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PhD Thesis

Identifying and changing attitudes toward palliative care: an exploratory study

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ABSTRACT

Research suggests that palliative care is poorly understood and often associated with imminent death (Canny, 2002). This, in turn, can negatively impact upon the transition to palliative care services. The aims of this three phase, multi-method study were to: (1) examine and compare the attitudes of health professionals toward palliative care; (2) examine and compare the attitudes and personal constructs of four key participant groups including patients receiving palliative care services, people living with cancer and the carers of both of these groups; and (3) to examine potential strategies for changing attitudes through education. ***Phase One*** involved a detailed assessment of health professionals' attitudes toward, and understanding of, palliative care by means of a postal survey (182/700) and a small number of one-to-one interviews (n=5). Attitudes toward palliative care, as measured by the *Health Professional Attitude Questionnaire (HPAQ)***,** were explained by a number of key factors including: (1) knowledge of palliative care services; (2) relationship with the patient and family; and (3) personal reflection on mortality. Thematic analysis of the qualitative data further illuminated and developed this factorial model. ***Phase Two*** utilised one-to-one semi-structured interviews (n=30) and a battery of quantitative measures (n=75) to identify and compare attitudes toward, and experiences of, palliative care amongst patients receiving palliative care services (n=15), people living with cancer (n=25) and the carers of both of these groups (n=35). Repertory grids (n=12) were also used to explore and compare participants' constructs of palliative care. Thematic analysis of the interview data revealed four key themes and associated subthemes that described patients' and carers' attitudes toward palliative care. Within each theme, different perspectives were adopted by each of the participant groups and these were explored and quantified by means of the repertory grid analysis. The findings from Phases One and Two were then used to inform the development of two health professional and patient interventions for ***Phase***

Three that aimed to: (1) provide information about palliative care services; (2) utilise the patient ‘voice’ and story; (3) focus on the health promoting benefits of palliative care; and (4) demystify hospice, palliative care and the dying process**.** The study adds to the relatively small pool of evidence in this area and the use of the repertory grid technique, in particular, offers an interesting psychological tool for investigating palliative care research and practice.

CHAPTER ONE

Introduction

As life expectancy in developed countries continues to rise, people are becoming much more likely to die from serious chronic and terminal illnesses. Hence, health and health care at the end of life is becoming increasingly important and an urgent need to improve the care of dying patients has been the central message of many recent reviews of end-of-life care (e.g. Davies and Higginson, 2004; O'Shea et al., 2008). Palliative or hospice care aims to improve a person's quality of life at the end of life and has been defined as:

"*…an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*" (WHO, 2002).

Palliative care services can be provided at differing levels depending on both patient need (National Advisory Committee for Palliative Care (NACPC), 2001) and the availability or expertise of relevant personnel. Thus, it may encompass the provision of a basic palliative approach to care within a primary or acute healthcare setting or extend to the need to provide full multidisciplinary specialist palliative care to enable management of complex symptoms. Research suggests that palliative care is poorly understood and is often associated with imminent death. For example, in Ireland, a recent palliative care needs assessment (Canny et al., 2002), conducted on foot of the recommendations of the NACPC (2001), indicated that there are strong negative attitudes associated with terminal illness and, in particular, the term 'palliative care'. This negativity amongst service providers, service users and the general public has important implications for service delivery as well as referral to, and uptake of, palliative care services. For example, the late referral of patients to these services may create considerable anxiety for patients at a time in their life when they are already feeling very fearful and vulnerable (Barbato, 1999). Several commentators (e.g. Kellehear, 1999; Byock 2001) have suggested that changing care and practice at the end of life will require a fundamental shift in attitudes toward terminal illness amongst the general public and those health professionals who act as the gatekeepers to palliative care.

Traditionally, little is known about the attitudes toward, and understanding of, palliative care. A few recent studies have been undertaken both in the US and Europe in order to assess, the attitudes of health professionals, often with a unidisciplinary focus (e.g. Vejlgarard and Addington-Hall, 2005; Peretti-Watel, Bendiane and Moatti, 2005). These studies have provided researchers with reliable and valid tools that can be used to measure the attitudes of health professionals toward palliative care, whilst also highlighting the complexity of attitudes amongst these groups. Those studies which have focused on service users have tended to assess their satisfaction with, and/or experience of, palliative care services rather than their attitudes toward palliative care *per se* (e.g. McKay et al., 2010). Furthermore, no published studies have attempted to include comparisons between groups, such as cancer patients receiving and not receiving palliative care services, despite such comparisons in areas such as quality of life measurement (e.g. Yohannes, 2007). The World Health Organisation (2002) also emphasises the importance of the family or carers in their widely adopted definition of palliative care services and carers are considered to be of particular importance when considering how the decision to make the transition to palliative care services is made and communicated (Casarett, 2005). However, no published studies which have specifically focused on assessing carers' attitudes toward palliative care have been identified from the literature**.**

As outlined previously, the central focus of palliative care (i.e. *improving the quality of life* of patients and carers) is comparable to the broad aim of mainstream public health approaches in areas such as cardiology, sexual health and obstetrics. However, very little research has examined the application of health promotion to palliative care. This may be due, in part, to the often paradoxical concepts and contrasting ideas involved in the links between palliative care, health promotion and quality of life (Pegg and Tan, 2002). Arguably, seriously ill people can, and should, have periods of well-being and a reasonably good quality of life. There is a small, but growing pool of evidence to indicate the benefits (e.g. improvement in aspects of QoL) that can accrue from the active engagement of palliative care staff in health promotion. For example, health professionals in the UK who work with cancer patients are increasingly encouraged to adopt a health promoting approach (Saving Healthier Lives, Our Healthier Nation, 1999). The innovative work of Kellehear (1999; 2005) and colleagues in Australia has been fundamental in defining and advancing both academic and practice principles of a health promoting or public health approach to palliative care. Indeed, it is Kellehear's work that provides the empirical and practical context for this study focusing, in particular, on the potential for health and death education within a health promoting palliative care framework to serve as one important and potentially useful means by which attitudes toward, and ultimately practices involved in, palliative care transition might be shaped.

Closer to home, a key impetus for this study was the set of findings to emerge from the needs assessment exercise conducted by the Midland Health Board (Canny et al., 2002) in response to the NACPC recommendations (2001). This report stated that: "*A health promotion campaign should be developed to raise public awareness and to counter fear and stigma. This should focus on Quality of Life for patients and should develop the understanding of the role of palliative care in achieving this*". Thus, this study addresses one of the key recommendations suggested in the report and is firmly embedded, therefore, within the Irish health care and health policy context and one of the quantitative measures completed in this study focuses on the measurement of quality of life in patients as highlighted specifically in Canny's work. In addition, the relationship between quality of life and attitudes toward palliative care has not yet been explored in the literature.

Ultimately, whilst it is recognised that fear and stigma are associated with palliative care, it is most likely not palliative care *per se* that evokes such reactions, but what it represents. Death, dying and loss are universal experiences and terror or fear of death can be traced back to antiquity (Zimmermann, 2007). In the last 40 years, there has been considerable debate regarding whether or not Western society can be described as '*death denying'* in sociological literature (Aries, 1974; Kellehear, 1984) and descriptions in clinical literature discuss patients and families living in denial of death (Zimmermann and Roden, 2004). Such denial is considered to present an obstacle to open discussions of death, dying (Zimmermann, 2007) and advanced care planning issues such as the preferred place of death and care (O'Reilly and McLoughlin, 2011). Psychological literature has focused heavily on individual *'fear of death'* (e.g. Templer, 1970) and a number of tools have been developed to measure the degree to which people accept death (e.g. Ray and Najman, 1974), or experience *'death threat'* (e.g. Krieger, Epting and Leitner, 1974) or anxiety (e.g. Wong, Reker and Gesser, 1994).

Whilst these tools can prove useful in clinical situations, they are also often used to determine the effectiveness of death education (e.g. Johansson and Lally, 1990).

Personal Construct Psychologists have added considerably to thinking regarding fear of death, death threat and death anxiety. In the context of this study, the inability to integrate one's notions about life with one's preset notions about death is indicative of death threat as outlined by George Kelly, the founder of Personal Construct Psychology (PCP):

> *"Death is threatening to most people. We describe it as threatening to them because they perceive it as both likely to happen to them and as likely to bring about drastic changes in their core structure."* (Kelly, 1955).

However, whilst death is a threatening stimulus, death may not be perceived as threatening to a person whose system is structured in such a way as to anticipate it; that is, where death is consistent with the existing core. Therefore, it may be that death threat (or indeed death anxiety or fear of death) explains patients' and carers' fears of palliative care (and subsequent referral to the service). As indicated later in Chapters Five and Eight, this study was conducted, in part, within a PCP framework in order to identify and compare some constructs of palliative care with a view to obtaining insights into these kinds of questions.

This study was funded jointly by the Irish Hospice Foundation and The Health Research Board under the *Building Partnerships for a Healthier Society Research Award Scheme (*2005). It was designed to address an important gap in our knowledge by using a novel, empirical and partly theoretically driven approach in order to identify and examine attitudinal barriers to the effective utilisation (and delivery) of palliative care services in Ireland. It is hypothesised that such barriers relate mainly to issues of fear and stigma which, it was hoped, might be addressed sensitively and effectively by means of a pilot health promotion and education programme aimed at people living with advanced cancer and health care professionals respectively.

Therefore, the study reported here, had three principal aims:

(1) to examine and compare the attitudes and understanding of health professionals toward palliative care;

(2) to examine and compare the attitudes and personal constructs of four key participant groups including: (a) patients receiving palliative care services; (b) people living with cancer but not in receipt of palliative care; (c) the carers of patients receiving palliative care; and (d) carers of people living with cancer; and

(3) to examine potential strategies for changing attitudes toward palliative care.

The study was conducted in three phases in line with each of the above overarching aims. The specific objectives of <u>Phase One</u> of the research were as follows:

(a) to assess the attitudes of health professionals toward palliative care;

(b) to evaluate health professionals' understanding of palliative care services;

(c) to examine perceived barriers toward the transition to palliative care services from a health professional perspective; and

(d) to determine factors influencing attitudes toward palliative care.

