sic] with Church of Ireland we would contact their local [**clergy**]…sus them out and what, you know. Does your faith mean a lot to be you?…if it was someone who was A-religious [**non-religious**] and end of life was there and normally, we'd light a candle and have the holy water and all for the Roman Catholic if that was their faith. You know, we've a Church of Ireland end of life box cos there's a few little differences in that and then like if it was, like I'd just say to family, well would you like just a candle…and not, you know a crucifix or anything like that or would you like just flowers beside their bed, or some people would be very clear and just, 'nothing', and that's ok.'
>
> **[Participant J]**

> 'We have a hospital chaplain here and I think a lot of people here if they want to tap into that they can access it pretty well in whatever religion.'
>
> **[Participant E]**

Religious diversity has considerably evolved within the last ten years in Ireland with the most common religious affiliations being Catholicism, Church of Ireland, Islamism, Orthodoxism and Christianity (CSO, 2017). The comments made by ***Participant J*** clearly display a professional commitment to integrate social changes in practice. Both professional groups fully acknowledge the importance of providing diverse religious supports to the terminally ill. Although no public participant divulged if religious supports would be important to them, seven professionals (50%) confirmed the significance of this element for the terminally ill. Five professionals (35.7%) said it was something they had routinely witnessed in practice. However, six professionals (42.6%) also mentioned secularism is becoming more evident in the Irish landscape *(Table 22*).

Table 22: Professional Perceptions on the Importance of Religious Supports[6]

Generalised Professionals	**Yes**	**Regularly witnessed in Practice**	**Secularity becoming More Evident**
	n=6 (66.6%) **A, B, U, V** ***Older Generation especially*** **- G, X**	n=3 (33.3%) **B, G & J**	n=3 (33.3%) **F, J & R**
Specialised Professionals	n=1 (20%) **K**	n=2 (40%) **K & E**	n=3 (60%) **I, S & T**
Overall Total	7	5	6
Total Percentage of Overall Population	(50%) n=7	(35.7%) n=5	(42.6%) n=6

Ireland has witnessed a marked decline in religious practice. For instance, in 2016, Catholicism accounted for 78% of the population compared to 84% in 2011 (CSO, 2018). Despite this, the significance of religious supports discussed by all professionals suggests that religion is an important aspect for those approaching death.

4.11.2 Social Support

The public (40% n=4) and generalised (55.5% n=5) professionals perceived current social supports to be satisfactory (*Table 21*). This equated to 37.5% (n=9) of the overall study population. Both groups discussed this supportive element in terms of professional and familial support working in tandem. Having a sense of social support increases an individual's ability to manage socially, spiritually, emotionally and physically when nearing EOL (CareSearch, 2019; Samerchua et al., 2016; Meier et al., 2016; Weafer, 2014; McCarthy et al., 2009).

---

[6] Some participants selected more than one option.

Family/Loved Ones

Mirroring existing literature (Hong et al., 2016; Ko et al., 2015; Zaider & Kissane, 2009), five (35.7%) participants from professional domains, three from specialised (60%) and two (22.2%) from generalised domains and one (10%) participant from the public described the family of the terminally ill as an invaluable source of support. While all responses in conjunction with this were similar, one participant currently employed within a youth residential service who had prior experience working within community palliative care stated:

> 'That it **[referring to social support]** should be looked on that the family member, you know, can be involved. That there's one main person that can be there with them because your family, as you know is the best.'
>
> [**Participant U**]

Formal Social Supports

Professional social supports encompass all elements of a total pain approach; bio-psycho, social, religious, spiritual and financial components. Supports are facilitated by:

> '…carers and staff make sure they are as comfortable as they possibly can be. You know that everything is done the way that they would like it to be done.'
>
> **[Participant U]**

This is implemented by establishing strong, therapeutic relationships between the individual and professionals (Salehe & Njine, 2016; Borimnejad et al., 2014; Kirby et al., 2013). Of the 37.5% (n=9) of the study population who stated this support factor was effective, 29.1% (n=7) argue that social supports emanated from family/community. Whereas 60% (n=3) of specialised professionals highlighted inadequacies of informal social supports (*Table 21*) discussed in-depth further in this chapter in ***section 4.19 Challenges with Informal Supports*.**

4.11.3 Spiritual Supports

Evident from *Table 10,* 42.8% (n=6) of professionals suggested Ireland is increasingly becoming a more secular society. This view is depicted within the most recent statistics concerning religious practice in Ireland, showing the category of 'no religion' has increased from 6% of the population in 2011 to currently 10% (CSO, 2018). This figure approximates to 468,400 individuals (CSO, 2017) who may potentially require spiritual assistance if terminally ill.

With increased secularisation one participant stated:

> '…religion is not going to be a factor anymore.'
>
> **[Participant S]**

An overall total of 33.3% (n=8), of the study population involving both public (40% n=4) and generalised professionals (44.4% n=4) deemed current spiritual supports favourably:

> 'Yeah, whatever, we try and hone in…Some of the night nurses here will hear some of their **[referring to residents in eldercare residential setting]** deepest thoughts at 3 o'clock in the morning'.
>
> **[Participant J]**

Of note, the public were unsure if professionals could accommodate spiritual supports. Although four (40%) stated they believed individuals were effectively supported in a spiritual sense, they implied it may be the individual's themselves who facilitated this more than professionals:

> **'**…some of that is down to the person themselves whether they believe in spirituality…A lot of people will have a different interpretation of what they feel spirituality will be…a professional in spirituality and religion I would consider to be a priest or someone who has spent their life studying this element. But, then again, they haven't really experienced life. So, how can they tell me, if I'm having a moment with for instance, within a relationship they haven't understood they've never had a relationship in the way that would be perceived as being like a marriage or a girlfriend. They have dedicated their whole life to God or spirituality then how can they really be a professional helping me with a spiritual based issue…so I'm not sure, I don't know how to answer that question.'
>
> **[Participant D]**

Four (16.6%) professionals, two (22.2%) from generalist and two (40%) from specialist domains, shared this opinion:

> 'Spiritually that bit I'm very interested in. Unless the person has become interested in things spiritually coming up to their death it's a bit late at the last minute to sort of start thinking how things are going or to get into it then…if they have already begun to pray in a spiritual way, the support will be there… but that is very much dependent on the people and it's not something you can put in place.' In a professional capacity, by the time you see people they have already reached a stage where they have gone a particular spiritual path, or they have no particular spiritual path. There was a man…he was Buddhist and he managed very well to calm himself and keep himself in the present through his meditation.I suppose if you're with somebody and I'm often with people who are dying because of where I'm working [**working in an eldercare residential service with a palliative care unit**] and what I have worked out, you can at least be present to them which means an awful lot, which kind of is a spiritual dimension…just be present.'
>
> **[Participant F]**

Rego et al., (2018) maintain religion and spirituality frequently cause confusion and are often viewed inseparably, yet distinctions between the two have been made. In this study, all professional participants (58.3% n=14) and 50% (n=5) of the public saw spirituality and religion as separate entities:

> ‘Some people, I suppose as things have changed in the church some people still have their spiritual beliefs but they’re not practicing religion.’
>
> [**Participant N**]

> ‘I think that from what I know, there are hospital chaplains now and pastoral care workers…that go beyond the boundaries of religion and…religious beliefs and so on. To be able to address spirituality and spiritual needs in their own right… regardless of religion. So, and I think that’s a great thing and I would love to see more done to help people. In other words, to take spirituality out of the realms of religion.’
>
> [**Participant L**]

> ‘We, we don’t give particular spiritual support but, we give I suppose what I would call ‘Humanity Support’. You know, it’s not based on any religion but, ‘with the grace of God, go I’ type. We give that kind of support which is hopefully of some help.’
>
> [**Participant K**]

This finding also challenges Quinlan and O’Neill’s (2013) study into patient autonomy in hospitals in Ireland, claiming religion and spirituality are often unacknowledged within health and social care domains. Spiritual supports are becoming prominent features both in individuals’ lives and in EOLC. This was further developed in this study as both the public and professionals separated spirituality and alluded to its individualistic nature. In agreement with ***Participant S***, change has and will need to continuously evolve to accommodate this element in palliative care service in order to incorporate a total pain approach to care. Although responses convey spirituality may be an innate, private component, providing a sense of presence and accompaniment may help professionals facilitate this important support. Therefore, it is essential that professionals have the necessary time to accommodate this in practice.

4.12 Finding Two from RO2: Perceived Unmet Supports in the BPSSM

Table 23: Ineffective Components of the BPSSM		
Financially – Majority View Pertaining to Each Group		
Public	**No** n=8 (80%) **C, D, H, L, W, O & P**	**Percentage of Study Population** 15 No = 62.5% 3 did not know = 12.5% 2 Somewhat = 8.3% 2 Yes = 8.3% 2 No = 8.3%
Generalised Professionals **The majority did not know if terminally ill individuals are supported financially**	**Don't Know** n=3 (33.3%) **A, B, & G** **Divided on this component** **Yes** n=2 (22.2%) **J & V** **Somewhat** n=2 (22.2%) **F & X** **No** n=2 (22.2%) **R & U**	
Specialised Professionals	**No** n=5 (100%) **K, E, S, I & T**	
Psychologically – Majority View Pertaining to Each Group		
Public	**No** n= 7 (70%) **D, H, L, N, O, P & W**	**Percentage of Study Population** 12 No =50% 4 not enough = 16.6%
Generalised Professionals	**No** n= 5 (55.5%) **F, G, R, U & X**	
Specialised Professionals	**Not Enough** n=4 (6.6%) **E, I, S &T**	

4.12.1 Financial and Psychological Support

All participant groups considered the inadequacy of psychological and financial supports, with 62.5% (n=15) deeming financial and 50% (n=12) psychological support as insufficient in current palliative care services (*Table 23*).

4.12.2 Support for Family/Loved Ones

Previous literature verifies informal caregivers' needs are just as crucial as those of the terminally ill who may equally experience biological, social and psychological ramifications owing to caregiving responsibilities (Lambert et al., 2012).

Table 24: Perceptions on Current Support for Informal Caregivers

The Public	
Rating	**Number of Participants**
1. Good	n=3 (30%) **Participants L, M & Q**
2. Poorly	n=3 (30%) **Participants O, C & N**
3. Minimal	n=2 (20%) **Participants H & P**
4. Don't Know	n=2 (20%) **Participants W & D**

Table 24 highlights 50% (n=5) of the public feel informal caregivers are insufficiently supported by professionals in palliative care services. However, this finding may have been an assumption given that 40% (n=4) who made this claim suggested they did not possess any specific knowledge of supports for informal caregivers. The main tenet of palliative care is to provide care for both an ill individual and their families/loved ones. Including both groups in the care trajectory, diminishes adverse effects such as carers unintentionally transferring their psychological distress to the ill person and a possible breakdown of social connectedness (Lambert et al., 2012). Instead, their responses implied opinions were largely based upon preconceptions obtained from media, hearsay or just a general preconceived idea:

> 'Ok, again I'd have to go on what I hear…on Joe Duffy…what I'd read in newspapers or hear people talking about. The overwhelming sense is that people feel very unsupported. That they might be getting kind of 15 minutes to wash somebody which is so brutal you know…from what I hear I don't think they are.'
>
> **[Participant C]**

Of the three participants (30%) who viewed support structures for informal caregivers favourably, two (20%) confirmed they had personal experience of these supports:

> '[from my personal experience]…The caregiver is also supported by the palliative care team or the hospice services. So, from what I know, I think …their needs are also heard and addressed.'
>
> **[Participant L]**

Reference was also made to living in the rural community:

> 'Sure, I think everybody steps up to the mark like when…and does all they can. It's something that you'd nearly do automatically …it's what happens in the community.'
>
> **[Participant Q]**

This response displayed the beneficial aspects of social and communal connectivity (Centre for Ageing Research and Development in Ireland, 2010). Therefore, it could be interpreted ***Participant Q's*** sense of community correlated to this assumption should EOL draw near, social supports would be available to him from his community. In agreement with most of the public (*Table 12*), specialised professionals perceived supports as unsatisfactory indicating they were either poor (60% n=3), minimal (10% n=1) or in need of improvement (60% n=3). On the other hand, generalised professionals provided comments on supports in various settings (*Table 25).*

Table 25: **Professional Perceptions on Current Support for Informal Caregivers**[7]

<table>
<tr><th colspan="4">Generalised Professionals</th></tr>
<tr><td>1. Inpatient Hospice Services</td><td colspan="3">Good
n=5 (55.5%)
Participants A, B, G, U & X</td></tr>
<tr><td>2. Community & Homecare Services</td><td colspan="2">Good
n=3 (33.3%)
Participants G, U & X</td><td>Minimal
n=1 (11.1%)
Participant R</td></tr>
<tr><td>3. Eldercare Residential Services</td><td colspan="2">Good
n=2 (22.2%)
Participants R & X</td><td>Not Enough
n=2 (22.2%)
Participants G & U</td></tr>
<tr><th colspan="4">Generalised Professionals</th></tr>
<tr><td>4. General & Acute Hospital</td><td>Good
n=1
(11.1%)
Participant R</td><td>Poor
n=3
(33.3%)
Participants G, U & X</td><td>Not Enough
n=1 (11.1%)
Participants X &G</td></tr>
<tr><td>Across all Sectors</td><td colspan="2">Good
n=1 (11.1%)
Participant B</td><td>Variable
dependent upon locality, accessibility and the family's openness to avail of supports
n=3 (33.3%)
Participants J, A & F</td></tr>
<tr><th colspan="4">Specialised Professionals</th></tr>
<tr><td rowspan="2">Across all Sectors</td><td>Poor</td><td>Minimal</td><td>In need of improvement</td></tr>
<tr><td>n=3 (60%)
Participant K, I & E</td><td>n=1 (20%)
Participant S</td><td>n=3 (60%)
Participant T, S, I, K & E</td></tr>
</table>

---

[7] Some participants selected more than one option.

Hospice services were championed by 55.5% (n=5) of this group for providing good supports to informal caregivers:

> ‘I found hospice to be fantastic. I found the whole idea of hospice…their approach to the caregivers and their approach to the person who was dying they have it as good as you can get it. And hospice is in the community and the hospice works very well in the community.’

[Participant F]

Secondly, Community Care and Homecare services were reported positively by 33.3% (n=3) of participants:

> ‘Absolutely I do. Like I look at one of the girls who works in the area and she does all those kind of services where I come from…the family look on her for support…because they knew that she was with their mam or their dad in the times before they got really ill and she would’ve spent a lot of time with them because they would’ve been working or whatever [**the family**]. And they look on her and they draw back to,
>
> ‘What do you think that he or she would’ve liked.’

[**Participant U]**

Thirdly, Residential Care Services were also viewed favourably by 22.2% (n=2) of generalised professionals:

> **‘**If a family member calls to the nursing home they are going to have the opportunity to speak to somebody. There is always going to be somebody there.’

[**Participant G**]

> ‘…there’s always people in residential services. Like there’s always carers, always nurses, always doctors…in most of them now you have the social workers as well...That do sit and chat with them…’

[**Participant R]**

Whereas general and acute hospital services were deemed negatively by 44.4% (n=4) of generalised professionals:

> ‘And then with the hospital I don’t think that hospital would…give any support to informal caregivers…it’s just basically meeting the patients’ basic needs and after that they are just moving on to the next person...I’d say it’s fairly impersonal as well.’

[Participant G]

This finding parallels McKeown’s (2014) who also portrayed a lack of personalisation and individualism in hospitals. A further four (44.4%) generalised professionals gave general descriptors on their views of formal supports for informal caregivers.

4.12.3 Perceptions on Aftercare Supports for Informal Caregivers

Aftercare bereavement services for families, loved ones and informal caregivers were ranked poorly by all participant groups totalling to 37.5% (n=9) *(Table 26*) of the overall population. While many professionals discussed giving bereavement support services' contact details to the bereaved, condolence cards and brief follow-ups, most implied current support services needed serious improvement. Only one professional (20%), a palliative care consultant spoke highly of aftercare supports for informal caregivers in both community homecare and a residential care service with palliative care beds that she is affiliated with:

> '…the aftercare is superb; the people are allowed stay in the room as long as they want to. They are given soup and sandwiches you know, indefinitely. The staff are very considerate of them…some people have had their wakes in the unit. Whatever religious or non-religious service afterwards…the unit has catered for that, which is fantastic.'
>
> **[Participant E]**

Likewise, she detailed supports available through community and homecare services:

> 'If they were involved with the homecare team, the homecare team do a bereavement visit and we send out a bereavement pack. If you are talking to any of the homecare team, they will show you a bereavement pack that goes out as well. So, that's kind of offering to people some of the telephone numbers and things that they can make contact with if needs be.'
>
> **[Participant E]**

These responses reflect supports for informal caregivers, families/loved ones immediately after the death of a loved one. Therefore, they do not truly represent the totality of aftercare supports provided. One could speculate that ***Participant E*** may not have been fully aware of the long-term bereavement supports available.

Table 26: Perceptions of aftercare support for informal caregivers[8]

Q21-24 How would you rate aftercare supports for informal caregivers of a terminally ill individual?

Public	**Poor** n=4 (40%)	**Variable** **Individuals openness to avail of services, accessibility of services/ professionals** n=2 (20%)	**Don’t Know** n=2 (20%)	**Improved** n=1 (10%)	**In Need of Improvement** n=1 (10%)	
Participant Name	**H, L, M, O**	**Q, W**	**D, N**	**P**	**C**	
Generalised Professionals	**Poor** n=3 (33.3%)	**In Need of Improvement** n=2 (22.2%)		**Don’t Know** n=2 (22.2%)	**Variable** n=1 (11.1%)	
Participant Name	**G, J, R, X**	**F, U**		**B, V**	**A**	
Specialised Professionals	**Poor**	**Good**	**In Need of Improvement**	**More so informal social supports**	**Don’t Know if Current Supports are Enough**	
	n=2 (40%)	n=1 (20%)	n=2 (40%)	n=1 (20%)	n=1 (20%)	
Participant Name:	**K, I**	**E**	**E, S**	**S**	**T**	
	In Eldercare Residential Service with palliative care unit n=1 (20%) **in community homecare**	n=1 (20%) **challenging in hospitals**				
Overall Percentage	**Poor** n= 9	**Variable** n=3	**In Need of Improvement** n=3	**Don’t Know** n=4	**Improved** n=1	**More so informal social supports** n=1
	37.5%	**12.5%**	**12.5%**	**16.6%**	**4.1%**	**4.1%**

---

[8] Some participants selected more than one option

Three generalised (33.3%) professionals relayed how they had personally experienced a lack of support when they themselves adopted a caring role of a loved one:

> ‘None, absolutely no support there for them. Who do they…like after a family member is after passing away there’s nobody to say [**stated her name here omitted to maintain anonymity and confidentiality**] you need to talk to someone, we’ll give you a number. You know, there’s nobody to say that. There’s nothing there and there was never support given to me anyway.’ **[referring to her experience while caring for her terminally ill father].**
>
> **[Participant R]**
>
> Also recounting minimal supports following the death of her father ***Participant X*** stated:
>
> ‘There is none and a from personal experience when my father died, we got nothing. We were told to get on with it. You got on with it…we left the hospital and that was it. You know, and we were young at the time and mam, my mam never got anything. Nobody even spoke to her…and like that’s 18 years ago and it’s still not there.’
>
> **[Participant X]**
>
> ‘…I know that from my own experience with my own family...Your folks are declining. This is all brand new. Nobody taught me this. What do I do? Where do I go?’
>
> **[Participant B]**

Also mentioned was a public lack of awareness which also diminishes their accessibility:

> ‘I think if there was some, if there was a greater awareness...to have some person who is able to say, ‘Look this is how you start your enquiry. This is what you need to do. This is the person you need to go to. I would see…to maybe give that sort of a service a bit more of a profile may be helpful for people.’
>
> **[Participant B]**
>
> ‘Yes. Like the service is out there but, they don’t know about it.’
>
> **[Participant X]**

These statements contradict **Participants *S*** and ***E’s*** earlier claims that service contact details are routinely provided to the bereaved, families/loved ones in need of supports. Most of the public presumed once bereaved it would be time to get on with your life.

In efforts to diminish this gap in current service provision, two generalised professionals (22.2%) recall how they would call on the bereaved '*a few days later after all the hustle and bustle for a cup of tea'*[9] to check in with them. Both maintained formal caregivers in the community '*are the ones that do the support afterwards*'[10]. This finding also suggests a lack of awareness of the availability and accessibility of supports for informal caregivers. ***Participant* Q** and ***W i***mplied it varies depending individuals' circumstances, service and professionals' ability to support informal caregivers. Five (50%) other members of the public expressed little to no knowledge of these supports.

4.12.4 Support for Professionals

Assisting individuals and their family/loved ones along their EOL journey can be emotionally taxing (Aycock and Boyle, 2006, cited in IHF, 2013 p. 1). Consequently, stress, burnout and emotional fatigue are commonplace in these sectors (Davis et al., 2014). Reflecting the literature (Davis et al., 2014; IHF, 2013), four (44.4%) generalised professionals and one (10%) specialised professional described the emotional turmoil experienced in their daily roles:

> '…there are personal challenges obviously because there's a lot of distress in giving bad news all the time, being around where people are tearful, emotional is hard.'
>
> **[Participant E]**

Another participant spoke of feeling powerless:

> 'Every time you are accompanying somebody, if somebody is really, really struggling with the whole thing you can feel quite powerless. I think there's a sense of powerlessness.'
>
> **[Participant B]**

Another referred to forming attachments with the terminally ill:

> '…the emotional part. Even in a short space of time, you will get attached to somebody. Even in only a couple of weeks you can get very attached to someone because you know what's going to happen. And their talking to you about their life and stuff like that and you do get very attached and you don't get any support after that.'
>
> [**Participant X]**

---

[9] **GPX, (F), (I) (AB 37-47)**

[10] **GPV (F), (I), (AB 59-69)**

The Public also acknowledge the difficult role of professionals:

> '…it's a vocation…I can't ever see myself ever wanting to be in the position where I would get to experience people's passing. Because I imagine they'll want to talk about things, their life their stories and who they are. And, I don't know if emotionally and spiritually within myself I'd be ok with dealing with that.'
>
> **[Participant D]**

Owing to the nature of the work, Odhiambo and Rutto, (2018) stressed the importance of professionals also receiving occupational support such as receiving adequate training, having effective communication pathways and regular supportive supervision. However, 78.5% (n=11) of professionals involved in this study did not mention support. Of the 35.7% (n=5) of professionals who did discuss this topic, only one (10%) participant revealed occupational supports:

> 'I suppose we do a little bit of debriefing here amongst the staff…There'll always be that gentle debriefing there in the staff room…You know…there is a sense of community around…within the staff...I suppose, the carers and the nurses have each other like you know.'
>
> **[Participant J]**

Another professional participant mentioned the need for support to avoid burnout:

> 'And then supporting the people who are providing that support...the staff…It's very, very hard for staff to do that and the demands on them doing it day in day out. For some it's no wonder people burn out.'
>
> **[Participant A]**

The lack of discourse on support from professionals may suggest their preoccupation with supports for the individual and their families/loved ones, thus placing minimal attention to their own needs. Although many professionals expressed emotional turmoil in their role, only two spoke of self-care strategies:

> 'My male colleagues say to me that when they leave the door of the hospital here, they can just switch a switch and switch off. I can't, it takes me…I have to filter it out. It might be a few walks with the dog to let go of that and that's just my nature. So, you know all those personal challenges.'
>
> **[Participant E]**

It may be interpreted that walking her dogs incurs a form of reflective practice (Kolb, 1984 cited in Arnott et al., 2019, p.130) and offloading of the distress encountered in her role as a consultant in palliative medicine.

This activity seems to assist her in assessing and addressing her emotional and professional developmental needs through recalling professional experiences encountered, the learning and feelings it incurred that may need to be addressed.

Similar to ***Participant J*, *Participant E*** described her clinical supervisory role with staff members:

> 'I am always saying to the nursing staff that we are inclined to relate to our peer group. So, it might be based on age, or situation or what children you have, you know all those sorts of things. Or somebody might remind you of somebody in your own life that's going to be more challenging. So, there are challenges of dealing with that, of trying to separate your role from being too involved.'
>
> **[Participant E]**

Aside from ***Participants J*** and ***E*,** no other professionals discussed any form of supervision or reflective practice. This indicates a possible lack of professional supervision in these professions, even though in clinical and social care practice, supervision and reflective practice are core codes of professional conduct (CORU, 2018; HSE, 2015). Additionally, the HSE, (2015) issued a supervision policy for all health and social care professionals demonstrating the importance of supervision for frontline staff. However, this study found a lack of this in practice. Furthermore, governing bodies of both health and social care professionals state, in relation to supervision, staff should ensure they have sought and engaged in supervision practice (Irish Association of Social Workers, 2019). Yet, there was no evidence of this policy in this study, implying that staff are dealing alone with occupational stressors. It further suggests a lack of organisational accountability and responsiveness in support structures for frontline staff.

4.12.5 Exploration of Support Services

While exploring perceptions of the effectiveness/ineffectiveness of current supports for terminally ill individuals and their families/loved ones all participants provided a broader perceptions of palliative care service *(Table 27).*

4.12.6 Public View(s) on Current Supports

Table 27: Public Perceptions on Support Services

Q19. How would you rate current end of life care support services?

Rating	Number of Participants	Participant Name
Good	n=3 (30%)	**D, L & Q**
In Need of Improvement	n=4 (40%)	**H, P, M & O**
Depends on Illness Type	n=1 (10%)	**P**
Don't Know	n=2 (20%)	**C & W**

Table 27 depicts overall the public deemed current support needs improvement. However, answers obtained from question 17 and 18 (**Appendix C**) which investigated public awareness of palliative and hospice services, revealed their opinions were again largely based on perceptions.

Table 28: Public Awareness of Palliative and Hospice Care Services

Q17.-18 Do you have an awareness of Palliative & Hospice care services?

Rating	Number of Participants	Participant Name
Yes	n=2 (20%)	**M & O**
Minimal	n=3 (30%)	**W, L & C**
Confusion between both services	n=2 (20%)	**D & P**
No	n=3 (30%)	**H, Q & N**

Only two members of the public (20%) possessed some knowledge of these services (*Table 28*). ***Participant O*** stated her honours degree in professional social care had provided her with knowledge of such services. While ***Participant M's*** awareness was attributed to her personal experience concerning the care and subsequent death of her terminally ill father. A total of 80% (n=8) of this group had little or no knowledge of palliative and hospice services; 30% (n=3) had minimal awareness, 20% (n=2) displayed confusion between these services and a further 30% (n=3) had no knowledge of them. These findings are consistent with previous research which portrayed a public lack of awareness and confusion on distinguishing features of these services (Schreibeis-Baum, et al., 2016). They showed public unfamiliarity may lead to a lack of demand for and accessing of services, potentially diminishing funding initiatives and policy enhancements in these sectors. Additionally, most of the public (60% n=6) believed individuals were not currently supported to have a GD due to the prohibition of euthanasia in Ireland (*Table 29*).

Table 29: Public Perceptions on the Facilitation of a GD		
Q19. Do you believe people are supported to have a good death?		
Rating	**Number of Participants**	**Participant Name**
Yes	n=1 (10%)	**Q**
No	n=6 (60%) ***all implied no due the prohibition of euthanasia practices in Ireland***	**P, O, M, N, H & D**
Don't know	n=1 (10%)	**C**
Depends on individual circumstances and service provided	n=2 (20%)	**L & W**

Therefore, irrespective of supports, this finding implies some individuals' aspirations towards a GD may not be obtained in Ireland owing to a lack of current legislation on euthanasia practices (House of Oireachtas, 2018).

4.12.7 Professionals' Views on Current Service Delivery

Table 30: Generalised Professionals' Views on Current Services[11]		
Q21. How do you view current end of life care in the following settings?		
Generalised Professionals		
1. Hospice Care		
Rating	**Number of Participants**	**Participant Name**
Perceived as Good	n=9 (100%)	**A, B, F, G, J, R, U, V, X**
Don't Know	n=1 (11.1%)	**B**
	3 (33.3%) **Participants had experience of these services** **3** (33.3%) **stated they had no experience of these services** **3** (33.3%) **did not reveal if they had experience of these services.**	**X, J & R** **B, A & G** **F, U & V**
2. Community Care & Homecare		
Rating	**Number of Participants**	**Participant Name**
Good	n=6 (66.6%)	**B, F, J, U, X,G**
Depends on location of Residence	n=2 (22.2%)	**A, J**
Lacking	n=1 (11.1%)	**R**
3. Eldercare Residential Care Setting		
Rating	**Number of Participants**	**Participant Name**
Good	n=7 (77.7%)	**A, B, F, J, V, R & X**
Poor	n=2 (22.2%)	**G & U** **G –** working in an Eldercare Residential setting at the time of this research
4. General & Acute Hospital Setting		
Rating	**Number of Participants**	**Participant Name**
Challenging in this setting	n=5 (55.5%)	**J, V, F, G & R**
Improving however, more enhancements need to be made	n=2 (22.2%)	**F & A**
Lacking – Impersonal	n=2 (22.2%)	**G & U**
Depends on the Hospital	n=1 (11.1%)	**R**
Don't Know	n=1 (11.1%)	**X**

---

[11] Some participants selected more than one option.

Table 31: Specialised Professionals' Views on Current Services [12]

Q21. How do you view current end of life care in the following settings?		
Specialised Professionals		
1. Community Care & Homecare		
Rating	**Number of Participants**	**Participant Name**
As good as it possibly can be	n=4 (80%)	**T, K, S & I**
Challenging	n=1 (20%)	**E**
2. Hospice Care		
Rating	**Number of Participants**	**Participant Name**
Good	n=3 (60%)	**K, I & S**
Poor in Southeast	n=1 (20%)	**E**
Challenging	n=1 (20%)	**I**
Only assists the minority	n=1 (20%)	**T**
3. Eldercare Residential Care Services		
Rating	**Number of Participants**	**Participant Name**
Good	n=2 (40%)	**E & S**
Improving	n=2 (40%)	**T & I**
Variable	n=1 (20%)	**K**
4. General & Acute Hospital Setting		
Rating	**Number of Participants**	**Participant Name**
Poor	n=2 (20%)	**S & E**
Challenging	n=2 (20%)	**E & I**
Improving	n=2 (20%)	**K & T**

Hospice care was ranked the leading service in current palliative, hospice and EOLC by all generalised professionals. However, caution must be exercised as 33% (n=3) of professionals who stated this acknowledged they had no experience in these services. Therefore, it could be hypothesised their opinions are primarily based on perceptions not fact. This group at 66.6% (n=6) ranked eldercare residential settings and community and homecare care the second leading services.

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[12] Some participants selected more than one option.

Whereas, general and acute hospital services were reported the least effective in current service delivery at 55.5% (n=5) *(Table 31)*. In contrast to generalists' views, 80% (n=4) of specialised professionals reported community and homecare services were currently the most effective service available *(Table 30).* For them, hospice care was considered the second leading in current service delivery at 60% (n=3). Whilst somewhat in agreement with generalised professionals general and acute hospital and residential care settings were both categorised lowest by this group at 40% (n=2).

4.13 Findings from RO3: Challenges in Obtaining a GD.

The literature highlighted numerous challenges encountered in palliative care (Vlug et al., 2013, Quinlain & O'Neill, 2013). According to professionals, most challenges were attributed to factors beyond their control and aligned with funding inadequacies, government initiatives and socio-cultural factors. The public also recounted various obstacles, some of which corresponded with professional insights.

4.14 Finding One from RO3: Resource Issues

The Southeast of Ireland is considered the most underdeveloped region of palliative care in Ireland with only two specialist in-patient beds allocated, limited out-of-hours services and inadequate staff level (HSE, 2017; McCarron, et al., 2010). Regarding inpatients beds, the HSE's Palliative Care Services Three Year Development Framework (2017 – 2019) affirms with a population of 510, 33 the southeast region warrants between 40 to 51 specialist in-patient beds. The framework further reports major outstanding deficits in community services in the region; there are currently 17.3 clinical nurse specialist as opposed to the recommended 20.4 in the NACPC report (2001), 2.5 occupational therapists, no designated medical social workers and 3.4 regional general nurses and clinical nurse managers in contrast to the recommended 4.0 of each professional (HSE, 2017). Lack of resources, mainly staff shortages and regional inequalities were the most concerning issues cited by all professionals in this study. Two participants spoke of the lack of specialist in-patient facilities in the Southeast.

While both discussed present developments with a 22 bed, in-patient specialist palliative care unit nearing completion in Waterford Regional Hospital to replace the current two bed unit for the entire region (HSE, 2017), this also raised concerns:

> ‘There’ll be a new 22 bedded unit which is fantastic. But, we’ve maybe 500 homecare patients throughout the Southeast. So, it’ll be a 22 bedded unit….it’s getting all the funding and it’s getting all the services.
>
> **[Participant K]**
>
> ‘There’s an inequality there…It’s great for the few who can get in…but, is it suitable for everybody? It’s not appropriate…it’s too far away for a lot of people. So, it’s inequitable that you have a…it’s like having a 5 star hotel beside you and everybody else having to go to the local hostel.’
>
> **[Participant K]**

Furthermore, while this new venture is a welcomed addition in the development of palliative services in the Southeast, it does not fulfil earlier projected Government plans proposing a 35-bed specialist facility in the hospital (Department of Health, 2019; IHF, 2007).

4.14.1 Personnel Shortages

Four (44.4%) generalised and five (100%) specialised professionals all discussed the shortage of social workers, pastoral care workers, psychologists and physiotherapists and the extreme difficulty in accessing them. Owing to these shortcomings current practice is:

> ‘very much a nursing and medical model and that’s fine they have their place. But, there’s only so far, they can take a person...so, there’s a huge dearth of care there that people aren’t getting at all.’
>
> **[Participant K]**

4.14.2 Time Constraints

All professionals stated lack of time was a major concern in practice with two professionals (22.2%) implying this leads to ethical dilemmas:

> ‘They are running around really, really busy. Sometimes what they feel they should be doing they’re not able to be doing because they have got a million other jobs to do. So, there’s still that contrast between knowing what you’re not able to do and what you want to do’.
>
> **[Participant A]**

> ‘For me that is the worst thing not being able to give the care that I’d hope to be able to give because of lack of time...You are expected to have a certain amount, of patients up, dressed everything by a certain time. You know you are under a lot of pressure and when you are under that pressure you can’t give the care that you want to give. **[Participant G]**

> You can do hygiene care and make sure they have their food and that kind of thing. But you are literally just meeting their basic needs and I think there is more to caring then that.’

[Participant G]

Additionally, some family members can devalue the role of HCAs in eldercare residential care:

> ‘… families a lot of the time don’t understand the kind of pressure that carers are under. They will come in and say like, ‘Oh, you only spent like 10 minutes with my dad this morning. But they don’t understand that if we could spend a lot more time with them, we would but, we genuinely don’t have time because it’s understaffed.’

[Participant G]

These views are concurrent with Vlug et al.,’s (2013) findings on the impacts of time constraints among nursing home staff and from an Irish perspective, McKeown, (2014) reported in hospitals this results in ethical dilemmas and feelings of guilt for staff as time constraints restricts time spent with patients.

4.14.3 Limited Communication Opportunities

Four professionals (28.5%), ***Participant A, E, I*** and ***K,*** argued time constraints diminish opportunities for effective communication. Speaking from an acute hospital perspective:

> ‘…the opportunity to have a conversation with people is really reduced particularly in acute hospitals and that’s the key bit. That sitting down and having that conversation and it might be that a patient might be in the bed and they are worried about something spiritually, psychologically whatever and a staff member may come in and they start to talk to the staff member who is so busy that they look, and they go, ‘I’m too busy, I can’t talk to her now…and then it’s gone. I really do worry about the poor person who is dying in the bed, that that’s the environment that they’re in and that’s what they are seeing. So, when do I, if it’s me that’s dying actually crack that or when do I actually start chipping away at that to speak to people if I want to and I’m not sure that the staff members will come in and talk to me because they don’t have the time.’

[**Participant A**]

> ‘In general and acute hospitals, I suppose it’s, staff [**shortages**] but it’s also the actual environment. It’s essentially the physical environment…the design of rooms, it’s based around beds. It’s a privacy element and it’s the environment where it’s very noisy and you’re kinda trying to have a special conversation about whether it’s somebody dying, whether it’s what’s important to people, it’s their fears and their wishes.’

[Participant I]

Another participant elaborated on the challenges facing patients in this setting:

> 'You might be seeing somebody in a six bedded bay and to try and get any sort of room or quiet place to speak to that person or their family is very difficult. We are always trying to avoid having a corridor conversation with families because they might be upset. The curtain around a bed only gives visual privacy. It doesn't give auditory privacy.
>
> [**Participant E**]
>
> Quite hard for other people in a six bedded bay if somebody is dying and their trying to allow that family some space and privacy. But they are also embarrassed and you know, they are uncomfortable with having somebody dying in the same room as them. So, we can't actually deliver hospice care here yet.'
>
> [**Participant E**]

4.14.4 Efficacy of Multi-Disciplinary Teams

The efficacy of multi-disciplinary team involvements was called into question by three (21.4%) professional participants. Two specialised professionals (40%) recounted the difficulty in accessing home visits from GPs:

> '…you're at the mercy of getting a GP who will actually call out to the house.'
>
> **[Participant S]**
>
> '…it's very rare.'
>
> **[Participant K]**

Equally, accessibility of nursing staff raised concerns:

> 'The PHNs [**public health nurses**] once they hear we're involved [**referring to Hospice Homecare**] they step away and say…Look sure, that's one nurse coming in, I'm not, I don't have time…Look everybody is busy…we are stretched and under pressure trying to find ways of doing more work in the same amount of time.'
>
> **[Participant K]**

These points highlighted the pressures placed on professionals due to limited resources.