The objectives of <u>Phase Two</u> of the research were as follows:

(a) to obtain and compare relevant background information on all participants;

(b) to identify and compare attitudes toward palliative care amongst the four groups mentioned above (i.e. patients receiving palliative care services; people living with cancer and carers of both groups);

(c) to examine quality of life in people living with cancer when compared to those receiving palliative care services with a view to examining how this might relate to their overall attitudes toward palliative care;

(d) to compare fear of death between patient and carer groups and explore its relationship to attitudes toward palliative care; and

(e) to compare the personal constructs of palliative care of a small number of patient and carer participants.

The specific objective of Phase Three was to design two pilot health education/promotion programmes based on the findings from Phases One and Two and modelled on similar the work at La Trobe University (2000-2) by Kellehear and Rumbold (i.e. one programme for health professionals and one for people living with advanced cancer). Originally this part of the study was also designed to include a comparative pilot evaluation of both programmes, but this was not possible due to reasons outside the researcher's control. Further details are provided later in the thesis.

The above objectives provided the framework to this study, a number of elements of which require detailed consideration within an empirical, theoretical and policy/practice context. The remainder of this chapter provides a brief outline of the content of the remainder of the thesis.

Chapter Two provides an overview of the purpose and development of palliative care services both internationally and in Ireland. A review of international palliative care development places Ireland most favourably in terms of the quality of its overall palliative care service provision and quality of dying (Centeno et al., 2010). However, it is recognised that within Ireland, there are still gaps in palliative care service provision (IHF, 2005) and access to care remains inequitable for a number of reasons.

Chapter Three has a more specific focus and explores the complexity of the transition to palliative care services from the health professional, patient and carer perspective. The factors that are considered important in the transition to services are critically examined including the extent to which information and knowledge of palliative care services and attitudes toward palliative care might complicate this transition.

Chapter Four documents the development of, and rationale for, a public health approach to palliative care that may help to address issues of equity and accessibility described in Chapter Two, whilst also facilitating an easier transition for patients to palliative care.

Chapter Five outlines the broad overarching methodological and ethical considerations that straddle all three phases of this study. A brief introduction to the study design is provided, outlining the multi-method three-phase design and the focus on the four specific participant groups. This chapter describes the mainly mixed methods epistemological approach adopted in this study and refers to the debate regarding the link between attitudes and behaviour. The key ethical considerations and decisions that shaped the study design and outcomes are also described. The use and relevance of the repertory grid technique as a methodology utilised in Personal Construct Psychology (PCP), is also explained and some of the key theoretical underpinnings of PCP are also described in more depth.

Chapter Six provides a comprehensive explanation of the methodology used in Phase One of this study. This phase comprised: (1) a postal survey of health professionals to determine their attitudes toward palliative care; and (2) a series of one-to-one semi structured interviews with a subset of participants.

Chapter Seven presents the findings of Phase One derived from both the postal survey and the one-to-one interviews. These findings were used to inform the development of a potential model that can be used to describe the factors influencing the attitudes of health professionals toward palliative care. The role of training, communication skills and knowledge of palliative care services in the referral process, is also highlighted.

Chapter Eight describes the methodology used in Phase Two. This phase utilised one-to-one semi-structured interviews (n=30) and a battery of quantitative measures (n=75) to determine and compare attitudes toward, and experiences of, palliative care amongst patients receiving palliative care services (n=15), people living with cancer (n=25) and the carers of both groups (n=35). Repertory grids (n=12) were also used to explore and compare participants' constructs of palliative care.

Chapter Nine explores the findings from Phase Two of this study, the main focus of which was the qualitative analysis of patients' and carers' attitudes toward, and experiences of, palliative care services. The key findings for the quantitative analysis are also presented, followed by a case study approach to the analysis of two repertory grids and comparison of key PCP measures across groups.

Chapter Ten documents the design and development of the two pilot education programmes that were the focus of Phase Three of the study. The findings from Phases One and Two were used to inform the development of interventions for this phase that aimed to: (1) provide information about palliative care services; (2) utilise the patient voice and story; (3) focus on the health promoting benefits of palliative care and (4) demystify hospice, palliative care and the dying process**.** The challenges associated with this element of the study are also described and discussed.

Chapter Eleven provides a synthesis, critical discussion and interpretation of the collective findings emanating from all three phases of the study with particular reference to relevant literature, policy and practice. Some of the key issues in this chapter include: the development of a model to understand attitudes toward palliative care; implications of the study for future development of health promoting palliative care in Ireland; the importance of this study to psychology; ethical and other difficulties in conducting research with palliative care populations; a critical analysis of the strengths and limitations of study; and recommendations for future research.

CHAPTER TWO

Palliative Care: An Overview

2.1 Introduction

'No other area of health care seems to have gone to such lengths to write a definition of itself as has palliative care' (Cairns, 2001).

Although palliative care has only been recently acknowledged as a medical speciality, it is one of the oldest types of care. Before the dawn of medicine, when curative options were few and far between, patients were comforted and cared for, symptoms were treated and suffering relieved (Donnelly, 1999; Groves, 2008). The dying entered their journey with their 'Anam Cara' – soul friend (Groves, 2007). Christian hospices aided injured travellers, the ill and victims of disasters and the dying were seen as special, honoured guests, close to God. Within the Judeo-Christian religious tradition, the concepts of *diakonia* (serving and caring for others), *metanoia* (turning within to a deeper self or divine power) and *kairos* (a unique moment of fulfilment) formed the basis of hospice care.

The term 'palliative care' has now been in use for more than 30 years following its introduction by Balfour Mount in 1973 in his search for an appropriate label for a unit focusing on care of the dying (Billings, 1998). He had intended to call this unit a 'hospice', but this word was already in use by the French to describe a nursing home for the poor and destitute (Pastrana, Junger, Ostgathe, Elsner, & Radbrunch, 2008). In November 1987, palliative care became recognised as a medical speciality in the UK and so the field of 'palliative medicine' emerged. The word 'palliative' comes from the Latin 'pallium' (a cloak) (Twycross, 2003) and 'to palliate' means 'to improve the quality of something', although in a medical context, the term means 'to mitigate', 'to alleviate', 'to lessen the severity of' or 'to give temporary relief' (Pastrana, Junger, Ostgathe, Elsner, & Radbrunch, 2008).

The modern hospice movement is synonymous with the work of Saunders and Kubler-Ross (see below) and since the 1970s; the development of palliative care has varied widely across the globe. Further information on the historical development of palliative care is provided later in Section 2.3. There is often overlap and transfer between the term 'palliative care' and terms such as 'care of the dying', 'terminal care', 'hospice', 'end-of-life care' and 'continuing care'. These terms have emerged over time and whilst all have different meanings, they are sometimes used interchangeably, particularly by health professionals when explaining to patients and their families, the transition to palliative care services. Indeed, these terms may be more familiar to the general public than the term 'palliative care' *per se*. Whilst considerable debate exists around the term itself, its definition and the common use of alternatives, it is true to say that probably the most accepted and widely used definition of 'palliative care' is that provided by the World Health Organisation (WHO, 2002) as indicated earlier in Chapter One. Whilst there remains a lack of consensus on a standard definition (Pastrana et al., 2008), the WHO definition is that adopted in Irish health service policy (NACPC, 2001) and is the definition around which this thesis is written.

2.2 Principles of palliative care

The primary goal of palliative care, in line with the WHO (2002) definition, is to improve the quality of life of patients and their families at the end of life through the provision of care focusing on addressing physical, psychological, spiritual and social needs (Robin Cohen et al., 2001). Palliative care seeks to do this by:

- *Affirming life and regarding dying as a normal process;*

- *Neither hastening nor postponing death;*
- *Providing relief from pain and other distressing symptoms;*
- *Integrating the psychological and spiritual aspects of care;*
- *Offering a support system to help patients live as actively as possible until death; and by*
- *Offering a support system to help the family cope during the patient's illness and in their own bereavement*

(Adapted from WHO, 1998)

The report of the National Advisory Committee on Palliative Care (NACPC, 2001) for the Department of Health and Children in Ireland, recommends that palliative care services are structured in three levels of ascending specialisation. These levels refer to the expertise of the staff providing the service and the varying degrees of patient need as follows:

- **Level 1 - Palliative Care Approach:** Palliative care principles should be appropriately applied by all health care professionals;
- **Level 2 - General Palliative Care:** At an intermediate level, a proportion of patients and families will benefit from the expertise of health professionals who, although not engaged in full-time palliative care, have had some additional training and experience in palliative care; and
- **Level 3 - Specialist Palliative Care:** Specialist palliative care services are those services which are limited, in terms of their core activities, to the provision of palliative care.

Palliative care can be delivered independent of a particular setting and at one or more of the above levels of provision depending on the patients' needs and staff expertise. Thus, it can be provided in the home by multidisciplinary hospice-at-home teams, in a specialist palliative care in-patient unit (or hospice), in an acute hospital, or in a residential care setting. For well over a decade, it has been acknowledged that people with diseases other than cancer should have their palliative care needs met (Lee et al., 2001). In Ireland, the NACPC's 2001 report asserts that good palliative care should be available to all who need it, when they need it and where they need it, thereby extending the provision of palliative care beyond the traditional focus of a service specifically for those dying from cancer or HIV.

The philosophy of palliative care focuses on: improving and advocating for high quality care for dying patients; providing multidisciplinary care for patients and families regardless of setting; delivering education and support to other health professionals who may care for patients at the end of life; and promoting research, audit and evaluation as core service activities (Faull, 1998). Palliative care also includes the provision of bereavement support services and promotes the use of volunteers to assist with service delivery.

2.3 The historical development of palliative care

2.3.1 The international context

The development of palliative care throughout the world has recently been documented by Wright et al. (2006) who categorised 234 countries according to four observatory typologies:

- No known hospice-palliative care activity;
- Capacity building activity (but no service yet);
- Localised provision of hospice-palliative care; and
- Hospice-palliative care activities are approaching integration with the wider healthcare system.