4.15 Finding Two from RO3: Public Lack of Awareness on Resource Issues

Most (90% n=9) public participants seemed unaware of resource issues in services. When one public participant was asked about care options, she stated hospice and home would be preferred and she believed she would receive sufficient care in her area. Only one public participant referenced resource issues:

> 'From what I understand of it **[palliative and hospice services]**, it's very underfunded they have to raise their own money and stuff like that.'
>
> **[Participant N]**

A contributor to this finding may be the fact that 80% (n=8) of the public have little awareness of palliative and hospice services displayed earlier in ***section 4.12.6 Public View(s) on Current Supports*** in *Table 28*. How can the public have awareness of the challenges if basic knowledge of these sectors is lacking?

4.16 Finding Three from RO3: Lack of Financial Supports

Terminal illness incurs financial outlay for individuals and families/loved ones (Irish Cancer Society, 2019). 80% (n=8) of the public, 22.2% (n=2) of generalised and 80% (n=4) of specialised professionals reported a lack of monetary supports. Although professionals acknowledged positives in the form of voluntary aid by the Irish Cancer Society for night nurses, the government's 'Fair Deal Scheme' and discretionary and emergency medical cards (**Appendix W**), financial supports were ranked ineffective by 45.8% (n=11) of the study population. While government and voluntary initiatives (**Appendix W**) are available, evidence shows they may only 'scratch the surface' in alleviating the financial burden (Irish Cancer Society, 2019). The cost of care for cancer patients alone highlights their outgoings largely exceed welfare supplements; on average this client group accumulates extra monthly outgoings of €862.00 (Irish Cancer Society, 2019). One participant particularly highlighted parking costs:

> 'So, financially it's a nightmare ...I've just come from Waterford Regional and I'm thankfully hale and hearty, but you know, you'd be trying to find parking and then the cost of the parking…if you've a relative down there that you were worried about it's just an unbelievable strain to be paying 20 quid a day just to park your car. That is not, like I mean financially it's so costly to be sick in this country. There's no support I find. The only bit is that medical card but by God you have to be at end of life for that. And you'll [***only]*** have it for a few months.'

[Participant K]

Another participant recounted travelling to St. Luke's hospital daily to visit her terminally ill father. She stated it was help from the Irish Cancer Society, rather than government initiatives that assisted her in travel costs. Two (40% n=2) specialised professionals highlighted lack of social workers in the region means individuals have no guidance on the availability of financial assistance. The public were unaware of financial assistance:

> '…no there's not really any financial support for people either is there?'

[Participant N]

Instead half (50% n=5) of this cohort believed supports would very much depend on individual financial circumstances.

4.17 Finding Four from RO3: Socio-Cultural Aspects

All participants involved in this study discussed three socio-cultural aspects which impact negatively on EOLC and death and dying discourse.

4.17.1 Change in Family Structures

Current literature outlines societal shifts have greatly affected the availability of informal supports. Disparity in geographic localities and changing social roles has resulted in men and women now routinely working outside the home and experiencing long commutes (Scottish Government, 2010). This has limited both the availability and ability of family/loved ones to adopt a caregiving role:

> 'And to me a good death I suppose, a reflection of my upbringing, is where family are around and where possible, I suppose it's [**referring to family support**] something that's becoming more challenging as society evolves.'

[**Participant I]**

> 'We now have few people working at home. Women are working in outside jobs and the availability of people around the clock is very hard.'

[**Participant E]**

Participant K and ***I*** also attributed a lack of community-familial support to shifts in family dynamics and Ireland increasingly becoming a less collective society. Consequently, literature reports care of the terminally ill is mainly provided by professionals, thus limiting an individual's choice regarding POC (Scottish Government 2010):

> 'I suppose socially Ireland has changed as in, you know anyone that's elderly at home and end of life is started there's much less family units able to carry out EOL at home. So, I'd say 80% end up in hospital for their EOLC much more than 40 years ago.'

[Participant J]

This obstacle may be heightened in the future:

> '…I find that children…are spending too much time playing video games and not enough time on social interaction, with social media and things so it's hard to deal with these subjects if you don't understand how to interact with people socially.'

[**Participant D**]

This response suggests younger individuals may lack the capacity to provide informal care. This is concerning, as demographic projections heighten the demand for both formal and informal supports. Formal caregiving cannot possibly accommodate the enormity of palliative care needs; informal caregiving is equally crucial (Hanley & Sheerin, 2017).

4.17.2 Lack of Public Discourse

Highlighted in *Table 32*, 70% (n=7) of the public contend death and dying discourse is uncomfortable and the topic remains a social taboo, mirroring existing literature (Mannix, 2016; Gire, 2014, Weafer, 2014; McCarthy et al., 2009).

Table 32: Socio-Cultural Aspects

Q14. Do you think as a society the topic of death and dying is openly discussed?

The Public

Participant Name	Yes	No	Improving	Rationale
Participant C		✓		No rationale given.
Participant D		✓		Complete taboo.
Participant H		✓		Complete taboo.
Participant L			✓	❖ More educated through media ❖ Age brings awareness of death ❖ Experience of death enables one to be more comfortable on death and dying matters.
Participant M		✓		Not spoken about unless faced with death or a terminal illness.
Participant N		✓		Reluctant to talk about death because it is not something we like to think about.
Participant O		✓		It's an uncomfortable topic.
Participant P	✓			In Ireland we thrive on death. But in general choice of death is discussed.
Participant Q	✓			No rationale given.
Participant W		✓		It's an uncomfortable topic.

Similarly, most professionals (64.2 % n=9) also feel death is a taboo topic.

This was attributed to cultural undertones in Ireland of death avoidance and paternalistic protective factors in agreement with the literature (Galbin, 2014; McCarthy et al., 2010). Evident in *Table 21*, fear and a lack of openness regarding death were prominent factors recalled by professionals.

Table 33: Professionals' Perceptions of Death Discourse.

Question Posed: Q14. Do you think as a society the topic of death and dying is openly discussed?

Participant Name	**Yes**	**No**	**Somewhat**	**Improving**	**Rational**
Generalised Professionals					
Participant A		✓			***Due to:*** ❖ Fear ❖ Paternalistic protective factors
Participant B			✓		Narrowly discussed in the context of the Euthanasia debate.
Participant F		✓			Culture of denial & avoidance of death discourse.
Participant G		✓	✓		❖ No not really openly discussed ❖ But did imply gender difference on discourse
Participant J				✓	Starting to improve – ❖ Implied generational differences in discourse
Participant R		✓			Uncomfortable
Participant U		✓			❖ Uncomfortable ❖ Culture *'It's an Irish thing'.*
Participant V			✓		Not as much as it should be ❖ Viewed as private, yet it should be a shared experience ❖ Lack of discourse due to fear
Participant X		✓			***Due to:*** ❖ Fear
Specialised Professionals					
Participant Name	**Yes**	**No**	**Somewhat**	**Improving**	**Rational**
Participant K		✓			❖ Collusion ❖ Paternalistic protective factors
Participant E			✓		❖ Among the elderly ❖ Nervousness or stigma around death. Tends to be discussed without any depth, more so in humorous manner.
Participant I		✓		Will improve in the future	*'But AHDs will bring death discussions to the fore'.*
Participant S		✓			*'No. They're probably are some, but they are more the minority than the majority, I think'.*
Participant T			✓		❖ Death still regarded a taboo topic ❖ Depends on culture

Seven (70%) members of the public stated they personally felt comfortable discussing death (*Table 34*). This finding was different to McCarthy et al.,'s (2009) study which found the Irish public believed it to be almost 'tempting fate' or 'morbid' to engage in conversations on death. As their study sought to ascertain rationale for lack of public discourse on death in Ireland, this finding is significant for future practice.

Table 34: Public Attitudes on Death Discourse

Q12. How do you feel when talking about the topic of death and dying?

Participant Name	**Comfortable**	**Uncomfortable**	**Somewhat**
Participant C	✓		I would have no issue with it.
Participant D	✓		I am quite open to it.
Participant H	✓		Personally, it doesn't bother me at all.
Participant L	✓	✓	I'm better able to talk about it now. But there are times and I'm upset I would say also. I think …it's especially where there are people, loved ones, ...It's hard to see them, you know, …gone from this world and no longer part of my life. So, sometimes I'm upset, but sometimes I'm ok about it.
Participant M	✓		Fine. It doesn't bother me. It's something that comes to us all.
Participant N		✓	It's something you don't like thinking about, so you don't like talking about it.
Participant O	✓		Well I'm comfortable enough.
Participant P	✓		I'm quite relaxed about it. I'm quite fine with it.
Participant Q	✓		I'd be open about it.
Participant W		✓	Uncomfortable.

Therefore, it could be speculated if given the chance to discuss death and dying matters, the public may feel comfortable talking about it. Professionals maintain the most substantial challenges arising in practice as a result of socio-cultural factors, is the effect it has on an individual's ability/willingness to:

1. Discuss and plan for death.
2. Openly express wishes.
3. To stop paternalistic, protective actions.

Many professionals (42.8 % n=6***)*** described how their professional role therefore becomes pivotal to stimulate death conversations with individuals if they want them:

> ‘Whether people offer that line of discussion spontaneously themselves or not, we would try to open up that line of discussion. So obviously in palliative care, part of our work is about planning for the future and anticipating, so that if somebody hasn’t spontaneously brought that up and we see that their situation is changing and that maybe they are coming towards an EOL scenario, we usually try to couch it in what we call the ‘WHAT IF’ question and by saying to somebody, ‘what if things didn’t go well, would you like to tell us about any of your wishes or are there things that you’d like to consider.’ So, we would see it as part of our day to day role to open up on that discussion.’
>
> **[Participant E]**

This suggests some terminally ill individuals need encouragement to commence these conversations. This finding contradicts Punjani, (2013) and Bequiri, (2012), who argued, due to ethical dilemma some professionals may censor information to individuals in their care. However, professionals in this study actively seek these conversations and are open with individuals and their families/loved ones.

4.18 Finding Five from RO3: Media Influences on Death Attitudes

Numerous authors (Florea & Rabatel, 2011; Williamson et al., 2011; McQuinlan, 2009) contend the media is the most powerful source of health information to the public. Yet, it generates misinformation (Williamson et al., 2011). As was revealed in ***section 4.12.2 Support for Family/Loved Ones***, two members of the public (20%), ***Participant L*** and ***M*** had either direct or indirect experience of palliative care services. Four (40%) participants responses indicated media influence when asked question 9 in *Table 35*:

> ‘Media and anecdotal stories.’ **[Participant C]**

Table 35: Perceived influencers of public opinions on a GD **Q9. What has influenced your opinion on a good death?**		
THE PUBLIC		
Participant Name	**Personal Experience**	**Media**
1. Participant C		✓
2. Participant D	✓	
3. Participant H		✓
4. Participant L	✓	
5. Participant M	✓	
6. Participant N		✓
7. Participant O	✓	
8. Participant P		✓
9. Participant Q	✓	
10. Participant W	✓	

4.18.1 Preconceived Ideas

Additionally, ***Participant J*** discussed how individual interpretations of events could be completely different to the actual situation. She further relayed misconceptions witnessed in practice:

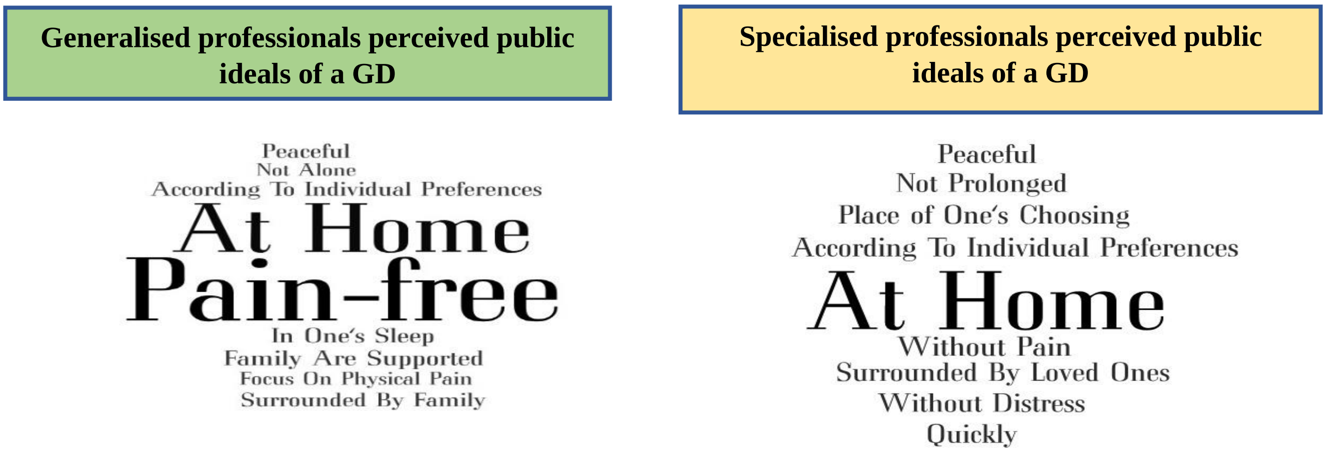
> '...preconceptions, it's funny yeah, you'd often hear;
> 'Now, when granny died the pump went up and she was gone within the day.'
> …as if the pump killed her rather than the illness. The only reason the pump went up was because she was in her last day of life…To make her comfortable...I would often hear the conversation …The pump is gone up now, sure that'll be three days now. That's all they last on the pump'…or people's misperceptions of you know, they starve to death…You'd be surprised…there's still a lot of misperceptions out there.'
>
> **[Participant J]**

Medical literature (Grant et al., 2017; 2014) refers to certain public 'myths' on the use of morphine, especially its apparent addictive and/or ineffectual properties associations with passive euthanasia and its introduction to treatment signifying imminent death.

4.18.2 Unrealistic Perceived ideals

Weighted national/international literature maintains home is the public's preferred POC if terminally ill (The Choice in End of Life Care Programme Board, 2015; Joint Committee on Health & Children, 2014; Palliative Care Australia, 2014, Gomes et al., 2013; McQuinlan, 2009). Summarised in *Figure 13*, three specialised (60%) and two (22.2%) generalised professionals shared this opinion.

Figure 13: Wordel depicting Professionals' Views on the Publics Perceived Ideals of a GD



Generalised professionals perceived public ideals of a GD

Specialised professionals perceived public ideals of a GD

However, specialised professionals who made this claim stated, although home is prioritised by the public, in many cases it is unrealistic due to:

> ‘I think overall people think and I think it’s changing but they feel that a good death involves being at home…that everyone wants to die in their own home, but, that’s the public perception I feel on what a good death would be. But, that’s not always the case.’
>
> **[Participant T]**

> ‘I think there’s an ideal out there that the place of care, especially at home is achievable because there is huge support in the community from homecare teams, from public health nurses, that there’s kinda 24 hr round the clock there, but there’s not by a long shot.’
>
> **[Participant I]**

> ‘I think there’s a lot of talk out there that, you know, to be a good death you need to die at home, and I mean that’s just not always the case and it’s not always appropriate.’
>
> **[Participant K]**

Media undoubtedly informs and shapes societal views on numerous topics. While implicit negatives were noted in this study, one participant believed there is more discussion on death now:

> ‘It’s improved through the media.’
>
> [**Participant L**]

4.19 Finding Six from RO3: Challenges with Informal Supports

Responding to question 22, in *Table 36* below, one specialised professional (10%) and two generalised professionals (22.2%) implied insufficiency in current informal supports. Referring to male carers:

> ‘[they]…are not great at that kind of care.’
>
> **[Participant F]**

<table>
<tr><th colspan="5">Table 36: Perceived Effectiveness of Informal Support Networks</th></tr>
<tr><th colspan="5">Q22. How would you rate care provided by informal caregivers of a terminally ill individual?</th></tr>
<tr><td rowspan="2">Generalised Professionals</td><td>Good</td><td>Poor</td><td>Variable</td><td>3</td></tr>
<tr><td>n=5
(55.5%)
A, U, B, F & X</td><td>n=2
(22.2%)
F & G</td><td>Dependent on the Individual
n=2
(22.2%)
B & F</td><td>Dependent on family Involvement
n=1
(11.1%)
G</td></tr>
<tr><td rowspan="4">Specialised Professionals</td><td colspan="2">Variable</td><td colspan="2">4</td></tr>
<tr><td>Depends on cognitive capacity of potential caregiver
n=1
(20%)
S</td><td>Age of caregiver
n=1
(20%)
S</td><td>Needs of the Individual
n=1
(20%)
T</td><td>General capability of family to provide care
n=1
(20%)
I</td></tr>
<tr><td colspan="3">Good</td><td>Poor</td></tr>
<tr><td colspan="3">n=1
(20%)
E</td><td>n=1
(20%)
K</td></tr>
</table>

Illustrating paternalistic factors in the literature (Cheng et al., 2015; Shin et al., 2011), a generalised professional recalled her experience of families:

> ‘[**referring to the family**]…kind of baby, mother the person, their spouse like they’re kind of afraid to be upfront about things like instead of telling them, ‘Look you are not coming home’, They kind of give them false hope.’

[Participant G]

Both these scenarios were deemed difficult to navigate in practice. Another issue with families was raised:

> ‘…when you’re talking to the patient themselves about their end of life care, the family aren’t involved in that at all. So, a thing that happens often is like the patient might have told you that they want to wear their brown shoes, but they might have told the family before that they want to wear their black shoes. So, there is kind of a miscommunication between the two so that can cause problems.’

[Participant G]

Another participant, although she had witnessed exceptional informal caregiving stated:

> ‘It’s a funny one here in Ireland I suppose…there’s a kind of a weird dynamic I find that when people are dying certain people gravitate towards them and want to be the ones that are involved and important…They may not always have their best intentions ...that’s why…that’s part of the AHD, I’d be a bit worried about…there’s some funny dynamics that go on with relatives I find, and I see it all the time. It’s a very unPC thing to say but, it’s always to do with women, in my experience, almost always. You know, there’d be an in-law, a daughter-in-law, a sister-in-law, a daughter…Would be just really difficult to deal with…It takes up a lot of our time dealing with those kinds of dynamics, you know.’

[Participant K]

This contradicted the earlier finding from ***section 4.11.2 Social Support***, whereby 55.5% (n=5) of generalised professionals saw social supports, both formal and informal networks as effective. Dying is a complex and emotive journey, therefore contradictory views are expected.

4.19.1 Family Conflict

Thirteen (92.8%) professionals discussed family conflict. Eleven (78.5%) of them attributed this to their inability to confront death. Two (14.2%) others argued conflict particularly arises when families try to persuade an individual to prolong life even if it is futile or impacts upon his/her QOL. Professionals also noted conflict within families:

> ‘…occasionally there’s sort of family conflict and it might be more between the family members as opposed to the family member and the terminally ill person. But families are kind of like a committee. And we have one family at the moment with 10 and they seem to be having their own little fights that we get embroiled in because it’s just the tail end of a whole lot of other baggage.’

[Participant E]

All participants involved in this finding suggest conflict could be resolved by effective communication between professionals, the individual and family/loved ones. Only one professional said she had never experienced conflict of this nature in 20 years’ experience in generalised palliative care practice. This seems unprecedented in comparison to all other professionals. Her responses throughout her interview were consistently affirmative of family/loved ones. Perhaps she felt to discuss conflict within and between families/loved ones might be disrespectful, thus accounting for her responses.

4.20 Finding Seven from RO3: Professional Challenges

4.20.1 Lack of Information Sharing Among Professionals

Table 37: Lack of Information Sharing Among Professionals

Q27. In your opinion, are all professionals involved in the care of a terminally ill individual adequately informed when an individual dies?

Participant Group	**Responses**			
Generalised Professionals	**Yes**	**Improving**	**No**	**Don't Know**
	n= 2 (22.2%)	n=1 (11.1%)	n=5 (11.1%)	n=1 (11.1%)
Participant Name:	**J & U**	**A**	**F, G, R, V & X**	**B**
Specialised Professionals	**Yes**	**In Need of Improvement**	**No**	**Don't Know**
	n=3 (60%)	n=1 (20%)	n=1 (20%)	**0**
Participant Name:	**K & T - in relation Hospice homecare supports** **I - referring to both hospital and community homecare support services**	**E**	**S**	

Overall, 55.5% (n=5) of professionals believe they are inadequately informed when an individual dies:

> 'There has never been any policy of informing individuals when a death occurs. The Hospice, Home and GP would be the only ones informed as a rule. The rest of us hear it on death notices.'
>
> **[Participant F]**

This has potentially devastating effects for both professionals and the individual's family/loved ones:

> 'Often if people **[referring to staff]** were on holidays, or you weren't on that day, you wouldn't know that the patient had died until you went to their room and found they weren't there and then when you ask your told. You are not informed in any other way. Unless you are there you won't know really.'
>
> **[Participant G]**

> **Researcher probes: do you find that upsetting then as a professional?**
>
> **‘**Yeah, definitely. Like you have a relationship with them at the end of the day. You have been looking after them for a certain length of time. It’s not nice to just go in and suddenly know that they are not there…it’s hard. And then it can lead to you making mistakes too. You could say something to another resident about them just saying like,
> ‘Oh, where is whoever today’ and that could upset that person. Whereas, if you knew you’d know to be sensitive about it. But when you don’t you can’t be.’
>
> **Researcher probes: So, are residents not informed either then?**
>
> **S**ometimes no. The ones that are cognitively impaired, they are not told because often they don’t really understand. But then some patients that are not cognitively impaired, they are kind of lied to a little bit. They are told oh, whoever is gone to hospital because of fear of upsetting them. But, that’s not right either they are adults. They have a right to know where their friend is gone. I suppose people are just afraid of their emotions and their reaction to it.’

[Participant G]

Although two (22.2%) other generalised professionals, ***Participants R*** and ***X,*** stated they are informed via an email or text by their organisation, they assert this practice is inappropriate and insensitive. A common thread among these comments is the organisational undertones of paternalism and a lack of attention to the welfare of staff who may need bereavement supports themselves. Additionally, information sharing regarding referral forms was also raised:

> ‘…we have a lot of challenges with regards to how the referrals come in. A lot of the GPs don’t use a national referral form…So, really what I mean by that is we get a referral on a hand-written note…**‘**Dear girls, kindly see so and so’, Regards, Doctor so and so…I’ve gotten referrals where there hasn’t been a surname…a date of birth…a phone number, a proper address. I don’t know if the patient knows we’re involved. I don’t know what the diagnosis is. I don’t know whether the family are aware.…so, I think how could we professionally take on a patient like that. So, there’s a lot of time I spend gathering information before we even get on the road and get to the person…I think there’s a lot of these cuts, doctors cuts, their payment for certain things have been cut and some of them are very militant and refuse to do anything over and above.’

[Participant K]

While she justifies her opinion, it cannot be construed that GPs are intentionally trying to hinder the process.

4.20.2 Issues Regarding Palliative and EOLC Training

Twelve (85.7%) professionals rated their palliative care training as good, while a further two (22.2%) generalised professionals, namely ***Participant U*** and ***G*** confirmed they had no palliative or EOLC training. Correspondingly, ***Participant A*** and ***F*** recommended all healthcare professionals should have mandatory training because the likelihood of providing palliative or EOLC is '*fairly high'*. ***Participant X*** and ***K*** propose practical training with competent, experienced personnel is just as crucial as theory. Recapping on her theoretical training:

> '…down in UL [**University of Limerick**]…they'd be talking about Dame Cicely Sanders and all this craic. Now it's fine, it's ok to maybe know a little knowledge and history but really now, truthfully when you're stuck out in a house in Mullinahone and somebody is…you know, it's not relevant. I think that practice theory gap…'The 'Cowman Gap', it's very wide…some of those lectures are a little bit far removed from what it is actually like.'
>
> **[Participant K]**

Croxon et al., (2017) noted minimal caring experience while training was also problematic. Furthermore, Nielson and Glasdam, (2013) suggested lack of experience may leave professionals susceptible to emotional fatigue. ***Participant S***, ***E*** and ***J*** spoke of the need for continuous professional development (CPD).

4.20.3 Lack of Knowledge of AHDs Among Professionals

All professionals welcomed AHDs in palliative care. Significantly, findings showed prior to being given a definition of AHDs, 55% (n=5) of generalised professionals were unaware of them (*Table 38*), thus highlighting knowledge gaps in generalist services on new initiatives in the area. This implies a lack of CPD in this sector. All specialist professionals possessed detailed knowledge of AHDs (*Table 39)* and voiced concerns about their implementation, especially in terms of safeguards for vulnerable client groups.

Table 38: Professionals' Opinions of AHDs

Generalised Professionals

Participant Name	Good	Lack of Awareness	Concerns
Participant A	✓		❖ In infancy. ❖ No structure in place on their implementation. ❖ Questions whether individuals will see a value in them. ❖ Worried about media generating misinformation. ❖ Individuals do not understand the work palliative care entails therefore may seek euthanasia option.
Participant B	✓	✓ *Only in the context of DNR orders*	❖ Fears regarding how they may be used. ❖ May incur an 'ethical minefield.'
Participant F	✓		Extremely difficult to draft such a document.
Participant G		✓ *Only in the context of DNR orders*	❖ Individual may change their mind on prior decisions made but may not be able to express this. ❖ Decline of mental capacity.
Participant J	✓		❖ Presently a minefield to navigate. ❖ Accessibility of AHDs is vague. ❖ How will alterations to AHDs be catered for individually.
Participant R	✓	✓	Lack of awareness both in public and professional domains.
Participant U	✓	✓	Terminology is confusing - said it was like a living will.
Participant V	✓	✓	Confused it with a living will.
Participant X	✓	✓	Was not something she came across in practice.

Table 39: Professionals Opinions of AHDs

Specialised professionals

Participant Name	Good	No Lack of Awareness	Concerns
Participant K	✓		❖ Worried about appointing a representative. ❖ Could be vulnerable to coercion or manipulation.
Participant E	✓		Should not be confused with euthanasia.
Participant I	✓		❖ Fears on how AHDs can be accessed/updated. ❖ Will it lead to a push towards euthanasia? ❖ Who is driving the AHD?
Participant S	✓		Overall impression is they are welcomed.
Participant T	✓		Lack of public awareness on AHDs. Still in infancy.

Many challenges were expressed predominantly by professionals. Yet, the public seem to lack awareness regarding the obstacles encountered in palliative care services.

Given the weight and scope of challenges discussed, a summarised version is presented in **Appendix X**.

4.21 Overall Analysis of Study Findings

4.21.1 RO1: What Constitutes a GD

This study uncovered distinct yet similar definitions of a GD by all groups (*Figure 14*).

Figure 14: Definitions of a GD by All Groups

The Public

‘A GD for the public is one that is pain and fear free, surrounded by loved ones, having choice, control, dignity, respect, independence maintained and being at peace with a life well lived.’

Generalised Professionals

‘A GD is one that is pain, fear and suffering free, surrounded by family/others, having individualistic, person-centred care and making care preferences known and having them followed and being at peace.’

Specialised Professionals

‘A GD is one without suffering of any kind, surrounded by family, being aware and informed, having death preparation in place and followed, being treated with dignity and being at peace.’

The public and generalised professionals’ definition of a GD is broadly similar. This is valuable as these groups are likely to provide the majority of direct care to the terminally ill and their family/loved ones (Jansen et al., 2017; O’Mahoney, 2018). The introduction of independence by two male members of the public was an unexpected finding. It amplifies the need to establish, understand and decipher where individual core values have come from and how they may influence psycho-social symptoms if terminally ill. Ascertaining these aspects may anticipate and decrease future distress as illness progresses, while also enhancing a holistic, person-centred approach. It also highlighted the need for gender sensitivity regarding care. Generalised professionals overall and specialised professionals who worked in community palliative care discussed family dynamics more than professionals who worked in hospital settings.

Specialised professionals who worked within hospitals seemed to be less exposed to this aspect. Homecare staff are more likely to spend more time with family. Families and the individual may feel more comfortable, relaxed and able to express themselves more freely than in formal care settings which are likely to be more hectic. This study found the public prioritise choice and control, yet they feel they would not be afforded either if nearing EOL. DPP initiatives which would assert one's choice and control were given minimal consideration by the public. These findings coupled with the lack of public knowledge of AHDs highlight a lack of awareness of initiatives such as the 'Think Ahead Programme' and the 'Have Your Say' campaign in 2016 which promoted the importance of EOLC planning. This suggests that campaigns and initiatives are perhaps not capturing public attention or far-reaching enough. Other findings on parameters of control unveiled beneficence for others may hamper individuals' true expressions of EOLC preferences. Therefore, this highlights the need for professionals to ensure adequate time alone with the terminally ill is allocated to assist them in recognising that they too matter in the process and that asserting beneficence for oneself is crucial. Beneficence for others also indicates the public do not comprehend the beneficial effects DPP may incur for an individual's family/loved ones. If family/loved ones perceived the care their loved one received was in accordance with his/her wishes this could potentially lead to less complicated grief patterns when bereaved (Office of the Ombudsman, 2018). It would seem from the findings that members of the public have not considered this aspect.

4.21.2 RO2: Exploration of Current Supports to have a GD

The findings convey some components of the BSPSSM are unmet. This suggests achieving a GD is largely unattainable in current service. Some services were viewed more favourably than others and home remains the public's preference. While professionals are willing and eager to provide care in accordance with individualised preferences, the support structures to facilitate a GD for all are simply not in place.

4.21.3 RO3: Challenges to having a GD

This study shows that members of the public lack awareness of palliative and hospice services and their challenges. This was unexpected given death is inevitable making the likelihood of public exposure to these services a distinct possibility. They are also uninformed of fiscal initiatives or supports available if terminally ill.

This implies if some received a terminal diagnosis, they may try to continue working which could negatively impact their physical condition or suffer undue financial hardship as they are unaware of supports or how to access them. This highlights the need to address the absence of social workers in current palliative service as fiscal advice can be vital for the terminally ill. The presence of family and/or having a sense of accompaniment was deemed an important aspect in achieving a GD. The public assumed family/loved ones would be present. Some professional responses made implied some individuals may die alone because of resource issues. Perhaps if lone-deaths due to these difficulties in practice were acknowledged in a public context, more public funding would ensue which may assist in diminishing staff shortages and time constraints increasing accompaniment thus, reducing isolation when nearing EOL.

Findings convey while religion is still considered important for those approaching death, spirituality is becoming a prominent feature in palliative care. It is important professionals have the necessary skillset and time to accommodate this. Social supports were deemed to be provided more by communal or familial structures than professional. Providing both physical and social supports may be unsustainable for these groups. Both the public and specialised professionals believed that supports for family/loved ones were severely lacking. The findings suggest a need to provide more formal structures to lessen both the physical and emotional burden of care for informal caregivers. All three participant groups maintained aftercare supports for informal caregivers is severely lacking and in need of immediate improvement. Findings outlining generalised professionals out-of-hours efforts to support bereaved families/loved ones deserves recognition at government level and across all generalised and specialised palliative care services. This study found professionals also feel devalued, unheard and unsupported in their role.

Additionally, the apparent lack of supervision was concerning and may have detrimental effects for professionals and the terminally ill, as it may also potentially lead to neglect or even abuse of individuals if not rectified. The safety and welfare of both staff and those using the service should be a priority incorporating a top-down approach at organisational level to frontline staff. Yet it is evident, change is needed as currently it seems to be implemented from the bottom-up which is likely to add to stressors and feelings of underappreciation. This could lead to a loss of valuable staff in the sector. Findings affirmed death remains a social taboo in Ireland.

Yet, seven out of ten members of the public also revealed they felt comfortable discussing it. This is beneficial for practice as it indicates if health and social care professionals were to broach these topics with the public on a one-to-one basis, they may be more inclined to discuss it. The media was said to influence four members of the publics ideals on what constitutes a GD. Yet, this platform may be negatively leading to misinformed, idealistic public expectations of achieving a GD. The public possess uninformed preconceived ideas on medical treatments, especially concerning the administration of morphine to those nearing EOL. These preconceived ideas may cause psychological distress for family and the terminally ill. This study found a need for both knowledge, skill and practical palliative care training for professionals. Some professionals determine college modules may be too far removed from the inner working of generalist and specialist palliative care. Weighted challenges mean social, psychological and financial elements of the BPSSM are underrepresented in current services thus it is impossible for professionals to fully implement a total pain approach. This contradicts palliative care principles stipulating the fundamental importance of incorporating a total pain approach (Brant, 2017). This may add to feelings of powerlessness and ethical dilemmas expressed by many professionals in this study. Despite all the challenges identified, the dedication, compassion, warmth and empathy professionals hold for the individuals, their families/loved ones were apparent throughout the data collection.

4.21 Conclusion

All research objectives were achieved. Findings revealed the complexity of palliative care. Public and professional perceptions collectively uncovered what it means to have a GD in Ireland. Findings indicate supports that are currently effective and gaps that remain aspirational. Various challenges were identified where improvements can and must be made in order to achieve a GD for all.

CHAPTER FIVE

CONCLUSIONS

AND

RECOMMENDATIONS

CHAPTER FIVE CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter details conclusions and recommendations from this study which sought to investigate public and professional perceptions of a GD. Firstly, the conclusions will be presented in line with the research objectives (RO). Thereafter, corresponding to the conclusions, recommendations for practice, policy, training and education and avenues of further research will be deliberated. Finally, the ability of this study to address the ROs, my reflections of the research process, growth as a researcher and the study limitations are all discussed.

5.2 Contribution of This Study

This is the first known study in Ireland to incorporate both public and professional opinion(s) on the concept of a good death (GD). With the emergence of the newly identified theme, namely independence, it provides new public insight on a GD in an Irish context. It extends previous national research in the area of palliative care in Ireland and adds further insight to international literature on what it means to obtain a GD in contemporary society from both public and professional viewpoints. This study also provides an invaluable line of enquiry into perceptions of palliative care (Miele et al., 2016).

5.3 Conclusions from the Study Findings

5.3.1 Conclusions from RO1: What Constitutes a GD

1. While there is increased discourse on the topic, death remains a social taboo.
2. The public and generalised professionals are largely in agreement on their views of a GD; both perceived it is as one that is pain and fear free, surrounded by family/loved ones, person-centred, in accordance with individual preferences and where an individual is at peace.
3. Owing to the uniqueness of individual interpretations, a GD may be impossible to define definitively.

5.3.2 Conclusions from RO2: Exploration of Supports to Obtain A GD

1. Due to shortcomings identified in the bio-psycho-social-spiritual model (BPSSM) of palliative care, this study concludes Ireland lacks a total pain approach to care. This suggests a medical model of care dominates current palliative care services.
2. Home remains the publics preferred place of care (POC) if terminally ill.
3. The public lack awareness of advanced healthcare directives (AHDs) and the benefits of death preparation and planning (DPP) for individuals and their family/loved ones.
4. Socio-cultural issues and beneficence for others hinders public engagement in DPP.
5. Females may be more difficult to engage in death and dying discourse than their male counterparts.
6. The public do not make distinctions between palliative and hospice care services. They are unaware of the important role these services play in the lives of the terminally ill and their families/loved ones and the challenges staff experience in their professional roles.
7. Whilst religion remains relevant for some, both the public and professionals affirm spirituality is gaining significance in Ireland.
8. This study suggests age, gender, personal experience of death and dying, media coverage and socio-cultural norms may influence public perception(s) on these matters.

5.3.3 Conclusions from RO3: Challenges in Obtaining A GD

Conclusions Regarding Internal Challenges

1. Generalised professionals may have no formal training in palliative care and hence, may have few competencies in this area.
2. This study confirms an apparent lack of supervision in both generalist and specialist palliative care sectors. Furthermore, the lack of information sharing evident in this study, implies many professionals may feel unsupported, unheard and in some instances devalued in their professional roles.

Conclusions Regarding External Challenges

1. Professionals identified informal social supports are diminishing due to changes in family structures.
2. Socio-cultural norms of death avoidance and misinformed media coverage have led to preconceived, misinformed public ideals on death and dying and a lack of openness on this topic.

This makes it extremely difficult for professionals to instigate public engagement on death and dying. Yet, findings from this study show if encouraged, most of the public (70% n=7) may be at least be open to the possibility of discussing this topic.

3. Various resource issues impede generalist and specialist professionals in assisting individuals and their families/loved ones.

5.4 Key Recommendations

Concurrent with the findings and conclusions of this study the following recommendations for practice, policy, education, training and further research are made.

5.4.1 Recommendations for Practice

1. There needs to be ongoing discussion with each group on the definition of a GD to ensure a GD for all.
2. Managers in all generalist and specialist service must;
   - Ensure adequate notification procedures are in place to inform frontline staff of the death of an individual in their care and support structures for staff surrounding this event must also be made available.
   - Provide adequate supervision to enhance support structures for frontline staff.
   - Ensure frontline staff possess relevant training in order for them to engage in supervision models of care (Social Care Institute for Excellence, 2019).

5.4.2 Recommendations for Policy

1. Public awareness of palliative and hospice care and AHDs by government, state and voluntary bodies and media sources is required to provide public distinctions between these sectors, resource issues encountered in practice and promote death preparation and planning.
2. Government policy needs to acknowledge changing family structures and reduced availability and capacity of informal caregivers (Abel et al., 2013).
3. Increased funding for multi-disciplinary teams in all EOLC services and enhanced supports in the community must be prioritised (IHF, 2017).
4. More supports for professionals and informal caregivers of the terminally ill, both pre and post-death, is also of pivotal concern.

5. Supervision policy and enhanced inspectoral reviews of such in practice must be enforced (Social Care Institute for Excellence, 2019).
6. Coinciding with financial challenges revealed in this study the following suggestions are recommended:
   - Amendments to the Health Act, (2005), giving the terminally ill or those in receipt of EOLC an automatic entitlement to a medical card without renewal.
   - To assist in the cost of in/out-patient hospital appointments for the terminally ill and an informal caregiver parking and food expenses be considerably reduced or abolished for these client groups (Irish Cancer Society, 2017).
   - Remedies to waiting periods for the approval of the Fair Deal Scheme would reduce prolonged hospital stays, relieve financial pressures and resource issues and reduce discrimination of older people.
7. Professional clarity in the implementation (**Appendix Y**), safeguarding and monitorisation of AHDs is needed (Irish Medical Times, 2018). Therefore, this study recommends:
   - The Director of the Decision Support Service must seek feedback from health and social care professionals on AHDs.
   - Policy guidelines should provide clearer direction for professionals.
   - Individual Health Identifiers (**Appendix Z**) could be implemented for individuals availing of palliative and EOLC to increase early identification, information sharing, recording, modification(s) and the efficacy of AHDs (eHealth Ireland, 2019).

5.4.3 Recommendations for Training and Education

1. Enhanced palliative care training on key initiatives is needed for generalised professionals and informal caregivers of the terminally ill to strengthen competencies and confidence.
2. Mandatory EOLC practical and theoretical training across all health and social care disciplines would ensure all professionals have competencies and baseline knowledge in this area.
3. Improving the accuracy of the educational content of media sources and thereafter information sharing must be prioritised to enhance dissemination of health information to the public and dispel misinformation on pain management treatments (Williamson et al., 2011).

4. Implementing public education initiatives on the pitfalls of masculine ideologies regarding healthcare utilisation will potentially diminish the occurrence of males experiencing psychological distress if independence were to become compromised due to illness deterioration (Himmelstein and Skulason, 2014).
5. TUSLA collaborates with third level institutes to increase social work student numbers and attract graduates (TULSA, 2019). This study recommends the HSE provide similar incentives to increase the availability of social workers.

5.4.4 Key Recommendations for Future Research

1. An All-Ireland study on what constitutes a good death: Public and professional perceptions.
2. Independence as a construct of a GD among the public in Ireland to gain greater understanding of this aspect of a GD.
3. An investigation into media influences on public perceptions of death and dying. To investigate the extent of media influence on death and dying attitudes.
4. An exploratory investigation of supervision in palliative care services in Ireland.
5. An exploratory investigation into occupational stress experienced among health and social care professionals in generalised and specialised palliative care services. To establish the main contributors of stress and what supports, if any, are currently available in generalist and specialist palliative care sectors.
6. An Investigation of the effectiveness of public awareness campaigns on death and dying in Ireland. This will assist in developing strategies on how to improve public engagement on these topics.
7. An exploration of informal caregiving for the terminally ill is also needed as research in Ireland into this client group is currently lacking (Care Alliance Ireland, 2015).

5.8 Ability of This Study to Answer the Research Objectives

All three ROs were achieved in this study. In terms of defining a GD, from a total of 24 participants, 34 similar characteristics of a GD were obtained, encapsulated under 5 themes namely; (1) Pain, (2) Family and/or companionship, (3) Choice and control, (4) Maintaining personhood and (5) Independence. Findings established that generalised professionals' views of a GD largely reflected public opinion.

The study also revealed how individuals are currently supported by services to have a GD. Finally, participants identified several challenges that currently hinder acquisitions towards a GD.

5.9 Reflection on The Research Process

Critical learning (Taleff, 2006 cited in Myer & Salt, 2013, p.319) and evaluation are a vital component in the research process (Wallmann & Hoover, 2012). Critically evaluating all stages of this research enhanced the validity and rigour of the overall project. Although the methodology and sample selection enabled the collection of rich data relevant to the phenomenon under investigation (Vasileiou et al., 2018), a quantitative approach involving the use of an open-ended survey would have provided generalisation of the findings and eliminated the limited scope of this study. While this study gave a broad focus to the concept of a GD from public and professional perspectives collectively, further investigations could explore in greater detail the specific challenges in palliative care in Ireland revealed from the study findings, sole themes ascertained, specific groups, professionals and or service settings.

5.10 Study Limitations put before future research

Gaining ethical clearance in palliative care, especially for qualitative research can be a taxing and lengthy process (Sivell et al., 2019). This study required ethical clearance from both the Institute of Technology Carlow and the HSE South East Ethics Committee. Further researchers should accommodate for the duration, rigour and number of ethical applications needed to conduct research in their desired area of investigation, as this may limit the study scope, time dedicated to aspects of the research project and determine when data collection can happen. The length of time it took to gain ethical clearance for this study meant data collection was conducted during the summer months. In retrospect, this timing was significant. Many public clubs, groups and societies close for the summer months and many professionals take leave during this period. This may have restricted data obtained. Time constraints of participants due to heavy workloads in health and social care fields meant long delays or scheduling of interviews. A member of the public chose to withdraw from this study before the commencement of an interview reducing the participant size. Future researchers should consider these aspects in their data collection timeframe going forward. Due to the small sample, generalisation of findings is difficult.

Additionally, the female dominance of professional participants may have influenced results obtained. Despite best efforts, no GP or PHN participated in this research. This may have been due to heavy workloads or the timing of data collection. However, insight from these professionals may have enriched findings and confirmed or denied claims made by some participants in this study. The development of the Hawthorne Effect (Roethlisberger & Dickson, 1939, cited in Annetta & Bronack, 2011, p.175) was a potential risk factor in this study, meaning some participants might have modified their behaviour due to an awareness of researcher observation. The imbalance between the interviewee/interviewer poses an ideal environment for this to manifest (Sivell et al, 2019). It is difficult to ascertain if the Hawthorne effect did evolve however, some participants may have perceived negative implications for themselves, their professions or the organisations they work in thus, embellished or withheld truths regarding questions posed. Researcher bias is also a potential challenge in research (Ranjit, 2017). To counteract the possibility of this manifesting, reflective practice (Kolb, 1984 cited in Arnott et al., 2019, p.130) and critical thinking of the research process, note taking and full engagement with supervision was employed.

5.11 Growth as A Researcher

Conducting this study developed higher-order, critical thinking (Taleff, 2006 cited in Myer & Salt, 2013, p.319), enhancing my confidence and problem-solving skills, which were especially important in seeking and subsequently gaining ethical approval. This assisted in establishing the need for and background of this research, the current context and theoretical underpinnings and the refinement of the literature review by increasing my ability to critically appraise prior research in palliative care and the concept of a GD. Having had prior professional experience in generalist palliative care, my aim for this research was to provide an equal platform for professional and potential service user perspectives on what may constitute dying well to ascertain if professional opinions reflected public expectations. I believed this would give a more comprehensive, all-inclusive view of this topic in an Irish context, enhance palliative care service delivery and diminish this gap in current literature in Ireland. Through dissection of literature, I recognised the importance of obtaining a balanced sample, incorporating both male and female perspectives in order to provide true representations of participant groups.
Age, gender, personal experience, occupational, familial status and gendered cultural norms are all influential factors on public perceptions of death and dying.

This research heightened my appreciation of ethical codes of conduct, which guided all aspects of this study from commencement to completion. Beneficence supported the methodological approach, the development and wording of the interview questions, interview locations and data analysis techniques utilised to represent all participant voices equally. I was ever mindful that prior experiences of bereavement among participants may have been a possibility and that these experiences affect individuals in differing ways. Therefore, I repeatedly asked participants if they felt comfortable participating in this study and if clarity was needed on any question. I continuously reminded them of their right to withdraw and they did not have to answer any question they did not feel comfortable with, without providing rationale or incurred penalty. To enhance safeguards, all participants were offered a list of online or low-cost counselling services in their locality should they feel the need to do so. One participant became upset in an interview when reflecting on the death of a client in her care because of a perceived lack of organisational support for the staff member. The interview immediately stopped and she was offered empathic support. She was given time to reminisce with the researcher on this event. She was informed she could withdraw from the research if she so wished yet, she requested to proceed. The participant was debriefed afterwards and offered counselling support information, which she refused, feeling they were not needed. I followed up with this participant three days later to check-in. I had encountered similar experiences in practice enhancing my ability as a researcher to relate and empathise with this participant. Although my professional encounters benefited this scenario, I learned through this experience the fundamental importance of ongoing reflection in action (Schön, 1983 cited in Chalofsky, 2014, p.594**)** throughout the research process.

In using self-reflection and fully engaging in supervision, this enhanced my ability to be honest and truthful in data analysis, data findings and drawing conclusions by respecting participants’ perspectives. Conducting this research also enhanced my data analysis skills by self-teaching and then employing the use of the data storage software, NVivo 12. This improved my ability to encode the vast amount of data collected. I also learned how to integrate and give equal weight to three distant participants groups in a single research project. This research increased my interview skills, time management, public speaking, presentation and computer skills. I also learned how to effectively collaborate with two supervisors, individuals in diverse academic areas and how to network with agencies and organisations in EOLC.

This research project overall has reinforced my capacity as a researcher to conduct ethical, unbiased research with beneficence for participants at the forefront.
A further skill was also acquired. A requirement of the postgraduate masters by research programme within the Institute of Technology Carlow stipulates students conduct weekly teaching sessions under the guidance of their supervisors. This enabled me to also gain teaching experience within the institute. Throughout the two-year duration of my postgraduate studies, I had the pleasure of teaching 1st, 2nd, 3rd and 4th year undergraduate students' various modules in Applied Social Studies (Professional Social Care) and 1st year undergraduate students in Early Childhood and Care.

5.12 Conclusion

Mortality is an inescapable aspect of life yet, it remains a difficult area to talk about (University of Glasgow, 2014). Death, like birth only happens once therefore, it is fundamental to have discussions on this topic, especially concerning EOLC preferences (Murphy, 2015). Dying is not an isolated event, rather it is a path taken by the terminally ill, their family/loved ones and allied professionals in EOLC (Broom & Kirb, 2013). Consequently, all must be involved in these discussions and included in any exploration of this topic. This study aimed to do this by incorporating public and professional opinions on what may constitute a GD. With global trends on ageing demographics, this study is both crucial and timely (University of Glasgow, 2014).
What is abundantly apparent from the study findings is a public desire to achieve a GD and professionals unrelenting pursuit to provide it, despite numerous challenges. The compassion, dedication, empathy and warmth portrayed by professionals involved in this study is both humbling and inspiring. Although change is evolving, the promotion of death and dying discourse needs to be accelerated. By encouraging a more open culture about death and empowering the public and professionals to have these conversations, we can provide a future where the terminally ill can have a GD as they define it (University of Glasgow, 2014).

REFERENCE

SECTION

REFERENCES:

Abel, J., Walter, T., Carey, L., Rosenberg, J., Noonan, K., Horsfall, D., Rosemary Leonard, R., Rumbold, B. and Deborah Morris, D. (2013). Circles of care: should community development redefine the practice of palliative care? *BMJ Supportive & Palliative Care,* [online], 3(4), pp: 1–6, available: [accessed 12th May 2019].

Adams, C., Arratoon, C., Boucher, J., Cartier, G., Chalmers, D., Dell, C., Dell, D., Dryka, D., Duncan, R., Dunn, K., Hopkins, C., Longclaws, L., MacKinnon, T., Sauve, E., Spence, S., & Wuttunee, M. (2015). The Helping Horse: How Equine Assisted Learning Contributes to the Wellbeing of First Nations Youth in Treatment for Volatile Substance Misuse. *Human-Animal Interaction Bulletin,* [online], 1(1), pp. 52-75, available: file:///C:/Users/seamusg/Downloads/Helping-Horse.pdf [accessed: 12th of May 2018].

Age Action. (2014). *Public Consultation Response: Advance healthcare directives*. [online], available: https://www.ageaction.ie/sites/default/files/attachments/advance_healthcare_directives_final_submission_7th_march_2014.pdf [accessed: 5th may 2019].

Ahmed, N. (2017). *A Pilot Randomised Controlled Trial of a Holistic Needs Assessment Questionnaire in a Supportive and Palliative Care Service*. Unpublished (Ph.D.) thesis, The University of Sheffield, UK.

Alemneh, D., Allen, J. & Hawandeh, S. (2017). *Knowledge Discovery & Data Design Innovation.* [online], available: https://books.google.ie/books?id=L-Y7DwAAQBAJ&pg=PA149&dq=colaizzi+method+of+data+analysis&hl=en&sa=X&ved=0ahUKEwiZnYTr0qXiAhXrTxUIHUupAAIQ6AEIWzAJ#v=onepage&q=colaizzi%20method%20of%20data%20analysis&f=false [accessed: 5th December 2017].

All Ireland Institute of Hospice & Palliative Care. (2015). *All Ireland Palliative Care Education Network: Position Statement on Palliative Care Education on the Island of Ireland*. [online], available: https://aiihpc.org/wp-content/uploads/2018/12/Palliative-Care-Education-Position-Statement-.pdf [accessed: 6th May 2019].

Almack, K., Cox, K., Moghaddam, N., Pollock, K. & and Jane Seymour, J. (2012). After You: Conversations Between Patients and Healthcare Professionals in planning for End of Life Care. *BMC Palliative Care*, [online], 11(15), pp. 1-10, available: https://bmcpalliatcare.biomedcentral.com/track/pdf/10.1186/1472-684X-11-15 [accessed: 20th of September 2018].

Alsehenqeeti, H. (2014). Interviewing as a Data Collection Method: A Critical Review. *English Linguistic Research,* [online] 3 (1), pp. 39-45 available: https://www.researchgate.net/profile/Hamza_Alshenqeeti/publication/269869369_Interviewing_as_a_Data_Collection_Method_A_Critical_Review/links/55d6ea6508aed6a199a4fd34.pdf [accessed: 17th January 2017].

American Academy of Hospice & Palliative Medicine (2017*). Frequently Asked Questions about Hospice & Palliative Care.* [online] available: http://palliativedoctors.org/faq [accessed: 9th March 2017].

Anstey, S., Powell, T., Coles, B., Hale, R. & Gould, D. (2016). Education and Training to Enhance End-of-Life Care for Nursing Home Staff: A Systematic Literature Review. *BMJ Supportive & Palliative Care,* [online], 6, pp:353–361, available: https://spcare.bmj.com/content/bmjspcare/6/3/353.full.pdf [accessed: 1st November 2018].

Annetta, L. & Bronack, S. (2011). *Serious Educational Game Assessment. Practical Methods & Models for Educational Games, Simulations & Virtual Worlds.* [online], available: https://books.google.ie/books?id=87zzTvNY1RgC&pg=PA175&dq=the+Hawthorne+effect&hl=en&sa=X&ved=0ahUKEwiPps-Ir43jAhWIgVwKHcu_A784ChDoAQhBMAQ#v=onepage&q=the%20Hawthorne%20effect&f=false [accessed: 10th May 2018].

Aramesh, K. (2016). History of Attitudes Toward Death: A Comparative Study Between Persian and Western Cultures. *Journal of Medical Ethics and History of Medicine*, [online], 9, pp.2-6, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5432944/pdf/JMEHM-9-20.pdf [accessed: 18th February 2018].

Armat, M. (2018). Inductive and Deductive: Ambiguous Labels in Qualitative Content Analysis. *The Qualitative Report,* 23(1), 219-221, available: https://nsuworks.nova.edu/cgi/viewcontent.cgi?article=2872&context=tqr [accessed: 3rd March 2018].

Arnott, N., Paliadelis, P. & Cruickshank, M. (2019). *The Road to Nursing.* [online], available: https://books.google.ie/books?id=MHaIDwAAQBAJ&pg=PA130&dq=Kolb+Reflection&hl=en&sa=X&ved=0ahUKEwiIv4OjtY3jAhVToVwKHbozBK4Q6AEIPTAD#v=onepage&q=Kolb%20Reflection&f=false [accessed: 3rd April 2018].

Baillie, J., Anagnostou, D., Sivell, S., Van Godwin, J., Byrne, A. & Nelson, A. (2018). Symptom management, nutrition and hydration at end-of-life: a qualitative exploration of patients', carers' and health professionals' experiences and further research questions. *BMC Palliative Care*, [online], 17(60), pp. 1-13, available: https://orca-mwe.cf.ac.uk/110569/1/Publishers%20PDF.pdf [accessed: 10th April 2019].

Banerjeea, S., Mannaa, R., Coylea, N., Shena, M., Pehrsona, C., Zaidera, T., Hammondsa, S., Kruegera, C., Parkera, P. & Bylunda, C. (2016). Oncology Nurses' Communication Challenges with Patients and Families: A Qualitative Study. *Nurse Education in Practice,* [online], 16(1), pp. 193–201, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4961044/pdf/nihms803906.pdf [accessed: 15th of October 2018].

Barazzetti, G., Claudia Borreani, C., Miccinesi, G., Toscan, F. (2010). What "Best Practice" Could Be in Palliative Care: An Analysis of Statements on Practice and Ethics Expressed by the Main Health Organizations. *BMC Palliative Care,* [online], 9(1), pp. 1-9, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2823604/pdf/1472-684X-9-1.pdf [accessed: 27th of August 2-18].

Barfield, W. (2015). *Cyber-Humans: Our Future with Machines.* [online], available: https://books.google.ie/books?id=eVo-CwAAQBAJ&pg=PA56&lpg=PA56&dq=Bodily+integrity+is+the+inviolability+of+the+physical+body+and+emphasizes+the+importance+of+personal+autonomy+and+the+self-determination+of+human+beings+over+their+own+bodies&source=bl&ots=BSWLRdXbD6&sig=i2nyavvNGKs7GD3xZWnDfASedeo&hl=en&sa=X&ved=2ahUKEwiUvfOx8JneAhULD8AKHRWIAM0Q6AEwCXoECAIQAQ#v=onepage&q=Bodily%20integrity%20is%20the%20inviolability%20of%20the%20physical%20body%20and%20emphasizes%20the%20importance%20of%20personal%20autonomy%20and%20the%20self-determination%20of%20human%20beings%20over%20their%20own%20bodies&f=false [accessed: 22nd October 2018].

Barooah, A., Boerner, K., Isabelle van Riesenbeck, I. & Burack, O. (2015). Nursing Home Practices Following Resident Death: The Experience of Certified Nursing Assistants. *Geriatric Nursing*, [online], 36(2), pp. 120–125, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4393773/pdf/nihms-652265.pdf [accessed: 10th May 2019].

Beach, M., SC. Claudia J. Sadler-Gerhardt, C. & Hollenbach, G. (2011). Legacy Work: Helping Clients with Life-Threatening Illness to Preserve Memories, Beliefs, and Values for Loved Ones. *Vistas*, [online], 95, pp. 1-8, available: https://www.counseling.org/resources/library/vistas/2011-v-online/article_95.pdf [accessed: 19th February 20-19].

Becker, E. (1974). *The Denial of Death*. [online], available: https://ia800905.us.archive.org/22/items/DenialOfDeath/DenialOfDeath.pdf [accessed: 12th November 2017].

Beckstrand, R. L., Collette, J., Callister, L., & Luthy, K. (2012). Oncology Nurses' Obstacles and Supportive Behaviours in End-of-Life Care: Providing Vital Family Care. *Oncology Nursing Forum*, [online], 39(5), pp. E398-E406, available: https://www.researchgate.net/profile/Karlen_Luthy/publication/230782773_Oncology_Nurses'_Obstacles_and_Supportive_Behaviors_in_End-of-Life_Care_Providing_Vital_Family_Care/links/54e751d50cf2cd2e029316cf/Oncology-Nurses-Obstacles-and-Supportive-Behaviors-in-End-of-Life-Care-Providing-Vital-Family-Care.pdf [accessed: 2nd October 2018].

Beqiri, A., Toci, E., Sallaku, A., Qirjako, G. & Burazeri, G. (2012). Breaking Bad News in a Southeast European Population: A Survey Among Cancer Patients in Albania. *Journal of Palliative Medicine*, [online], 15(10), pp. 1100-1105, available: http://eds.a.ebscohost.com/eds/pdfviewer/pdfviewer?vid=1&sid=3e9c3293-7fd3-489c-b212-bcefae526b7f%40sessionmgr4008 [accessed: 14th October 2018].

Biasini, G. & Mergier, A. (2016). The change in public attitudes to danger and its implications for major projects. *The Journal of Field Actions*, [online], 14, pp. 43-49, available: https://journals.openedition.org/factsreports/4062 [accessed: 8th April 2019].

Bloomer, M., Tan., H. & Lee, S. (2010). End of Life Care: The Importance of Advance Care Planning, Australian family physician. *Deakin University Research Repository,* [online], 39(10), pp.734-737, available: http://dro.deakin.edu.au/eserv/DU:30081921/bloomer-endoflife-2010.pdf [accessed: 20th of September 2018].

Borimnejad, L., Hamooleh, M., Seyedfatemi, N. & Tahmasebi, M. (2014). Human Relationships in Palliative Care of Cancer Patient: Lived Experiences of Iranian Nurses. *Mater Sociomed,* [online], 26(1), pp. 35-38, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3990400/pdf/MSM-26-35.pdf [accessed: 28th September 2018].

Bouhnik, D. & Deshen, M. (2014). WhatsApp Goes to School: Mobile Instant Messaging between Teachers and Students (2014). *Journal of Information Technology Education*, [online], 13, pp. 217-231, available: http://www.jite.org/documents/Vol13/JITEv13ResearchP217-231Bouhnik0601.pdf [accessed: 10th May 2019].

Brant, J. (2017). Holistic Total Pain Management in Palliative Care: Cultural and Global Considerations. *Palliative Medicine and hospice Care Open Journal,* [online], SE 1, pp. S32-S38, available: https://openventio.org/Special-Edition-1/Holistic-Total-Pain-Management-in-Palliative-Care-Cultural-and-Global-Considerations-PMHCOJ-SE-1-108.pdf [accessed: 12th March 2019].

Braun, V. & Clarke, V. (2012). Using Thematic Analysis in Psychology. *Qualitative Research in Psychology,* [online], 3 (2), pp. 77-101, available: http://0-www.tandfonline.com.www.library.itcarlow.ie/doi/pdf/10.1191/1478088706qp063oa?needAccess=true [accessed: 17th September 2017].

Brick, A., Normand, C., O'Hara, S., Smith, S., et al, (2015), *Economic Evaluation of Palliative Care in Ireland.* [online], available: https://www.tcd.ie/medicine/health_policy_management/assets/pdf/palliative-care-report.pdf [accessed: 23rd of August 2018].

Broom, A. & Kirby, E. (2013). The End of Life and the Family: Hospice Patients' Views on Dying as Relational. *Sociology of Health & Illness*, [online], 35(4), pp. 499–513, available: https://onlinelibrary.wiley.com/doi/epdf/10.1111/j.1467-9566.2012.01497.x [accessed: 25th of September 2018].

Bruan, V., Clarke, V. & Gray, D. (2017*). Collecting Qualitative Data: A Practical Guide to Textual, Media & Virtual Techniques*. [online], available: https://books.google.ie/books?id=DEM4DwAAQBAJ&pg=PA263&dq=formulating+interview+questions+in+a+research+project&hl=en&sa=X&ved=0ahUKEwjMqNORyp3iAhXHRxUIHZXfB7cQ6AEIKjAA#v=onepage&q=formulating%20interview%20questions%20in%20a%20research%20project&f=false [accessed: 13th May 2019].

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology,* [online], 3 (2). pp. 77-101, available: https://core.ac.uk/download/pdf/1347976.pdf [accessed: 13th May 2019].

Brussel, L. & Carpenter, N. (2014). *The Social Construction of Death: Interdisciplinary Perspective.* [online], available: https://books.google.ie/books?id=by-GDAAAQBAJ&printsec=frontcover&dq=The+social+construction+of+death:+interdisciplinary+perspectives+PDF&hl=en&sa=X&ved=0ahUKEwid_tHN4aHcAhUOesAKHUMdDeUQ6AEIKTAA#v=onepage&q&f=false [accessed: 15th July 2018].

Bullington, J. & Fagerberg, I. (2013). The Fuzzy Concept of 'Holistic Care': A Critical Examination. *Scandinavian Journal of Care Sciences,* [online], 27(3), pp. 493-494, available: http://content.ebscohost.com/ContentServer.asp?T=P&P=AN&K=88980032&S=R&D=a9h&EbscoContent=dGJyMNHr7ESeqK84zdnyOLCmr1Cep7BSrqi4SLSWxWXS&ContentCustomer=dGJyMPGqsEmyqrRKuePfgeyx43zx [accessed: 21st October 2018].

Butler, M. (2017). *Factors that Influence Good End of Life Care in Long Stay Residential Care for Older People.* Unpublished (Ph.D.) thesis, Galway University, Galway.

Callahan-Lesher, A. (2010). *The Phenomenon of a Good Death.* [online], available: file:///C:/Users/c00186113/Downloads/BBL_Feb_2011_Gooddeath%20(1).pdf [accessed: 12th of November 2017].

Campbell, A., Taylor, B. & McGlade, A. (2016). *Research Design in Social Work: Qualitative, Quantitative and Mixed Methods*. [online], available: https://books.google.ie/books?id=J7jSAwAAQBAJ&printsec=frontcover&dq=qualitative+and+quantitative+research&hl=en&sa=X&ved=0ahUKEwjo9Mm1tPDXAhXXFsAKHa7GDBMQ6AEIQzAF#v=onepage&q=qualitative%20and%20quantitative%20research&f=false [accessed: 4th December 2017].

Cancer Council. (2017). *Facing End of Life Care: A Guide for People Dying with Cancer, their Families and Friends.* [online], available: https://www.cancercouncil.com.au/wp-content/uploads/2014/05/UC-Pub-Facing-End-of-Life-CAN4407-lo-res-March-2017.pdf [accessed: 17th September 2018].

Care Alliance Ireland. (2015). *Family Caring in Ireland: Guiding Support for Family Carers.* [online], available: https://www.carealliance.ie/userfiles/file/Family%20Caring%20in%20Ireland%20Pdf.pdf [accessed: 2nd March 2019].

Carr, D. & Luth, E. (2017). Advance Care Planning: Contemporary Issues and Future Directions. *Innovation in Aging,* [online], 1(1), pp. 1-10, available: https://www.researchgate.net/publication/319343349_Advance_Care_Planning_Contemporary_Issues_and_Future_Directions
[accessed: 23rd July 2018].

Central Statistics Office. (2017). *CSO Statistical Release: Information Society Statistics – Household.* [online], available: https://www.cso.ie/en/releasesandpublications/er/isshh/informationsocietystatistics-households2017/ [accessed: 9th October 2018].

Central Statistics Office. (2017). *Religion*. [online], available: https://www.cso.ie/en/media/csoie/releasespublications/documents/population/2017/Chapter_8_Religion.pdf [accessed: 6th March 2019].

Central Statistics Office. (2018). *Census of Population 2016 – Profile 9 Health, Disability and Carers.* [online], available: https://www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/p9cr/ [accessed:12th March 2019].

Central Statistics Office. (2018). *Life Expectancy Tables.* [online], available: https://www.cso.ie/en/interactivezone/statisticsexplained/birthsdeathsandmarriages/lifeexpectancytables/ [accessed: 24th March 2019].

Central Statistics Office. (2018). *The Proportion of Catholics in Ireland, 1881 to 2016*. [online] available: https://www.cso.ie/en/releasesandpublications/ep/p-cp8iter/p8iter/p8rrc/ [accessed: 5th March 2019].

Centre for Ageing Research and Development in Ireland. (2010). *Illustrating Ageing in Ireland North and South: Key Facts and Figures*. [online] available: http://www.cardi.ie/userfiles/Healthy%20Ageing%20%28Web%20Low%20Res%29.pdf [accessed: 18th March 2019].

Chalofsky, N. (2014). *Handbook of Human Resource Development.* [online], available: https://books.google.ie/books?id=o3rDBAAAQBAJ&pg=PA594&dq=Schon+concept+of+reflection+in+action&hl=en&sa=X&ved=0ahUKEwik0vjct43jAhWNUMAKHTBbA7M4ChDoAQhHMAU#v=onepage&q=Schon%20concept%20of%20reflection%20in%20action&f=false [accessed: 13th May 2018].

Cheng, S., Suh, S., Morita, T., Oyama, Y., Chiu, T., Koh, S., Hwany, S., Yoshie, T. & Tsuneto, S. (2015). A Cross-Cultural Study on Behaviors When Death Is Approaching in East Asian Countries What Are the Physician-Perceived Common Beliefs and Practices? *Medicine*, [online], 94(39), pp. 1-6, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4616852/pdf/medi-94-e1573.pdf [accessed: 1st August 2018].

Chochinov, H., Susan McClement, S., Hack, T., Thompson, G., Dufault, B. & Harlos, M. (2015). Eliciting Personhood Within Clinical Practice: Effects on Patients, Families, and Health Care Providers MD. *Journal of Pain & Symptom Management*, [online], 49 (6), pp. 974-980, available: https://www.jpsmjournal.com/article/S0885-3924(14)00914-2/pdf [accessed: 16th December 2018].

Cipolletta, S. & Oprandi, N. (2014). What is a Good Death? Health Care Professionals' What is a Good Death? Health Care Professionals' Narrations on End-of-Life Care. *Death Studies,* [online], 38(1), pp. 20-27, available: https://www.researchgate.net/profile/Sabrina_Cipolletta/publication/260167538_What_is_a_Good_Death_Health_Care_Professionals%27_Narrations_on_End-of-Life_Care/links/02e7e53c6944312519000000/What-is-a-Good-Death-Health-Care-Professionals-Narrations-on-End-of-Life-Care.pdf [accessed: 9th November 2017].

Cithambaram, K. (2017). *Preserving Self in the Face of Death and Dying: A Grounded Theory of End-of Life Care Needs of People with Intellectual Disabilities.* Unpublished (Ph.D.) thesis, School of Nursing and Human Sciences, Dublin City University, Dublin.
Citizens Information. (2019). *Health Service Executive.* [online], available: https://www.citizensinformation.ie/en/health/health_system/health_boards.html [accessed: 28th September 2017].

Corey, G. (2017). *Theory & Practice of Counselling & Psychotherapy*. [online], available: https://books.google.ie/books?id=IrgaCgAAQBAJ&printsec=frontcover&dq=Carl+Rogers+(1905-1987)+person+centred+care+in+social+care&hl=en&sa=X&ved=0ahUKEwjtq8XLwd7XAhUoI8AKHWenDGc4ChDoAQgvMAI#v=onepage&q=Carl%20Rogers%20(1905-1987)%20person%20centred%20care%20in%20social%20care&f=false [accessed: 27th November 2017].

Cortês, A, Moreira, J, Jorge, & Ferreira, J. (2017). Satisfying Needs and Expectations of Terminal Cancer Patients: Organizational Challenges to Social Workers. *International Journal of Healthcare Management*, [online], 10 (3), pp. 167-177, available: http://content.ebscohost.com/ContentServer.asp?T=P&P=AN&K=123514844&S=R&D=bth&EbscoContent=dGJyMNHr7ESep7c4zOX0OLCmr0%2Bep7VSsqe4SraWxWXS&ContentCustomer=dGJyMPGqsEmyqrRKuePfgeyx43zx [accessed: 17th October 2017].

CORU (2016). *Standards of Proficiency for Social Care Workers.* [online], available: http://coru.ie/uploads/documents/Draft_SOPs_SCWRB.pdf [accessed: 22nd October 2018].

CORU. (2010). *Code of Professional Conduct and Ethics for Social Workers*. [online], available: http://www.coru.ie/uploads/documents/typeset_Social_Worker_Code_Feb_2010.pdf [accessed: 24th September 2018].

CORU. (2018). *Social Care Workers Code of Professional Conduct and Ethics*. [online], available: http://coru.ie/uploads/documents/SCWRB_Draft_Code_2018.pdf [accessed: 23rd March 2019].

Cox, K., Bird, L., Arthur, A., Kennedy, S., Pollock, K, Kumar, A., Stanton, W. & Seymour, J. (2012). Public Attitudes to Death and Dying in the UK: A Review of Published Literature. *BMJ Supportive & Palliative Care*, [online], 3, pp. 37–45, available: https://spcare.bmj.com/content/bmjspcare/3/1/37.full.pdf [accessed: 12th July 2018].

Creswell, J. (2014). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches. 4th ed.* [online], available: https://books.google.ie/books?id=PViMtOnJ1LcC&pg=PA1&dq=chapter+one+the+selection+of+a+research+approach&hl=en&sa=X&ved=0ahUKEwiw3MGkl-PWAhUEmrQKHQS4DxMQ6AEIJjAA#v=onepage&q=chapter%20one%20the%20selection%20of%20a%20research%20approach&f=false [accessed: 9th October 2017].

Croxon L., Deravin, L. & Anderson, J. (2014). Dealing with End of Life—New Graduated Nurse Experiences. *Journal of Clinical Nursing,* [online], 27, pp:337–344, available: https://onlinelibrary.wiley.com/doi/abs/10.1111/jocn.13907.[accessed: 22nd of October 2018].

Cruz, V., Camalionte, L. & Caruso, P. (2015). Factors Associated with Futile End-of-Life Intensive Care in a Cancer Hospital. *Am J Hosp Palliat Med,* [online], 32, pp. 329–34, available: http://journals.sagepub.com/doi/10.1177/1049909113518269 [accessed: 21st September 2018].

Cruz-Oliver, D. (2017). Palliative Care: An Update. *Missouri Medicine,* [online], 114(2), pp. 110-115, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6140030/ [accessed: 10th September 2017].

Dalal, S. & Bruera, E. (2017). End-of-Life Care Matters: Palliative Cancer Care Results in Better Care and Lower Costs. *The Oncologist,* [online], 22, pp. 361-368, available: http://theoncologist.alphamedpress.org/content/22/4/361.full.pdf+html [accessed: 12th March 2019].

Dassen, M., & Iliffe, S. (2014). Barriers to the Provision of High-Quality Palliative Care for 32 People with Dementia in England: A Qualitative Study of Professionals' experiences. *Health & Social Care in the Community,* [online], 22(4), pp. 386-394, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4265301/pdf/hsc0022-0386.pdf [accessed: 2nd October 2018].

Davies, N., Maio, L., Vedavanam, K., Manthorpe, J., Vernooij-Dassen, M., & Iliffe, S. (2014). Barriers to the Provision of High-Quality Palliative Care for 32 People with Dementia in England: A Qualitative Study of Professionals' Experiences. *Health & Social Care in the Community,* [online], 22(4), pp. 386-394, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4265301/pdf/hsc0022-0386.pdf [accessed: 2nd October 2018].

De Roo, M., Guido, G., Onwuteaka-Philipsen, B., Van Den Noortgate, N., Van den Block, L., Bonacchi, A., Donker, G., Alonso, J., Moreels, S., Deliens, L. & Francke, A. (2014). Actual and Preferred Place of Death of Home-Dwelling Patients in Four European Countries: Making Sense of Quality Indicators. *PLOS ONE,* [online], 9(4), pp. 1-9, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3979710/pdf/pone.0093762.pdf [accessed: 11th September 2018].

Death Cafes. (2018). *Death Cafes Ireland.* [online], available: https://deathcafe.com/c/Ireland/ [accessed: 16th October 2018].

Delaney, L. (2018). Patient-Centred Care as an Approach to Improving Health Care in Australia. *Collegian,* [online], 25 , pp.119–123, available: https://www.collegianjournal.com/article/S1322-7696(17)30042-2/pdf [accessed: 22nd October 2018].

Dempsey L, Dowling M, Larkin P, Murphy K (2015) 'The Unmet Palliative Care Needs of Those Dying with Dementia'. *International Journal of Palliative Nursing,* [online], 21 (3), pp. 24-31 available: https://aran.library.nuigalway.ie/bitstream/handle/10379/5920/The%20unmet%20palliative%20care%20needs%20of%20those%20dying%20with%20dementia.pdf?sequence=4&isAllowed=y [accessed: 28th August 2018].

Department of Children & Health. (2014). *Report on the National Advisory Committee on Palliative Care.* [online], available: https://health.gov.ie/wp-content/uploads/2014/03/nacpc.pdf [accessed: 13th November 2017].

Department of Health & Children, (2001). *Quality and Fairness: A Health System for You*. [online], available: https://health.gov.ie/wp-content/uploads/2014/03/strategy-report.pdf [accessed: 6th October 2017].

Department of Health & Children. (2001). *National Advisory Committee Report of the on Palliative Care.* [online], available: http://hospicefoundation.ie/wp-content/uploads/2012/07/Report-of-the-National-Advisory-Committee-on-Palliative-Care-2001.pdf [accessed: 18th December 2017]

Department of Justice and Equality. (2018). *Minister Flanagan announces €2.6 billion allocation to Justice sector in Budget 2018.* [online], available: http://www.justice.ie/en/JELR/Pages/PR17000324 [accessed: 5th May 2019].

DeSpelder, L. (2008). *The Last Dance: Encounters with Death and Dying. 8th ed*, [online], available: file:///C:/Users/seamusg/Downloads/DeSpelder_8e.pdf [accessed: 10th November 2017].

Dezutter, J., Soenens, B., Lucyckk, K., Bruyneel, S., Vansteenkiste, M., Duriez, B. & Hutsebaut, D. (2008). The Role of Religion in Death Attitudes: Distinguishing Between Religious belief & Style of Processing Religious Content. *Death Studies*, [online], 33, pp. 73-92, available: http://content.ebscohost.com/ContentServer.asp?T=P&P=AN&K=35651092&S=R&D=a9h&EbscoContent=dGJyMNHr7ESep7c4zOX0OLCmr0%2Bep65Ssaq4TLaWxWXS&ContentCustomer=dGJyMPGqsEmyqrRKuePfgeyx43zx [accessed: 19th November 2017].

Digitális Tankönyvtar. (2019). *Experience and Memories of Pain.* [online], available: https://www.tankonyvtar.hu/hu/tartalom/tamop412A/2011-0094_neurologia_en/ch03s10.html [accessed: 12th October 2017].

Donegal Hospice. (2016*). The Hospice.* [online], available: http://www.donegalhospice.ie/ [accessed: 24th May 2018].

eHealth Ireland. (2019). *Latest Progress.* [online], available: https://www.ehealthireland.ie/A2I-HIDs-Programme/Individual-Health-Identifier-IHI-/Latest-Progress/ [accessed: 6th May 2019].

Elder, R., Evans, K. & Nizette, P. (2009). *Psychiatric & Mental Health Nursing. 2nd ed*. [online], available: https://books.google.ie/books?id=LyLInW5_cjYC&pg=PA167&dq=how+does+society+shape+attitudes+towards+death&hl=en&sa=X&ved=0ahUKEwjWuKmJ9qHcAhXJK8AKHSP6CSsQ6AEIMzAC#v=onepage&q=how%20does%20society%20shape%20attitudes%20towards%20death&f=false [accessed: the 15th July 2018].