Wright et al. found that approximately half of the 234 countries reviewed, had established one or more hospice-palliative care services, although only 15 per cent had achieved some degree of, albeit highly variable, integration within their wider healthcare systems, especially in the USA, Europe and Australasia. No palliative care activity was identified in one third of the countries. Further information is provided below.

Historically, the UK has played a leading role in developing the modern hospice movement. In the 1960s, Cecily Saunders established St Christopher's Hospice in London and identified the concept of 'total pain' as central to the assessment and treatment of patients facing the end of life (Clarke, 2002). Saunders pioneered the development of a philosophy of 'total care' that aimed to assess the difficulties faced by dying people from a holistic perspective, and to implement a plan of care that enabled them to address these difficulties, whilst experiencing as little pain as possible (Du Boulay & Rankin, 2007). Saunders identified for the first time, the importance of attending to the holistic needs of patients at the end of life, and her vision provided the basis for a new and innovative model of care in the UK (Policy Department Economic and Scientific Policy [PDESC], 2008). For example, a number of organisations and bodies in the UK have advocated for the development of palliative care policy, practice, education and research, including the Help the Hospices, the Cecily Saunders Institute for Palliative Care and the International Observatory on End of Life Care. Hospice and palliative care services are available in most towns in the UK and are typically resourced by means of both statutory mainstream and voluntary funding. In recent years, there has been a policy shift in both England (DoH, 2008) and Scotland (The Scottish Government, 2008) toward the development of generalist end of life care for all. This has led to the roll-out of *hospice at home services* (i.e. multidisciplinary teams of staff working in specialist palliative care services providing specialist palliative home care), the *Gold Standards Framework* for residential care settings (i.e. a systematic evidence-based approach to optimise the care of patients nearing the end of life) and a drive towards *Advanced Care Planning* and public education around death, dying, loss and care (e.g. Dying Matters, 2009).

In a recent study of palliative care service development throughout Europe, the UK and Ireland were ranked first and second respectively in terms of the extent and nature of palliative care service provision. Interestingly, these are currently the only two countries in the world where palliative medicine has full speciality status (Centeno et al., 2007**.** Since the pioneering work of Saunders in the UK in the 1960s, palliative care services have developed steadily across Western and Eastern Europe and, in 1988, the European Association for Palliative Care was established to bring together the European voices of palliative care to develop and promote services through the exchange and provision of information and development of education and research.

In parallel to the developments in the UK in the 1960s, Glaser and Strauss (1965; 1968) examined patterns of death and dying in the USA. Their findings later influenced the development of awareness theory: that is where patients' initial awareness of death and dying changes over time - moving from suspicion awareness to full awareness of accepting a poor prognosis and/or death (Copp, 1998). In their later work - based on observing the character of dying trajectories - they acknowledged the capacity of acute hospitals to care for the dying. Glaser and Strauss concluded that there was considerable scope for improvement in the care of the dying in America, particularly in the area of psychological and social care. As a result, they went on to: develop education and training for medical and nursing staff; pioneered the planning and review of psychological, social and organisational aspects of end of life care; planned for phases of dying occurring outside of the hospital or institution of care; and encouraged staff to discuss aspects of death, dying, loss and care that might be perceived to be outside of their professional responsibilities or boundaries (Rosenberg, 2007). Later that decade, *On Death and Dying* was written by Swiss-American Elisabeth Kubler–Ross (1969). Her work, describing the emotional and psychological reactions to death - based on the transcripts of interviews with people facing the end of life - formed the basis for the *Stages Theory of Grief* that was adopted largely without question or criticism in subsequent years (Copp, 1998). Despite the more recent criticisms of this work (e.g. relating to the generalisability of her findings and the Stages model specifically), her work provided a 'voice' for the dying that was heard in America by healthcare providers and planners; and ultimately shaped palliative and end of life care services in the years that followed. The International Association for Hospice and Palliative Care is now based in the US whilst other bodies (e.g. The National Hospice and Palliative Care Organisation) advocate for the development of policy, practice, education and research in palliative care across the country.

The development of palliative care services elsewhere in the world has been slower to emerge. For example, in Australia, the first palliative care services were developed as a result of localised community action, interest from clinicians and the availability of hoc funding (Palliative Care Australia, 2003), all of which led in the late 1980s, to a strategy for palliative care and subsequent government funding for the development of services. Around the same time, a national group, *Palliative Care Australia*, was formed to enable health professionals and other interested stakeholders to share ideas and develop training and education in palliative care. More recently, public policy has focused on the delivery of palliative care for conditions other than cancer and the Australians have pioneered academic and practice thinking with some innovative pilot projects in health promoting palliative care (Kellehear, 1999) and ‘compassionate cities’ (Kellehear, 2007; Manion et al., 2009; Noonan et al., 2009; Rumbold, 2009). These initiatives aim to raise public awareness of death, dying, loss and care in society and motivate palliative care service providers to use their expertise to empower communities to support, and become engaged with, matters relating to death dying, loss and care. These concepts are described more fully in Chapter Four.

2.3.2 The Irish Context

As indicated earlier, Ireland ranks second in the world for the provision of palliative care services (Centeno et al, 2010) whilst it also ranks fourth overall in Europe as shown in a recent report, entitled *The Quality of Death (*The Economist, 2010*).* Indeed, Ireland has a long, rich history in the provision and development of palliative care services dating back to the 19th Century, when the Sisters of Charity established Our Lady’s Hospice in Dublin and St Patrick’s Hospital in Cork. These institutions, known locally at the time as ‘hospices for the dying’ or ‘the home for the incurables’, were developed by nuns who witnessed the painful deaths of people at home or in hospital, who suffered from advanced, non curative illness.

In the late 1970s and 1980s, the modern hospice movement gathered pace in Ireland with the further development of Our Lady’s Hospice in Dublin (in 1979) and the addition of Marymount Hospice as a unit within St Patrick’s Hospital in Cork (in 1984). Milford House in Limerick (founded by the Little Company of Mary in 1928) also changed its focus to the provision of care for the dying in 1977 whilst in the 1980s; a specialist palliative care inpatient unit was commissioned (now known as Milford Care Centre). In the 1990s, four other hospices opened throughout the country including St

Francis Hospice, Dublin; Donegal Hospice; North-West Hospice and Galway Hospice. More recently, Blackrock Hospice opened (in 2003) and is now under the auspices of Our Lady's Hospice in Dublin. Each hospice provides specialist palliative inpatient care, home care and day care services to people living in the local catchment areas and are intended to operate as level 3 'hubs' to support the provision of palliative care services at level 1 and 2 by other service providers in the locality. Many of the hospices also provide education services to health professionals working locally and nationally as well as conducting and commissioning research, audit and evaluation in palliative care.

Despite the existence of eight hospices in Ireland, a recent review indicates considerable inequality of access to hospice services with no dedicated specialist palliative care inpatient unit in the south east of Ireland and limited provision of services for the population of the Midlands (IHF, 2005). This inequity and other disparities in service provision remain an issue of some contention in Ireland, as it was anticipated that these issues would be addressed following the report of the National Advisory Committee on Palliative Care in 2001 (IHF, 2005). This report identified the need for each former Health Board in Ireland to conduct a palliative care needs assessment, upon which funding for future service development would be allocated by the Department of Health. However, despite the conduct and submission of such palliative care needs assessments, funding was not allocated/utilised leading to service inequity for the general population (Irish Times, 2010).

Voluntary service providers have lead much of the palliative care movement in Ireland and such services tend to be subsidised with funding from the Department of Health and Children through the Health Service Executive. The Irish Hospice Foundation is a key player in the field and, in partnership with Hospice providers, advocates, and raises funds, for the provision of grants to patients and families in need, as well as granting annual development awards to service providers, allocating research, education and travel bursaries and providing education programmes in the areas of grief and loss and children and bereavement. In recent years, the Irish Hospice Foundation has initiated two major projects – the Hospice Friendly Hospitals (HfH) programme and The Forum on End of Life. The HfH programme seeks to instil hospice principles in acute hospitals and residential care settings whilst the Forum aims to engage society in conversation regarding death, dying, loss and care. Both programmes, in turn, seek to improve the experience of death for patients and their families and to drive organisational and societal change in attitudes. Currently, other key organisations in Ireland for the development of palliative care include the Irish Association for Palliative Care (IAPC) and the newly established All Ireland Institute for Hospice and Palliative Care (see below).

In 1995, palliative medicine was recognised as a medical specialty by the Irish Medical Council. This, in turn, raised Ireland’s profile in palliative care internationally. Ireland’s first Professor in Palliative Medicine is currently being recruited and will complement Ireland’s first Professor in Palliative Nursing, Professor Phil Larkin, who was appointed to University College Dublin (UCD) in 2008. It is anticipated that such academic appointments and the current academic focus on palliative care will gain momentum as a result of the All Ireland Institute for Hospice and Palliative Care. This Institute was set up in 2010 following a protracted tendering process and has the central aim of developing education, research, policy and practice in palliative care in Ireland. It is managed by a consortium of academic organisations and hospice providers in Ireland with funding from several sources including The Atlantic Philanthropies, the Health Research Board and the Irish Cancer Society.

Traditionally, as was the case in other countries, palliative care services in Ireland were aimed at people with a diagnosis of cancer or HIV. However, more recently, the focus has begun to shift as a result of several influential studies and reports including: the O'Shea report (2007); the Extending Access Study (2008); HIQA Standards for Residential Care Settings (2009); and the Hospice Friendly Hospitals (HfH) Programme (2006 – 2010). Importantly, the O'Shea study and the HIQA standards both highlight the need for the provision of high quality end of life care, training and education in residential care settings. This has increased the requirement for palliative care service providers to focus their education activities on meeting the needs of staff working in these settings. Furthermore, the Extending Access study, through the development of three pilot projects, is exploring ways in which palliative care services can become more involved in end of life care throughout the illness trajectory for patients living with Chronic Obstructive Pulmonary Disease, Dementia and Heart Failure. Likewise the HfH programme advocates the principles of palliative care (particularly regarding design, dignity and communication) for all patients dying in hospital care, regardless of diagnosis. These reports have challenged palliative care service providers to stop and think about the way in which they provide services, their admission and discharge criteria and to help them improve their role as educators to those health professionals who engage in level 1 and 2 palliative care service provision.