Emmel, N. (2013). *Sampling & Choosing Cases in Qualitative Research: A Realist Approach*. [online], available: https://books.google.ie/books?id=yQZEAgAAQBAJ&printsec=frontcover&dq=purposeful+sampling+and+sampling+selection&hl=en&sa=X&ved=0ahUKEwjFoaCpgKHiAhXnUhUIHTuhCA0Q6AEIKjAA#v=onepage&q=purposeful%20sampling%20&f=false [accessed: 20th October 2017].

Environment & Ecology. (2019). *What is Holism*. [online], available: http://environment-ecology.com/holistic-view/111-what-is-holism.html [accessed: 13th April, 2019].

Estebsari, F., Taghdisi, M., Davood Mostafaei D. & Rahimi, Z. (2017). Elements of Healthy Death: A Thematic Analysis. *Medical Journal of the Islam Republic of Iran,* [online], 31(24), pp. 1-7, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5804441/pdf/mjiri-31-24.pdf [accessed: 25th September 2018].

Fazio, S., Pace, D., Flinner, J. & Kallmer, B. (2018). The Fundamentals of Person-Centered Care for Individuals with Dementia. *Gerontologist,* [online], 58(S1), pp.S10–S19, available: https://academic.oup.com/gerontologist/article/58/suppl_1/S10/4816735 [accessed: 10th October 2017].

Fehr, C. (2015). *What constitutes a good death? Implications for family nurse practitioners in Rural British Columbia*. Unpublished, (Ph.D.), thesis, University of British Columbia, America.

Fernandes, A. (2008). *Euthanasia, Suicide, & the Philosophical Anthropology of Karol Wojtyla.* Unpublished (Ph.D.) thesis, Graduate School of Arts and Sciences of Georgetown University.

Filej, B., Kaučič, B., Žvanut. B. & Saje, M. (2016). Holistic Treatment of the Patient in Palliative Care – The Nurses View. *De Gruyter Open Access*, [online], 15(4)(57), pp. 42-47, available: https://www.degruyter.com/downloadpdf/j/pielxxiw.2016.15.issue-4/pielxxiw-2016-0036/pielxxiw-2016-0036.pdf [accessed: 21st of October 2018].

Flicker, R. (2012*). Sampling Methods for Web and E-mail Surveys*. [online], available:https://calhoun.nps.edu/bitstream/handle/10945/38713/5123-Fielding-Ch11.pdf?sequence=1 [accessed: 4th February 2018].

Florea, M. & Rabatel, A. (2011). Media Representations of Death and the Issues Involved in the Construction of the Event. *Questions de communication*, [online], 20, pp. 1-12, available: file:///C:/Users/seamusg/Downloads/questionsdecommunication-8886.pdf [accessed: 23rd February 2019].

Fong, J., Anat, S. & Longnecker, N. (2010). Doctor-Patient Communication: A Review. *The Ochsner Journal,*[online], 10, pp:38–43, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3096184/pdf/i1524-5012-10-1-38.pdf [accessed: 23rd October 2018].

Freeman, B. (2015). *Compassionate Person-Centred Care for the Dying: An Evidence-Based Palliative Care Guide for Nurses.* [online], available: https://books.google.ie/books?id=mHbNBgAAQBAJ&pg=PA154&dq=Carl+Rogers+person+centred+care+in+palliative+care&hl=en&sa=X&ved=0ahUKEwjxlJq65KHeAhXLJsAKHevZCO4Q6AEIQjAE#v=onepage&q=Carl%20Rogers%20person%20centred%20care%20in%20palliative%20care&f=false [accessed: 25th October 2018].

Frost, T., Sunha, D. & Gilbert, B. (2014). Should Assisted Dying Be Legalised? *Philosophy, Ethics and Humanities in Medicine,* [online], 9(3), pp. 10-5, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3901751/pdf/1747-5341-9-3.pdf [accessed: 24th September 2018].

Galbin, A. (2014). An Introduction to Social Constructionism. *Social Research Reports,* [online], 26, pp. 82-92, available: file:///C:/Users/c00186113/Downloads/srr_2014_vol026_004.pdf [accessed: 31st July 2018].

Galdas, P. (2017). Revisiting Bias in Qualitative Research: Reflections on Its Relationship with Funding and Impact. *International Journal of Qualitative Methods,* [online], 16, pp. 1–2, available: https://journals.sagepub.com/doi/pdf/10.1177/1609406917748992 [accessed: 12th August 2017].

Galway Hospice. (2018). *Inpatient Care.* [online], available: https://www.galwayhospice.ie/about-us/inpatient-care/ [accessed: 24th May 2018].
Gire, J. (2015) How Death Imitates Life: Cultural Influences on Conceptions of Death and Dying. *Online Readings in Psychology and Culture,* [online], 6(2), pp. 2-22, available: https://scholarworks.gvsu.edu/cgi/viewcontent.cgi?article=1120&context=orpc [accessed: 19th November 2017].

Girgis, A., Lambert, S., McElduff, P., Bonevski, B., Lecathelinais, C., Boyes, A. & Stacey, F. (2013). Some Things Change, Some Things Stay the Same: A Longitudinal Analysis of Cancer Caregivers' Unmet Supportive Care Needs. *Psycho-Oncology,* [online], 22, pp. 1557–1564, available: http://content.ebscohost.com/ContentServer.asp?T=P&P=AN&K=88939850&S=R&D=a9h&EbscoContent=dGJyMMTo50SeprM4zdnyOLCmr1CeprdSsq24TLeWxWXS&ContentCustomer=dGJyMPGqsEmyqrRKuePfgeyx43zx [accessed: 5th October 2018].

Githaiga, J. & Swartz, L. (2017). Socio-Cultural Contexts of End-of-Life Conversations and Decisions: Bereaved Family Cancer Caregivers' Retrospective Co-Constructions. *BMC Palliative Care,* [online], 16(40), pp. 1-8, available: https://bmcpalliatcare.biomedcentral.com/track/pdf/10.1186/s12904-017-0222-z [accessed: 1st October 2018].

Gomes, B., Calanzani, N., Gysels, M., Hall, S. & Higginson, I. (2013). Heterogeneity and Changes in Preferences for Dying at Home: A Systematic Review. *BMC Palliative Care,* [online], 12(7), pp. 1-13, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3623898/pdf/1472-684X-12-7.pdf [accessed: 11th September 2018].

Gordon, D., Hawes, S., Reid, A., Callands, T., Magriples, U., Divney, A., Niccolai, L. & Kershaw, T. (2013). The Many Faces of Manhood: Examining Masculine Norms and Health Behaviors of Young Fathers Across Race. *American Journal of Men's Health,* [online], 7(5), pp. 394–401, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3731397/pdf/nihms-477163.pdf [accessed: 17th February 2019].

Government of Ireland, *Data Protection Act* 1988 and 2003, Dublin: Stationary Office.

Government of Ireland, *Freedom of Information Act* 2014, Dublin: Stationary Office.

Grant, M., Ugalde, A., Vafiadis, P. & Philip, J. (2014). Exploring the myths of morphine in cancer: views of the general practice population. *Support Care Cancer,* [online], 23(2), pp. 483-489, available: https://www.mascc.org/assets/Pain_Center/2014_September/september2014-17.pdf [accessed: 9th April 2019].

Green, J. & Thorogood, N. (2018). *Qualitative Methods for Health. 4th ed.* Sage: London.

Gysels, M., Evans, N., Men, A., Andrew, E., Toscani, F., Finetti, S., Pasman, R., Higginson, I., Harding, R., Pool, R. (2012). Culture and End of Life Care: A Scoping Exercise in Seven European Countries. *PLoS ONE,* [online], 7 (4), pp. 1-16, available: http://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0034188&type=printable [accessed: 4th August 2018].

Hackett, J. (2017). The Importance of Holistic Care at the End of Life. *Ulster Medical Journal,* [online], 86(2), pp. 143-144, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5846001/pdf/umj-86-02-143.pdf [accessed: 21st October 2018].

Hanley, P. & Sheerin, C. (2017). Valuing Informal Care in Ireland: Beyond the Traditional Production Boundary. *The Economic and Social Review,* [online],48(3), pp. 337-364, available: https://www.esr.ie/article/view/773/167 [accessed: 12th March 2019].

Hawley, P. (2017). Barriers to Access to Palliative Care. *Palliative Care: Research and Treatment*, [online], 0, pp. 1-6, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5398324/pdf/10.1177_1178224216688887.pdf [accessed; 20th January 2019].

Heale, R. & Forbes, D. (2013). Understanding triangulation in research. *Evidenced Based Nursing*, [Online], 16(4), pp. 98, available: https://ebn.bmj.com/content/ebnurs/16/4/98.full.pdf [accessed: 18th October 2018].

Health Information & Equality Authority. (2019). *Overview of 2016 HIQA regulation of social care and healthcare services*. [online], available: https://www.hiqa.ie/sites/default/files/2017-04/Regulation-overview-2016-web.pdf [accessed: 7th May 2019].

Health Service Executive and Irish Hospice Foundation. (2008). *Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks.* [online], available: http://hospicefoundation.ie/wp-content/uploads/2012/07/Palliative-Care-For-All-report.pdf [accessed: 2nd March 2018].

Health Service Executive. (2018). *Draft Code of Practice on Advance Healthcare Directives for Health and Social Care Professionals.* [online], available: https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/assisteddecisionmaking/healthandsocialcareprofessionalcodedraftforconsultation.pdf [accessed: 5th May 2018].

Health Information & Equality Authority. (2009). *National Quality Standards for Residential Care Settings for Older People in Ireland.* [online], available: https://www.hiqa.ie/system/files/Residential_Care_Report_Older_People_20090309.pdf [accessed: 23rd February 2018].

Health Service Executive. (2013). *National Strategy for Service User Involvement in the Irish Health Service 2008-2013.* [online], available: https://www.tusla.ie/uploads/content/Publications_National_Strategy_for_Service_User_involvement.pdf [accessed: 2nd January 2019].

Health Service Executive. (2014). *Palliative Care Competence Framework*. [online], available: https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/palliative-care-framework-document.pdf [accessed: 7th October 2017].

Health Service Executive. (2015). *Supervision for Health and Social Care Professionals; Improving Performance and Supporting* Employees. [online], available: https://circulars.gov.ie/pdf/circular/hse/2015/02.pdf [accessed: 23rd March 2015].

Health Service Executive. (2017) *Assisted Decision Making Guide – Consultation*. [online], available: https://www.hse.ie/eng/about/who/qid/other-quality-improvementprogrammes/assisteddecisionmaking/assisteddecisionmakingguideconsultation.html [accessed: 19th October 2017].

Health Service Executive. (2017). *Palliative Care Development Framework 2017-2019.* [online], available: https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/palliative-care-services-development-framework.pdf [accessed: 28th November 2018].

Health Service Executive. (2017). *Palliative Care Services Three Year Development Framework (2017 – 2019)* [online], available: https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/palliative-care-services-development-framework.pdf [accessed: 11th October 2017].

Health Service Executive. (2018). *Draft Code of Practice on Advance Healthcare Directives for Health and Social Care Professionals.* [online], available: https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/assisteddecisionmaking/healthandsocialcareprofessionalcodedraftforconsultation.pdf [accessed: 5th May 2019].

Health Service Executive. (2018). *National Service Plan 2018.* [online], available: https://www.hse.ie/eng/services/publications/serviceplans/national-service-plan-2018.pdf [accessed: 1st of February 2019].

Health Service Executive. (2018). *Regional Specialist Inpatient & Day Service in Palliative medicine at Waterford Regional Hospital (WRH) Progressed.* [online], available: https://www.hse.ie/eng/services/news/media/pressrel/newsarchive/2013archive/mar2013/regionalspecialistinpatientanddayserviceinpalliativemedicineatwrhprogressed.html [accessed: 3rd of March 2019].

Health Service Executive. (2018). *Your Service Your Say: Guidance Resource (Full Document).* [online], available: https://www.hse.ie/eng/about/qavd/complaints/ysysguidance/ysysguidancefulltext.html [accessed: 26th October 2018].

Health Service Executive. (2019). *'Adult Palliative Care Model of Care: The National Clinical Programme for Palliative Care.* [online], available: https://www.lenus.ie/bitstream/handle/10147/624170/Palliative-Care-Model-of-Care-2019.pdf [accessed: 12th of May 2019].

Himmelstein, M and Sanchez, D. (2014). Masculinity impediments: Internalized masculinity contributes to healthcare avoidance in men and women. *Journal of Health Psychology*, [online], 21(7), pp. 1–10, available: https://pdfs.semanticscholar.org/0df3/a43c13c8e36f8ab24417fb1e9f5009625cbc.pdf [accessed: 20th June 2019].

Ho, A., Chan, C., Leung, P., Chochinov, H., Neimeyer, R., Pang, S. & Tse, D. (2013). Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong. *Age and Ageing*, [online], 42(4), pp. 455–461, available: https://academic.oup.com/ageing/article/42/4/455/9246 [accessed: 17th February 2019].

Hold, J. (2017). A good death: Narratives of experiential nursing ethics. *Nursing Ethics*, [online], 24(1), pp.10-19, available: https://journals-sagepub-com.ezproxy.itcarlow.ie/doi/pdf/10.1177/0969733015602051 [accessed:10th December 2018].

Hong, S., Caglea, J., Plantb, A., Cullerc, K., Carriond, I. & Van Dussenb, D. (2016). Quality of death among hospice decedents: Proxy observations from a survey of community-dwelling adults in the contiguous United States. *Death Studies*, [online], 40(9), pp. 529–537, available: http://content.ebscohost.com/ContentServer.asp?T=P&P=AN&K=119500085&S=R&D=a9h&EbscoContent=dGJyMNXb4kSeqLI4zdnyOLCmr1Cep7VSsKa4Sa%2BWxWXS&ContentCustomer=dGJyMPGqsEmyqrRKuePfgeyx43zx [accessed: 8th August 2018].

House of Oireachtas. (2019). *Assisted Decision Making: Dáil Èireann Debate, Tuesday – 16 October 2018.* [online], available: https://www.oireachtas.ie/en/debates/question/2018-10-16/313/#pq-answers-313 [accessed: 5th May 2019].

Howe, K. (2011). Mixed Methods, Mixed Causes? *Qualitative Inquiry*, [online], 17(2), pp.166 –171, available: http://66.208.62.164/@api/deki/files/2013/=Mixed_Methods_Howe_2011.pdf [accessed: 29th March 2013].

Huenchuan, S. (2017). *The Right to End-of-Life Palliative Care and a Dignified Death.* [online], available: https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2017/11/ECLAC-contribution.pdf [accessed: 12th August 2018].

Hutter, N., Pestle, U., Meffert, C., Körner, M., Bozzaro, C., Becker, G., Baumeiste, H. (2015). Conceptual clarification and status of research "Good dying" - definition and current state of research. *Dtsch Med Wochenschr*, [online], 140(70), pp. 1296-1301, available: https://www.thieme-connect.com/products/ejournals/html/10.1055/s-0041-102676 [accessed: 6th August 2018]

Huynh, T., Kleerup, E., Raj, P. & Wenger, N. (2014). The Opportunity Cost of Futile Treatment in the ICU. *Critical Care Medicine*, [online], 42, pp. 1977–82, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4134705/pdf/nihms607356.pdf [accessed: 21st September 2018].

Irish Association of Social Worker. (2019). *Supervision: Introduction to Professional Supervision for HSCPs*. [online], available: https://www.iasw.ie/Social-Worker-Supervision [accessed: 24th of March 2019].

Irish Cancer Society. (2017). *Park the Charge Campaign. Irish Cancer Society Report*. [online], available: https://www.cancer.ie/sites/default/files/content-attachments/ics_cost_of_parking_8pp_v5.pdf [accessed: 7th May 2019].

Irish Hospice Foundation. (2007). *Staffing Levels and Bed Numbers in Specialist Palliative Care in Ireland, 2007: Update of Baseline Study (2005) data*. [online], available: http://hospicefoundation.ie/wp-content/uploads/2012/04/Staffing-Levels-and-Bed-Numbers-in-Specialist-Palliative-Care-in-Ireland-2007.pdf [accessed: 4th March 2019].

Irish Hospice Foundation. (2010). *Making end-of-life care central to hospital care: quality standards for end-of-life care in hospitals*. [online], available: https://epubs.rcsi.ie/cgi/viewcontent.cgi?referer=https://www.google.com/&httpsredir=1&article=1001&context=icubhrep [accessed:3rd October 2017].

Irish Hospice Foundation. (2013). *Competence & Compassion End-of-Life Care Map*. [online], available: http://hospicefoundation.ie/wp-content/uploads/2013/04/End-of-Life-Care-Map-2013-version.pdf [accessed: 16th February 2019].

Irish Hospice Foundation. (2013). *End of Life & Supporting Staff; A Literature Review*. [online], available: http://hospicefoundation.ie/wp-content/uploads/2013/04/End-of-Life-Care-Supporting-Staff-a-literature-review.pdf [accessed: 20th March 2019].

Irish Hospice Foundation. (2013). *End-of-Life Care Resources: Caring for a Dying Patient*. [online], available: http://hospicefoundation.ie/wp-content/uploads/2013/04/7.Caring-for-a-Dying-Patient.pdf [accessed: 21st October 2018].

Irish Hospice Foundation. (2013). *Impact on patients and families: Perspectives on future service delivery*. [online], available: http://hospicefoundation.ie/wp-content/uploads/2013/01/The-strategic-importance-of-palliative-care-within-the-Irish-health-service-Perspectives-on-future-service-delivery.pdf [accessed: 27th of September 2018].

Irish Hospice Foundation. (2013). *Primary Palliative Care in Ireland. Identifying improvements in primary care to support the care of those in their last year of life.* [online], available: https://hospicefoundation.ie/wp-content/uploads/2012/05/Primary-Palliative-Care-in-Ireland.pdf [accessed: 16th December 2018].

Irish Hospice Foundation. (2013). *The Ethics of Life Prolonging Treatments (LPTs).* [online], available: http://hospicefoundation.ie/wp-content/uploads/2013/10/Module-6-The-Ethics-of-Life-Prolonging-Treatments.pdf [accessed: 19th September 2018].

Irish Hospice Foundation. (2013). *The strategic importance of palliative care within the Irish health service: Perspectives on future service delivery.* [online], available: http://hospicefoundation.ie/wp-content/uploads/2013/01/The-strategic-importance-of-palliative-care-within-the-Irish-health-service-Perspectives-on-future-service-delivery.pdf [accessed: 30th October 2018].

Irish Hospice Foundation. (2016). *A Briefing Paper on Advanced Healthcare Directives: Prepared by the Forum on End of Life in Ireland and the Irish Hospice Foundation*. [online], available: http://hospicefoundation.ie/wp-content/uploads/2016/07/Advance-Healthcare-Directives-Briefing-Paper-January-2016.pdf [accessed: 9th October 2018].

Irish Hospice Foundation. (2016). *IHF – the peoples charter on death, dying and bereavement in Ireland.* [online], available: http://hospicefoundation.ie/wp-content/uploads/2017/10/Charter.pdf [accessed: 15th November 2017].

Irish Hospice Foundation. (2016). *The Irish Hospice Foundation Strategic Plan 2016-2019.* [online], available: http://hospicefoundation.ie/wp-content/uploads/2016/05/Irish-Hospice-Foundation-Strategic-Plan-2016-2019.pdf [accessed: 12th January 2019].

Irish Hospice Foundation. (2017). *Key Facts on Death, Dying & Bereavement: Death & Dying in Ireland.* [online], available: https://hospicefoundation.ie/supporting/wayswesupport/key-facts/ [accessed: 7th of September 2018].

Irish Hospice Foundation. (2018). *What is Palliative Care.* [online], available: https://hospicefoundation.ie/aboutus/hospice-palliative-and-end-of-life-care/what-is-palliative-care/ [accessed: 12th February 2019].

Irish Hospice Foundation. (2019). *What is an Advanced Healthcare Directive*? [online], available: https://hospicefoundation.ie/programmes/advance-care/questions-and-answers-on-advance-healthcare-directives/ [accessed; 18th September 2017].

Irish Hospice Foundation. (2019). *What is Hospice Care?* [online], available: https://hospicefoundation.ie/aboutus/hospice-palliative-and-end-of-life-care/what-is-hospice-care/ [accessed: 10th October 2017].

Irish Human Rights & Equality Commission, (2015). *Human Rights Explained Guide to Human Rights Law.* [online], available: https://www.ihrec.ie/download/pdf/ihrec_human_rights_explained.pdf [accessed: 21st October 2017].

Irish Medical Times. (2018). *A Code of Practice on Advanced Healthcare Directives.* [online], available: https://www.imt.ie/features-opinion/code-practice-advanced-healthcare-directives-13-06-2018/ [accessed: 5th May 2019].

Irish Times. (2017). *What is the truth about 'bed blocking' in Irish hospitals*?[online], available: https://www.irishtimes.com/news/health/what-is-the-truth-about-bed-blocking-in-irish-hospitals-1.2940689 [accessed: 7th April 2019].

Jansen, B., Brazil, K., Passmore, P., Buchanan, H., Maxwell, D., McIlfatrick, S., Morgan, S., Max Watson, M. & Parsons, C. (2017). Exploring Healthcare Assistants' Role and Experience in Pain Assessment and Management for People with Advanced Dementia Towards the End of Life: A Qualitative Study. *BMC Palliative Care*, [online], 16(6), pp. 1-11, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5247820/pdf/12904_2017_Article_184.pdf [accessed: 17th January 2019].

Jasemi M, Valizadeh L, Zamanzadeh V, Keogh B. (2017). A concept analysis of holistic care by hybrid model. *Indian Journal of Palliative Care, [*online], 23, pp.71-80, available: https://pdfs.semanticscholar.org/1529/99c26dd5177629f8c505158279fc296676fc.pdf [accessed: 21st October 2018].

Joarder, T., Cooper, A. & Zaman, S. (2014). Meaning of Death: An Exploration of Perception of Elderly in a Bangladeshi Village. *Journal of Cross Cultural Gerontology,* [online], 29, pp. 299-314, available: http://content.ebscohost.com/ContentServer.asp?T=P&P=AN&K=97444667&S=R&D=a9h&EbscoContent=dGJyMMTo50SeprE4v%2BvlOLCmr1CeprNSsay4SLeWxWXS&ContentCustomer=dGJyMPGqsEmyqrRKuePfgeyx43zx [accessed: 2nd August 2018].

Johnson, A. (2011). *Nursing the Dying: A mixed method study*. Unpublished (Ph.D.) thesis, University of Western Sydney, Australia.

Johnson, M., King, D., Arora, S., Behar, N., Athanasiou, T., Sevdalis,. & Darzi, A. (2015). Smartphones let surgeons know WhatsApp: an analysis of communication in emergency surgical teams. *American Journal of Surgery*, [online], 209(1), pp. 45-51, available: https://spiral.imperial.ac.uk:8443/handle/10044/1/60416 [accessed: 10th May 2019].

Johnston, B. & Christensen, L. (2012). *Educational Research: Quantitative, Qualitative & Mixed Approaches. 4th ed.* [online e] available: https://books.google.ie/books?id=b2ujHWrRpVQC&pg=PA231&dq=participant+sampling+in+research&hl=en&sa=X&ved=0ahUKEwi85eq-ltjQAhVlGsAKHVVcAlgQ6wEILjAC#v=onepage&q=participant%20sampling%20in%20research&f=false [accessed: 2nd December 2016].

Kane, P., Daveson, B., Ryan, K., McQuillan, R. & Higginson. I. (2015). The Need for Palliative Care in Ireland: A Population-Based Estimate of Palliative Care Using Routine Mortality Data, Inclusive of Non-malignant Conditions. *Journal of Pain and Symptom Management,* [online], 49(4), pp. 727-733, available: https://www.aoti.ie/attachments/b8127802-9e63-4b8c-967a-c51223df773a.PDF [accessed: 21th December 2017].

Kao, Y., Liu, Y., Koo, M. & Chiang, J. (2018). Factors Associated with Emergency Services Use in Taiwanese Advanced Cancer Patients Receiving Palliative Home Care Services During Out-of-Hours Periods: A Retrospective Medical Record Study. *BMC Palliative Care,* [online], 17 (1), pp. 1-7, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5848533/pdf/12904_2018_Article_302.pdf [accessed: 11th September 2018].

Keall, R., butow, R., Steinhauser, K. & Clayton, J. (2013). Nurse-Facilitated Preparation and Life Completion Interventions Are Acceptable and Feasible in the Australian Palliative Care Setting Results from a Phase 2 Trial. *Cancer Nursing,* [online], 36(3), pp. E39-45, available: file:///C:/Users/seamusg/Downloads/Nurse-Facilitated_Preparation_and_Life_C.pdf [accessed: 17th February 2019].

Kelly, C. (2014). What is a Good Death? An Exploration of Issues at the End of Life Through Phenomenological Analysis of Selected Dramatic Literature. *The New Bioethics,* [online], 20(1), pp. 35–52, available: http://content.ebscohost.com/ContentServer.asp?T=P&P=AN&K=95516291&S=R&D=a9h&EbscoContent=dGJyMNLe80Seprc4zOX0OLCmr0%2BeprNSsKi4TLaWxWXS&ContentCustomer=dGJyMPGqsEmyqrRKuePfgeyx43zx [accessed: 9th November 2017].

Kennedy, C., Brooks-Young, P., Gray, C., Larkin, P., Connolly, M., Wilde-Larsson, B., Larsson, M., Smith, T. & Chater, S. (2014). Diagnosing dying: an integrative literature review. *BMJ Supportive & Palliative Care,* [online], 4, pp:263–270, available: https://spcare.bmj.com/content/bmjspcare/4/3/263.full.pdf [accessed: 13th May 2019].

KildareStreet. (2018). *Dáil Debates: Medical Card Eligibility.* [online], available: https://www.kildarestreet.com/debates/?id=2018-05-02a.420 [accessed: 7th March 2019].

Kim, H. & Yi, M. (2015). Unmet Needs and Quality of Life of Family Caregivers of Cancer Patients in South Korea. *Asia-Pacific Journal of Oncology Nursing,* [online], 2(3), pp. 152-159, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5123473/pdf/APJON-2-152.pdf [accessed: 5th October 2018].

Kim, H. & Yi, M. (2015). Unmet Needs and Quality of Life of Family Caregivers of Cancer Patients in South Korea. *Asia-Pacific Journal of Oncology Nursing,* [online], 2(3), pp. 152-159, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5123473/pdf/APJON-2-152.pdf [accessed: 5th October 2018].

Kinghorn, P. & Coast, J. (2018). Assessing the Capability to Experience a ’Good Death’: A Qualitative Study to Directly Elicit Expert Views on a New Supportive Care Measure Grounded in Sen’s Capability Approach. *PLOS ONE,* [online], 13(2), pp. 1-14, available: http://content.ebscohost.com/ContentServer.asp?T=P&P=AN&K=128116667&S=R&D=a9h&EbscoContent=dGJyMMvl7ESep7U40dvuOLCmr1CeprdSsKu4TLOWxWXS&ContentCustomer=dGJyMPGqsEmyqrRKuePfgeyx43zx [accessed: 17th February 2018].

Kirby, E., Broom, A. & Good, P. (2014). The Role and Significance of Nurses in Managing Transitions to Palliative Care: A Qualitative Study. *BMJ Open*, [online], 4, pp. 1-8, available: https://bmjopen.bmj.com/content/bmjopen/4/9/e006026.full.pdf [accessed: 30th September 2018].

Kirk, A. (2010). Public Health, Populations and Lethal Ingestion. *Disability and Health Journal,* [online], 3, pp.56-70, available: http://0-ac.els-cdn.com.www.library.itcarlow.ie/S1936657409001514/1-s2.0-S1936657409001514-main.pdf?_tid=8196c698-a069-11e6-8f62-00000aacb361&acdnat=1478028748_db10bf669fc647c2b85b46faeb5f6cd3 [accessed: 22nd October 2016].

Kissane, L., Ikeda, B., Akizukib, R., Nozakic, S., Yoshimuraa, K. & Ikegami, N. (2015). End-of-Life Preferences of the General Public: Results from a Japanese National Survey. *Health Policy,* [online], 119, pp. 1472–1481, available: https://ac.els-cdn.com/S0168851015001219/1-s2.0-S0168851015001219-main.pdf?_tid=3397dd7d-a304-4158-b770-9d7647b7af20&acdnat=1532949850_6f77c875e525029d495bace1e6247f18 [accessed: 30th July 2018].

Ko, E., Kwak, J. & Nelson-Becker, H. (2015). What Constitutes a Good and Bad Death: Perspectives of Homeless Older Adults. *Death Studies*, [online], 39, pp. 422–432, available: https://www.tandfonline.com/doi/pdf/10.1080/07481187.2014.958629?needAccess=true [accessed: 12th April 2018].

Koesel, N. & Link, M. (2014). Conflicts in Goals of Care at the End of Life Are Aggressive Life-Prolonging Interventions and a ‘‘Good Death’’ Compatible? *Journal of Palliative Care,* [online], 16(6), pp. 330-335, available: https://nursing.ceconnection.com/ovidfiles/00129191-201408000-00003.pdf [accessed: 24th September 2018].

Kpanake, L., Dassa, S. K, Sorum, P. C., & Mullet, E. (2014). Togolese Lay People’s and Health Professionals’ Views About the Acceptability of Physician-Assisted Suicide. *Journal of Medical Ethics,* [online], 40, pp. 621-624, available: http://r-libre.teluq.ca/1301/1/PAS%20Togo.pdf [accessed: 24th September 2018].

Krau, S. (2016). The Difference between Palliative Care and End of Life Care: More than Semantics. *Palliative and End-of-Life Care,* [online], 51(3), pp. ix-x, available: https://www.nursing.theclinics.com/article/S0029-6465(16)30027-5/pdf [accessed: 10th September 2017].

Krishna, L. & Yong, C. (2014). The role of palliative rehabilitation in the preservation of personhood at the end of life. *BMJ Case Rep,* [online], available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4091257/pdf/bcr-2014-204780.pdf [accessed: 14th February 2019].

Kumar, R. (2014). *Research Methods: A Step-by-Step Guide for Beginners*. 4th ed. Sage: London.

Kubler-Ross, E. (1997). *On Death and Dying.* [online], available: https://books.google.ie/books?id=zb-ZNYFUXhsC&printsec=frontcover&dq=Kubler+Ross+death+denying+culture&hl=en&sa=X&ved=0ahUKEwi1roiUz9XkAhVFWxUIHeDuCowQ6AEIKjAA#v=onepage&q=denial&f=false [accessed: 12th October 2017].

Lambert, S., Harrison, D., Smith, E., Bonevski, B., Carey, M., Lawsin, C., Chris Paul, C. & Girgis, A. (2012)The Unmet Needs of Partners and Caregivers of Adults Diagnosed with Cancer: A Systematic Review. *BMJ Supportive & Palliative Care,* [online], 2, pp. 224–230, available: https://www.researchgate.net/publication/261000455_The_unmet_needs_of_partners_and_caregivers_of_adults_diagnosed_with_cancer_A_systematic_review [accessed: 5th October 2018].

Lee, S. & Hawkins, R. (2015). Disclosure Preferences Towards Terminally Ill Patients in Singapore: Are We Ready to Confront the “Elephant in the Room”? *Asian Journal of Cancer,* [online], 14 (1), pp. 9-17, available: file:///C:/Users/seamusg/Downloads/Disclosure%20Preferences%20Towards%20Terminally%20Ill%20Patients%20in%20Singapore_%20Are%20We%20Ready%20to%20Confront%20the%20%E2%80%9CElephant%20in%20the%20Room%E2%80%9D_.pdf [accessed: 6th October 2018].

Leon., A., Davis, L & Kraemer, H. (2011). The Role and Interpretation of Pilot Studies in Clinical Research. *Journal of Psychiatric Research,* [online], 45(5) pp.626–629, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3081994/pdf/nihms245890.pdf [accessed: 9th January 2018].

Loucka, M., Payne, S. & Brearley, S. (2014). Where Do People Not Want to Die? A Representative Survey of Views of General Population and Health Care Professionals in the Czech Republic. *Progress in Palliative Care,* [online], 0, pp. 1-8, available: https://www.researchgate.net/publication/260994653_Place_of_death_in_the_Czech_Republic_and_Slovakia_A_population_based_comparative_study_using_death_certificates_data [accessed: 16th August 2018].

Lueng, K., Liu, W., Cheng, S., Chiu, T. & Chen. C. (2009). What Do Laypersons Consider as a Good Death? *Support Care Cancer,* [online], 17, pp. 691-699, available: http://ntur.lib.ntu.edu.tw/bitstream/246246/173131/1/151.pdf [accessed: 18th July 2018].

Lugo, L., Cooperman, F. & O’Connell, E. (2013). *Views on End-of-Life Medical Treatment: Growing Minority of Americans Say Doctors Should Do Everything Possible to Keep Patients Alive.* [online], available: http://www.pewresearch.org/wp-content/uploads/sites/7/2013/11/end-of-life-survey-report-full-pdf.pdf [accessed: 22nd September 2018].

Mack. L. (2010). The Philosophical Underpinnings of Educational Research. *Polygossia,* [online],19, pp. 5-11, available: http://r-cube.ritsumei.ac.jp/bitstream/10367/1887/1/1-Polyglossia19_The%20Philosophical%20Underpinnings%20of%20Educational%20Research.pdf [accessed: 22nd February 2018].

Mak, M. (2017). Death: Good Death. *Encyclopaedia of Global Bioethics,* [online], 132-1, pp. 1-9, available: https://link.springer.com/content/pdf/10.1007/978-3-319-05544-2_132-1.pdf [accessed: 13th March 2018].

Makewa, L., Nygussa, M. & Kuboja, J. (2019). Technology-Supported Teaching and Research Methods for Educators. [online], available: https://books.google.ie/books?id=EjFtDwAAQBAJ&pg=PA35&dq=kolb%27s+learning+cycle+in+research&hl=en&sa=X&ved=0ahUKEwi58efnjKbiAhUIUBUIHRaDBV0Q6AEIQDAE#v=onepage&q=kolb's%20learning%20cycle%20in%20research&f=false [accessed: 8th January 2019].

Mallett, R. & Runswick-Cole, K. (2014). *Approaching Disability: Critical Issues & Perspectives.* [online], available: https://books.google.ie/books?id=19XpAwAAQBAJ&pg=PA21&dq=Wolfenberger+normalisation+theory&hl=en&sa=X&ved=0ahUKEwjjrvKGoKveAhUCYVAKHblDBeA4ChDoAQhIMAY#v=onepage&q=Wolfenberger%20&f=false [accessed: 29th October 2018].

Marhardt, D. & Spira, M. (2013). From Person-Centered Care to Relational-Centered Care. *Journal of the American Society on Aging*, [online], 37 (3), pp. 37-44, available: file:///E:/Psychology%20Adjustment%20%20&%20Positive%20Change%20Notes/ASSIGNMENT%20WORKS/CHALLENGING%20BEHAVIOUR%20ASSIGNMENT%20WORKS/Person%20centred%20care%20and%20relational%20centred%20care%20in%20dementia.pdf [accessed: 17th February 2017].

Marie Claire. (2018). *Emotional experiences and concerns.* [online], available: https://www.mariecurie.org.uk/help/support/terminal-illness/preparing/end-of-life-experiences# [accessed: 17th September 2018].

McCaffrey, N., Bradley, S., Ratcliffe, J. & Currow, D. (2016). What Aspects of Quality of Life Are Important from Palliative Care Patients’ Perspectives? A Systematic Review of Qualitative Research. *Journal of Pain & Symptom Management*, [online], 52(2), pp. 318-328, available: https://www.jpsmjournal.com/article/S0885-3924(16)30078-1/pdf [accessed: 22nd October 2018].

McCarron, M., Higgins, A., Larkin, P., Drennan, J., Mc Callion, P., Payne, S., Hynes, G. & May, P. (2010). *Evaluation of the programme to support palliative and hospice care in the Republic of Ireland: Final report.* [online], available: https://www.lenus.ie/bitstream/handle/10147/301442/PalliativeandHospiceCare%20RepIreland.pdf?sequence=1&isAllowed=y [accessed: 4th March 2019].

McCarthy, J., Donnelly, M., Dooley, M., Campbell, L. & Smith, D. (2010). *The Complete Ethical Framework for End of Life Care.* [online], available: https://epubs.rcsi.ie/cgi/viewcontent.cgi?article=1000&context=gprep [accessed; 12th July 2018].

McCarthy, J. (2013). *End -of-Life Care in Ireland: ethical challenges and solutions*. [online], available: https://www.oireachtas.ie/parliament/media/committees/healthandchildren/health2014/Vol-2-complete-part-E.pdf [accessed: 5th December 2017].

McCarthy, J., Loughrey, M., Weafer, J. & Doley, D. (2009). *Conversations with the Irish public about death and dying.* [online], available: http://hospicefoundation.ie/wp-content/uploads/2013/06/Conversations-with-the-Irish-public-about-death-and-dying.-McCarthy-Loughry-Weafer-Dooley-2009.pdf [accessed: 10th November 2017].

McCormack, B. & McCance, T. (2017). *People's Needs Defining Change – Health Services Change Guide*. [online], available: https://www.hse.ie/eng/staff/resources/changeguide/resources/person-centred-principles-and-person-centred-practice-framework.pdf [accessed:13th of February 2019].

McEvoy, L. & Duffy, A. (2008). Holistic practice – A concept analysis. Nurse Education in Practice, [online], 8, pp. 412–419, available: https://ac-els-cdn-com.ezproxy.itcarlow.ie/S147159530800019X/1-s2.0-S147159530800019X-main.pdf?_tid=8b7e48c0-3652-4b06-bf5b-fc3374ff30c4&acdnat=1540140339_22a1a4b557e16552d81c3213346796b5 [accessed: 21st October 2018].

McIlfatrick, S. & Murphy, T. (2013). Palliative care research on the island of Ireland over the last decade: a systematic review and thematic analysis of peer reviewed publications. *BMC Palliative Care,* [online], 12(33), pp.4-9, available: https://bmcpalliatcare.biomedcentral.com/track/pdf/10.1186/1472-684X-12-33 [accessed: 23rd February 2018].

McKeown, K. (2014). *Enabling More People to Die at Home: Making a Case for Quality Indictors as Drivers for Change on Place of Care and Place of Death in Ireland.* [online], available: http://hospicefoundation.ie/wp-content/uploads/2014/12/Enabling-More-People-to-Die-at-Home1.pdf [accessed: 20th November 2017].

McLoughlin, K. (2017). *Have Your Say Initial Analysis of Data from a National Survey to Inform the Development of an Irish Charter on Death, Dying and Bereavement in Ireland.* [online], available: http://hospicefoundation.ie/wp-content/uploads/2017/10/Have-Your-Say-Report.pdf [accessed: 10th October 2017].

McManus, P., Mulhall, S. & Ragab. (2017). *An Investigation in the Methodological Approaches used in Doctoral Business Research in Ireland.* [online], available: https://arrow.dit.ie/cgi/viewcontent.cgi?article=1168&context=buschmarcon [accessed: 13th August 2018].

McVeigh, C., Reid, J., Larkin, P., Porter, S. & Hudson, P. (2018). The provision of generalist and specialist palliative care for patients with non-malignant respiratory disease in the North and Republic of Ireland: a qualitative study. *BMC Palliative Care,* [online], 17(6), pp. 1-12, available: https://bmcpalliatcare.biomedcentral.com/track/pdf/10.1186/s12904-017-0220-1 [accessed: 26th May 2019].

Medical Council. (2016). *Guide to Professional Conduct & Ethics for Registered Medical Practitioners.* [online], available: https://issuu.com/mcirl/docs/guide_to_professional_conduct_and_e?e=12642421/35694606 [accessed: 22nd of October 2018].

MedlinePlus. (2019). *What is palliative care?* [online], available: https://medlineplus.gov/ency/patientinstructions/000536.htm [accessed: 12th October 2017].

Meier, E., Gallegos, J., Thomas, L. Depp, C., Irwin, S & Jeste, D. (2016). Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue. *Am J Geriatr Psychiatry*, [online], 24 (4), pp. 261-271, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4828197/ [accessed: 6th November 2017].

Mental Health Commission. (2014). *Director of the Decision Support Service.* [online], available: https://www.mhcirl.ie/DSS/dir_dss/ [accessed: 5th May 2019].

Mesa, J., Chica, D., Duquia, R., Bastos, J. & Onamigo, R. (2016). Sampling: How to Select Participants in My Study? *Anais Brasileiros de Derminatologia*, [online], 91(3), pp. 326-330, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4938277/pdf/abd-91-03-0326.pdf [accessed: 5th April 2018].
Milford Care Centre. (2015). *History of Milford.* [online], available: https://www.milfordcarecentre.ie/about-us/history-of-milford/ [accessed: 24th may 2018].

Mills, J., Wand, T. & Fraser, J. (2017) Palliative Care Professionals' Care and Compassion for Self and Others: A Narrative review. *International Journal of Palliative Nursing,* [online], 23(5), pp. 219-229, available: https://eprints.qut.edu.au/107928/2/107928.pdf [accessed: 2nd October 2018].

Milnes, S., Corke, C., Orford, N., Bailey, M., Savulescu, J. & Wilkinson, D. (2017). Patient Values Informing Medical Treatment: A Pilot Community and Advance Care Planning Survey. *BMJ Supportive & Palliative Care*, [online], 0, pp.1–6, available: https://spcare.bmj.com/content/bmjspcare/early/2017/08/08/bmjspcare-2016-001177.full.pdf [accessed: 25th July 2018].

Milnes, S., Corke, C., Orford, N., Bailey, M., Savulescu, J. & Wilkinson, D. (2017). Patient Values Informing Medical Treatment: A Pilot Community and Advance Care Planning Survey. *BMJ Supportive & Palliative Care*, [online], 0, pp.1–6, available: https://spcare.bmj.com/content/bmjspcare/early/2017/08/08/bmjspcare-2016-001177.full.pdf [accessed: 25th July 2018].

Mistry, B., Bainbridge, D., Toyofuku, S. & Seow, H. (2015). What Matters Most for End-of-Life Care? Perspectives from Community-Based Palliative Care Providers and Administrators. *BMJ Open,* [online], 5, pp. 1-8, available: https://bmjopen.bmj.com/content/bmjopen/5/6/e007492.full.pdf [accessed: 10th January 2018].

Mohaian, H. (2017). Two Criteria for Good Measurements in Research: Validity and Reliability. *Annals of Spiru Haret University,* [online], 17(3), pp. 58-82, available: https://mpra.ub.uni-muenchen.de/83458/1/MPRA_paper_83458.pdf [accessed: 10th October 2018].

Moon, M. (2018). Triangulation: A Method to Increase Validity, Reliability, and Legitimation in Clinical Research. *Journal of Emergency Nursing*, [online], 45(1), pp. 103-105, available: https://jenonline.org/article/S0099-1767(18)30588-9/fulltext [accessed: 14th November 2018].

Morris, A. (2015). *Practical Introduction to In-depth Interviewing*. [online], available: https://books.google.ie/books?id=JN9tBgAAQBAJ&printsec=frontcover&dq=what+are+in-depth,+semi-structured+interviews+in+research&hl=en&sa=X&ved=0ahUKEwiN46fdqJziAhWluXEKHcY_C6cQ6AEIQjAE#v=onepage&q=semi-structured%20interviews%20in%20research&f=false [accessed: 12th October 2018].

Mosoiu, D., Dumitrescu, M. & Connor, S. (2014). Developing a Costing Framework for Palliative Care Services. Journal of Pain and Symptom Management, [online], 48(4), pp. 719-723, available: https://www.jpsmjournal.com/article/S0885-3924(14)00154-7/pdf [accessed: 9th May 2019].

Murphy. L. (2015). *Advance Healthcare Directives: Friend or Foe?* Unpublished Ph.D.) thesis, Royal College of Surgeons in Ireland, Dublin.
Myers, P. & Salts, N. (2013). *Becoming an Addictions Counselor: A Comprehensive Text.* [online], available: https://books.google.ie/books?id=ZWuhGCgZf4QC&pg=PA319&dq=Taleff+critical+thinking&hl=en&sa=X&ved=0ahUKEwii2u_Is43jAhVRSsAKHenNA1cQ6AEINjAC#v=onepage&q=Taleff%20critical%20thinking&f=false [accessed: 6th May 2018].

Nair-Collins, M. (2015). Laying Futility to Rest. *Journal of Medicine and Philosophy*, [online], 40, pp. 554–583, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4562372/ [accessed: 21st September 2018].

Nasrullah, G. (2017). *Caregivers' Experiences of Unmet Needs During Palliative Care.* [online], available: https://pdfs.semanticscholar.org/cba6/3547f6165ca686b50f5219c35cd60cf2395b.pdf [accessed: 1st of October 2018].

NatGen Social Research. (2013). *British Social Attitudes: Dying Discussing and planning for end of life*. [online], available: http://www.bsa.natcen.ac.uk/media/38850/bsa_30_dying.pdf [accessed: 8th September 2018].

National Cancer Institute US. (2017). *Grief, Bereavement, and Coping with Loss: Health Professional Version.* [online], available: https://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0032576/ [accessed: 1st October 2018].

National Centre for the Protection of Older People. (2010). *Abuse and Neglect of Older People in Ireland; REPORT ON THE NATIONAL STUDY OF ELDER ABUSE AND NEGLECT.* [online], available: http://www.ncpop.ie/userfiles/file/ncpop%20reports/Study%203%20Prevalence.pdf [accessed: 22nd March 2019].

National Clinical Programme for Palliative Care. (2019). *Adult Palliative Care Services Model of Care for Ireland*. [online], available: https://rcpi-live-cdn.s3.amazonaws.com/wp-content/uploads/2019/04/NCP-Palliative-Care-Model-of-Care-24.04.0219.pdf [accessed: 2nd May 2019].

Nici, L. & ZuWallack, R. (2014). *Clinics Review Articles Pulmonary Rehabilitation: Role & Advances.* [online], available: https://books.google.ie/books?id=uXXAAwAAQBAJ&pg=PA415&dq=end+of+life+care+and+the+importance+of+planning&hl=en&sa=X&ved=0ahUKEwjOj7DWnLXcAhWTT8AKHU22C9EQ6AEINjAD#v=onepage&q=end%20of%20life%20care%20and%20the%20importance%20of%20planning&f=false [accessed: 23rd July 2018].

Nicol, J. & Nyatanga, B. (2017). *Palliative and End of Life Care in Nursing. 2nd ed.* Sage Publications: London.

Nielsen, K. & Glasdam, S. (2013). Professional Caregivers' Work with the Dying in Nursing Homes – a Foucault-Inspired Analysis of Discourses in the Last Decade in a Danish Context. *Scandinavian Journal of Caring Sciences,* [online], 27, pp. 983–993, available; http://content.ebscohost.com/ContentServer.asp?T=P&P=AN&K=91615329&S=R&D=a9h&EbscoContent=dGJyMNXb4kSeprY4zOX0OLCmr0%2BeprdSr6e4SK6WxWXS&ContentCustomer=dGJyMPGqsEmyqrRKuePfgeyx43zx [accessed: 8th November 2017].

North West Hospice. (2017). *Out History*. [online], available: https://northwesthospice.ie/our-history/ [accessed: 24th May 2018].
Nursing Homes Ireland. (2015). *Drogheda Memorial Hospital*. [online], available: http://www.irishnursinghomes.eu/INH/HSEDublinMidLeinster/Kildare/2275 [accessed: 24th May 2018].

Nwodoh, C., Okoronkwo, I., Nwaneri, A., Ndubuisi, I., Ani, G. & Dyages, E. (2018). Terminally Ill Patients' Perception on Healthcare Providers' Communication of Prognostic Information: A Qualitative Study from Nigeria, West Africa. *Cogent Medicine,* [online], 5, pp. 1-10, available: https://www.tandfonline.com/doi/pdf/10.1080/2331205X.2018.1457232?needAccess=true [accessed: 6th August 2018].

O'Callaghan, S. (2014). Social Workers Coming to Voice within Multi-Disciplinary Palliative Care Settings: An Exploration of Practitioners' Views and Experiences. *Critical Social Thinking,* [online], 6, pp. 204-224, available: https://www.ucc.ie/en/media/academic/appliedsocialstudies/cstpdfs/vol6/SineadOCallaghan.pdf [accessed: 3rd January 2019].

O'Mahaony, S. (2017). *The Way We Die Now*. UK: Head of Zeus.

O'Shea, B., Martin, D., Brennan, B., Bailey, O., McElwee, O., O'Leary, F., Darker, C. (2014). *Are We Ready to Think Ahead Study in Ireland?* [online], available*:*http://www.lenus.ie/hse/bitstream/10147/316737/1/Article7542.pdf [accessed: 2nd August 2018].

O’Sullivan, D. (2019). *Spotlight: Mind the care gap Exposing the health system’s vulnerability to the gap between family care provision and anticipated demand.* [online], available: https://data.oireachtas.ie/ie/oireachtas/libraryResearch/2019/2019-04-02_spotlight-mind-the-care-gap-exposing-the-health-system-s-vulnerability-to-the-gap-between-family-care-provision-and-anticipated-demand_en.pdf [accessed: 5th September 2019].

Odhiambo, J. & Rutto, M. (2018). *Challenges That Nurses Face in Offering Effective Palliative Care for the Elderly: A Literature Review.* Unpublished, (Ph.D.) thesis, Lahti University of Applied Sciences, Finland.

O'Shea, E., Murphy, K., Larkin, P., Payne, S., Froggatt, K., Casey, D., Ni Leime, A., Keys, M. (2008). *End-of-life care for older people in acute and long-stay care settings in Ireland.* [online], available: https://www.lenus.ie/bitstream/handle/10147/324825/103EOLCareReport.pdf?sequence=1&isAllowed=y [accessed:12th October 2018].

Office of the Ombudsman. (2018). *A Good Death: Progress Report*. [online], available: https://www.ombudsman.ie/publications/reports/a-good-death-progress-rep/GoodDeathProgressWeb.pdf [accessed: 20th December 2018].

Office of the Ombudsman. (2018). *Managing Complaints*. [online], available: https://www.ombudsman.ie/publications/reports/a-good-death-progress-rep/ [accessed: 2nd January 2019].

Otani, H., Yoshida, S., Morita,T., Aoyama, Kizawa, Y., Shima, Y., Tsuneto, S. & Miyashita, M. (2017). Meaningful Communication Before Death, but Not Present at the Time of Death Itself, Is Associated with Better Outcomes on Measures of Depression and Complicated Grief Among Bereaved Family Members of Cancer Patients. *Journal of Pain and Symptom Management*, [online], 54(3), pp. 273-279, available: https://ac-els-cdn-com.ezproxy.itcarlow.ie/S0885392417302737/1-s2.0-S0885392417302737-main.pdf?_tid=5f037044-0e78-44e5-b748-31aea1e267b6&acdnat=1529956927_fe4163c206c313ba2751c946f943751a [accessed: 25th June 2018].

Our Lady’s Hospice and Care Services. (2018). *Blackrock*. [online], available: http://olh.ie/our-services/palliative-care/blackrock/ [accessed: 1st June 2018].

Palliative Care Australia. (2014). *2014-15 Pre-Budget Submission.* [online], available: http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2015/08/January-2014-PCA-2014-15-Pre-Budget-Submission.pdf [accessed: 8th September 2018].

Palliative Care Australia. (2018). *Media Release Sunday 20 May 2018 National survey shows majority of Australians not prepared for end of life*. [online], available: http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/05/Media-Release-National-survey-shows-majority-of-Australians-not-prepared-for-end-of-life.pdf [accessed: 8th September 2018].

Pallimed. (2014). *Lizzy Miles: We Don’t Know Death: 7 Assumptions We Make about Dying.* [online], available: https://www.pallimed.org/2014/08/we-dont-know-death-7-assumptions-we.html [accessed: 20th January 2019].

Palinkas, L., Horwitz, S, Green, C., Wisdom, J., Duan, N. & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Policy Ment Health,* [online], 42(5), pp. 533–544, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4012002/pdf/nihms-538401.pdf [accessed: 13th October 2018].

Park, S., Kim, Y., Kim, S., Choi, J., Lim, H., Choi, Y., Hong, Y., Kim, S., Heo, D., Kang, K., Jeong, H., Lee, C., Moon, D., Choi, J., Kong, I. & Yun, Y. (2010). Impact of Caregiver's Unmet Needs for Supportive Care on Quality of Terminal Cancer Care Delivered and Caregiver's Workforce Performance. *Supportive Care in Cancer*, [online], 18(6), pp. 699-706, available: https://link.springer.com/article/10.1007%2Fs00520-009-0668-5 [accessed: 5th October 2018].

Pathak, V., Jena, B. & Kalra, S. (2013). Qualitative Research. *Perspectives in Clinical Research,* [online], 4(3), pp. 192, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3757586/?report=classic [accessed: 13th May 2019].

Pendleton, H. & Krohon, W. (2018). *Pedretti's Occupational Therapy: Practice Skills for Physical Dysfunction.* [online], available: https://books.google.ie/books?id=CoFUDgAAQBAJ&pg=PA1196&dq=people+with+chronic+and+terminal+illness+are+living+longer&hl=en&sa=X&ved=0ahUKEwi6m8X6h5nYAhXhDMAKHZEsBXwQ6AEIMjAC#v=onepage&q=people%20with%20chronic%20and%20terminal%20illness%20are%20living%20longer&f=false [accessed: 19th December 2017].

Pet Sitters Ireland. (2018). *2018 Irish Pet Owners Survey Results [Infographic].* [online], available: https://petsittersireland.com/pet-survey/ [accessed: 18th September 2018].

Pharr, J., Francis, C., Terry, C. & Clark, M. (2014). Culture, Caregiving, and Health: Exploring the Influence of Culture on Family Caregiver Experiences. *ISRN Public Health,* [online], 0, pp.1-9, available: https://www.hindawi.com/journals/isrn/2014/689826/ [accessed: 1st October 2018].

Planing, P. (2013). *Innovation Acceptance: The Case of Advanced Driver-Assisted Systems.* [online], available: https://books.google.ie/books?id=ETTABAAAQBAJ&pg=PA87&lpg=PA87&dq=triangulation+is+the+mixing+of+methods+so+that+diverse+viewpoints&source=bl&ots=fuW5rXbsaw&sig=rYAzgM2F53trh5wlumkgV2fmNlc&hl=en&sa=X&ved=0ahUKEwi9lcLm5qvaAhVIIlAKHf0wAa0Q6AEIggEwCA#v=onepage&q=triangulation%20is%20the%20mixing%20of%20methods%20so%20that%20diverse%20viewpoints&f=false [accessed: 9th April 2018].

Pollock, K. (2015). Is Home Always the Best and Preferred Place of Death? The Current Orthodoxy is That Home is the Best and Preferred Place of Death for Most People. *BMJ,* [online], 351, pp. 1-3, available: http://eprints.nottingham.ac.uk/34320/1/Pollock%20Is%20home%20always%20best%20BMJ%202015.pdf [accessed: 7th September 2018].

Prince-Paul, M. & DiFranco. (2016). Upstreaming and Normalizing Advance Care Planning Conversations—A Public Health Approach. *Behavioural Sciences,* [online], 7(18), pp.1-7, available: file:///C:/Users/c00186113/Downloads/behavsci-07-00018.pdf [accessed: 25th July 2018].

Public Health England. (2016). *Public Perceptions and Experiences of Community-Based End of Life Care Initiatives: A Qualitative Research Report*. [online], available; https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/569711/Public_Perceptions_of_Community_Based_End_of_Life_Care_Initiatives_Resea....pdf [accessed: 29th June 2018].

Punjani, N. (2013). Truth-Telling to Terminally Ill Patients: To Tell or Not to Tell. *Journal of Clinical Research Bioethics,* [online], 4(4), pp. 1-2, available: https://www.researchgate.net/profile/Neelam_Punjani/publication/276197697_Truth_Telling_to_Terminally_Ill_Patients_To_Tell_or_not_to_Tell/links/5a6a307b0f7e9b1c12d17e62/Truth-Telling-to-Terminally-Ill-Patients-To-Tell-or-not-to-Tell.pdf [16th October 2018].

Quinlan, C. & O’Neill, C. (2009). *Practitioners’ Perspectives on Patient Autonomy at End of Life.* [online], available: http://hospicefoundation.ie/wp-content/uploads/2013/06/Practitioners-Perspectives-on-Patient-Autonomy-at-End-of-Life.-Quinlan-O-Neill-2009.pdf [accessed: 8th November 2017].

Quinlan, C. & O’Neill, C. (2013). Practitioners’ Perspectives on Patient Autonomy at End of Life. [online], available: http://hospicefoundation.ie/wp-content/uploads/2013/06/Practitioners-Perspectives-on-Patient-Autonomy-at-End-of-Life.-Quinlan-O-Neill-2009.pdf [accessed: 8th November 2017].

Quinlan, C. (2009). Media Discourses on Autonomy in Dying and Death. *Irish Communication Review,* [online], 11(1), pp. 37-49, available: https://arrow.dit.ie/cgi/viewcontent.cgi?article=1102&context=icr [accessed: 13th July 2018].

Quinn, D., Henry, A., O’ Neil, E., Duggan, A., Cawley, J., Dwane, A., O’Sullivan, M. & Griffin, L. (2017). *The Assisted Decision-Making (Capacity) Act 2015: Interpretation and Practical Application.* [online], available: https://www.ul.ie/engage/sites/default/files/2017,%20No%2014%20The%20Assisted%20Decision-making%20(Capacity)%20Act%202015_Interpretation%20and%20Practical%20Application.pdf [accessed: 23rd October 2018].

Radio Telefis Éireann. (2018). *Cork, Galway & Dublin Listed in World’s Top 10 Friendliest Cities*. [online], available: https://www.rte.ie/lifestyle/travel/2018/0814/984979-cork-galway-dublin-listed-in-worlds-top-10-friendliest-cities/ [accessed: 8th February 2019].

Rainford, S., MacLeod, R., Glasgow, N., Wilson, D., Philips, C. & Wiles, B. (2016). Rural residents’ perspectives on the rural ‘good death’: A Scoping Review. *Health & Social Care in the Community,* [online], pp.1-22, available: file:///C:/Users/c00186113/Downloads/Rainsford_et_al-2018-Health_%2526_Social_Care_in_the_Community.pdf [accessed: 12th December 2017].

Reader, T. & Gillespie, A. (2013). Patient Neglect in Healthcare Institutions: A Systematic Review and Conceptual Model. *BMC Health Services Research,* [online], 13(156), pp. 1-15, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3660245/pdf/1472-6963-13-156.pdf [accessed: 23rd October 2018].

Reidy L., Bailey, ME, and Doody, O. (2018). Family caregivers' perceptions of an Irish palliative daycare unit: A qualitative descriptive study. *Nursing and Palliative Care,* [online], 3(2), pp: 1-7, available: https://www.oatext.com/pdf/NPC-3-182.pdf [accessed: 23rd October 2017].

Research Methodology. (2019). *Research Philosophy.* [online], available: https://research-methodology.net/research-philosophy/ [accessed: 12th October 2018].

Rider, H. (2016). *Case Study Research: Approaches, Methods, Contributions to Theory.* [online], available: https://books.google.ie/books?id=S5Z-DQAAQBAJ&pg=PA59&dq=philosophical+orientation+in+research&hl=en&sa=X&ved=0ahUKEwjIgqGww-TWAhUMJ1AKHeZ-AxIQ6AEITzAG#v=onepage&q=philosophical%20orientation%20in%20research&f=false [accessed: 9th October 2017].

Ritchies, J., Lewis, J., Nicholls, C., Ormston, R. (2013). *Qualitative Research Practice: A Guide for Social Science Students & Researchers.* [online] available: https://books.google.ie/books?id=EQSIAwAAQBAJ&printsec=frontcover&dq=qualitative+research+methods+in+social+care+research+design&hl=en&sa=X&ved=0ahUKEwj4__vusNHQAhVEIMAKHYHnB1QQ6AEIGjAA#v=onepage&q=qualitative%20research%20methods%20in%20social%20care%20research%20design&f=false [accessed: 29th November 2016].

Rodríguez-Prat, A., Monforte-Royo, C., Porta-Sales. J., Escribano, X. & Balaguer, A. (2016). Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography. *PLoS ONE* [online], 11(3), pp. 1-18, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4806874/pdf/pone.0151435.pdf [accessed: 14th February 2019].

Rome, R., Luminais, H., Bourgeois, D. & Blais, C. (2011). The Role of Palliative Care at the End of Life. *The Ochsner Journal,* [online], 11, pp. 348–352, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3241069/pdf/i1524-5012-11-4-348.pdf [accessed: 18th September 2018].

Rudbruch, L., Leget, C., Müller-Busch, C. Ellershaw, J., de Conno, F. & Vanden Berghe, P. (2016). Euthanasia and Physician-Assisted Suicide: A White Paper from the European. *Palliative Medicine* [online] 30 (2), pp. 104-116 available: http://0-web.a.ebscohost.com.www.library.itcarlow.ie/ehost/pdfviewer/pdfviewer?sid=2af12616-485f-4fe7-b91f-69a5480240da%40sessionmgr4005&vid=1&hid=4109 [accessed: 10th March 2016].

Ruijs, C., Van der Wal, G., Kerkhof, A. & Onwuteaka-Philipsen, B. (2014). Unbearable Suffering and Requests for Euthanasia Prospectively Studied in End-of-Life Cancer Patients in Primary Care. *BMC Palliative Care*, [online], 13(62), pp. 1-11, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4292985/pdf/12904_2014_Article_238.pdf [accessed: 9th January 2019].

Rwegoshora, H. (2014). *A Guide to Social Science Research*. [online], available: https://books.google.ie/books?id=hj8iDAAAQBAJ&pg=PA173&dq=semi-structured+interviews+allow+for+a+relaxed+atmosphere&hl=en&sa=X&ved=0ahUKEwiPtLGZi8rSAhUlBMAKHfvtAR8Q6AEINDAF#v=onepage&q=semi-structured%20interviews%20allow%20for%20a%20relaxed%20atmosphere&f=false [accessed: 1st December 2016].

Salehe, B. & Njine, D. (2016). *Good quality interaction between the registered nurse and the patient*. Unpublished (Ph.D.) thesis, Seinäjöki University of Applied Sciences, West Finland.

Sallnow, L., Kumar, S. & Kellehear, A. (2012). *International Perspectives on Public Health & Palliative Care.* [online], available: https://books.google.ie/books?id=cl-pAgAAQBAJ&pg=PA114&dq=the+importance+of+gaining++public+opinion+on+death+and+dying+matters&hl=en&sa=X&ved=0ahUKEwih_qmUu7XcAhWFTcAKHVG6BRcQ6AEIJzAA#v=onepage&q=the%20importance%20of%20gaining%20%20public%20opinion%20on%20death%20and%20dying%20matters&f=false [accessed: 23rd July 2018].

Samerchua, W., P. Nantachaipan, P. & Sittisombut, S. (2016). Good Death as Perceived by Cancer Survivors. *International Journal of Evidence-Based Healthcare*, [online], 14, p. S27, available: https://journals.lww.com/ijebh/fulltext/2016/12001/Good_Death_as_Perceived_by_Cancer_Survivors.55.aspx [accessed: 27th September 2018].

Saunders, C. (2006). *Cicely Saunders selected Writings 1958-2004.* [online], available: https://books.google.ie/books?id=_synvZSMXLUC&pg=PR23&dq=You+matter+because+you+are+you,+and+you+matter+to+the+last+moment+of+your+life&hl=en&sa=X&ved=0ahUKEwi_r9mRzK3iAhUDSxUIHZghDIkQ6AEINjAC#v=onepage&q=You%20matter%20because%20you%20are%20you%2C%20and%20you%20matter%20to%20the%20last%20moment%20of%20your%20life&f=false [accessed: 3rd October 2017].

Scarre, G. (2012). Can There Ever Be A ‘Good Death’? *Journal of Evaluation in Clinical Practice*, [online], 18, pp. 1082-1086, available: http://eds.a.ebscohost.com/eds/pdfviewer/pdfviewer?vid=12&sid=1b7939c2-24e0-4866-a883-76bd2b4eabed%40sessionmgr4008 [accessed: 15th November 2017].

Schooneneboom, J. & Johnson, J. (2017). How to Construct a Mixed Methods Research Design? *Köln Z Soziol*, [online], 69(2), pp. 107–131, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5602001/pdf/11577_2017_Article_454.pdf [accessed: 28th March 2018].

Scottish Government. (2010). *Short Life Working Group 7. Final Report: Addressing palliative and end of life care from a public health and health promotion perspective: facilitating wider discussion of death, dying and bereavement across society*. [online], available: https://www.palliativecarescotland.org.uk/content/publications/SLWG7-FINAL-REPORT.pdf [accessed: 30th July 2018].

Schreibeis-Baum, H., Xenakis, L., Chen, E., Hanson, M., Ahluwalia, S., Ryan, G. and Karl A. Lorenz, K. (2016). A Qualitative Inquiry on Palliative and End-of-Life Care Policy Reform. *Journal of Palliative Medicine,* [online], 19(4), pp. 400-407, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4827304/pdf/jpm.2015.0296.pdf [accessed: 22nd March 2019].

Semino, E., Zsófia Demjén, Z. & Koller, V. (2014). 'Good' and 'bad' deaths: narratives and professional identities in interviews with hospice managers. *Discourse Studies,*[online], 16(5) pp. 667–685, available: http://oro.open.ac.uk/43341/1/Semino%20Demjen%20%26%20Koller%20%282014%29%20-%20Good%20and%20Bad%20deaths.pdf [accessed:3rd March 2018].

Sharf, R. (2016). Theories of Psychotherapy & Counselling: Concepts and Cases. 6th ed. [online], available: https://books.google.ie/books?id=M5-aBAAAQBAJ&pg=PA164&dq=S%C3%B8ren+Kierkegaard+(1813-1855)+concept+of+existential&hl=en&sa=X&ved=0ahUKEwjq9qfbqpHjAhV9QUEAHfVLDyoQ6AEIKjAA#v=onepage&q=S%C3%B8ren%20Kierkegaard%20(1813-1855)%20concept%20of%20existential&f=false [accessed: 12th September 2017].

Sheedy, M. (2013). *Core Themes in Social Work: Power, Poverty, Politics and Values.* [online], available: https://books.google.ie/books?id=_0FFBgAAQBAJ&pg=PA40&dq=Foucault+power+imbalance+between+service+users+and+organisations&hl=en&sa=X&ved=0ahUKEwje9460laveAhVNKlAKHSJHDxUQ6AEINTAC#v=onepage&q=Foucault%20power%20imbalance%20between%20service%20users%20and%20organisations&f=false [accessed: 27th October 2018].

Shin, D., Choi, J., Miyashita, M., Choi, J., Kang, J., Baik, Y., Choi, J., Son, Y. & Lee, H. (2011). Measuring Comprehensive Outcomes in Palliative Care: Validation of the Korean Version of the Good Death Inventory. *Journal of Pain & Symptom Management,* [online], 42(4), pp. 632-642, available: https://www.jpsmjournal.com/article/S0885-3924(11)00113-8/pdf [accessed: 13th November 2018].

Shosha, G. (2012). Employment of Colaizzi's Strategy in Descriptive Phenomenology: A Reflection of a Researcher. *European Scientific Journal*, [online], 8(27), pp. 31-43, available: http://www.eujournal.org/index.php/esj/article/viewFile/588/657 [accessed: 15th October 2017].

Singh, K. (2013). Fundamental and Holistic Aspects of Palliative Care. *GM Peer-Reviewed Medicine,* [online], 11, available: https://www.gmjournal.co.uk/fundamental-and-holistic-aspects-of-palliative-care [accessed: 20th October 2018].

Sivell, S., Prout, H., Hopewell-Kelly, N., Baillie, J., Byrne, A., Edwards, M., Harrop, E. Noble, S., Sampson, C. & Nelson, A. (2019). Considerations and recommendations for conducting qualitative research interviews with palliative and end-of-life care patients in the home setting: a consensus paper. *BMJ Supportive & Palliative Care,* [online], 9(14), pp. 1-7. available: https://spcare.bmj.com/content/bmjspcare/9/1/e14.full.pdf [accessed: 9th May 2019].

Skulason, B., Hauksdottir, A., Ahcic, K. & Helgason, A. (2014). Death Talk: Gender Differences in Talking about One's Own Impending Death. *BMC Palliative Care,* [online], 13(8), pp. 1-11, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3975272/pdf/1472-684X-13-8.pdf [accessed: 27th January 2019].

Smebye, K. & Kirkevold, M. (2013). The influence of relationships on personhood in dementia care: a qualitative, hermeneutic study. *BMC Nursing,* [online], 12(29), pp. 1-13, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3878215/pdf/1472-6955-12-29.pdf [accessed: 14th February 2019].

Sridhar, P., Renuka, P. K., & Bonanthaya, R. (2012). End of Life and Life After Death - Issues to be Addressed. *Indian journal of palliative care*, [online],18(3), 226-9, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3573479/?report=reader [accessed: 5th February 2019].

St. Francis Hospice. (2018). *Our History.*[online], available: https://www.sfh.ie/our-history [accessed: 24th May 2018].
Taylor, M. (2008). *Patient Preferences - A Process Based Approach*. [online], available: http://www.lawreform.ie/_fileupload/Speeches/July%20Uploads/08/Mervyn_Taylor.pdf [accessed: 10th October 2018].

Taylor, R. (2017). *Kielhofener's Research in Occupational Therapy: Methods of Research Inquiry for Enhancing Practice.* [online] available: https://books.google.ie/books?id=BkvoDQAAQBAJ&pg=PA25&dq=philosophical+orientation+in+research&hl=en&sa=X&ved=0ahUKEwiB5NvU7OPWAhVDa1AKHb1FBxIQ6AEIRzAF#v=onepage&q=philosophical%20orientation%20in%20research&f=false [accessed: 9th October 2017].

Tenzek, K. & Depner, R. (2017). Still Searching: A Meta-Synthesis of a Good Death from the Bereaved Family Member Perspective. *Behavioural Science*, [online], 7, pp. 2-18, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5485455/pdf/behavsci-07-00025.pdf [accessed: 9th November 2017].

Tomer, A., Eliason, G. & Wong, P. (2007). *Existential and Spiritual Issues in Death Attitudes.* [online], available: https://books.google.ie/books?id=7BY4UtRFcE4C&printsec=frontcover&dq=Existential+and+spiritual+issues+in+death+attitudes.&hl=en&sa=X&ved=0ahUKEwim5rvG8tXkAhXmSxUIHSXWBQkQ6AEIKjAA#v=onepage&q=regret&f=false [accessed: 13th August 2017].

The Barre Centre Buddhist Studies (2017). Death Contemplation: Interview with Bhikkhu Anālayo. [online], available: https://www.buddhistinquiry.org/article/death-contemplation/ [accessed: 7th February 2019].

The Choice in End of Life Care Programme Board. (2015). *What's important to me. A Review of Choice in End of Life Care*. [online], available: http://www.ncpc.org.uk/sites/default/files/CHOICE%20REVIEW_FINAL%20for%20web.pdf [accessed: 12th July 2018].

The Department of Health. (2017). *Working Together for Health*. [online], available: https://health.gov.ie/wp-content/uploads/2017/11/13_11_2017_WFP_Framework_FINAL.pdf [accessed: 9th of December 2018].

The Department of Health. (2019). *Sláintecare Action Plan 2019.* [online], available: https://health.gov.ie/wp-content/uploads/2019/03/Sl%C3%A1intecare-Action-Plan-2019.pdf [accessed: 20th April 2019].

The Independent. (2016). *Ireland's largest pet ownership study: here's all the facts you need to know.* [online], available: https://www.independent.ie/life/family/irelands-largest-pet-ownership-study-heres-all-the-facts-you-need-to-know-34505427.html [accessed: 18th September 2018].

The Institute of Medicine. (2014). *Dying in America: Improving Quality & Honouring Individual Preferences Near the End of Life.* [online], available: https://www.ncbi.nlm.nih.gov/books/NBK285681/pdf/Bookshelf_NBK285681.pdf [accessed: 23rd July 2018].

The Irish Independent. (2018). *All Soul's Day: 'Remembering the dead is a true celebration of life'.* [online] available: https://www.independent.ie/life/all-souls-day-remembering-the-dead-is-a-true-celebration-of-life-37485142.html [accessed: 10th February 2019].

The National Council for Palliative Care. (2012). *Dying Matters: Progress with The Dying Matters Coalition.* [online], available: https://www.dyingmatters.org/sites/default/files/user/Standard%20DM%20powerpoint%20presentation%20August%202012-PDF.pdf [accessed: 6th January 2018]

The National Council for Palliative Care. (2016). *Dying Matters- Public Opinion on Death & Dying.* [online], available: https://www.dyingmatters.org/sites/default/files/files/NCPC_Public%20polling%2016_Headline%20findings_1904.pdf [accessed:10th January 2019].

The National Council of the Forum on End of Life. (2012). *From the Public Consultation Process Conducted by the Forum in 2009.* [online], available: http://hospicefoundation.ie/wp-content/uploads/2012/07/Issues-emerging-from-Forum-consultation.pdf [accessed: 27th August 2018].

The Palliative Hub. (2019). *Palliative Care Policy - Key Documents*. [online], available: http://www.thepalliativehub.com/what-palliative-care/palliative-care-policy-key-documents [accessed: 6th January 2019].

The Victorian Quality Council. (2008). *A Guide to Using Data for Health Care Quality Improvement.* [online], available: https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0006/273336/vqc-guide-to-using-data.pdf [accessed: 3rd August 2018].

The World Health Organisation. (2018). *Working paper on Gender & Equity in the Health and Social Care Workforce Consultative Draft Report*. [online], available: https://www.who.int/hrh/news/2018/GEHworking-paper-ZeroDraft.pdf [accessed: 8th December 2018].

Tim Sharp, T., Malyon, A. & Barclay, S. (2018). GPs' Perceptions of Advance Care Planning with Frail and Older People: A Qualitative Study. *British Journal of General Practice*, [online], o, pp. E44-E53, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5737319/pdf/bjgpjan-2018-68-666-e44-oa.pdf [accessed: 8th October 2018].

Tomlinson, J. (2015). Using Clinical Supervision to Improve the Quality and Safety of Patient Care: A Response to Berwick and Francis. *BMC Medical Education*, [online], 15(103), pp1-8, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4464130/pdf/12909_2015_Article_324.pdf [accessed:21st October 2018].

Trice, E. & Prigerson, H. (2009). Communication in End-Stage Cancer: Review of the Literature and Future Research. *Journal of Health Communication*, [online], 14(01), pp. 95-108, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3779876/pdf/nihms-515844.pdf [accessed: 1st July 2018].

Tuggey, E. & Lewin, W. (2014). A multidisciplinary approach in providing transitional care for patients with advanced cancer. *Annals of Palliative Medicine*, [online], 3(3), pp:139-143, available: http://apm.amegroups.com/article/view/4068/4968 [accessed: 3rd January 2018].

TUSLA Child and Family Agency. (2019). *TUSLA Business Plan-2019.* [online], available: https://www.tusla.ie/uploads/content/Tusla-Business-Plan-2019.pdf [accessed: 9th May 2019].

University of Glasgow. (2014). *Open and honest conversations about death and dying – by Richard Meade.* [online], available: http://endoflifestudies.academicblogs.co.uk/open-and-honest-conversations-about-death-and-dying-by-richard-meade/ [accessed: 10th November 2017].

Vasileiou, K., Barnett, J., Susan Thorpe, S. and Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology* [online], 18(148), pp. 2-18, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6249736/ [accessed: 9th May 2019].