It is anticipated that, over the next one to five years, palliative care services in Ireland will begin to embrace the ideology of health promoting palliative care. In addition, the work of the Forum and the work packages planned for the All Ireland Institute will hopefully help national policy makers to focus more on a population health approach to palliative care as advocated in Australia, Canada and the UK. The next chapter describes the complexities of the transition to palliative care services from a range of perspectives.

CHAPTER 3

Transition to Palliative Care

3.1 A complicated referral

The benefits of early referral to palliative care are well documented (e.g. Kane et al., 1985; Longman 1994; Nolen-Hoeksema et al., 2000; Teno et al., 2004). However, referral to, and uptake of, palliative care services remains typically low (Casarett et al., 2005) and patients are often referred to services only in the final days of life. Thus, many patients may make this important transition with just hours, or days to live and for some that transition might never occur. The move from curative to palliative care has been shown to be one of the most confusing and traumatic transitions that a patient can experience (Larkin, 2007).

Despite its importance, a recent review of the literature (Marsella, 2007) highlighted a paucity of research in this area. This review outlined ***three*** factors that potentially complicate the transition into palliative care services: (1) its intrinsic nature; (2) its timing; and (3) the lack of information surrounding the transition. For many, the complex interplay between known factors impacting upon the transition to palliative care services can often undermine the defined goal of palliative care and the quality of care provided (Rayson and McIntyre, 2007). Therefore, it is important that these factors are examined from a range of perspectives, including those of healthcare professionals, patients, their families and wider society. A review of the literature completed as part of this study, suggests that a complex interplay of ***five*** factors might describe more comprehensively the transition to palliative care services (see Figure 3.1). These build on the work of Marsella (2007) and are outlined in detail below.

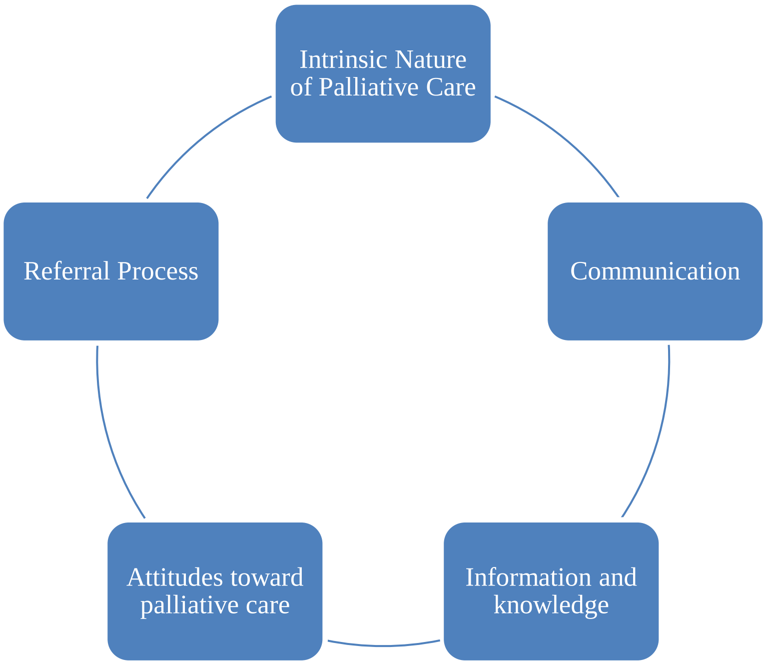

Figure 3.1 Factors Complicating the Transition to Palliative Care Services

3.2 The nature of the transition to palliative care

In Ireland, as in most health services where palliative care is available, the transition to palliative care is made by referral from a health professional (usually a doctor) to the Consultant in Palliative Medicine working in a hospital, hospice or community setting. However, this is no ordinary referral, simply because it marks an important transition - a monumental event in the life of a person and his/her family, as succinctly described by Davies (1995): *"…transition must be seen to be much more than just the referral process between organisations but as the individual's passage through one set of hopes and expectations to another"*. The transition to palliative care services presents a major clinical challenge (Marcella, 2007) due to its implications for patients and families, of impending death, whilst fears of helplessness, abandonment and sorrow are also common (Ronaldson and Devery, 2001; Schofield et al, 2006). Larkin et al. (2007) described the variety of intense emotional reactions of patients faced with the transition to palliative care, as they become suddenly confronted by their own mortality. Ultimately, the nature of the transition suggests that the patient is moving a step closer to death, thereby triggering a shift from *'hoping for a cure'* to *'hoping for not suffering'* and ultimately, *'hoping for a peaceful death'* (Duggleby and Berry, 2005). Therefore, it is not palliative care *per se* that is the issue here, but what it represents for those who are faced with this potentially complex transition.

3.3 The complexities of referral to palliative care services

3.3.1 Service availability

Whilst it may seem obvious, patients can only be referred to palliative care services where such services exist. As indicated earlier, these services have historically developed in an ad hoc manner across the world (e.g. Wright et al., 2006) and currently, in Ireland, there is significant inequity in palliative care service provision across the country (IHF, 2005). The manner, in which services are staffed, may also deviate markedly from national policy recommendations (e.g. NACPC, 2001) due to variable funding allocations.

3.3.2 Eligibility based on diagnosis and prognosis

Existing palliative care services usually have clearly defined admission criteria, which obviously impact upon the transition of a patient to palliative care. These criteria are developed according to staff availability, expertise and knowledge, existing resources and identified local needs. There has been criticism by many commentators in the past (e.g. Kellehear, 1999), of the tendency for palliative care services to accept referrals that involve mainly (and sometimes, only involve) malignant or HIV diagnoses and there is now considerable debate as to where specialist palliative care ends and generalist palliative care begins. Some government policy/lobby groups in Ireland and the UK have attempted to widen the palliative care net to include structured care for patients with non malignant conditions (IHF / HSE, 2008). As a result of such developments, admission policies are constantly kept under review by palliative care service providers and funders.

3.3.3 Timing

There is also lack of clarity and guidance regarding the optimum timing of referral for patients to palliative care services. According to existing evidence, the first discussion regarding palliative care should, ideally, occur sometime prior to a discussion about ceasing any curative treatment (Jefford, 2007). This early intervention enables patients and their families to find out more about the services and to discuss their fears in advance of transition. However, there are conflicting views as to when patients should receive palliative care services (ASCO-ESMO, 2006; Schofield et al., 2006). Patients and health care professionals express concern over this timing divide and in practice, it is the decision to cease curative treatment that usually prompts the involvement of the palliative care team (Schofield, 2006).

Concerns about the lack of agreed guidelines regarding the timing of referral to palliative care services are compounded by attendant concerns regarding the lack of guidelines or procedures to enable healthcare professionals to operationalise the transition to palliative care (Rayson and McIntyre, 2007). In practice, healthcare professionals report a series of often, rapid, events that occur when a patient becomes ‘palliative’, whereby the suggestion of transition to palliative care services and the actual shift to the service can sometimes be just hours apart (Marsella, 2007). This, in turn, increases the confusion, fear and difficulty experienced by patients and their families (Larkin et al., 2007). Whilst it is not easy to decide when a patient should make the transition to palliative care services (Marsella, 2007), it is generally agreed that referral should take place as early as possible in the patient’s illness (Ronaldson and

Devery, 2001). This avoids the sense of urgency described by Larkin et al. (2007) and provides an opportunity for patients to come to terms with the transition. According to Schofield (2006), this decision should also be guided by patient preference on a case-by-case basis, whilst earlier involvement will also lead to better communication with all parties and a smoother transition for the patient and family.

3.4 The challenge of communication at the point of transition

Communication was not considered specifically by Marcella in her review, but a number of other authors have highlighted the importance of communication between health care professionals and patients, on the one hand, and families on the other (e.g. Hyman and Bulkin, 1991; McGorty and Bornstein, 2003). Indeed, failure by staff to communicate with patients effectively has been identified in many studies as a major impediment to the quality of care received by the patient and their family (NACPC, 2001). Schofield (2006) suggests that the late referral of patients to palliative care services reveals a lack of communication between healthcare teams and patients. Whilst there is some evidence to suggest that a lack of information and knowledge about palliative care services, may impede the ability of health care professionals to have an informed discussion with patients regarding palliative care services (Hyman and Bulkin, 1991; McGorty and Bornstein, 2003; Casarett et al., 2005), there are clearly more complex issues to be considered in the communication process.

According to Jefford (2007), communication around the transition to palliative care services, from a communications skills perspective, is an example of ‘breaking bad news’; this is an area in which healthcare professionals have highlighted difficulties as part of training courses in the UK and Ireland (Dias et al., 2003; McLoughlin et al., 2009). In fact, the ability of staff to communicate effectively has been recognised as a basic requirement to work with cancer patients, in particular (UK DoH, 2000; NICE 2004). It is especially important in palliative care, where there is a need to convey complex and distressing information on a regular basis (Fallowfield et al., 2002) and where the psychosocial and spiritual needs of patients are as important as their physical needs. Research examining the skills of healthcare professionals working in these areas, indicates a tendency to focus on the patients' physical needs (Wilkinson, 1998). For healthcare professionals, communication difficulties can be a source of stress (Wilkinson et al., 1999), leading to emotional burnout, depersonalisation and low levels of personal accomplishment (Fallowfield et al., 1998; Ungar et al., 2002).