Vlug, M., Pasman, R., Gennip, I., Willems, D. & Philipsen, B. (2013). Nursing Home Staff's Views on Residents' Dignity: A Qualitative Interview Study. *BMC Health Services Research* [online], 13 (353), pp.1-9 available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3850947/pdf/1472-6963-13-353.pdf [accessed: 7th November 2017].

Vrinten, C. & Wardle, J. (2016). Is cancer a good way to die? A population-based survey among middle-aged and older adults in the United Kingdom. *European Journal of Cancer,* [online], 56, pp. 172-178, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4788505/ [accessed: 20th December 2017].

Wachholtz, A., Fitch, C., Makwoski, S. & Jija, J. (2016). A Comprehensive Approach to the Patient at End of Life: Assessment of Multidimensional Suffering. *South Medical Journal,* [online], 109(4), pp. 200-206, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4824542/pdf/nihms-761081.pdf [accessed: 27th November 2017].

Wallmann, H. & Hoover, D. (2012). Research and Critical Thinking: An Important Link for Exercise Science Students Transitioning to Physical Therapy. *International Journal of Exercise Science,* [online], 5(2), pp. 93-96, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4738974/pdf/ijes_05_02_93.pdf [accessed: 9th May 2019].

Weafer (2014). *Irish Attitudes to Death, Dying & Bereavement*. [online], available: http://hospicefoundation.ie/wp-content/uploads/2014/12/Weafer-J-2014-Irish-attidudes-to-death-dying-bereavement-2004-2014.pdf [accessed: 20th September 2017].

Weafer, J. (2004). *A Nationwide Survey of Public Attitudes and Experiences Regarding Death and Dying.* [online], available: https://hospicefoundation.ie/wp-content/uploads/2012/04/Weafer-et-al-2004-A-nationwide-survey-of-public-attitudes-and-experiences-regarding-death-and-dying.pdf [accessed: October 18th 2017].

Weafer, J., Murphy, S. & Foley, S. (2016*). A Perspective on Advance Planning for end-of-life: An exploration of contemporary developments concerning the concept and practice of Advance Planning, Advance Care Planning and Advance Healthcare Directives.* [online], available: http://hospicefoundation.ie/wp-content/uploads/2016/06/IHF-Perspectives-4-A-Perspective-on-Advance-Planning-for-end-of-life.pdf [accessed: the 21st August 2018].

White, D., Ernecoff, N., J. Billings, A. & Arnold, R. (2013). Is Dying a Sign of Poor-Quality End-of-Life Care? Current Controversies in Critical Care. *American Journal of Critical Care,* [online], 22(3), pp. 263-265, available: http://ajcc.aacnjournals.org/content/22/3/263.full.pdf+html [accessed: 10th October 2018].

Whittington, F. (2011). Denying and Defying Death: The Culture of Dying in 21st Century America. *The Gerontologist,* [online], 51(4), pp. 571-579, available: https://academic.oup.com/gerontologist/article/51/4/571/599597 [accessed: 31st July 2018].

Wilder, HW., Parker Oliver, D., G Demiris, G. & Washington, K. (2008). Informal Hospice Caregiving: The Toll on Quality of Life. *Journal of Social Work End Life Palliative Care,* [online], 4(4), pp.312–332 available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2749275/pdf/nihms107358.pdf [accessed: 28th September 2018].

Williamson, J., Charlotte Skinner, C. & Hocken, D. (2011). Death and illness in the media. *International Journal of Clinical Practice*, [online], 65 (5), pp. 1-20 , available: https://hal.archives-ouvertes.fr/hal-00631700/document [accessed: December 2018].

Willmott, L., White, B., Gallois, C., Parker, M., Graves, N., Winch, S., Callaway, L., Shepherd, N. & Close, E. (2016). Reasons Doctors Provide Futile Treatment at the End of Life: A Qualitative Study. *Journal of Medical Ethics*, [online], 42, pp. 496-503, available: http://www.hsraanz.org/wp-content/uploads/Willmott-et-al-2016.pdf [accessed: 21st September 2018].

Woodby, L., Williams, B., Wittich, A. & Burgio. K. (2011). Expanding the Notion of Researcher Distress: The Cumulative Effects of Coding. *Qualitative Health Research*, [online], 21(6), pp. 830–838, available: http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.900.9611&rep=rep1&type=pdf [accessed: 3rd January 2019].

Woodman, C., Baillie, J. and Sivell., S. (2016). The preferences and perspectives of family caregivers towards place of care for their relatives at the end-of-life. A systematic review and thematic synthesis of the qualitative evidence. *BMJ Supportive & Palliative Care,* [online], 6, pp. 418–429, available: https://spcare.bmj.com/content/bmjspcare/6/4/418.full.pdf. [accessed: 10th April 2018].

Women Moving Millions. (2016). *A Guide to Investing in Social Change through Documentary Film.* [online], available: http://www.womenmovingmillions.org/wp-content/uploads/2016/11/2016-Documentary-Film-Guide.pdf [accessed: 22nd April 2019].

Wright, N. & Losekoot, E. (2012). Interpretative Research Paradigms: Points of Difference. *Proceedings of the European Conference on* ***Research*** *Methods for Business & Management Studies, [online], 7*, p. 416-422, available: https://pdfs.semanticscholar.org/7764/7d65875cff127190047af0ed9abca7d2681e.pdf [accessed: 10th October 2017].

Zahedi, F. (2011). The Challenge of Truth Telling Across Cultures: A Case Study. *Journal of Medical Ethics and History of Medicine*, [online], 4(11), pp. 1-9, available: https://pdfs.semanticscholar.org/0b97/5d72828627d4f801bd39b892a46ff6624fc9.pdf?_ga=2.22000699.1636151425.1539182870-966060041.1529412812 [accessed: 10th October 2018].

Zamanzadeh, V., Jasemi, M. & Taleghani, F. (2015). Effective Factors in Providing Holistic Care: A Qualitative Study. *Indian Journal of Palliative Care*, [online], 21(2), pp. 214-224, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4441185/ [accessed: 21st October 2018].

NON-PEER REVIEWED PUBLICATIONS ARISING FROM THIS STUDY

1. Somers, C. (2019). What constitutes a good death: Views of the public and professionals working within generalised and specialised palliative care services. Oral presentation. Research showcase, Institute of Technology Carlow, 13th March 2019. [came second place in overall social core research projects at the institute].

2. Somers, C. (2019). What constitutes a good death: public and professional perspectives in the South East of Ireland. Poster display. Research showcase, Institute of Technology Carlow, 13th of March 2019.

3. Somers, C. (2019). What constitutes a good death: From the perspective of the public and generalist and specialist palliative care professional in the South East region of Ireland. Oral Presentation. Research showcase, Institute of Technology Carlow, Wexford Campus, 5th of April 2019.

4. Somers, C. (2019). Perceptions a good death: public and professional viewpoints. Poster display. Research showcase, Institute of Technology Carlow, Wexford Campus, 5th of April 2019.

5. Somers, C. (2019). Characteristics of a good death. Poster display. Research showcase, Institute of Technology Carlow, Wexford Campus, 5th of April 2019.

APPENDICES

APPENDIX A: Foundations of Specialist and Generalist Palliative Care in Ireland

DUBLIN	
1. Harold's Cross	Established in 1879 by the Sisters of Charity (Our Lady's Hospice and Care Services, 2018).
2. Saint Francis Hospice Raheny Blanchardstown	Evolved from collaborations of the Irish Hospice Foundation and the Sisters of Charity. It originally began as a homecare service. However, with the financial support of numerous private and voluntary sectors, St Francis has extended its range of services to include generalised and specialised palliative care services, providing both inpatient, outpatient, home and community supports to the terminally ill and their family/loved and informal caregivers within Raheny and Blanchardstown in Dublin (St. Francis Hospice, 2018).
KILDARE	
3. St. Brigid's Hospice	This Hospice is situated on the right of the Drogheda Memorial Hospital in the Curragh and was opened in 2004 through the tireless efforts of the friends of St. Brigid's Hospice (Nursing Homes Ireland, 2015).
LIMERICK	
4. Milford Care Centre	Originated from an eldercare residential service which provided nine inpatient palliative and hospice care beds in 1977. Over the years, through supports from the voluntary and public sectors (HSE), it has expanded to include hospice, community and day service supports. Redevelopment have also led to an increase of palliative care inpatients services. Milford Care Centre is currently equipped with thirty palliative care beds (Milford Care Centre, 2015).
GALWAY	
5. Galway Hospice	Only service in Ireland not founded by a religious congregation. The inpatient unit was established in 1997 (Galway Hospice, 2018).
SLIGO	
6. North West Hospice	In 1986, a social worker named Claire Campbell set up numerous support groups for individuals suffering from cancer and their family/caregiver(s). This gradually led to the establishment of a specialist inpatient service, 'the North West Hospice'(North West Hospice, 2017).
DONEGAL	
7. Donegal Hospice	Opened in 2003, Donegal Hospice is a six-bed facility. It also has 2 apartments (Donegal Hospice, 2016).

APPENDIX B: Matrix of Irish Literature

Table 4: Gaps in Exiting National Literature

Issues in Prior Research Involving the Public in Ireland

Author /Year	**Study Name**	**Methodology/Instruments**	**Limitations**
McLoughlin. (2017) **Ireland**	'Have Your Say' Your Life, Your Death, Your Say.	2,563 public respondents	❖ Underrepresentation's of demographics, 84% consisting of females and 41% aged between 45 to 59 years old. ❖ Not explicitly focused on a GD.
Weafer, (2004-2014) **Ireland**	Public views on death dying and bereavement	1,000 public respondents in 2004 985 public respondents in 2014 Quantitative - Survey	❖ No rational behind data obtained. ❖ Not explicitly focused on a GD. ❖ The use of nine-point, categorical scale this scale may have been leading.
McCarthy, J., Loughrey, M., Weafer, J. & Doley, D. (2009) **Ireland**	Conversations with the Irish public about death and dying.	16 participants Qualitative - focus group Dublin focus group – adults aged 30 -45yrs Sligo Focus group - aged 50-70 years	❖ Minimal sample size. ❖ Problematic age range. ❖ Within a focus group data received may imitate beliefs or opinions held by the group rather than individual views or opinions potentially contaminating results thus leading to bias (Green & Thorogood, 2018).

How my research will address these issues:

1. Utilising a qualitative methodology and omitting predetermined lists, allowing participants to truly reflect upon questions asked. Additionally, this will give participants the freedom to comprehensively express what, why and how their opinion(s) of a GD are held.
2. My research aims to include an age range from 18 to 80 year olds and over to halt the exclusion of any adult age range and to incorporate a variety of generational and life stage views on the topic of a GD.
3. All studies above left unanswered questions which my study such as:
   Why did participants feel these elements of a GD outlined above were important?
   What had influenced their opinion(s) on a GD?
4. My study will address these unanswered questions by incorporating them into the interview list.

Issues in Prior Research Involving Professionals in Ireland

Author /Year	**Study Name**	**Methodology/Instruments**	**Limitations**
Butler, M. (2017). **Ireland**	Factors that Influence Good End of Life Care in Long Stay Residential Care for Older People	41 participants selected from 3 publicly managed long stay residential care services	❖ Involved generalised professionals (professional views within long-stay eldercare residential settings only). ❖ Unknown if themes ascertained resonate with the public, generalised professionals working within other generalised setting and specialised professionals.
Quinlan & O'Neill, (2009). **Ireland**	Practitioners' Perspectives on Patient Autonomy at End of Life.	Qualitative results, utilising narrative descriptions (102 written submissions), focus groups (104 participants) and interviews (57 interviewees	❖ Their focus was solely upon the concept of autonomy involving generalised professionals (professional views within hospitals only). ❖ Unknown if themes ascertained resonate with the public, generalised professionals working within other generalised setting and specialised professionals.
O'Shea, E., Murphy, K., Larkin, P., Payne, S., Froggatt, K., Casey, D., Ni Leime, A. & Keys, M. (2008). **Ireland**	End-of-life care for older people in acute and long-stay care settings in Ireland	Quantitative & Qualitative Survey - 592 care facilities Interviews - 35 interviews direct care staff - 30 interviews conducted with patients	❖ Focused on acute and long stay hospitals who possessed ;on-stay palliative care beds only – therefore excluded hospitals without inpatient palliative care beds. ❖ Involved generalised professionals (professional views within hospitals only) and terminally ill patients. ❖ Unknown if themes ascertained resonate with the public, generalised professionals working within other generalised setting and specialised professionals.

How my research will address these issues:

1. My research aims to explore the concept of a GD within both professional and public domains to ascertain if a general consensus on this topic exists in Ireland.
2. It will also incorporate the views of generalised palliative care professionals and specialised palliative care professionals to capture a broader professional insight on this topic.

APPENDIX C: Interview Questions for The Public

1. What is your job title?
2. What is your current age bracket?

18-25	48-58
26-36	59-69
37-47	70-80

3. What is your level of education to date?

4. What is your gender?

5. What is your ethnicity?

6. What is your religion?

7. What county of Ireland do you live in?

8. What in your opinion is a good death?

9. What has influenced this opinion?

10. How would you describe defining a good death?

11. Do you think as a society the topic of death and dying is discussed openly?

12. How to do feel when talking about the topic of death and dying?

13. What do you feel are the most important factors that help a person gain a good death?

14. What would you consider most important post-death (after death has occurred)?

15. Do you believe people are supported to have a good death?

16. Do you believe people are currently supported in the following areas;

a) socially
b) psychologically
c) financially

A definition of the following two components will be given to respondents, as it was determined through conducting the pilot study that these elements may cause confusion or may be discussed collectively rather than independently.

d) religiously - Religion is a set of behavioural manifestations connected to religious beliefs, values and social relationships that unit a common faith" (Canda & Furman, 2010, cited in Becker et al., 2015, p.105).

e) Spiritually – is described as the way in which an individual seeks and expresses meaning and purpose of one’s life (Puchalski et al., cited in Becker et al., p.106).

to have a good death?

17. Do you have an understanding of palliative care services?

18. Do you have an understanding of hospice services?

19. How would you rate current end of life care support services?

20. What has influenced this opinion?

21. What, if any, improvements could be made in current end of life care services?

22. How would you rate current supports for informal caregivers of a terminally ill person? ***Note:*** **Informal caregivers will be explained to respondents.**

23. What has influenced this opinion?

24. How would you rate aftercare support services for family and caregivers of a terminally ill person?

25. What has influenced this opinion?

26. An Advance Healthcare Directive (AHD) is defined as a written statement made by a person with capacity which informs family, friends and healthcare professionals of his or her wishes regarding healthcare treatment in the event that he/she no longer has the capability to communicate this or make sound, rational decisions concerning their care in the future (The Irish Hospice Foundation, 2018).

a) Are you aware of this term?
b) What is your opinion of it?
c) Would you see a value a drafting an advanced healthcare directive?

27. Do you think it is important to plan for one’s death?

28. Do you think people express their wants, needs and desires regarding their care when in the final stages of life?

29. Do you think people nearing death have choice and control over their care?

30. Have you ever discussed any of the following with anyone?

1. **Funeral arrangements**
2. **Where you would like to die.**
3. **If you have a living will.**
4. **Things you would like to do before you die.**

31. Where would you like to be cared for if you had a terminal illness?

32. Why have you chosen this location?

33. Have you ever discussed this information with anyone?

34. Do you feel you would have adequate end of life care and supports in this location?

35. **In your opinion who has the authority to make decisions about discontinuing medical treatment if a person was in the final stages of the dying process or in a coma?**

36. **In your opinion do family member’s wishes conflict with a terminally ill individuals wishes?**

37. **What issues may arise that could impact upon a person’s ability towards achieving a good death?**

APPENDIX D: Interview Questions for Professionals

1. What is your current age bracket? Are you between;

18-25	48-58
26-36	59-69
37-47	70-80

2. What is your gender?
3. What is your ethnicity?
4. What end of life care service do you currently work in?
5. How many years' experience do you currently hold in this sector?
6. What is your current job title?
7. What county of Ireland to you reside in?
8. Do you work in the same county?
9. What is your level of education to date?
10. What would you regard is a good death?
11. What has influenced this opinion?
12. What do you believe is the general public's perception of what may constitute a good death?
13. Do you feel the concept of a good death is easy to define?
14. In your opinion do you think as a society the topic of death is openly discussed.
15. In your professional opinion do individuals openly express their wishes regarding their care needs in the final stages of life.
16. An Advance Healthcare Directive (AHD) is defined as a statement made by an individual with capacity (the ability to make and understand information and make decisions) detailing his/her will and preferences about medical treatments that may arise in the future at a time when he/she no longer has the capacity and so cannot make decisions (The Irish Hospice Foundation, 2016).

    (a) Are you aware of AHD?
    (b) What is your opinion of it?

17. What would you consider most important to a terminally ill individual post-death?

18. **Do you believe people are currently supported in the following areas to have a good death;**

    a) **socially**
    b) **psychologically**
    c) **financially**

    A definition of the following two components will be given to respondents, as it was determined through conducting the pilot study that these elements may cause confusion or may be discussed collectively rather than independently.

    d) **religiously - Religion is a set of behavioural manifestations connected to religious beliefs, values and social relationships that unit a common faith" (Canda & Furman, 2010, cited in Becker et al., 2015, p.105).**

    e) **Spiritually – is described as the way in which an individual seeks and expresses meaning and purpose of one's life (Puchalski et al., cited in Becker et al., p.106).**

19. **What do you believe to be important supports in end of life care?**

20. **Who in your opinion has the authority to make decisions about discontinuing medical treatment if an individual was in the final stages of the dying process?**

21. **How do you view current end of life care service delivery in;**

a) **Community care and Homecare**
b) **General Hospital Care and Acute Hospital Care.**
c) **Hospice Care**
d) **Residential Care**

22. **How would you rate care provided by informal caregivers of a terminally ill individual?**

Will be probed on these areas;
a) **Family members**
b) **Partner or spouse**
c) **Friend**
d) **Neighbour**

23. **How would you rate current supports for informal caregivers of a terminally ill individual?**

Will be probed on the following settings:
a) **Community and Homecare Services**
b) **General Hospital Services & Acute Care Services**
c) **Hospice Services**
d) **Residential care Services**

24. **How would you rate aftercare support services for families and caregivers of a terminally ill individual?**

25. **In your opinion do family member's wishes conflict with a terminally ill individuals wishes.**

26. **If 'yes' how do professionals address this conflict in practice?**

27. **In your opinion are all professionals involved in the care of a terminally ill individual adequately informed when the individual dies?**

28. **What, if any, challenges do professionals encounter in current end of life care service deliver?**

29. **Where, if any, improvements could be made in current service delivery?**

30. **How would you rate the current level of end of life care training and education you hold?**

APPENDIX E: Alignment of Interview Questions to ROs (Public)

QUESTIONS POSED TO THE PUBLIC WHICH ADDRESSED OBJECTIVE ONE OF THIS STUDY	
OBJECTIVE ONE (A): What are the publics perceptions in Ireland concerning what constitutes a GD?	
Q8.	What in your opinion is a good death?
Q9.	What has influenced this opinion?
Q10.	How would you describe defining a good death?
Q13.	What do you feel are the most important factors that help a person gain a good death?
Q14.	What would you consider most important post-death (after death has occurred)?
Q26.	An Advance Healthcare Directive (AHD) is defined as a statement made by an individual with capacity (the ability to make and understand information and make decisions) detailing his/her will and preferences about medical treatments that may arise in the future at a time when he/she no longer has the capacity and so cannot make decisions (The Irish Hospice Foundation, 2016). Are you aware of AHD? What is your opinion of it? Would you see a value in Drafting an AHD? NOTE: Ascertain if planning is important and level of awareness on current initiates in palliative, Hospice and EOLC
Q27.	Do you think it is important to plan for one's death?
Q28.	Do you think people express their wants, needs and desires regarding their care when in the final stages of life?
Q29.	Do you think people nearing death have choice and control over their care?
Q30.	Have you ever discussed any of the following with anyone? Funeral arrangements Where you would like to die. If you have a living will. Things you would like to do before you die.
OBJECTIVE TWO: How are individuals and their families and loved one's currently supported to achieve a GD?	
Q15.	Do you believe people are supported to have a good death?
Q16.	Do you believe people are currently supported in the following areas; a) socially b) psychologically c) financially d) religiously e) spiritually to have a good death?
Q19.	How would you rate current end of life care support services?
Q20.	What has influenced this opinion?
Q21.	What, if any, improvements could be made in current end of life care services?
Q22.	How would you rate current supports for informal caregivers of a terminally ill person? *Note:* Informal caregivers will be explained to respondents.
Q23.	What has influenced this opinion?

CONTINUED **OBJECTIVE TWO:** How are individuals and their families and loved one's currently supported to achieve a GD?	
Q31.	**Where would you like to be cared for if you had a terminal illness?**
Q32.	**Why have you chosen this location?**
Q33.	**Have you ever discussed this information with anyone?**
Q34.	**Do you feel you would have adequate end of life care and supports in this location?**
Q35.	**In your opinion who has the authority to make decisions about discontinuing medical treatment if a person was in the final stages of the dying process or in a coma?**
OBJECTIVE THREE: What issues may arise which could impact upon individual opportunities to experience a GD in Ireland?	
Q11.	**In your opinion do you think as a society the topic of death is openly discussed?**
Q12.	**How to do feel when talking about the topic of death and dying?**
Q17.	**Do you have an understanding of palliative care services?**
Q18.	**Do you have an understanding of hospice services?**
Q36.	**In your opinion do family member's wishes conflict with a terminally ill individuals' wishes?**
Q37.	**What issues may arise that could impact upon a person's ability towards achieving a good death?**

APPENDIX F: Alignment of Interview Questions to ROs (Professionals)

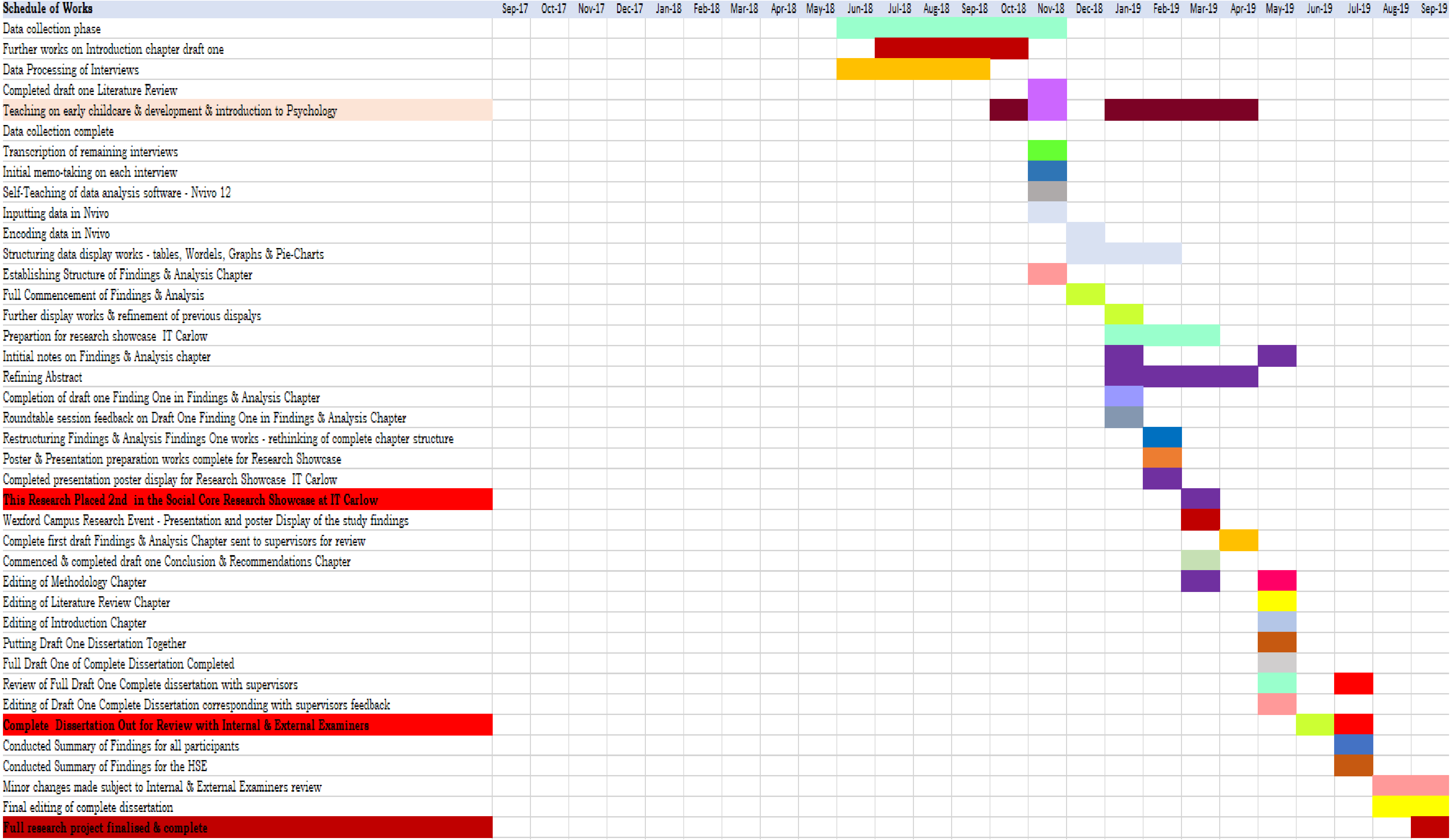
QUESTIONS POSED TO GENERALISED AND SPECIALISED PROFESSIONALS THAT ADDRESSED OBJECTIVE ONE OF THIS STUDY	
OBJECTIVE ONE (B): What are generalised and specialised palliative care professionals' perceptions in Ireland of what constitutes a 'good death'?	
Q10.	What would you regard is a good death?
Q11.	What has influenced this opinion?
Q12.	What do you believe is the general public's perception of what may constitute a good death? Note: Exploring if commonalties exist between these group
Q13.	Do you feel the concept of a good death is easy to define?
Q16.	An Advance Healthcare Directive (AHD) is defined as a statement made by an individual with capacity (the ability to make and understand information and make decisions) detailing his/her will and preferences about medical treatments that may arise in the future at a time when he/she no longer has the capacity and so cannot make decisions (The Irish Hospice Foundation, 2016). Are you aware of AHD? What is your opinion of it? Note: Ascertain if planning is important and level of awareness on current initiates in palliative, Hospice and EOLC
Q17.	What would you consider most important to a terminally ill individual post-death?
Q19.	What do you believe to be important supports in end of life care?
OBJECTIVE TWO: How are individuals and their families and loved one's currently supported to achieve a good death?	
Q18.	Do you believe people are currently supported in the following areas; a) socially b) psychologically c) financially d) religiously e) spiritually to have a good death?
Q21.	How do you view current end of life care service delivery in; Will be probed on these areas; Community care and Homecare General Hospital Care and Acute Hospital Care. Hospice Care Residential Care
Q22.	How would you rate care provided by informal caregivers of a terminally ill individual? Will be probed on these areas; Family members Partner or spouse Friend Neighbour
Q23.	How would you rate current supports for informal caregivers of a terminally ill individual? Probed on the following settings: Community and Homecare Services General Hospital Services & Acute Care Services Hospice Services Residential care Services
Q24.	How would you rate aftercare support services for families and caregivers of a terminally ill individual?

QUESTIONS POSED TO GENERALISED AND SPECIALISED PROFESSIONALS THAT ADDRESSED OBJECTIVE ONE OF THIS STUDY	
OBJECTIVE THREE: What issues may arise which could impact upon individual opportunities to experience a good death in Ireland?	
Q13.	Do you feel the concept of a good death is easy to define?
Q14.	In your opinion do you think as a society the topic of death is openly discussed?
Q15.	In your professional opinion do individuals openly express their wishes regarding their care needs in the final stages of life?
Q25.	In your opinion do family member's wishes conflict with a terminally ill individuals wishes?
Q26.	If 'yes' how do professionals address this conflict in practice?
Q27.	In your opinion are all professionals involved in the care of a terminally ill individual adequately informed when the individual dies?
Q28.	What, if any, challenges do professionals encounter in current end of life care service deliver?
Q29.	Where, if any, improvements could be made in current service delivery?
Q30.	How would you rate the current level of end of life care training and education you hold?

Appendix G: Research Timeframe

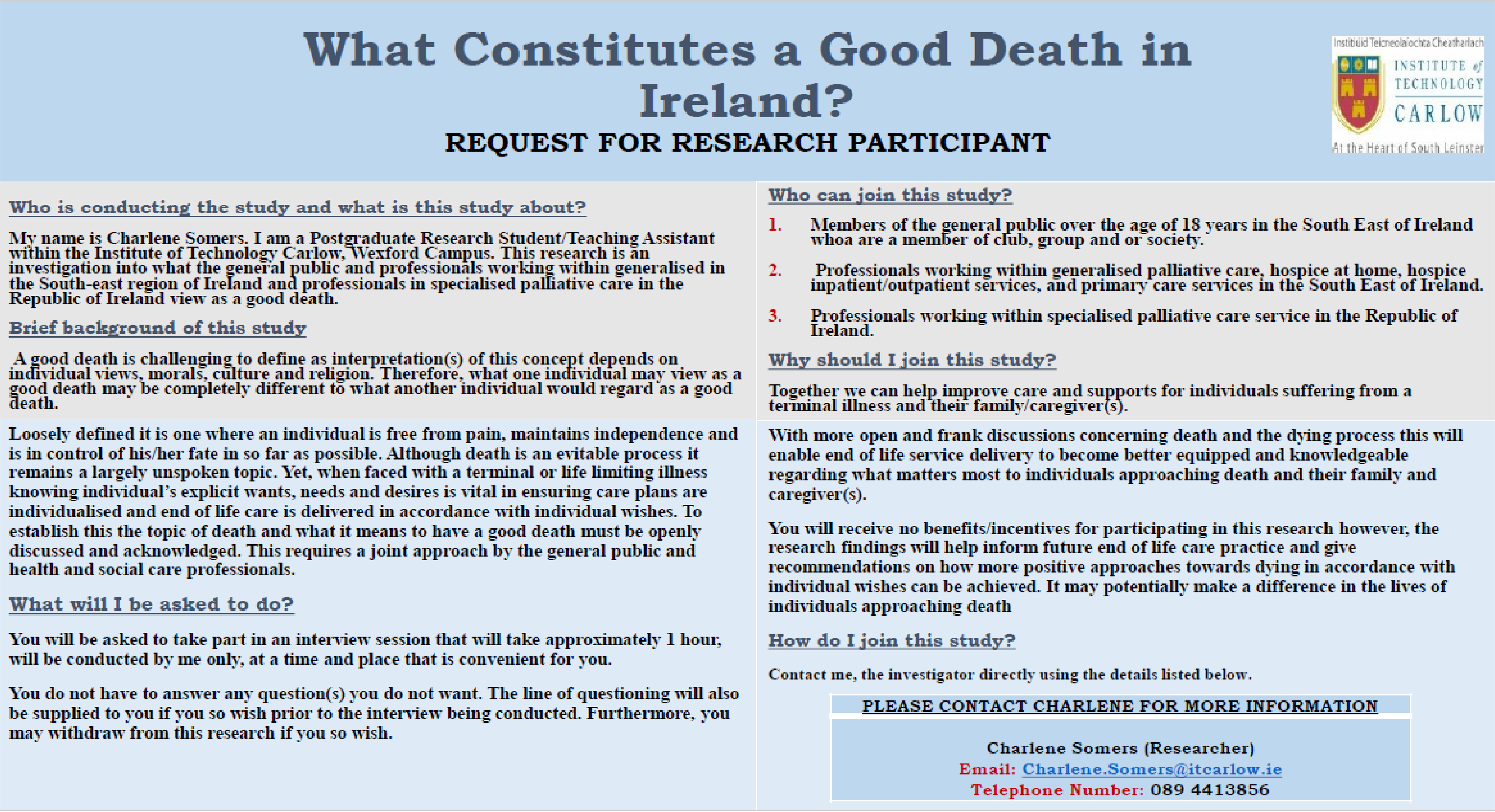
Schedule of Works	Sep-17	Oct-17	Nov-17	Dec-17	Jan-18	Feb-18	Mar-18	Apr-18	May-18	Jun-18	Jul-18	Aug-18	Sep-18	Oct-18	Nov-18	Dec-18	Jan-19	Feb-19	Mar-19	Apr-19	May-19
Research topic change from AD to GD	■																				
Formulating a research question/subquestions.	■	■																			
Reading around topic area		■																			
Ascertaining research objectives	■	■																			
Registration works - mini research proposal		■																			
Teaching on ealry childcare and social research methods modules	■	■	■	■	■	■	■	■					■	■	■	■	■	■	■	■	
Establishing theories, international research and gaps in existing literature		■	■	■																	
Reviewing existing literature to identify themes		■	■																		
Research proposal		■	■																		
Conducted mini Literature Review chapter		■	■																		
Identify Methodological Approach			■	■																	
Ethics application works			■	■	■	■	■	■	■												
Attended Death Cafè					■																
Population size calculations					■																
Refining information sheets, Flyers and consent forms for participant recruitment					■																
Preparing the research instruments, drafting of questions for online survey/interviews					■	■															
Refining Ethics application						■															
Ethics application completed and submitted to IT Carlow Ethics Committee						■	■	■													
Commencement of Methodology Chapter.						■	■														
Refining Research Title						■															
Pilot study of **interview questions**						■															
Creation of survey on Survey Monkey						■															
Commencement of Introduction chapter						■															
Final Registration works for extern							■														
Draft one of Methodology Chapter complete and submitted for review								■													
Pilot Study on **survey questions**							■	■													
Commenced Analysis of Pilot Study								■													
Commenced Ethics application to the HSE South East Research Ethic Committee								■	■												
Meeting with HSE South East Research Ethic Committee Member								■													
Recalulation of research population (from ROI study to study within the South east of Ireland)								■													
Research Proposal for HSE South East Research Ethic Committee								■													
Finished Analysis of Pilot Study																					
Refinement of Interview & Survey questions								■	■												
Introducton chapter works									■												
Commenced works on presentation for ethical approval from the HSE South East Research Ethic Committee									■												
Submitted Progress Report									■												
Ethics presentation to supervisors									■												
Presentation of my research seeking ethical approval to the HSE South East Research Ethic Committee									■												
HSE Ethical approval granted subject to ammendments - ammended conducted and submitted																					
Ethics Approval granted from HSE South East Ethics Committee										■											
Ethics Approval granted from IT Carlow Ethics Committee										■											
Redesign of Methodological approach changed from MMR to Qual										■											
Compiling spreadsheets of potential participant groups										■											
Review of pilot study analysis										■											
Minor editing works on Methodology chapter										■											
Introduction chapter works										■											
Further refinement of Interview & Survey questions in preparation for data collection										■											
Commencement of Full draft one Literature chapter										■											
New pilot study of interview questions										■	■										

Research Timeframe Continued



Schedule of Works	Sep-17	Oct-17	Nov-17	Dec-17	Jan-18	Feb-18	Mar-18	Apr-18	May-18	Jun-18	Jul-18	Aug-18	Sep-18	Oct-18	Nov-18	Dec-18	Jan-19	Feb-19	Mar-19	Apr-19	May-19	Jun-19	Jul-19	Aug-19	Sep-19
Data collection phase										■	■	■	■	■	■										
Further works on Introduction chapter draft one											■	■	■	■											
Data Processing of Interviews										■	■	■	■												
Completed draft one Literature Review															■										
Teaching on early childcare & development & introduction to Psychology														■	■		■	■	■	■					
Data collection complete																									
Transcription of remaining interviews															■										
Initial memo-taking on each interview															■										
Self-Teaching of data analysis software - Nvivo 12															■										
Inputting data in Nvivo															■										
Encoding data in Nvivo																■									
Structuring data display works - tables, Wordels, Graphs & Pie-Charts																■	■	■							
Establishing Structure of Findings & Analysis Chapter															■										
Full Commencement of Findings & Analysis																■									
Further display works & refinement of previous dispalys																	■								
Prepartion for research showcase IT Carlow																	■	■	■						
Intitial notes on Findings & Analysis chapter																	■				■				
Refining Abstract																	■	■	■	■					
Completion of draft one Finding One in Findings & Analysis Chapter																	■								
Roundtable session feedback on Draft One Finding One in Findings & Analysis Chapter																	■								
Restructuring Findings & Analysis Findings One works - rethinking of complete chapter structure																		■							
Poster & Presentation preparation works complete for Research Showcase																		■							
Completed presentation poster display for Research Showcase IT Carlow																		■							
This Research Placed 2nd in the Social Core Research Showcase at IT Carlow																			■						
Wexford Campus Research Event - Presentation and poster Display of the study findings																			■						
Complete first draft Findings & Analysis Chapter sent to supervisors for review																				■					
Commenced & completed draft one Conclusion & Recommendations Chapter																			■						
Editing of Methodology Chapter																			■		■				
Editing of Literature Review Chapter																					■				
Editing of Introduction Chapter																					■				
Putting Draft One Dissertation Together																					■				
Full Draft One of Complete Dissertation Completed																					■				
Review of Full Draft One Complete dissertation with supervisors																					■		■		
Editing of Draft One Complete Dissertation corresponding with supervisors feedback																					■				
Complete Dissertation Out for Review with Internal & External Examiners																						■	■		
Conducted Summary of Findings for all participants																							■		
Conducted Summary of Findings for the HSE																							■		
Minor changes made subject to Internal & External Examiners review																								■	■
Final editing of complete dissertation																								■	■
Full research project finalised & complete																									■

APPENDIX H: Sample Recruitment Poster and Flyer Distributed



What Constitutes a Good Death in Ireland?

REQUEST FOR RESEARCH PARTICIPANT

Who is conducting the study and what is this study about?

My name is Charlene Somers. I am a Postgraduate Research Student/Teaching Assistant within the Institute of Technology Carlow, Wexford Campus. This research is an investigation into what the general public and professionals working within generalised in the South-east region of Ireland and professionals in specialised palliative care in the Republic of Ireland view as a good death.

Brief background of this study

A good death is challenging to define as interpretation(s) of this concept depends on individual views, morals, culture and religion. Therefore, what one individual may view as a good death may be completely different to what another individual would regard as a good death.

Loosely defined it is one where an individual is free from pain, maintains independence and is in control of his/her fate in so far as possible. Although death is an evitable process it remains a largely unspoken topic. Yet, when faced with a terminal or life limiting illness knowing individual's explicit wants, needs and desires is vital in ensuring care plans are individualised and end of life care is delivered in accordance with individual wishes. To establish this the topic of death and what it means to have a good death must be openly discussed and acknowledged. This requires a joint approach by the general public and health and social care professionals.

What will I be asked to do?

You will be asked to take part in an interview session that will take approximately 1 hour, will be conducted by me only, at a time and place that is convenient for you.

You do not have to answer any question(s) you do not want. The line of questioning will also be supplied to you if you so wish prior to the interview being conducted. Furthermore, you may withdraw from this research if you so wish.

Who can join this study?

1. Members of the general public over the age of 18 years in the South East of Ireland whoa are a member of club, group and or society.
2. Professionals working within generalised palliative care, hospice at home, hospice inpatient/outpatient services, and primary care services in the South East of Ireland.
3. Professionals working within specialised palliative care service in the Republic of Ireland.

Why should I join this study?

Together we can help improve care and supports for individuals suffering from a terminal illness and their family/caregiver(s).

With more open and frank discussions concerning death and the dying process this will enable end of life service delivery to become better equipped and knowledgeable regarding what matters most to individuals approaching death and their family and caregiver(s).

You will receive no benefits/incentives for participating in this research however, the research findings will help inform future end of life care practice and give recommendations on how more positive approaches towards dying in accordance with individual wishes can be achieved. It may potentially make a difference in the lives of individuals approaching death

How do I join this study?

Contact me, the investigator directly using the details listed below.

PLEASE CONTACT CHARLENE FOR MORE INFORMATION

Charlene Somers (Researcher)
Email: Charlene.Somers@itcarlow.ie
Telephone Number: 089 4413856

APPENDIX I: **Interview Schedule**

Participant	Date	Location
1. Participant A:	*10/07/2018*	*Kilkenny* *Face-to-face*
2. Participant B:	*26/07/2018*	*Wicklow* *Telephone interview*
3. Participant C:	*8/08/2018*	*Wexford* *Face-to-face*
4. Participant D:	*8/08/2018*	Wexford *Face-to-face*
5. Participant E:	*13/08/2018*	*Waterford* *Face-to-face*
6. Participant F:	*21/08/2018*	*Bunclody,* *Co. Wexford* *Face-to-face*
7. Participant G:	*21/08/2018*	*Bunclody,* *Co. Wexford* *Face-to-face*
8. Participant H:	*28/08/2018*	*Our Lady's Island* *Co. Wexford* *Face-to-Face*
9. Participant I:	*30/08/2018*	*Wexford* *Telephone interview*
10. Participant J:	*31/08/2018*	*Wexford* *Face-to-face*
11. Participant K:	*31/08/2018*	*South tipperary* *Telephone interview*
12. Participant L:	*05/09/2018*	*Kilkenny* *Telephone interview*
13. Participant M:	*09/09/2018*	*Our Lady's Island* *Co. Wexford* *Face-to-Face*
14. Participant N:	*09/09/2018*	*Wexford Town* *Co. Wexford* *Face-to-Face*
15. Participant O:	*10/09/2018*	*Wexford Town* *Co. Wexford* *Face-to-Face*
16. Participant P:	*10/09/2018*	*Wexford Town* *Co. Wexford* *Face-to-Face*

CONTINUED: Interview Schedule		
Participant	**Date**	**Location**
17. Participant Q:	*22/09/2018*	*Our Lady's Island* *Co. Wexford* *Face-to-Face*
18. Participant R:	*04/10/2018*	*Enniscorthy* *Co. Wexford* *Face-to-Face*
19. Participant S:	*05/10/2018*	**Wexford** **Town** *Face-to-Face*
20. Participant T:	*05/10/2018*	**Wexford** **Town** *Face-to-face*
21. Participant U:	*09/10/2018*	**Wexford** **Town** *Face-to-face*
22. Participant V:	*11/10/2018*	**Wexford** **Town** *Face-to-face*
23. Participant W:	*13/10/2018*	*Bunclody,* *Co. Wexford* *Face-to-face*
24. Participant X:	*19/10/2018*	**Wexford** **Town** *Face-to-face*

APPENDIX J: Participant Coding System Employed (Full Version)

(A) THE PUBLIC

PARTICIPANT CODING: THE PUBLIC	
Participant Name	**Coding System**
Participant C **Public** **PPC**	**Coding: PPC, (F), (I), (AB 59-69)** **Female (F)** **Irish (I)** **Age bracket (AB 59-69)**
Participant D **Public** **PPD**	**Coding: PPD, (M), (I), (AB 37-47)** **Male (M)** **Irish (I)** **Age bracket (AB 37-47)**
Participant H **Public** **PPH**	**Coding: PPH, (M), (I) (AB 18-25)** **Male (M)** **Irish (I)**
Participant L **Public** **PPL**	**Coding: PPL, (F), (I), (AB 59-69)** **Female (F)** **Irish (I)**
Participant M **Public** **PPM**	**Coding: PPM, (F), (B), (AB 37-47)** **Female (F)** **British (Brit)** **Age bracket (AB 37-47)** **Lives in Wexford, (WX)**
Participant N **Public** **PPN**	**Coding: PPN, (M), (I), (AB 37-47)** **Male (M)** **Irish (I)** **Age bracket (AB 37-47)**
Participant O **Public** **PPO**	**Coding: PPO, (F), (I), (AB 48-58)** **Female (F)** **Irish (I)** **Age bracket (AB 48-58)**
Participant P **Public** **PPP**	**Coding: PPP, (F), (I), (AB 37-47)** **Female (F)** **Irish (I)** **Age bracket (AB 37-47)**
Participant Q **Public** **PPQ**	**Coding: PPQ, (M), (I), (AB 70-80)** **Male (M)** **Irish (I)**
Participant W **Public** **PPW**	**Coding: PPW (M), (I), (AB 26-3** **Male (M)** **Irish (I)** **Age bracket (AB 26-36)**

B) GENERALISED PROFESSIONALS

PARTICIPANT CODING: GENERALISED PROFESSIONALS	
Participant Name	**Coding System**
Participant A **Generalised** **GPA**	**Coding: GPA (F) (AB 37-47) (F) (B)** **British (B)** **Age bracket (AB 37-47)**
Participant B **Generalised** **GPB**	**Coding: GPB, (M), (I), (AB 48-58)** **Irish (I)** **Age bracket (AB 48-58)**
Participant F **Generalised** **GPF**	**Coding: GPF, (F), (I), (AB 59-69)** **Irish (I)** **Age bracket (AB 59-69)**
Participant G **Generalised** **GPG**	**Coding: GPG (F), (I) (AB 18-25)** **Female (F)** **Irish (I)** **Age bracket (AB 18-25)**
Participant R **Generalised** **GPR**	**Coding: GPR(F), (F) (I) (AB 37-47)** **Female (F)** **Irish (I)** **Age bracket (AB 37-47)**
Participant U **Generalised** **GPU**	**Coding: GPU, (F) (I), (AB 18-25)** **Female (F)** **Irish (I)** **Age bracket (AB 18-25)**
Participant V **Generalised** **GPV**	**Coding: GPV (F), (I), (AB 59-69)** **Female (F)** **Irish (I)**
Participant J **Generalised** **GPJ**	**Coding: GPJ, (F), (I), (AB 37-47)** **Female (F)** **Irish (I)** **Age bracket (AB 37-47)**
Participant X **Generalised** **GPX**	**Coding: GPX, (F), (I) (AB 37-47)** **Female (F)** **Irish (I)** **Age bracket (AB 37-47)**

(C) SPECIALISED PROFESSIONALS

PARTICIPANT CODING: SPECIALISED PROFESSIONALS	
Participant Name	**Coding System**
Participant E **Specialised** **SPE**	**Coding: SPE, (F), (I), (AB 48-58)** **Female (F)** **Irish (I)** **Age bracket (AB 48-58)**
Participant I **Specialised** **SPI**	**Coding: SPI (M), (I), (AB 37-47)** **Male (M)** **Irish (I)** **Age bracket (AB 37-47)**
Participant S **Specialised** **SPS**	**Coding: SPS (F), (I), (AB 37-47)** **Female (F)** **Irish (I)** **Age bracket (AB 37-47)**
Participant T **Specialised** **SPT**	**Coding: SPT, (F), (I) (AB 37-47)** **Female (F)** **Irish (I)** **Age bracket (AB 37-47)**
Participant K **Specialised** **SPK**	**Coding: SPK (F), (I), (AB 37-47)** **Female (F)** **Irish (I)** **Age bracket (AB 37-47)**

Participant Coding System Employed (Summarised Version)

PARTICIPANT CODING	
GROUP A PUBLIC	
Participant Group	Participant Coding
Public: Participant C (PPC)	Coding: PPC, (F), (I), (AB 59-69)
Public: Participant D (PPD)	Coding: PPD, (M), (I), (AB 37-47)
Public: Participant H (PPH)	Coding: PPH, (M), (I) (AB 18-25)
Public: Participant L (PPL)	Coding: PPL, (F), (I), (AB 59-69)
Public: Participant M (PPM)	Coding: PPM, (F), (B), (AB 37-47)
Public: Participant N (PPN)	Coding: PPN, (M), (I), (AB 37-47)
Public: Participant O (PPO)	Coding: PPO, (F), (I), (AB 48-58)
Public: Participant P (PPP)	Coding: PPP, (F), (I), (AB 37-47)
Public: Participant Q (PPQ)	Coding: PPQ, (M), (I), (AB 70-80)
Public: Participant W (PPW)	Coding: PPW (M), (I), (AB 26-36)
GROUP B GENERALISED PROFESSIONALS	
Participant Group	Participant Coding
Generalised: Participant A (GPA)	Coding: GPA, (F), (B), (AB 37-47)
Generalised: Participant B (GPB)	Coding: GPB, (M), (I), (AB 48-58)
Generalised: Participant F (GPF)	Coding: GPF, (F), (I), (AB 59-69)
Generalised: Participant G (GPG)	Coding: GPG (F), (I) (AB 18-25)
Generalised: Participant R (GPR)	Coding: GPR, (F) (I) (AB 37-47)
Generalised: Participant U (GPU)	Coding: GPU, (F) (I), (AB 18-25)
Generalised: Participant V (GPV)	Coding: GPV (F), (I), (AB 59-69)
Generalised: Participant J (GPJ)	Coding: GPJ, (F), (I), (AB 37-47)
Generalised: Participant X (GPX)	Coding: GPX, (F), (I) (AB 37-47)
GROUP C SPECIALISED PROFESSIONALS	
Participant Group	Participant Coding
Specialised: Participant E (SPE)	Coding: SPE, (F), (I), (AB 48-58)
Specialised Participant I (SPI)	Coding: SPI (M), (I), (AB 37-47)
Specialised Participant S (SPS)	Coding: SPS (F), (I), (AB 37-47)
Specialised Participant T (SPT)	Coding: SPT, (F), (I) (AB 37-47)
Specialised: Participant K (SPK)	Coding: SPK (F), (I), (AB 37-47)

APPENDIX K: Ethical Clearance from the HSE South East Ethics Committee

Ospidéal Ollscoile Phort Láirge
University Hospital Waterford
Regional Cancer Centre South East
Research Ethics Office Old School of Nursing
University Hospital Waterford

20th June 2018

Tel: 051- 842026/051-842391

Ms Charlene Somers
21 lakeside,
Our Lady's Island,
Broadway,
Co. Wexford.

STUDY TITLE: " What constitutes a good death: The view(s) of the general public and professionals working within generalised and specialised palliative care services in the Southeast of Ireland".

STUDY STATUS: APPROVED

Dear Ms Somers,

The Research Ethics Committee, HSE, South East reviewed the above Study and are happy to grant you Full Ethical Approval.

The following documents were reviewed and approved:

1. Research Ethics Standard Application Form.
2. Research Proposal
3. Interview Schedule
4. Survey
5. Participant Information Sheet
6. Participant Consent Form
7. Letter to Director of Nursing /General Manager /Department Head
8. Declaration Form
9. CV of Principal Investigator — Ms Charlene Somers

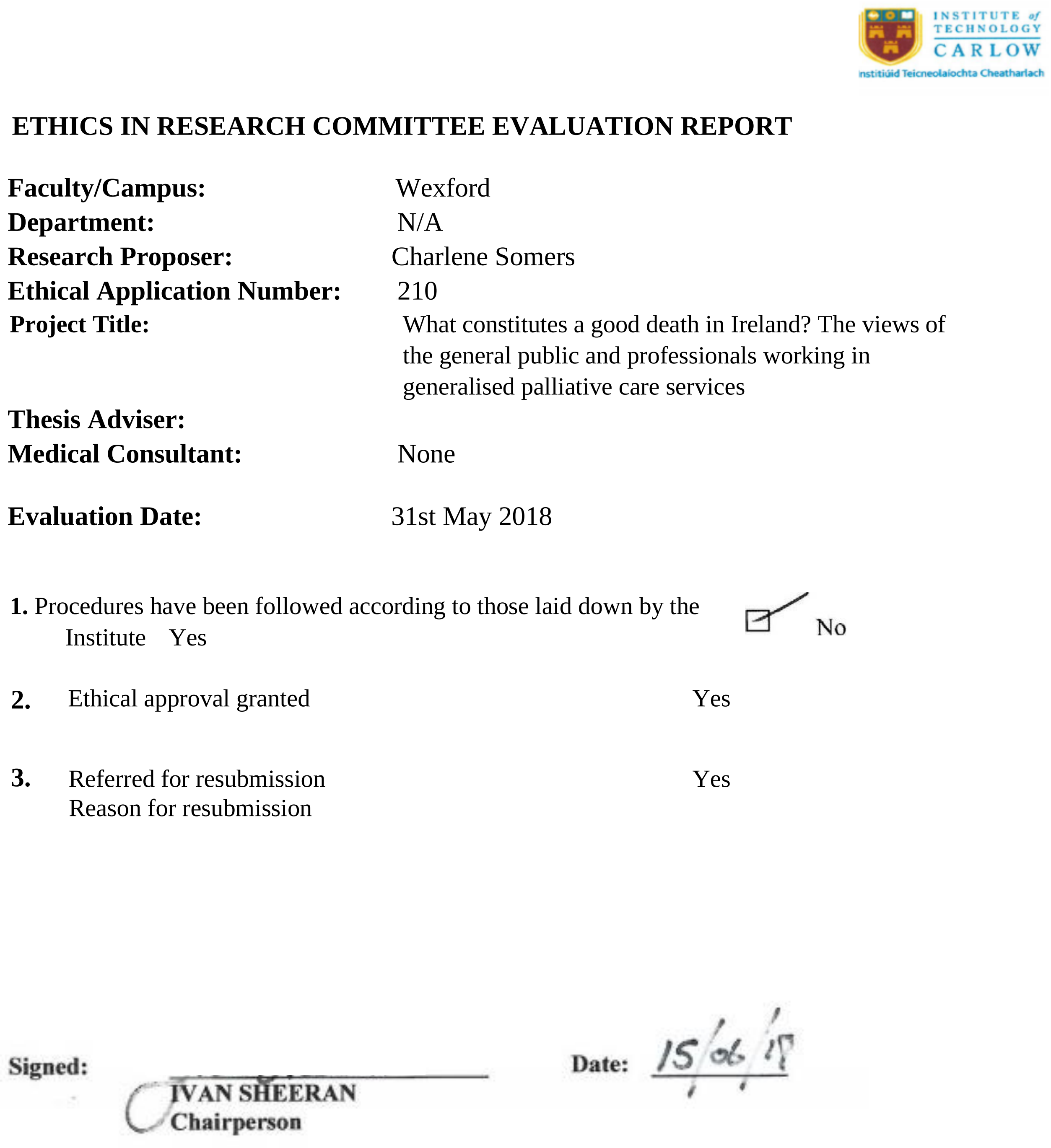
Yours sincerely,

Ms Caroline Lamb
Research Ethics Committee Coordinator
Health Service Executive, South Eastern Area

The Research Ethics Committee, HSE, South East is a recognized Ethics Committee under Regulation 7 of the European Communities (Clinical Trials on Medicinal Products for Human use) Regulations 2004 md as such is authorized to undertake ethical review of clinical trials of all descriptions and classes for the Republic of Ireland.

The Research Ethics Committee, HSE South East issues ethical approval on the basis of information provided. It is the responsibility of the researcher to notify the Research Ethics Office of any changes to a study to ensure that the approval is still relevant.

APPENDIX L: Ethical Clearance from the Institute of Technology Carlow



INSTITUTE of TECHNOLOGY CARLOW
Institiúid Teicneolaíochta Cheatharlach

ETHICS IN RESEARCH COMMITTEE EVALUATION REPORT

Faculty/Campus:	Wexford
Department:	N/A
Research Proposer:	Charlene Somers
Ethical Application Number:	210
Project Title:	What constitutes a good death in Ireland? The views of the general public and professionals working in generalised palliative care services
Thesis Adviser:	
Medical Consultant:	None
Evaluation Date:	31st May 2018

1. Procedures have been followed according to those laid down by the Institute Yes ☑ No

2. Ethical approval granted Yes

3. Referred for resubmission Yes
Reason for resubmission

Signed: **IVAN SHEERAN**
Chairperson

Date: 15/06/18

APPENDIX M: Sample Information & Request Letters for Participation

Letter to The Public and Professionals.

Date:

Title of this Research

What constitutes a good death: the views of the public and professionals working within generalised and specialised palliative care services in the Southeast of Ireland.

You are hereby invited to participate in this research study that is investigating public and professional perceptions of what it means to achieve a good death within Ireland. This study is being conducted as part of a Postgraduate Masters by Research Programme undertaken by the Researcher, Miss. Charlene Somers from the Department of Postgraduate Research at the Wexford Campus of the Institute of Technology Carlow. Dr. Veronica Kelly and Sheelagh Collier are the Research Supervisors overseeing this study. Both of whom are lecturers and highly experienced supervisors at the Institute of Technology Carlow, Wexford Campus.

You have been invited to participate in the research as you either provide end-of-life care and support services to individuals suffering from an incurable or terminal illness(es) and their family and caregiver(s), are over the age of 18 or you are a member of the general public. Please allow yourself time to think about partaking in this research before making a decision. The information you provide will be used for a master's dissertation project which, when completed a summary of findings can be made available to you, if you so wish, via a web link if you choose to participate in this research. It may also be used for possible academic publications such as peer-reviewed articles and conference materials. The research involves partaking in a semi-structured, face-to-face interview conducted by myself, Charlene Somers only, that will be arranged at a time and place that is convenient to you and will take approximately 1 hour to complete. If you would like to partake in this study, please contact the researcher via the contact details supplied at the end of this information letter.

While the information you provide for this study may not benefit you directly, it will help provide future recommendations for end of life care which will enhance service delivery, increasing supports and care for individuals suffering from a terminal illness(es) and their family/caregiver(s). Should the data be published, no individual information will be disclosed. Your participation in this study is voluntary. You may withdraw from this research at any stage without any incurring penalties. You also do not have to answer any question you do not want to.

The interview will be recorded using mobile voice recording software for the purpose of data transcriptions. No distinguishing features pertaining to you or in the case of professionals, the organisation you work in will be used to maintain confidentiality and anonymity. You will be assigned a pseudo name such as 'participant A'.

All data collected through interviews will be stored on a password-protected computer and an external hard drive, the sole property of the researcher that only she has access to for transportation purposes. All data collected from the hard drive will be stored in a securely locked filing system that only the researcher has access to in the Wexford Campus for the duration of 5 years. After this stage, all data will be destroyed beyond restoration. All data stored on the external hard drive will be deleted and the platter on the device will be destroyed. All data stored on the computer will be erased and all manual data obtained through transcriptions will be shredded.

Thank you for taking the time to read this material and also for volunteering, should you decide to do so. Please do not hesitate to contact me on the below details I would be happy to assist you should you require any further information or assistance regarding this research.

Name of the Researcher: Charlene Somers.
Department of Postgraduate Research.
Institute of Technology Carlow, Wexford Campus.
Email:

IT Carlow's Research Ethics Committee has reviewed and approved my request to conduct this project.

Kind regards,
Charlene Somers.

Permission Letter to Managers/Department Heads Requesting Access to Frontline Staff for This Research.

Date:

Dear: Manager/Department Head

RE: Permission to gain access to frontline staff for this research study.

My name is Charlene Somers and I am currently partaking in a two-year Postgraduate Masters by Research Programme, within the Wexford campus of the Institute of Technology Carlow. I am writing to you to request access to frontline staff in your organisation, over the age of 18 years old only (no patient involvement) for recruitment in a research study I am currently conducting. The title of my research is,

'What constitutes a good death: The views of the general public and professionals working within generalised and specialised palliative care services in the Southeast of Ireland.'

The concept of a good death largely depends upon individual interpretation. Loosely, it may be defined as one where an individual is free from pain, maintains independence and is in control of his/her fate in so far as possible. Although death is an inevitable human process, it remains a largely unspoken topic. Yet, when faced with a terminal or life limiting illness knowing individual's explicit wants, needs and desires is vital in ensuring care plans are individualised and end of life care is delivered in accordance with individual wishes. To establish this, the topic of death and what it means to have a good death must be openly discussed and acknowledged. This requires a joint approach by the general public and health and social care professionals working within generalised and specialised palliative care services.

By investigating what may constitute a good death from both the view of the general public and professionals the aim of this research is to ascertain if public ideals of a good death correlate to professional ideologies. It further aims to uncover what it means to have a good death in the 21st century and will explore if current end of life care service delivery meets these perceptions of a good death. Dr.Veronica Kelly and Sheelagh Collier are the Research Supervisors overseeing this research. Both of whom are lecturers and highly experienced supervisors at the Institute of Technology Carlow, Wexford Campus. Staff involvement, should access be granted, and they choose to partake in this research will include:

Partaking in a semi-structured, face-to-face interview that will be arranged at a time and location that is convenient to the participant and will take approximately 1 hour to complete. Interviews are anonymous. All participants will be given pseudo names.

While there are no incentives for partaking in this research, the findings will help provide future recommendations for end of life care which will enhance service delivery increasing supports and care for terminally ill individuals and their family/caregiver(s). Your approval to gain access to frontline staff in your organisation for this research would be greatly appreciated. I will follow up with a telephone call next week and would be happy to answer any queries or concerns that you may have at any stage.

You may contact me at any stage regarding this matter through the following email address: . I would like to thank you in advance for your consideration of this research and for taking the time to read this letter.

Kind regards,

Charlene Somers.

The Health Service Executive South-East Research Ethics Committee and IT Carlow's Research Ethics Committee has reviewed and approved my request to conduct this project.

APPENDIX N: Consent Form for all Participants.

Project Title

What constitutes a good death in Ireland: the views of the general public and professionals working within generalised palliative care services in the Southeast of Ireland.

Introduction

A good death is difficult to define owing to individual interpretation. Loosely, it may be defined as one where an individual is free from pain, maintains independence and is in control of his/her fate in so far as possible. Although death is inevitable it remains a largely unspoken topic. Yet, when faced with a terminal or life-limiting illness knowing individual's explicit wants, needs and desires is vital in ensuring care plans are individualised and end of life care is delivered in accordance with individual wishes. To establish this the topic of death and what it means to have a good death must be openly discussed and acknowledged. This requires a joint approach by the public and health and social care professionals.

Purpose of the study

By investigating what may constitute a good death from both the view of the general public and professionals working within end of life care, the aim is to discover if public ideals of a good death link to professional ideologies. It further aims to uncover what it means to have a good death in the 21st century and will explore if current end of life care service meets these perceptions of a good death.

Research Objective

1. What are the public and professional perceptions of what it means to have a 'good death?'
2. How are individual's and family/loved ones currently supported to achieve a good death?
3. What issues may arise which could impact upon individual opportunities to achieve a good death in Ireland?

You have been invited to participate in the research because you are either a member of the public over the age of 18 years old, a professional working within [13]generalist or specialist palliative care support services.

Description of the Study Procedures

For members of the public and professionals working within generalised and specialised palliative care services.

If you agree to take part in this research, your participation involves partaking in an interview session which will be arranged at a time and place that is convenient to you, taking approximately 1 hour to complete.

---

[13] Palliative care provided by health and social care professionals who do not specialise in the area are termed generalised professionals care professionals: Community Nurse, General Practitioner, Social Care Worker. Professionals who do specialise in the area of palliative care is known as specialist palliative care professionals (McVeigh et al., 2018): Oncologists and palliative Care Consultants.

McVeigh, C., Reid, J., Larkin, P., Porter, S. & Hudson, P. (2018). The provision of generalist and specialist palliative care for patients with nonmalignant respiratory disease in the North and Republic of Ireland: a qualitative stud. *BMC Palliative Care,* [online], 17(6), pp. 1-12, available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5504568/pdf/12904_2017_Article_220.pdf [accessed: 20th September 217].

The interview will be conducted by myself only (Charlene Somers, the researcher). You may avail of the line of questioning of the interview prior to the session being conducted. Should you wish and agree to participate please contact the researcher, Ms. Charlene Somers on the contact details provided at the end of the flyer, the information letter or this consent form.

Confidentiality

Interviews will be recorded using mobile voice recording software for the purpose of data transcriptions. No distinguishing features pertaining to you or in the case of professionals the organisation you work will be revealed to maintain confidentiality and anonymity. Instead, you will be assigned a pseudo name: 'participant A'. For transportation purposes, all data collected through interviews will be stored on a password encrypted external hard drive, the sole property of the researcher. After each interview, the data collected will be transferred to the researchers' office computer located within the Wexford Campus. This hard drive will be stored in a securely locked filing system that only the researcher has access to in the Wexford Campus for the duration of 5 years.

All data on the password protected computer will also be stored for 5 years and thereafter destroyed. The results of this study will be used for the purpose of a master's dissertation, possible peer-reviewed journal publication(s) and conference presentations**.** A summary of the research findings will be made available to you if you so wish. Upon completion of the interview you will asked if you would like to be provided a summary of findings. If you express a desire to do your contact details will recorded and the summary will be supplied in late May, early June 2019.

Risks/Discomforts of Being in this Study

Participation in this research should not exceed risk that you would otherwise encounter throughout your normal daily routine. However, it is recognised throughout current literature that even though death is an inevitable human process, (Walker & Crawford, 2014) it is an emotive topic that may potentially cause discomfort. To minimise this risk, proceeding an interview session, you will be debriefed and offered contact details of online and low-cost counseling support services within your geographic locality should you feel the need to pursue such services.

Benefits of Participating in the Study

While there are no benefits/incentives monetary or otherwise for your participation in this research, the views that you may provide will be invaluable. Your responses will help provide future recommendations for end of life care which will enhance service delivery increasing supports and care for individuals suffering from a terminal illness(es) and their family/caregiver(s).

Right to Withdraw from this Research

The decision to participate in this research is entirely up to you. You have a right to withdraw from this research at any stage with no incurring penalty(ies). You also do not have to answer any question(s) in the interview if they do not want to without giving rationale. If you have any questions or concerns about the study, please do not hesitate to contact the researcher, Ms. Charlene Somers, on the following contact details:

Name of Researcher: Charlene Somers.
Department of Postgraduate Research.
Institute of Technology Carlow, Wexford Campus.
Email:

CONSENT

Your signature below indicates that you have decided to volunteer as a research participant in this study.

Signature: ____

I have read and understood the information in this form. My questions and concerns have been answered by the researcher, and I have a copy of this consent form. Therefore, I consent to take part in this research project entitled: “What constitutes a good death in Ireland: the views of the general public and professionals working within generalised palliative care services in the Southeast of Ireland.”

Participants Signature: __________________________ Date: __________________________

Researchers Signature: __________________________Date: _________________________

Thank You for your participation in this research.

APPENDIX O: Summary of Study Findings Given to Participants

This summary booklet was supplied to participants via email or in person.

Thank You

To all participants involved in this study. I would sincerely like to thank you all your involvement in this study. Without you this project would not have been possible.

Researcher: Charlene Somers

E-mail address:
charlene.somers@itcarlow.ie
charlenesomers1@googlemail.com

WEXFORD CAMPUS
INSTITUTE of TECHNOLOGY
CARLOW

WEXFORD CAMPUS
INSTITUTE of TECHNOLOGY
CARLOW

WHAT CONSTIUTES A GOOD DEATH: PERCEPTIONS OF THE PUBLIC & PROFESSIONALS WORKING WITHIN GENERALIST AND SPECIALIST PALLAITIVE CARE SERVICES IN THE SOUTHEAST OF IRELAND

Booklet Summary of Study Findings

Findings on What Constitutes a GD?

Definitions of a Good Death According to All Participant Groups

The Public

A Good Death for the public is one that is pain and fear free, surrounded by loved ones, having choice, control, dignity, respect, independence maintained and being at peace with a life well lived.

Generalised Professionals

A Good Death D is one that is pain, fear and suffering free, surrounded by family/others, having individualistic, person-centred care and making care preferences known and having them followed and being at peace.

Specialised Professionals

A Good Death is one without suffering of any kind, surrounded by family, being aware and informed, having death preparation in place and followed, being treated with dignity and being at peace.

Findings on What Constitutes a GD?

1. While change is evolving, death remains a social taboo.
2. The public and generalised professionals are largely in agreement on their opinions of a GD.
3. Owing to the uniqueness of individual interpretations, a GD may be impossible to definitively define.
4. Females may be less likely to engage in conversations on death and dying than males.

Findings on Views of Current Supports to Obtain A GD

1. A medical model of care dominates current palliative care service delivery much to the dismay of professionals.
2. Home remains the publics preferred place of care if suffering from a terminal illness.
3. The public lack awareness of Advanced Healthcare Directives and the benefits of death preparation and planning for individuals and their family/loved ones.
4. Socio-cultural aspects and beneficence for others hinders public engagement in death preparation and planning.
5. The public are unaware of the difference between palliative and hospice care services, the important role they play in the lives of the terminally ill and their families/loved ones and the challenges they experience in their professional roles.

6. Whilst religion remains significant for some, both the public and professionals affirm spirituality is gaining significance in Ireland
7. This study suggests age, gender, personal experience of death and dying, media reportage and socio-cultural norms may influence public perception(s) on death and dying matters.

Findings on Perceived Challenges in Obtaining a Good Death

1. Generalised professionals may have minimal training in the area of palliative care.
2. This study confirms a lack of supports for professionals and family/ loved ones of the terminal ill.
3. Professionals identified informal social supports are diminishing due to changes in family structures.
4. Socio-cultural norms of death avoidance and misinformed media coverage have led to preconceived, misinformed public ideals on death and dying and a lack of openness on this topic, making it extremely difficult for professionals to instigate public engagement on death and dying. Yet, findings from this study show if encouraged, most of the public (70%) may be at least be open to the possibility of discussing this topic.
5. Various resource issues impede generalist and specialist professionals in assisting terminally ill individuals and their families/love ones.

APPENDIX P: Sample Strategy to Minimise Potential Discomfort for Participants.

Given that this research is of a sensitive nature discomfort may unintentionally evolve. To eliminate potential harm the researcher repeatedly made participants fully aware of the research subject matter. They were also regularly informed at various stages throughout this study that they had a right to withdraw from this research at any stage if they so wish. Furthermore, low-cost counselling support numbers within participants geographic locations and online counselling links were made available should the need arise for all participants within phase two of this research. Below is an example of such within the Wexford locality.

1. 'It's Good 2 Talk' - counselling service

Address: Spawell Road, Wexford.

Contact Number: 053 9126596

Email Address: itsgood2talkwexford@gmail.com

Provides: Low-cost professional counselling and supports.

16 years' experience.

2. South East Counselling Services

Address: 19 South Day Point,
Rosslare,
Co. Wexford.

Contact Number: 059 9142208

Mobile: 087 245090

Email address: mary@southeastcounsellingservcies.ie

3. Turn 2 Me

Online Counselling Support Service

Email Address: www.turn2me.org

Provides: Low-cost professional counselling and supports.

Note to Reader: Although this research was significant from an academic point of view, my main priority was for the safety and well-being of the participants. Hence, a guiding principle was to do no harm. By fully informing all participants beforehand of the nature of this research, conducting a pilot study, providing a debriefing session after interviews and offering a list of local support services within participants geographic locations, I feel I minimised the possibility of the onset of discomfort in so far as possible.

APPENDIX Q: Demographic Profile of All Participants

a) The Public

TABLE 1: DEMOGRAPHIC PROFILE OF THE PUBLIC

Gender	Age (AB)	Ethnicity	County of Residence	Occupation	Group Affiliation	Educational Attainment	Religious Belief
Male (M) **5**	***37-47*** ***5***	**Irish (I)** 9	Wexford **(WX)** 9	Events Technician 1	GAA Club 4	Leaving Cert 5	Pantheism 1
	59-69 ***2***			Student Farm Assistant 1		Honours Degree 2	Atheist 1
	48-55 ***1***			Housewife 1	Drama Group 2	Masters Level	Catholic-Loosely practicing 2
				Retired 1	Liberal Studies Group 1		
Female (F) **5**		**English (E)** **1**		Property Valuer 1	Book Club 1		Catholic Non-Practicing 2
			Kilkenny **(KK)** 1	Engineer 1	Immigrant Group 1	Junior Cert & Diploma 1	Catholic – practicing 4
	18-25 ***1***			Outreach Worker 1		PhD 1	
				Social Care Worker 1	Relay for Life 1		
	26-36 ***1***			Farmer 1	Community Committee Group 1		
	70-80			Butcher 1			

b) Generalised Professionals

<table>
<tr><th colspan="9">TABLE 2: DEMOGRAPHIC PROFILE OF GENERALISED PROFESSIONALS</th></tr>
<tr><th>Gender</th><th>Age (AB)</th><th>Ethnicity</th><th>County of Residence</th><th>County of Workplace</th><th>Service Setting</th><th>Job Title</th><th>Educational Attainment</th><th>Level of Experience</th></tr>
<tr><td rowspan="4">Female (F)
8</td><td rowspan="2"><i>37-47</i>
<i>3</i></td><td rowspan="4">English (E)
1</td><td rowspan="2">Kilkenny (KK)
1</td><td rowspan="4">Wexford (WX)
7</td><td>Hospital Setting
1</td><td rowspan="3">Healthcare Assistant
4</td><td rowspan="3">FETAC level 5
3</td><td rowspan="2">19 years
2</td></tr>
<tr><td>Community Homecare
3</td></tr>
<tr><td rowspan="2"><i>59-69</i>
<i>2</i></td><td rowspan="3">Wexford (WX)
7</td><td>Eldercare Residential Setting with Hospice Unit
2</td><td rowspan="2">1 year
2</td></tr>
<tr><td rowspan="2">Eldercare Residential Setting without Hospice Unit
1</td><td rowspan="2">Nurse
2</td><td rowspan="2">Honours Degree
2</td></tr>
<tr><td rowspan="5">Male (M)
1</td><td rowspan="2"><i>48-58</i>
<i>2</i></td><td rowspan="5">Irish (I)
8</td><td rowspan="2">Kilkenny/Carlow (C/KK)
1</td><td>6 years
1</td></tr>
<tr><td rowspan="4">Wicklow (WW)
1</td><td rowspan="3">Youth Residential Care Setting
1</td><td>Social Care Worker
1</td><td>Ordinary Degree
1</td><td>5 years
1</td></tr>
<tr><td rowspan="3"><i>18-25</i>
<i>2</i></td><td rowspan="3">Wicklow (WW)
1</td><td rowspan="2">Outreach Officer HfH Programme
1</td><td>Conventional Nursing Training
1</td><td>8 years
1</td></tr>
<tr><td>Masters Level
1</td><td>15 years
1</td></tr>
<tr><td>Community Pastoral Care
1</td><td>Catholic Priest
1</td><td>PhD
1</td><td>20 years
1</td></tr>
</table>

SUMMARY OF PROFILE SIMULARITIES AMONG GENERALISED PROFESSIONALS			
Gender	Females		
Total:	**9**		
Age Range	37-47	48-58	59-69
Total:	**4**	**2**	**2**
Ethnicity	Irish		
Total:	**9**		
County of Workplace	County Wexford		
Total:	**7**		
Service Setting:	Community Homecare	Eldercare Residential Service with Palliative Care Beds	
Total	**4**	**2**	
Occupation	Nurse	Healthcare Assistant	
Total:	**2**	**4**	
Education:	FETAC level 5	Honours Degree Level 8	Masters Level 9
Total:	**3**	**2**	**2**
Experience	**19 years**		
Total:	**2**		

SUMMARY OF PROFILE SIMULARITIES AMONG THE PUBLIC			
Religion	Catholic Practicing	Catholic Loosely practicing	Catholic Non-practicing
Total:	**3**	**2**	**2**
County of Residence	Wexford	Kilkenny	
Total:	**9**	**1**	
Ethnicity	Irish	British	
Total:	**9**	**1**	
Education	Leaving Certificate Masters	Masters Level	
Total:	**4**	**2**	
Gender	Male	Female	
Total:	**5**	**5**	
Age	**37-47**	**59-69**	
Total:	**4**	**2**	

c) Specialised Professionals

TABLE 3: DEMOGRAPHIC PROFILE OF SPECIALISED PROFESSIONALS

Gender	Age (AB)	Ethnicity	County of Residence	County of Workplace	Service Setting	Job Title	Educational Attainment	Level of Education
Female (F) 4	***37-47*** ***4***	Irish **(I)** 5	Wexford **(WX)** 3	Wexford **(WX)** 3	Palliative /Hospice Homecare 3	Clinical Nurse Specialist In Palliative Care 3	Masters in Palliative Care 2	28 years 1
								5 years 1
							Higher Diploma in Palliative Care 1	4 years 1
Male (M) 1	***48-58*** *1*		Kilkenny **(KK)** 1	Wexford & Waterford **(WX/WW)** 1	Acute & General Hospital Setting 2	Consultant in Palliative Medicine 1	Postgraduate Diploma 1	15 years 1
			Waterford **(WW)** 1	South Tipperary **(TS)** 1		Clinical Nurse Manager 1	Masters & Fellowship 1	25 years 1

SUMMARY OF PROFILE SIMULARITIES AMONG SPECIALISED PROFESSIONALS		
Gender	Females	
Total:	**4**	
Age Range	37-47 age bracket	
Total:	**3**	
Ethnicity	Irish	
Total:	**4**	
County of Workplace	County Wexford	
Total:	**3**	
Service Setting:	Palliative/Hospice Homecare	Specialised Palliative Care in Acute Hospital Setting
Total	**2**	**2**
Occupation	Nurse	
Total:	**3**	
Education:	Postgraduate Diploma	Masters Level 9
Total:	**2**	**2**

APPENDIX R: All Characteristics of a GD Uncovered.