As discussed by Larkin (2007), the transition to palliative care services can lead to strong emotional reactions by patients, and it has been shown that one quarter of patients are only prepared to discuss their emotions with a doctor when the latter initiates a conversation in this respect (Detmar et al., 2000). Thus, such emotional reactions may remain unexplored prior to the transition to palliative care, in situations where a healthcare professional finds such conversations difficult, or is ill-prepared to address such issues. The difficulties encountered by the healthcare professional - whether due to a of lack of information regarding services, poor communication skills generally, or a fear of breaking bad news regarding the transition to palliative care - can often leave patients feeling that there is something to hide, thereby increasing their fears and reluctance to accept palliative care intervention (Ronaldson and Devery, 2001). Schofield et al. (2006) suggest several recommendations for professionals who have a role in discussing the transition from curative cancer treatment to palliative care. Such guidelines (e.g. Evans, 2006) refer to the provision of evidence-based communication skills training (Wilkinson, 1999; McLoughlin, 2009) and the development of an agreed, common language regarding palliative care (Lofmark et al., 2005).

Casarett et al. (2005) found that a substantial proportion of family members (57%) often make the decision regarding the transition to palliative care services, on behalf of the patient. Thus, the above factors are also important when considering communication between the healthcare professional and the family. However, an additional component – collusion - can often add to the complexities involved in the communication between healthcare professionals and the patient. The findings from the literature on this, are well summarised by Fallowfield et al. (2002) and, whilst their study focuses on the, often misguided, protection of patients by healthcare professionals, it is very often the case that family members seek to ensure that their loved one is not told that they are dying. The rationale for such decision making includes a perceived need to ensure that the patient remains hopeful, concern that the patient will not cope with their diagnosis and prognosis, and/or fear that the patient will deteriorate more quickly if they are made aware that they are dying (Fallowfield et al., 2002). Indeed, cultural variances mean that, in some cultures, family members are expected to manage medical decision making on behalf of the patient, in consultation with healthcare professionals (Blackhall et al., 1995). These requests for such collusion can cause considerable distress for healthcare professionals who use an autonomy-focused approach to clinical decision making (McCabe et al. 2010); this may lead to communication difficulties that could ultimately, delay the transition of the patient to palliative care services.

3.5 Information and knowledge to inform the transition

It is vital that information about palliative care services is clearly communicated to patients and their families and to healthcare professionals who have the ability to refer patients. This information seeks to increase knowledge of services, so that informed decisions can be made during the patient's transition from curative to palliative care. Many primary care service providers have identified the need for greater information on both service availability and admission criteria and there is an onus, therefore, on palliative care service providers to supply this information (Lofmark et al., 2005; McKay et al, 2010). Patients often arrive at the hospice with significant information needs and know little about services with the result that hospice staff are often the primary source of information (Casarett, 2005). The literature suggests that healthcare professionals may be better able to support patients and families to make decisions by anticipating their common information needs (outlined below) (Casarett, 2005). This involves placing an onus on the referring healthcare professional to keep abreast of the literature and developments in palliative care and an onus on palliative care services to provide continuing education in line with their service philosophy (NACPC, 2001).

As outlined in the NACPC document, palliative care can be provided at different levels according to patient needs and often, the palliative care needs of a patient can be managed in primary care settings. However, evidence suggests that for some patients, their palliative care needs are poorly managed (Addington-Hall and McCarthy, 1995). This, in turn, can lead to the admission of patients to specialist palliative care or acute hospital services, as their difficulties escalate (Shipman et al., 2003). It is recognised that these difficulties are often due to service structures within the primary healthcare system. However, they may sometimes also be related to the challenge for primary care providers, in maintaining their palliative skills and expertise, particularly in situations where they may see, on average (in the UK), approximately two cancer patients per year die under their care and approximately six patients dying from a non-malignant condition (Barclay, 2001). Again this places an onus on palliative care service providers and primary health care teams to ensure that they provide, and attend, palliative care education updates. Evidence suggests that such education updates should provide information regarding symptom control, communication and bereavement counselling as core areas (Macleod and Nash, 1991; Jeffery, 1994; Barclay et al., 1997; and Shipman et al., 2001).

Patients' understanding of palliative care underpins their acceptance of, and preparation for the transition and it follows, therefore, that patients and families need information in order to understand, and participate in, the planning of their care with the referring healthcare professional (Marsella, 2007). However, it is widely recognised that there is a lack of information provided to patients and families regarding palliative care (Constantine et al., 1999) and there is a lack of awareness and understanding of the term itself. For example, in Canada, only half of the population surveyed had ever heard of the term 'palliative care' and only one third of those who had, were able to provide an accurate description (Fainsinger, 2002). Hence, palliative care providers ought to communicate with potential patients and the general public in order to raise awareness of their services and to attempt to address some of the fear and stigma associated with palliative care (Canny et al., 2002; Blanco-Campal et al., 2006). The type of information that should be provided to patients and families was explored by Casarett (2005) who found that, on referral, patients were most concerned with issues regarding practical help, financial support and service availability. Whilst this was an American study and the findings might not, therefore, be generalisable to other contexts, it provides useful insights into how palliative care services might focus their provision of information for patients and families at the time of referral, whilst also providing health care professionals with a guide to some pertinent issues of concern that might be discussed during the initiation of a referral to palliative care services.

3.6 Attitudes toward palliative care

3.6.1 Healthcare professionals

Recent research has examined the attitudes of healthcare professionals toward palliative care and/or caring for the dying in a number of countries including: Germany (Schnieder et al., 2006); Denmark (Vejlgarard and Addington-Hall, 2005); the UK (Shipman et al., 2003; Addington-Hall and Karlsen, 2005; Burt et al., 2006; Hanratty et al., 2006); the Netherlands (Groot et al., 2005); Wales (Barclay et al., 2003); California (Wessel and Rutledge, 2005); and America (Frommelt, 1991: 2003; and Strumpf, 2002). These studies have, amongst other things, provided palliative care researchers with reliable and valid tools that can be used to measure the attitudes of healthcare professionals toward palliative care/care of the dying. These include the Frommelt Attitude Toward Care of the Dying Scale (FATCOD-Form B, Frommelt, 1991), the Attitudes Toward Death Survey (Strumpf, 2002) and Bradley's (2000) quick, reliable and valid assessment instrument used to identify attitudes about care at the end of life among clinicians.

Research has identified considerable variation in the attitudes of different groups of healthcare professionals. Hospital doctors tend to encounter patients who require transition to palliative care more frequently than their GP counterparts, and are more likely to report that that they tend to leave the care of dying patients to others and find it more rewarding to work with patients who are expected to improve (Vejlgaard and Addington-Hall, 2005). Thus, their attitudes toward palliative care are generally more negative than those of GPs. However, whilst GPs may be more positive about palliative care, they also perceive barriers to available services. As outlined in Chapter One, Groot et al. (2005) describe a three-pronged typology of perceived barriers to service utilisation including: barriers relating to knowledge, skills and emotions; barriers concerning communication and collaboration; and barriers related to the organisation of care and compartmentalisation in healthcare. Further barriers, described by other authors, include the healthcare professionals' fear of and a sense of failure when referring patients to palliative care (Raudonis, 2003; Hanratty et al., 2006). Nurses are another key group with widely differing attitudes toward palliative care. In one study of Danish healthcare professionals, nurses were more likely than doctors to agree that palliative care was a rewarding part of their work and were less likely to prefer to leave the care of dying patients to others (Vejlgaard and Addington-Hall, 2005). They reflected more on existential matters and were more likely than doctors, to agree that dealing with a dying patient made them more aware of their own feelings about death. In general, nurses were more positive than doctors about palliative care. The contrasting attitudes in this study were attributed to job role and work location rather than (the perhaps more obvious) factors of age or gender.

Certain aspects of palliative care provision are deemed to be more important than others amongst healthcare professionals. For example, a sample of volunteers and healthcare professionals working in UK hospice settings identified several factors to be of central importance. These included: care of the whole person; pain and symptom control; quality of life; and dying peacefully (Addington-Hall and Karlsen, 2005). Doctors, in particular, were most likely to choose the first of these as the most important. Volunteers had no strong views with regard to extending hospice care to non-cancer patients, although, by contrast, healthcare professionals felt that the service could be more accessible to people with chronic and non-malignant diagnoses. This work demonstrates interesting differences in attitudes toward elements of palliative care provision, whilst also highlighting the need to educate the public in issues concerning palliative care and the importance of their involvement in debates concerning service development.

No published studies of attitudes toward palliative care amongst health professionals have been conducted in Ireland, to date, and the relevance of existing tools to an Irish context, is unknown. However, the work from elsewhere, reflects a general negativity that, arguably, presents a challenge to health systems that are working to improve palliative care provision and, ultimately, the quality of life of patients at the end of life. Positive attitudes toward palliative care are important to enable good communication between primary and specialist palliative care providers (Shipman et al., 2003), particularly in view of the ongoing debate and polarised views about palliative care, between generalist and specialist palliative care providers (Fordham et al., 1998; Field, 1998; Shipman, 2008). For example, some health professionals working in primary care and acute hospital settings have questioned whether or not specialist palliative care is really “specialist territory at all?” (Fordham et al., 1998). Furthermore, Constantini et al. (1999) suggest that the late referral of patients to palliative care services reflects a generally poor acceptance of palliative care in medical culture. Thus, the improvement of attitudes toward palliative care is crucial to enable healthcare professionals who have a role in referring patients to palliative care, to discuss services in a positive way and facilitate a seamless transition to palliative care.

Importantly, the existing evidence provides encouraging indications that attitudes can change through the provision of palliative care education for healthcare professionals

(Frommelt, 2003; Wessel and Rutledge, 2005) and through the provision of palliative care link staff in the community. For example, 'Macmillan nurses' have worked successfully with GPs in the UK to improve their awareness of, and attitudes toward, palliative care (Shipman et al., 2003). Therefore, it is vital to understand both the general attitudes toward palliative care and the information knowledge needs of health care staff, when exploring the factors that complicate transition to palliative care services.

3.6.2 Patients and families

Previous research suggests that, in the early stages, some patients are distressed and annoyed that a palliative care referral has been made (Canny et al., 2002; Blanco-Campal and Keegan, 2006). They typically perceive the service to be for patients on the verge of dying and are, therefore, hesitant about engaging with their services at the outset. The term 'palliative care' also had negative connotations for many family members in the above studies and the definition of the term by the referring health professional, was also restricted and defined as little more than a 'talking, back up service' (Canny et al., 2002). This, in turn, negatively affected the perception of patients and their relatives regarding the true nature of palliative care.

However, in Canny's study, once patients had received palliative care services, most acknowledged that they had been mistaken and that their initial perceptions and concerns had been misplaced. In fact, some patients acknowledged their well being at the time of the study, as directly related to their receipt of palliative care services, whilst others wished they had been referred earlier. The Canny et al., (2002) study, in particular, recognised that the fear and stigma of palliative care, cancer and death, had serious implications for the palliative care service, leading to late or non-referrals. The authors went on to recommend that measures be put in place to raise awareness of palliative care in order to reduce the fear and stigma associated with it and to enable healthcare professionals and the public to better understand that palliative care is not only about managing the terminal phase of illness, but also about improving the patient's quality of life when cure is no longer an option.

Ronaldson and Devery (2001) reported that people's attitudes toward palliative care are strongly influenced by their understanding and fear of the service, which is synonymous with imminent death and which can manifest in delayed acceptance of palliative care services. Whilst it is recognised that patients' attitudes toward palliative care prior to referral are important, Catt et al. (2005) found that the relative under-utilisation of hospice and specialist palliative care services by older people with cancer in the UK, cannot be explained solely by their attitudes toward end of life issues and palliative care. These authors highlight the need to examine attitudes in conjunction with other factors that influence transition (e.g. practice of referral agencies and admission policies of services).

3.7 Summary

The review of the literature undertaken as part of this study, suggests that the transition to palliative care services, is complicated by a number of central factors, within which there are numerous sub-factors at play. Furthermore, these combine, in different ways, to complicate the transition process for patients, families and healthcare professionals. These factors and the complex interplay between them, often leads to the late or non-referral of patients to palliative care services. Thus, many people may miss the opportunity to experience the numerous potential benefits of palliative care at the end of life.

In her conclusion, Marcella (2007) recommends that patients be fully prepared for the transition to palliative care in an attempt to lessen their fears and anxiety, to gain more information about the service and to provide them (and their families) with more time to accept death. She calls for multidisciplinary teams to work more closely to ensure integration of palliative care with specialist services (e.g. oncology) that will, in turn, bridge the change in care focus and create a seamless transition. Finally, Marcella (2007) emphasises that better practice guidelines (e.g. Evans, 2006) need to be created to enable agreement regarding the important decision points in the transition that would, in turn, provide better structure, information and integration. Likewise, there is a need for guidelines to promote better communication between health professionals and patients and to encourage training in how best to communicate with patients facing the end of life. These are also important in addressing some of the complicating factors thereby reducing some of the difficulties around the transition to palliative care. Other educational opportunities and facilitated partnerships between palliative care and other healthcare providers may also positively influence attitudes, thereby improving communication and facilitating this difficult transition.

The next chapter provides an overview of Health Promoting Palliative Care that aims to reduce the fear and stigma associated with death, dying, loss and care and which may in turn provide a more seamless transition to palliative care services where they are required and address some of the challenges described above.

Chapter 4

Health Promoting Palliative Care

4.1 The context

The previous two chapters have provided, respectively, an overview of palliative care in general and identified some of the issues and factors underpinning the transition to palliative care services from patient, family and health professional perspectives. This chapter outlines the rationale for, and the development of, health promoting palliative care which may in turn enable health care providers and society in general to change the way their think about death, dying, loss and palliative care.

Arguably, the manner by which palliative care has developed in the Western world has lead to the over-medicalisation of death and dying, where death is often construed as a failure by society (Illich, 1976; Kellehear, 1984: 1999; McCue, 1995) and tends to be used in health promotion campaigns as a negative outcome, associated with the non-compliance to a health behaviour (e.g. 'you must not smoke or you will die from cancer'; 'you must not have unprotected sex or you will die from HIV'). However, the reality is that death is a universal experience that society, particularly in the West, may more usefully reconstrue as a natural (rather than a medical) process (Zimmermann, 2004). Early leaders in palliative care placed a considerable emphasis on driving social change through individuals as opposed to evoking structural change (Abel 1986) and, subsequently, *"death, dying and loss are defined as personal problems rather than targets of social change in community attitudes, values and behaviour."* (Kellehear, 1999).

Health Promoting Palliative Care (Kellehear, 1999) offers society the opportunity to change the way it views death, dying, loss and care by taking a population-based health approach to change the ways in which: (a) people consider their own death; (b) communities care for people and their families as they encounter death; (c) healthcare service providers meet the needs of people facing the end of life; (d) palliative care services reach out to share their expertise in death, dying, loss and care; and (e) in the way in which national policy and plans are developed and understood. The adoption of a health promoting approach to palliative care is gaining momentum internationally (Kellehear, 1999: 2005; Miller and Rynades, 2005; Meecham, 2006) and it has been suggested by a number of key players in the field that putting health promotion at the heart of palliative care, can help to improve the quality of life of the dying (Miller and Ryndes, 2005; Meecham, 2006). This may also encourage those people who have the opportunity to make the transition to palliative care, to think more positively about the available services, thereby increasing the likelihood of early referral (Clough, 2002).

4.2 A brief overview of health promotion

In 1978, the World Health Organisation (WHO) defined health as: *"a complete state of physical, social and mental wellbeing and not merely the absence of disease or infirmity"* (WHO, 1978). It was recognised that the determinants of health, as defined by WHO, had physical, social and individual domains and were not purely determined in terms of an interaction with healthcare services for necessary interventions. Thus, according to the WHO, the core concepts necessary for improved health include: equity; community self-reliance; health promotion; disease prevention; and the involvement of government departments beyond health (Was, 2000). Later, in 1986, the Ottawa Charter for Health Promotion (WHO, 1986) outlined five inter-related, but discretely defined action areas to promote physical, social and emotional aspects of well being. Implicit in this Charter was the recognition that health is not solely the responsibility of healthcare services, but encompasses government, social and economic partners, industry and media, communities and individuals themselves. To summarise, health promotion aims:

- to be participatory;
- to recognise the importance of society in health and illness;
- to stress the need for information, education and policy development that extends beyond traditional healthcare boundaries;
- to encompass those who are healthy and unhealthy; and
- to make health a collective as opposed to an individual responsibility.

Whilst the Ottawa Charter remains the driving force behind current health promotion theory and practice, it is not without its critics (Bunton et al., 1995). Kellehear (1999) provides a succinct summary of the key points of criticism which include the following:

- traditionally, health promotion approaches tend to focus on individual, as opposed to the wider environmental or policy change;
- interpersonal interventions do not always consider whether a person has enough power or social resources to make the required changes;
- minority groups are often not consulted at the planning stages of information and education delivery and, therefore, may not be able to apply the learning in a way that meets their needs; and
- health promotion messages have sometimes reinforced stereotypes, social inequality and the notion that health is simply the absence of disease or disability.

Despite the above limitations an understanding of the Ottawa Charter is key to understanding health promoting palliative care. This is discussed in more detail below.

4.3 Health promotion at the end of life?

People facing death or experiencing loss, are a key group who, until very recently, were excluded from the health promotion discourse (Kellehear, 1999). This is despite the fact that a focus on health (as defined by maintaining a sense of wellbeing) is important for those facing the end of life (Kellehear, 1999). For example, in an Irish context, and based on the researcher's personal experience, health promotion workers are typically assigned to a wide spectrum of services ranging from child and family services, travelling communities and mental health services to cardiovascular health projects, lesbian, gay and bisexual services, and drug and alcohol intervention teams. However, there is a lack of any form of health promotion for those facing death, dying, loss or palliative care. Kellehear (1999) argues convincingly that the benefits of such an approach for the person facing the end of life might be:

- The maintenance of the immune system through a focus on maintaining a healthy mind, body and spirit;
- An acceptance of medical and complementary therapy to prolong life, increase quality of life and cope with treatment side effects;
- The provision of empowerment and support;
- The provision of information and education that can challenge personal fears and change attitudes toward death, dying, loss and care; and
- The renewal of a sense of confidence and agency that encourages hope and provides comfort.

Kellehear (1999) also argues that there are additional benefits – over and above those for patients and their families - for the development of both palliative care and health promotion as disciplines. For instance, the application of health promotion principles to palliative care enables the integration of social science and public health workers into the palliative care team and, therefore, offers greater potential for meeting the holistic needs of patients and their families.

Chapter Two in this thesis, focused on the complexities of the transition to palliative care services including issues related to late referral. The implementation of a health promoting approach would provide an ideal opportunity for early stage care to be provided to patients who face life-limiting illness through, for example, the provision of education and information about palliative care services/illnesses that may, in turn, challenge personal fears and change attitudes (Scott, 1992). However, Kellehear (2009) warns against merely understanding health promoting palliative care purely as an approach to changing attitudes through awareness raising, education provision and increasing access to services as suggested by Rao et al. (2005) and Gomez-Batista (2005). He emphasises the need to work in partnership with communities to stimulate community change and develop community led supports. For example, this is well demonstrated by Kumar (2007) in Kerala, India and through models of community development highlighted in Australia (Kellehear and Young, 2007; Kellehear and O'Connor, 2008), all of which focus on evoking real social and behavioural change and not simply changing attitudes.

Whilst the concept of health promotion and palliative care had been discussed prior to Kellehear's defining work in the late 1990s, references to the concept were often 'fleeting' and 'un-operationalised' (Rosenberg, 2007). Kellehear (1999) defined the goals of the approach with reference to the Ottawa Charter for Health Promotion (Table 4.1). He proposed that health promoting palliative care should aim to: combat death-denying health policies and change wider attitudes toward death dying, loss and care in society; provide social support, information and education (health and death) for individuals and communities dealing with end of life issues; and re-orientate palliative care services to enable them to better understand and appreciate the potential of a health promoting approach.