Characteristics of a GD According to the Public				
Members of the Public				
Characteristics of a GD	**Number of Participants**	**Participant Coding**	**% Per Group**	**% of Study Population**
1. Pain-Free	**5**	**P- C, L, M, O & W**	**50%**	**20.8%**
2. Choice and Control	**5**	**P- D, H, O, P & K**	**50%**	**20.8%**
3. Surrounded by Loved Ones	**4**	**P- C, L, M & W**	**40%**	**16.6%**
4. At Peace	**4**	**P- C, D, L & Q**	**40%**	**16.6.%**
5. Comfortable	**3**	**P- C, M & W**	**30%**	**12.5%**
6. Independence	**2**	**P- N & Q**	**20%**	**8.3%**
7. Dignity	**2**	**P- O & P**	**20%**	**8.3%**
8. Quickly	**2**	**P- M & Q**	**20%**	**8.3%**
9. Unaware	**2**	**P- M & W**	**20%**	**8.3%**
10. Without Fear	**2**	**P- C & L**	**20%**	**8.3%**
11. Respect	**1**	**P- C**	**10%**	**4.1%**
12. Affairs in Order	**1**	**P- C**	**10%**	**4.1 %**
13. Aware	**1**	**P- L**	**10%**	**4.1%**
14. At Home	**1**	**P- C**	**10%**	**4.1%**
15. Planning and Preparation	**1**	**P- C**	**10%**	**4.1%**
16. Individualistic	**1**	**P- C**	**10%**	**4.1%**
17. No Regrets	**1**	**P- L**	**10%**	**4.1%**
18. Natural Causes	**1**	**P- H**	**10%**	**4.1%**
19. Person-Centred	**1**	**P -C**	**10%**	**4.1%**
20. Acceptance of Death	**1**	**P- L**	**10%**	**4.1%**
21. Support for Family	**1**	**P- P**	**10%**	**4.1%**
22. Sudden	**1**	**P- Q**	**10%**	**4.1%**
23. Family Support	**1**	**P - P**	**10%**	**4.1%**
24. Adequate Pain and Symptom Control	**1**	**P - C**	**10%**	**4.1%**

Characteristics of a GD According to Generalised Professionals				
Generalised Professionals				
Characteristics of a GD	**Number of Participants**	**Participant Coding**	**% Per Group**	**% of Study Population**
1. Pain-Free	**6**	**P-, G, J, R, U, V, X**	**66.1%**	**25%**
2. Support for Family	**5**	**P-A, F, J, R, V**	**55.1%**	**20.8%**
3. Supports for Individuals	**5**	**P-A, F, G, J, V & R**	**55.1%**	**20.8%**
4. Surrounded by Loved Ones	**4**	**P-B, G, R & F**	**44.1%**	**16.6%**
5. Professional Support	**3**	**P-B, R, U**	**33.1%**	**12.5%**
6. Total Pain Approach to Care	**3**	**P-A, B, J**	**33.1%**	**12.5%**
7. Comfortable	**3**	**P-U, B & A**	**33.1%**	**12.5%**
8. Person-Centred	**3**	**P-A, B & X**	**33.1%**	**12.5%**
9. Not Alone	**2**	**P-B & G**	**22.1%**	**8.3%**
10. Family Support	**2**	**P—R & U**	**22.1%**	**8.3%**
11. Choice and Control	**2**	**P-B & X**	**22.1%**	**8.3%**
12. Planning and Preparation	**2**	**P-A & F**	**22.1%**	**8.3%**
13. At Peace	**2**	**P-J & F**	**22.1%**	**8.3%**
14. To be Unaware	**2**	**P-U & X**	**22.1%**	**8.3%**
15. Quickly	**2**	**P-U & X**	**22.1%**	**8.3%**
16. Adequate Symptom Management	**2**	**P-A & B**	**22.1%**	**8.3%**
17. Dignity	**2**	**P-X & B**	**22.1%**	**8.3%**
18. Support for Professionals	**2**	**P – A & J**	**22.1%**	**8.3%**
19. Love	**1**	**P-B**	**11.1%**	**4.1%**
21. Acceptance of Death	**1**	**P-F**	**11.1%**	**4.1%**
22. Affairs in Order	**1**	**P-F**	**11.1%**	**4.1%**
23. At Home	**1**	**P-R**	**11.1%**	**4.1%**
24. Without Dependents of any Kind	**1**	**P-F**	**11.1%**	**4.1%**
25. To Be Aware	**1**	**P-A**	**11.1%**	**4.1%**
26. Respect	**1**	**P-B**	**11.1%**	**4.1%**
27. Private Time with Loved One's	**1**	**P-F**	**11.1%**	**4.1%**
28. Facilitated with Enjoyment Through Meaningful Activities Where Possible	**1**	**P-G**	**11.1%**	**4.1%**
29. Natural Causes	**1**	**P- U**	**11.1%**	**4.1%**
30. In a Place of Ones Choosing	**1**	**P-R**	**11.1%**	**4.1%**
31.Without Fear	**1**	**P - V**	**11.1%**	**4.1%**

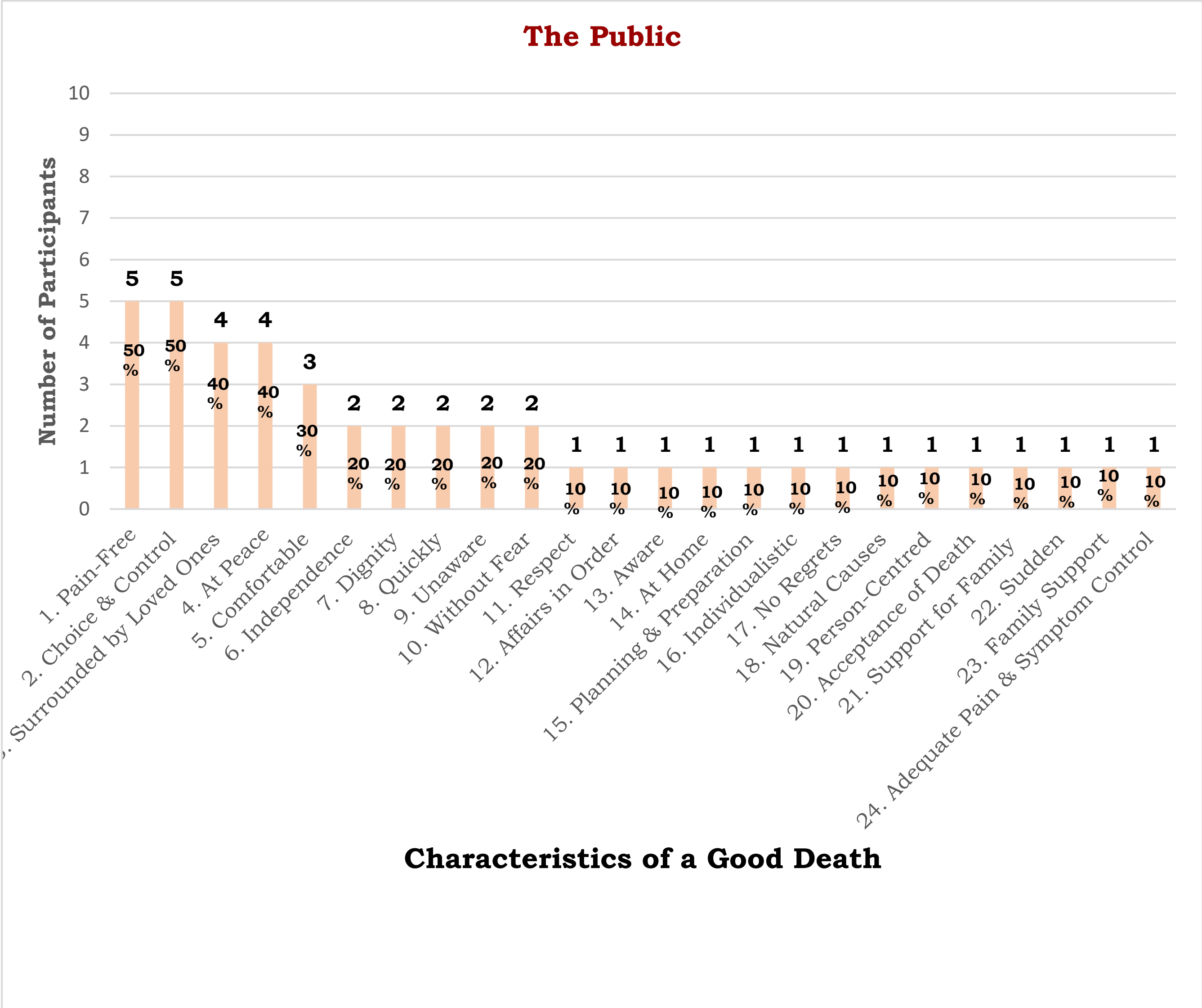
Characteristics of a GD According to Generalised Professionals				
Specialised Professionals				
Characteristics of a Good Death	**Number of Participants**	**Participant Coding**	**% Per Group**	**% of Study Population**
1. Professional Supports	4	P- E, I, K & S	80%	16.6%
2. Family Support	3	P- I, S & T	60%	12.5%
3. Comfortable - Peaceful	3	P- K, I & S	60%	12.5%
4. Without Suffering of Any Kind	2	P- E & T	40%	8.3%
5. Pain-Free	2	P-E & T	40%	8.3%
6. Total Pain Approach	2	P- I & T	40%	8.3%
7. Adequate Symptom Management	2	P- K & E	40%	8.3%
8. Surrounded by Loved Ones	2	P- I & K	40%	8.3%
9. Fully Informed [Aware]	2	P- K & T	40%	8.3%
10. Dignity	2	P-E & S	40%	8.3%
11. According to Personal Preferences-Individualistic	1	P- S	20%	4.1%
12. Planning and Preparation	1	P- T	20%	4.1%
13. Preferences Reviewed	1	P-K	20%	4.1%
14. Support for Family	1	P- S	20%	4.1%
15. Support for Individual	1	P- S	20%	4.1%
16. Choice and Control	1	P- K	20%	4.1%
17. Open Transparency Between the Individual and Family	1	P- I	20%	4.1%
18. Effective Multidisciplinary Team Involvement	1	P-S	20%	4.1%
19. Respect	1	P- S	20%	4.1%
20. Support for Professionals	1	P- K	20%	4.1%
21. Person Centred	1	P- K	20%	4.1%

Total GD Characteristics Uncovered	
The Public	**24**
Generalised Professionals	**31**
Specialised Professionals	**21**
Overall Total	**76**

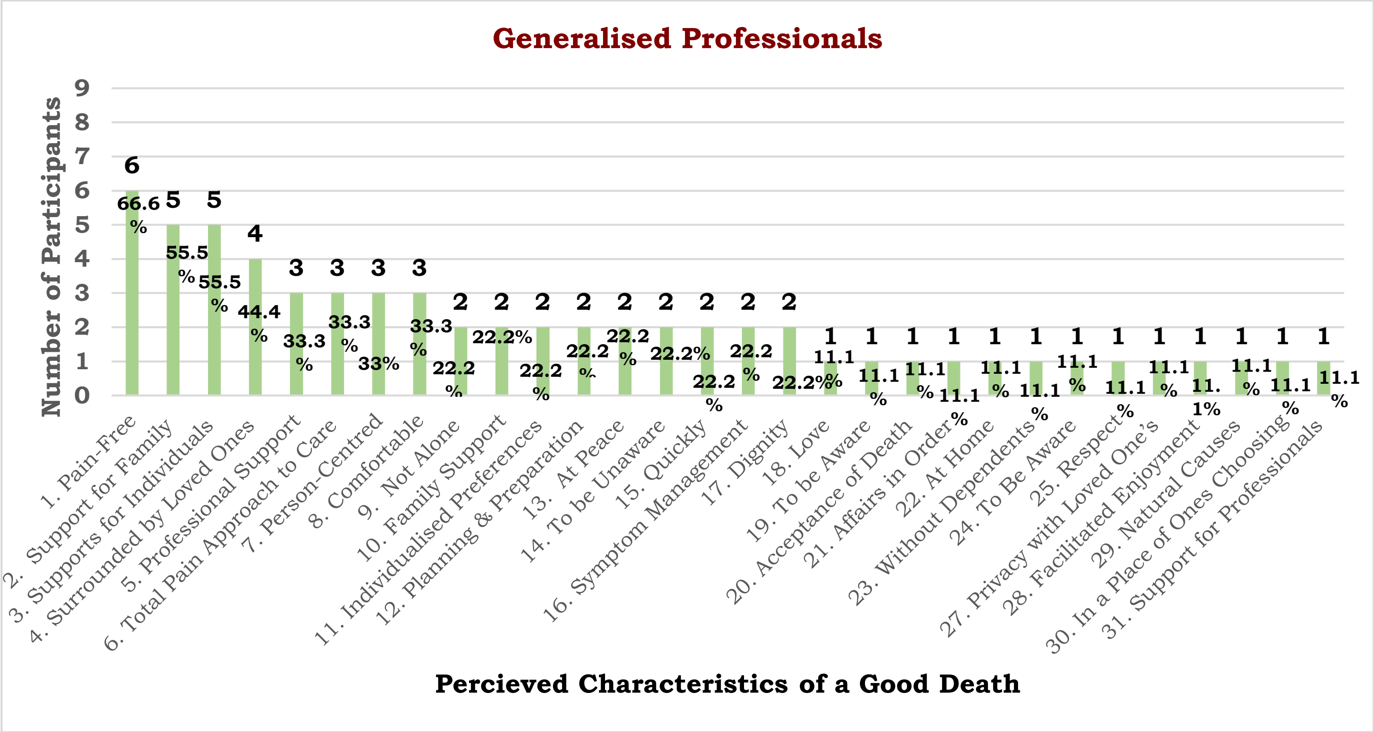
APPENDIX S: Perceived Characteristics of a GD Among Each Participant Group.

A full breakdown of GD characteristics according to each group.

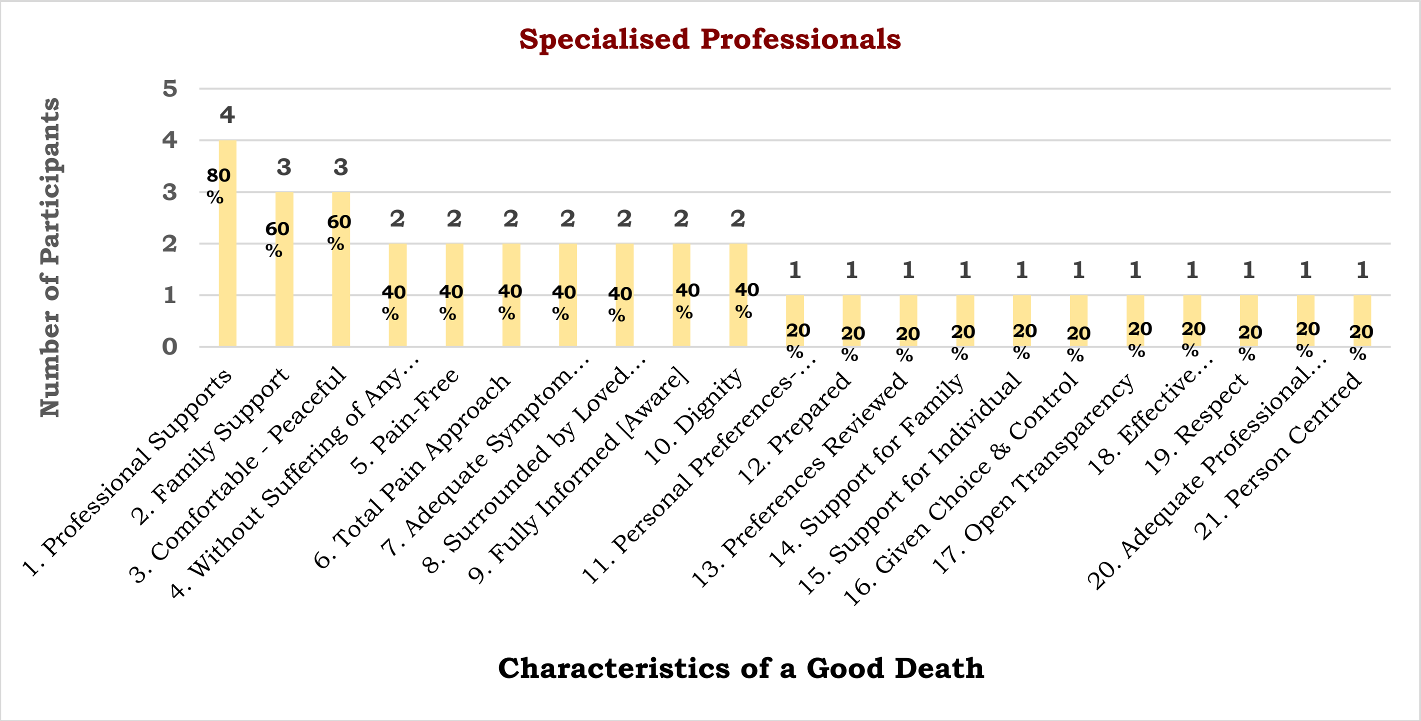
The Publics Perceived Characteristics of a GD



Generalised Professionals Perceived Characteristics of a GD



Specialised Professionals Perceived Characteristics of a GD



The Top Ten Characteristics of a GD uncovered by each group.

a. The Public

Publics Top Ten Characteristics of a GD	
Public Characteristics of a Good Death	**Percentage**
1. Pain-Free	5 (50%)
2. Choice and Control	5 (50%)
3. Surrounded by Loved Ones	4 (40%)
4. Life Completion	4 (40%)
5. Comfortable	3 (30%)
6. Independence	2 (20%)
7. Dignity	2 (20%)
8. Quickly	2 (20%)
9. Unaware	2 (20%)
10. Without Fear	2 (20%)

b. Generalised Professionals

Generalised Professionals Top Ten Characteristics of a GD	
Generalised Professionals Characteristics of a Good Death	**Percentage**
1. Pain-Free	6 (66%)
2. Support for Family	6 (66%)
3. Supports for Individuals	5 (55%)
4. Surrounded by Loved Ones	4 (44%)
5. Professional Support	3 (33%)
6. Total Pain Approach to Care	3 (33%)
7. Not Alone	3 (33%)
8. Family Support	3 (33%)
9. Comfortable	3 (33%)
10. Person-Centred	3 (33%)
11. According to Individual Preferences	2 (22%)
12. Planning and Preparation	2 (22%)
13. At Peace	2 (22%)
14. To be Unaware	2 (22%)
15. Quickly	2 (22%)
16. Adequate Symptom Management	2 (22%)
17. Dignity	2 (22%)
18. Love	1 (11%)

c. Specialised Professionals

Specialised Professionals Characteristics of a GD	
Specialised Professionals Characteristics of a Good Death	**Percentage**
1. Professional Supports	4 (40%)
2. Family Support	3 (30%)
3. Comfort	3 (30%)
4. Without Suffering of Any Kind	2 (20%)
5. Pain-Free	2 (20%)
6. Total Pain Approach	2 (20%)
7. Adequate Symptom Management	2 (20%)
8. Surrounded by Loved Ones	2 (20%)
9. Fully Informed [Aware]	2 (20%)
10. According to Personal Preferences-Individualistic	1 (10%)

APPENDIX T: Similarities and Differences Between All Groups on Perceived Characteristics of A GD

Characteristics Shared Across All Groups					
Characteristics	Public	Generalised Professionals	Specialised Professionals	Total	Percentage of Total Population
Pain free	5 **P- C, L, M, O & W**	6 **P-, G, J, R, U, V, X**	2 **P-E & T**	13	54.1%
Surrounded by Loved Ones	4 **P- C, L, M & W**	4 **P-B, G, R & F**	2 **P- K & E**	10	41.6%
Choice and Control	5 **P- D, H, O, P & K**	2 **P-B & X**	1 **P- K**	8	33.3%
Support for Family	1 **P - P**	5 **P-A, F, J, R, V**	1 **P - S**	7	29.1%
Dignity	2 **P- O & P**	2 **P-X & B**	2 **P-E & S**	6	25%
Family Support	1 **P - P**	2 **P- R & U**	3 **P- I, S & T**	6	25%
Person-Centred	1 **P- C**	3 **P-U, B & A**	1 **P - K**	5	20.8%
Adequate Pain and System Management	**1** **P - K**	2 **P-A & B**	2 **P- K & E**	5	20.8%
Planning and Preparation	1 **P - C**	2 **P – A & F**	1 **P - T**	4	16.6%
Aware/Informed	1 **P- L**	1 **P – A**	**2** **P- K & T**	4	16.6%
Respect	1 **P- C**	1 **P - B**	1 **P- S**	3	12.5%

Other Characteristic Shared Among the Public & Generalised Professionals		
Characteristic	**Public**	**Generalised Professionals**
1. At Home	**1** **P- C**	**1** **P-R**
2. Acceptance of Death	**1** **P – L**	**P-F**
3. Quickly	**2** **- M & Q**	**2** **P - U & X**
4. Unaware	**2** **P- M & W**	**2** **P - U & X**
5. Natural Causes	**1** **P - H**	**1** **P – U**
6. With Fear	**2** **P- C & L**	1 P - V

Characteristics Shared Among Professionals		
Characteristics	**Generalised Professionals**	**Specialised Professionals**
1. Support for Family	**5** **P-A, F, J, R, V**	**1** **P - S**
2. Support for Individual	**5** **P-A, F, G, J, V & R**	**4** **P- E, I, K & S**
3. Professionals Support	**3** **P-B, R, U**	**4** **P- E, I, K & S**
4. Total Pain Approach	**3** **P-A, B, J**	**2** **P- I & T**
5. Support for Professionals	**2** **P – A & J**	**1** **P – K**

APPENDIX U: Summarised Breakdown of Good Death Findings

SUMMARY OF MAIN RESEARCH FINDINGS				
THEME ONE: PAIN				
Overall total of study population		**Participants** **18**		**Percentage total** **75%**
Subtheme	**Public**	**Generalised Professionals**	**Specialised**	**Total**
1. Pain-free	5 ***P, C, L, M O & W***	6 ***G, J, R, U, V & X***	2 ***E & T***	13
2. Without Suffering of any kind	0	1 ***J***	2 ***E & T***	3
3. Pain Management and Symptom	**1** ***C***	**3** ***A, B & R***	**1** ***K***	5
1. Fear of Death in relation to pain	**1** ***C***	**2** **V & L**		3
THEME TWO: FAMILY/HAVING A SENSE OF ACCOMPANIMENT				
Overall total of study population		**Participants** **17**		**Percentage total** **71%**
Subtheme	**Public**	**Generalised Professionals**	**Specialised**	**Total**
1. Family	4 ***C, L, M & W***	4 ***B, G, R & F***	2 ***I & K***	10
2. Accompaniment of Any Kind	0	***3*** ***F, G & B***	0	3
3. Not to be Alone	1 ***C***	3 ***G, F & B***	1 ***K***	4
THEME THREE: CONTROL				
Overall total of study population		**Participants** **13**		**Percentage total** **54%**
Subtheme	**Public**	**Generalised Professionals**	**Specialised**	**Total**
1. Choice and Control	4 ***D, H, O & P***		2 ***K & T***	6
50% of the Public believe individuals do not have choice and control				
Due to: **1 (a):** Cognitive decline **1 (b):** Lack of euthanasia Practices in Ireland		Participant Name ***O, N, M & C*** ***P, M, N & D***		4 4
Subtheme	**Public**	**Generalised Professionals**	**Specialised**	**Total**
2. Dignity	2 ***P & H***			2
3. Aware and Informed	1 ***L***	2 ***A & F***	2 ***T & K***	4
4. Person-Centred	1 ***C***	4 ***X, B, A & G***	0	5
5. Death preparation and Planning	Conflicting views	9	5	14
Public gave conflicting views Only enact planning and preparation in relation to beneficence for others When older If faced with a terminal illness				*1 - C* 1 - ***D*** 2 – ***M & D***
THEME FOUR: MAINTAINING PERSONHOOD				
Overall total of study population		**Participants** **12**		**Percentage total** **50%**
Subtheme	**Public**	**Generalised Professionals**	**Specialised**	**Total**
1. At Peace	4 ***C, L, D & O***	2 ***J & F***	3 ***K, I & S***	9
(a) Life Completion	4 ***C, L, D & O***	0	0	4
(b) No Regrets	2 ***D & L***	0	0	2
(c) Closure	0	1 F	0	1
2. Dignity	2 ***O & P***	2 ***X & B***	2 ***S & E***	6
3. Respect	1 ***C***	1 ***B***	1 ***S***	3
Participant Name		**NEW THEME: INDEPENDENCE**		**Total**
Participant N		**Participant Q**		2

APPENDIX V: Evaluation of the BPSSM of Care in Palliative Care According to All Participant Groups.

Evaluation of the BPSS Model of Palliative Care					
Do you believe people are supported socially, psychologically, financially, religiously and spiritually to have a GD?					
The Public					
Socially	Yes	No	Yes & No	Don't Know	**Depends on Social Networks**
	4	**3**	**2**	**1**	**5**
Psychologically	No	Depends on Social Networks	Depends on The Individual		
	6	**2**	**2**		
Financially	Yes	No	Yes & No	Not Sure	Not Enough
	1	**5**	**1**	**2**	**1**
Religiously	Yes	No	Not Enough	**Not sure on Faiths other than Catholic Beliefs**	
	7	**2**	**1**	**4**	
Spiritually	Yes	Not Enough	Depends on the Individual	Don't Know	
	4	**2**	**1**	**2**	
Generalised Professionals					
Socially	No	Yes			
	4	**5**			
Psychologically	Yes	No	Somewhat		
	2	**5**	**2**		
Financially	Yes	No	Somewhat	Don't Know	
	2	**2**	**2**	**3**	
Religiously	Yes	No			
	7	**2**			
Spiritually	Yes	No	Depends		
	4	**2**	**2**		
Specialised Professionals					
Social	Yes	No	Somewhat		
	1	**3**	**1**		
Psychologically	Not Enough	Depends on the Individual			
	3	**2**			
Financially	No	Not Enough			
	4	**1**			
Religiously	Yes	No	Depends on the Individual		
	3	**1**	**1**		
Spiritually	No	Depends on the Individual	Not Enough		
	3	**1**	**1**		

APPENDIX W: Social Welfare Entitlements for Individuals Suffering from chronic or intractable Illness

a) The Fair Deal Scheme

The Fair Deal Scheme implemented to assist in Homecare packages and residential care costs is deemed incur untold stressors. The application process has been described as difficult to manoeuvre and can involve extended waiting periods for approval, meaning many older individuals have inappropriately being placed in acute hospital settings indefinitely where their needs are not fully addressed (KildareStreet, 2014). This further impacts upon resource issues in these settings and has condemned older individuals unjustly as 'Bedblockers' (The Irish Times, 2017).

b) Medical Cards

Implemented under the Healthcare Act (1970), eligibility of medical cards for applicants with an illness or disease is dependent upon an individual's financial means to cover expenditure costs of treatment, not by virtue of disease or illness (Department of Health, 2019). The HSE implemented the provision of emergency medical cards for individuals in receipt of palliative care services with a fast-tracking system of 24 hours from receipt of the application. In the case of the terminally ill, no means test applies and an emergency medical card is issued for the period of 18 months upon verification of a terminal diagnosis from a consultant or GP. Yet, many terminally ill individuals may live longer than this period meaning reapplication may be a distinct possibility at a time of great vulnerability. Furthermore, for those with non-terminal conditions or reversable illness such as, early stages of many forms of cancer in receipt of palliative care eligibility depends upon individual means. While the HSE introduced a discretionary medical card for individuals above the financial means threshold who can prove they may suffer 'undue hardships' if refused a card, the Irish Cancer Society, (2014) proclaims accessibility for the self-employed remains extremely difficult. Furthermore, the society concurs this application process is insensitive and can be taxing for applicants causing undue stress and discomfort at a time of great vulnerability (The Irish Cancer Society, 2014). The automated sanctioning of medical cards based on illness type was explored by the HSE, yet they concluded it would be unfeasible, undesirable and unethical to prioritise one illness over another. Therefore, no reform was made (KildareStreet, 2018).

c) Social Welfare Subsidies

Social Welfare Entitlements – for the chronic and terminally ill	
Illness Benefit Means tested	If no longer capable of work.
Supplementary Welfare Allowance	May be payable while awaiting a decision on decision of Illness benefit.
Invalidity Pension This payment also entitles a recipient to free travel pass	May be payable to individuals who as permanently incapable of employment.
All entitlements are means tested and subject to a medical assessment conducted by a medical assessor of the Department of Social Welfare (Department of Employment Affairs and Social Protection, 2019).	
Carers benefit €215.00 weekly	Applicable to those who leave employment to become a full-time caregiver.
Carers Allowance €214.00 to €262.00 weekly	Applicable to long-term full-time caregivers of an individual with a terminally illness or disability (Department of Employment Affairs and Social Protection, 2019).
Informal Caregiver Entitlements	
Carers Support Grant €1,700 for each individual cared for.	Annual payment made to caregivers to assist in the payment of respite, household modifications
Free Travel Companion Card	An ill individual may apply for a free travel companion card giving caregivers access to free public transport
Household Benefit package €35.00 weekly towards the cost of fuel and electricity	Assists in household expenditure (Department of Employment Affairs and Social Protection, 2019).

There are various social welfare payment options available for individuals suffering with an intractable or long-term illness and informal caregivers outlined in the table above. While they may assist in basis living sustainability, they do little in the way of relieving the financial burden of terminal illness (Irish Cancer Society, 2019). Research on the cost of care for cancer patients alone highlights their outgoings largely exceeds welfare supplements. For instance, on average this client group accumulates extra outgoings of €862.00 on a monthly basis. This figure is representative of both medical cardholders and those with private health insurance (Irish Cancer Society, 2019). Again, application processes pose challenges for applicants.

APPENDIX X: Breakdown of Perceived Challenges in Generalist and Specialist Palliative Care

Summary of Findings Corresponding with RO3		
Perceived Challenges Hampering Acquisitions Towards a GD		
1. DIMINISH RESOURCE ISSUES		
Participant Group	**Number of Participants**	**Participant Name**
Generalised Professionals	9	***A, B, F, G, J, R, U, V & R***
Specialised Professionals	5	***K E, I, S & T***
(a) Regional Inequities		
Generalised Professionals	9	***A, B, F, G, J, R, U, V & R***
Specialised Professionals	5	***K E, I, S & T***
(b) Lack of Personnel		
Generalised Professionals	4	***A, B, G & R***
Specialised Professionals	5	***K E, I, S & T***
(c) Resource Issues Diminishing Opportunities for Effective Communication		
Generalised Professionals	1	***A***
Specialised Professionals	3	***E, I & K***
(d) Resource Issues Straining the Efficacy of Effective Multi-disciplinary Team Involvements		
Generalised Professionals	1	***G***
Specialised Professionals	2	***K & S***
(e) Lack of Public Awareness of Resource Issues		
Public	9	***C, D, H, L, M,O, P, Q & W***
2. LACK OF FINANCIAL SUPPORTS		
Public	8	***C, D, H, L, W, O & P***
Generalised Professionals	2	***R & U***
Specialised Professionals	5	***K E, I, S & T***
3. SOCIO-CULTURAL IMPACTS ON INFORMAL CAREGIVING		
Public	1	***D***
Generalised Professionals	2	***R & J***
Specialised Professionals	3	***K, I & E***
(a) Socio-cultural impacts on death and dying related discourse		
Public	7	***C, D, H, M, N, O & W***
Generalised Professionals	6	***A, F, G, R, U & X***
Specialised Professionals	3	***K, I & S***
(b) Socio-cultural aspects hindering public engagements in death preparation and planning		
Generalised Professionals	2	***A & J***
Specialised Professionals	4	***E, S, I & T***
4. MEDIA INFLUENCE ON PUBLIC ATTITUDES TO DEATH, DYING AND A GD		
Public	4	***C, N, P & H***
(a) Misinformed Ideals		
Generalised Professionals	1	***J***
(b) Unrealistic perceived Ideals		
Specialised Professionals	3	***T, I & K***
5. CHALLENGES ENCOUNTERED WITH FAMILY/LOVED ONE'S OF THE TERMINALLY ILL:		
Generalised Professionals	2	***F & G,***
Specialised Professionals	5	***K***
(a) Conflict		
Generalised Professionals	8	***A, B, F, G, J, K, R & X***
Specialised Professionals	5	***K E, I, S & T***
6. LACK OF INFORMATION SHARE AMONG PROFESSIONAL		
Generalised Professionals	5	***F, G, R, V & X***
Specialised Professionals	2	***E & S***
7. ISSUES REGARDING PALLIATIVE AND EOLC TRAINING		
Generalised Professionals	3	***A, F & X***
Specialised Professionals	2	***K & T***

APPENDIX Y: Issues in the Assisted Decision Making (Capacity) Act, (2015), Concerning the Implementation of AHDs

a) The '*Draft Code of Practice on Advanced Healthcare Directives for Health and Social Care Professionals'* is misleading and poses ethical challenges for health and social care professionals, stating an individual may draft an independent AHD without seeking professional advice making the viability of informed decision-making questionable (Irish Medical Times, 2018).

b) Clarification is needed on procedures for professionals to undertake if they suspect an individual has drafted an AHD without the necessary information to enact choice eg: if they feel an individual may have been coerced.

c) Individuals need support in drafting an AHD with medical practitioners requiring time and adequate resources. Yet, the resources for preparations of AHDs are not currently provided for under the General Medical Service in Ireland (Irish Medical Times, 2018).

d) The Assisted Decision Making (Capacity) Act, (2015), stipulated the establishments of a Register of AHDs maintained by the Director of Decision Support Services (DSS). While Ms. Áine Flynn was appointed by the Mental Health Commission in October 2017, as the Director of the DSS and funding of 3.6 million has been allocated to this service the register has yet to be fully implemented (Department of Justice and Equality, 2019; Mental Health Commission, 2014). In 2018, Minster for Justice and Equality, Mr. Charles Flanagan stated the DSS is expected to be fully operational by 2020 subject to review (House of Oireachtas, 2019). This means professionals are currently promoting an initiative that is not fully implemented which may hinder their confidence and competence in encouraging individuals to engage in EOLC planning.

e) A mediation service should be made available to navigate disputes should they arise between a designated healthcare representative and professionals yet, at present the Act has not catered for this possibility (Age Action, 2014).

APPENDIX Z: Recommendations Made by All Participant Groups

A. The Public

Public Recommendations			
Q21. What, if any, improvements could be made in current palliative care practice?			
Recommendation	**Number of Participants**	**Participant**	**Gender**
1. Enhanced infrastructure & Resources.	**4**	***L, N, O & P***	
2. Legalisation of Euthanasia Practices.	**2**	***D & M***	***D*** – Male ***M*** – Female
3. Don't Know.	**2**	***W & Q***	
4. More training & education in generalised palliative care services.	**1**	***C***	Female
5. Individuals would be able to remain within the home environment .	**1**	***H***	

B. Generalised Professionals

Generalised Professionals Recommendations		
What, if any, improvements could be made in current palliative care service delivery?		
Recommendation	**Number of Participants**	**Participant**
1. Address all resource Issues.	**4**	***A, B, G & R***
2. Enhanced collaboration between professionals, the individual and families.	**2**	***G & U***
3. Enhanced professional training.	**2**	***X & A***
4. Support for informal caregivers, family/loved ones.	**2**	***R & V***
5. Enhanced Financial Support – especially concerning FairDeal/medical cards.		***A &G***
6. Enhance personnel, particularly community nurses/social workers to assist informal caregivers in accessing resources.	**1**	***B***
7. Introduce Single Patient Identifiers (Individual Health Identifiers).	**1**	***A***
8. Informal EOLC personnel (like the nuns did years ago) to provide accompaniment for those approaching death.	**1**	***F***
9. Enhanced communication on death and dying matters on both a societal and practice level.	**1**	***A***
10. Enhanced psychological care and support for both the individual and staff.	**1**	***J***

C. Specialised Professionals

Specialised Professionals Recommendations		
What, if any, improvements could be made in Current practice		
Recommendation	**Number of Participants**	**Participant**
1. Address resource issues.	**5**	***K, E, I, S & T***
2. Enhanced financial supports.	**3**	***E, I & S***
3. Enhance support for informal caregivers, family/loved ones.	**2**	***E & S***
4. Enhanced Financial Support – especially concerning FairDeal/medical cards, cost of care for family/loved ones.	**2**	***E &K***
5. Aftercare support for informal caregivers, family/loved ones.	**2**	***E & S***
6. Effective information sharing.	**1**	***K***
7. Enhance public awareness on all aspects outlined- distinctions between palliative and hospice care services, what they do, the importance of DPP, AHDs, common illnesses and treatment options and the QOL one can expect if succumbed to a terminal illness.	**1**	***E***
8. Introduce Individual Patient Identifiers.	**1**	***K***
9. Quicker hospital assessment, admission and discharge for those in receipt of palliative or hospice care.	**1**	***T***
10. Enhanced professional training.	**1**	***K***
11. More Integration with CareDoc.	**1**	***K***
12. Enhancement of palliative care training (both practical and theory) in colleges and universities in Irelands.	**1**	***K***