4.4 Definitions of health promoting palliative care

Interestingly, despite Kellehear's (1999) ground-breaking work in this area, health promoting palliative care remains difficult to define and operationalise concisely. Indeed, Rosenberg (2007) highlights a high degree of conceptual 'blurring' around health promoting palliative care that represents a significant risk to the effective implementation and practice of the approach. The operational definition used by the Milford Care Centre in Limerick is as follows:

> *"Health Promoting Palliative Care seeks to work with people, individuals and groups, to enhance the social, emotional and practical support available to those living with a serious life-threatening illness, facing loss, experiencing bereavement or providing care. It not only focuses on death as a result of illness, but considers death caused by the broadest circumstances (e.g. as a result of violent crime, suicide, accident, neonatal death). It is an approach that seeks to work in partnership with communities to:*
>
> - *provide information about health, dying, death and grief*
> - *explore and develop a range of personal and community supports*
>
> *Health Promoting Palliative Care does not replicate or displace service provision but builds on a community's ability to provide supportive care as neighbours, family and friends, recognising that services are not enough on their own and cannot provide all that people need".*
>
> *(McLoughlin, Rhatigan and Richardson, 2010).*

This definition is based on an understanding of health promoting palliative care obtained from Kellehear's writings, lectures and the work of other authors in the field (e.g. Conway and Rumbold). It is recognised that this definition is more closely aligned to the 'Compassionate Communities' (Kellehear, 2005) concept of health promoting palliative care (see on). Thus, it lacks any reference to public policy and assumes that the palliative care services have already been re-orientated to embrace the importance of this approach. With regard to the Irish context, this definition, together with the standards for a health promoting palliative care unit (Kellehear, Bateman and Rumbold, 2003) and a short DVD film about a cartoon person called 'Bill' (Lloydd, McLoughlin, Rhatigan and Richardson, 2010), have enabled local palliative care staff and participants on a bereavement education support programme, to better understand the concept (McLoughlin, Rhatigan and Richardson, 2010). Other studies have also operationalised definitions of health promoting palliative care utilising perspectives from research interviews or personal experience (van der Ploeg, 2001; Richardson, 2002).

The standards for health promoting palliative care units developed by Kellehear and colleagues, (Kellehear, Bateman and Rumbold, 2003) provide a useful benchmark against which to assess the extent of health promoting activity in palliative care services, as well as a basis upon which to develop a strategic approach to health promoting palliative care. To date, these standards have not been utilised in an Irish context, but have been successfully operationalised and implemented in Australia (Rosenberg, 2006). Furthermore, a recent review by Conway (2008) showed that health promotion interventions in UK hospices were extremely limited with respect to their potential under a health promoting palliative care philosophy. Hence there would appear to be considerable scope to further develop health promoting palliative care in these islands.

Table 4.1: Comparison of the goals of health promotion and palliative care

Adapted from Kellehear (1999).

Regular Health Promotion	Health Promoting Palliative Care
Build Healthy Public Policy Develop policies to remove the obstacles to health and empower people to make healthy choices	**Combat death denying health policies and attitudes in wider society**
Create Supportive Environments Make all environments conducive to health – workplace, schools, leisure facilities, health services	**Provide social supports – individual and community** For example, this might involve establishing support groups for those facing death, dying, loss and care and support structures for wider society involved in relevant issues (e.g. funeral directors, florists). **Encourage inter-personal reorientation** to provide people with the skills to cope with life limiting illness
Strengthen Community Actions Healthcare should be participatory where professionals work with as opposed to on others, recognising the importance of social relationships and strengthening existing networks	
Develop Personal Skills Development of personal skills through provision of information and education to enable people to prepare for and cope with maintaining health and dealing with illness	**Provide education and information for health, dying and death** Include health and death education at all life stages
Reorient the Health Services Health promotion should not be confined to health services and needs to involve many groups and disciplines	**Encourage reorientation of palliative care services** To enable palliative care services to better understand and appreciate the potential of health promoting palliative care

In 2005, Kellehear published “Compassionate Cities”, which focused on adopting a public health approach to end of life care and promoted action strategies to operationalise the theory behind the concept. The central thrust of this work was that nurturing compassionate communities might provide the focus for the "third wave" (Kellehear, 2006) of a public health approach to death, dying, loss and care. Specifically, Kellehear outlined seven instrumental building blocks that underpinned a public health approach to end of life care including: normalisation; community relationships; whole person care; the person as a social unit; state involvement; prevention; and the need to go beyond health services ideas and see the broader significance of other disciplines. Whilst Kellehear called for a greater degree of congruence between palliative care and public health/health promotion, other authors have also explored potential synergies between the fields. For example, Scott (1992) made an interesting comparison between the success of obstetrics and public health - outlined *"that palliative care has the potential to revolutionise the way we experience suffering and death."* He also called for increased funding for service user education around palliative care services. Byock et al. (2001) discussed the need for the transition to palliative care services to shift from a personal to a community transition whereby involvement in matters relating to death, dying, loss and care shape individual and collective perspectives and attitudes and vice versa.

4.5 The current status of Health Promoting Palliative Care

Since this study began in 2002, the health promoting palliative care landscape has slowly shifted, from what might have been perceived to be niche area at La Trobe University, Australia - to the development of nationwide public health and palliative care campaigns in the UK (Dying Matters) and Ireland (Forum on End of Life). It might be argued that this may be due, at least in part to Professor Kellehear's move to the UK and the establishment, in 2005, of an academic Centre for Death and Society at the University of Bath. However, this may also be due to a shift in the way policy makers are viewing palliative care and end of life care in general. For example, in the

UK, health promoting palliative care seems to complement the prime minister David Cameron's "Big Society" proposal whereby public and voluntary organisations are urged to take responsibility for delivering social services in communities; and in Ireland, a number of significant developments have taken place during the past number of years including: the development of quality standards for end of life care in hospitals (2010), national audits of the dying in acute hospitals (2009) and the Forum on End of Life has been established to enable the public to debate and engage in discussion around issues relating to death, dying, loss and care. In the current economic climate where health and social services budgets are being cut and demand for services is increasing, the development of health promoting palliative care assumes an even greater importance within society. It is no longer economically viable to continue increasing staffing levels to ensure that patients receive whole person care at the end of life. Therefore alternatives such as utilising volunteers or seeking to strengthen community capacity to provide support could usefully be explored. Kellehear (2009) argues that the use of volunteers in palliative care has had limited community impact and the only real alternative to increasing staffing levels, is to build the capacity of communities to support those living with life limiting illness.

In 2009, the first ever international public health and palliative care conference took place in Kerala, India. This was the first event where academics, public health workers, health professionals, volunteers and community workers from across the globe, met to discuss the theoretical underpinnings of health promoting palliative care, to network with like-minded individuals and to share practice examples. This event will be subsequently held every two years. The concept of compassionate communities seems to have captured the imagination of palliative care and wider health service providers. In the UK, a number of pilot compassionate communities projects have commenced (e.g. Teesside, 2010), whilst training in compassionate communities approaches to death, dying, loss and care has also been developed (Living Well, Dying Well, 2010). Likewise, in Ireland, Milford Care Centre (in Limerick) will commence the pilot of a compassionate communities project in January 2011 for a 12-month period. A number of Charters have also been draw up; for example, the International Work Group on Death, Dying and Bereavement have established a Charter for the Normalization of Death, Dying and Loss (2008) and in the North East of the UK, a Charter for a Good Death has been developed in collaboration with people living in the area. Such charters are consistent with health promotion methodologies (Kellehear, 2009) and seek to agree and publicise elements, action principles and strategies for achieving their goal. Other models of health promoting palliative care have been documented in India, Japan and the USA (Fook and Kellehear, 2010).

Furthermore, in 2009, at the first International Public Health and Palliative Care Conference, Kellehear outlined three, inter-related ‘great challenges’ for the future of health promoting palliative care. Firstly, there is a need to develop a real understanding amongst palliative care service providers and policy makers, of a public health approach to palliative care that goes beyond focusing purely on the provision of education and raising awareness of services and enables service providers to appreciate that community work goes beyond doing something ‘to’ a community and involves working ‘with’ the community. Secondly, Kellehear emphasises the need for education and training and acknowledges that, whilst practice models and pockets of education are available in Australia and India, these are not easily accessible to practitioners across the world. Finally, there is a need to convince public health workers that they have a role to play in palliative care and encourage them to share their expertise in community development, health promotion, critical reflection, legislative change, policy reform and social and political change with the palliative care community.

In summary, health promoting palliative care is a valuable framework that is gathering momentum in developed and developing societies. It offers an exciting opportunity for palliative care services to work with communities and public health experts and to increase the capacity of society to support those living with life limiting illness. Whilst this may impact positively upon attitudes, the central aim of health promoting palliative care is to evoke a social shift that ultimately changes behaviour around death, dying, loss and palliative care.

CHAPTER 5

General Methodological and Ethical Issues

This chapter outlines some of the general methodological issues associated with this study including: (1) an overview of the epistemological perspective underpinning its design; (2) a description of the relevance of the theory of Personal Construct Psychology to the study; and (3) consideration of other general methodological and ethical issues. Further detailed methodological information pertaining to each phase of the study, is provided in Chapters Six and Eight.

5.1 Main epistemological approach: mixed methods

"If the only tool researchers have is a hammer, they tend to see every problem as a nail. An appreciation of both quantitative and qualitative approaches can enhance a researcher's ability to answer complex questions in a manner which is efficient, internally valid, and generalizable"

(Stange and Zyzanski, 1989)

A mixed methods approach to data collection and analysis was utilised in this study. Mixed methods research brings together quantitative and qualitative research methods based on two rather divergent paradigms of positivism (where knowledge is based on observable, scientific fact) and interpretivism (where knowledge is constructed based on the whole phenomena). The use of mixed methods in health services research has become increasingly popular in recent years and provides a balance between qualitative and quantitative methodologies. Borkan (2004) defines mixed methods research as referring *"to those studies or lines of inquiry that integrate one or more qualitative and quantitative techniques for data collection and/or analysis".* The use of mixed methods expands the range of methodologies accessible to researchers (including psychologists who specialise in ‘real world’ research) and enables researchers to explore the findings from a range of perspectives and insights (Borkan, 2004) so that data can be integrated, related, or mixed at some stage of the research process (Creswell et al., 2004). The combination of qualitative and quantitative methodologies enables the researcher to supplement numerical findings (that may enable conclusions to be generalised and statistically significant results obtained) with rich description of a ‘lived reality’. The mixed methods approach also provides an opportunity for data triangulation, whereby data are validated from two or more sources to increase the credibility and validity of the results (Denzin, 1978). The use of mixed methods in palliative care research can be particularly beneficial (Farquhar et al., 2011) in that the mix of quantitative findings often required by commissioners, is balanced with qualitative techniques that answer questions that are (arguably) more important to the patient and service provider and that promote interest in patient experience as advocated in policy (HSE, 2008).

Creswell et al. (2004) have developed a useful conceptual framework for designing and assessing the quality of mixed methods research. This includes the following five criteria: rationale for mixing; types of data collected and analysed; the priority given to qualitative or quantitative research; the implementation sequence; and the phase of the study in which the integration occurred. The current study was designed with these criteria broadly in mind. Firstly, the use of mixed methods was considered appropriate and necessary in order to capture the complexity of the phenomena under investigation. Thus, the study is based on a pragmatic approach incorporating mixed methodologies which were driven by the nature and context of the research question, the population under investigation and the nature of inquiry in palliative care. Qualitative and quantitative methods were used concurrently with the same research participants (see Section 5.2, and Chapters 6 & 8 for more details). These included the use of a wide range of methods including: postal questionnaires; semi structured interviews; psychometric instruments (some of which were designed by personal construct psychologists); the repertory grid technique; and content analysis of qualitative data using a framework associated with personal construct psychology (see below). Equal priority was given to the quantitative and qualitative research and the findings are integrated in the final chapter of this thesis.

5.1.1 Personal Construct Psychology – relevance to this study

One of the psychological methods used in this study, was the repertory grid technique. The decision to use this technique emerged from recognition of the 'fit' between the theoretical perspective promulgated by George Kelly (the well known personality psychologist) (1955) and some of the issues being explored in this study. According to PCP (Kelly, 1955), each person employs a system of many bipolar personal constructs, each of which serves to organise and attribute meaning to some portion of the world. A construct is defined as *"a way in which some things are alike and different from others" (Jankowicz, 2004).* The 'things' in this definition are referred to as elements of the construct. An element may refer to a concrete object, person, and event or to an abstract process or concept. The theory holds that a person's system of constructs is organised in a hierarchical fashion, with relationships of superordination and subordination among constructs (Kelly, 1955). Among the most superordinate constructs in the system are the 'core' constructs. These are especially important as they are the centre of a person's existence and personal identity and any change in them will disturb the person deeply. If a person's identity and understanding of the world is challenged, he/she is said to experience threat (e.g. death threat in the context of this study) which impairs the individual's ability to accurately predict events in the world. The person becomes aware of a need to undertake systematic change in order to re-predict events accurately.

There are degrees of threat according to the extent to which a person's construct system has been challenged. The more superordinate the construct, the greater the portion of the system being challenged (Winter, 1992). In the context of this study, the inability to integrate one's notions about life with one's preset notions about death is indicative of what is known as death threat and as indicated earlier in Chapter One. Relevant constructs and elements may be accurately identified using the widely applied and empirically derived Repertory Grid Technique (Kelly, 1955).

5.2 Epistemological Assumption - Attitude Influences Behaviour

A core epistemological assumption underpinning this study is that attitude influences behaviour and, that attitude research permits us to understand and/or change behaviour**.** In Chapter three, it was outlined how varying attitudes toward palliative care can impact upon transition to the service. In this context, it is important to understand a little more about attitudes and the links (or not) between attitudes and behaviour. In order to change attitudes, it is essential that attitudes are understood (Clutter, 2006). There is no universally accepted and agreed definition of what attitudes are, but they are usually defined in terms of mood, thought processes, behavioural tendencies and evaluation (Hernandez et al., 2000). For example, Triandis et al. (1984) state that "*an attitude is an idea (cognitive component) charged with emotion (affective component) which predisposes a class of actions (behavioural component) to a particular class of social situations".* Thus, cognitive, affective and behavioural elements are central to the notion of attitudes. A distinction must be made between the two types of attitude – those general attitudes toward physical objects, racial and ethnic groups, institutions, policies and events and attitudes toward specific behaviours with respect to an object or target (Ajzen and Fishbein, 1975). The attitude 'object' in the current study is mainly the notion of palliative care and hospice, but also includes broader constructs, such as death, dying, loss and care.

While attitudes can be considered in terms of internal individual processes (implicit attitudes), they link people to a social network of other people, activities and issues and, therefore, are part of a framework by which the social environment can be interpreted (Eby et al. 1998). There are many theories explaining how attitudes are formed including, for example, Katz's Functionalist theory, cognitive dissonance theory, and Bem's Self-Perception theory. However, **a**ttitudes are generally considered to be learned (Zimbardo et al, 1969) as opposed to being innate and represent relatively stable attributes. Social learning theorists (e.g. Bandura, 1977) highlight the role of important others such as parents, teachers and peers in shaping one's attitudes whilst personal constructivists (e.g. Kelly, 1955) discuss attitudes relative to constructs that can be shaped by experience.

The link between attitudes and behaviour is complex and historically has been widely debated in psychology and sociology (e.g. LaPiere, 1934; Wicker, 1969; Fishbein and Ajzen, 1975; Simonson, 1977; Eagly and Chaiken, 1993). It is now considered that the extreme oppositional sides of the debate regarding the attitude and behaviour link (or not as the case may be), are incorrect (AECT, 2001) and that behaviour is likely to be at least partly determined by attitudes (Eagly and Chaiken, 1993; AECT, 2001). In fact, a review on attitudes toward disability conducted on behalf of the National Disability Authority (UCD, 2006) concludes that current thinking favours the existence of a clear relationship between attitudes and behaviour. Much attitude research tends to focus on the circumstances which lead to attitudes predicting and changing behaviour (Eby, 1998). For example, a number of studies have found that differences in the extent to which attitudes guide behaviour, are a product of how easily or quickly a person can retrieve that attitude from memory (Roskos-Ewoldsen, 2008). Other mediating factors include habit or past behaviour, stability of attitudes over time (Schwarz and Bless, 1992), volitional control of behaviour (Ajzen, 1991) and the degree of direct experience with the attitudinal object (Fazio and Zanna, 1991). Attitudes can also be influenced by a number of predisposing factors including age and gender (Shrigley, 1990; Sipploa, 1997).

On sensitive topics, there can often be a conflict between an individual's implicit and explicit attitudes (UCD, 2006) whereby an individual may express a particular sentiment in a socially appropriate way (explicit attitude). but may actually feel very differently (implicit attitude). This social desirability phenomenon presents several challenges since such responses may not necessarily be reflected in behaviour or measured easily. Researchers have attempted to surmount these difficulties using a number of different approaches, including the use of mixed methods in research design, inclusion of sub-scales measuring other items (e.g. prejudice) and procedures such as the Implicit Relational Assessment Procedure (IRAP) that has been designed to measure implicit cognition (e.g. Barnes-Holmes et al. (2006); Cullen, Barnes-Holmes and Stewart, 2009).

As indicated earlier, the current study examined attitudes toward palliative care using a mixed methods approach. Specific factors influencing attitudes toward palliative care were examined using Principal Components Analysis and supplemented with an analysis of qualitative data. In addition, the use of the repertory grid technique with patient and carer groups, facilitated the identification/examination of the cognitive structure of individual constructs of palliative care and broader issues of death, dying, loss and care. This multi-method approach was used in order to arrive at a comprehensive assessment of attitudes which also attempted to address the limitations of using a single approach.

5.3 Study design: an overview

The study design was quite complex in that it involved three phases utilising a number of mixed methodologies (Figure 5.1). **Phase One** involved a postal survey (HPAQ) and a small number of one-to-one semi-structured interviews with health professionals to determine their attitudes toward palliative care. In **Phase Two,** a series of one–to- one interviews was conducted with patients and carers to assess their attitudes toward, and experience of, illness and palliative care. In addition, a battery of psychometric questionnaires was completed by a larger number of patients and carers whilst a small number of repertory grids were also elicited. The findings from Phase One and Two were then used, in **Phase Three** to inform the design and development of two interventions for health professionals and people living with cancer respectively. The aim of these interventions was to change participants' attitudes toward death, dying, loss and care.

5.4 Inclusion and Exclusion Criteria

Given the nature of the study, it was important that participants were considered to be well enough to participate in the interview process and were aware of their diagnosis and prognosis. Exclusion criteria for the study were agreed by the research and medical teams and the majority of patients recruited to the study were approached initially by their Consultant in Palliative Medicine to determine whether or not they would be interested and willing to participate. The exclusion/inclusion criteria were as follows:

- **Patients were aged between 18 and 65 years of age** – The lower age limit of 18 ensured that no minors were recruited to the study and the upper age limit of

65 was set because evidence suggests that once people reach 65, they may construe death and illness as more acceptable and less threatening when aged under 65 (Hendon and Epting, 1989). This may, in turn, impact upon their attitudes toward referral to palliative care services.

- **Patients must have had a diagnosis of cancer** – Whilst it is acknowledged that palliative care can be provided to patients with a range of conditions, the majority of referrals to specialist palliative care services are made for patients with a diagnosis of cancer.
- **Patients must have been aware and willing to discuss their condition and prognosis** – As the study explored attitudes toward palliative care, it was vital that patients were aware that they were receiving specialist palliative care services and were willing to discuss their illness and future openly with the researcher.
- **Patients must have been physically and psychologically well enough to take part in an interview or series of interviews with the researcher lasting 60 minutes in total** – It is recognised that patients at this stage in their illness are often tired and fatigue easily (Addington-Hall, 2002). Therefore it was important to ensure that participating in the interview would not be burdensome on the patient, or cause their condition to worsen in any way.

Similar criteria were also applied to patients living with cancer and to both carer groups, although these individuals were recruited to the study by self selection based on the provision of informed consent. Further information is provided in Chapter Eight.

5.5 Ethical Considerations

The study received ethical approval from three hospital research ethics committees and was carried out in strict accordance with the ethical Code of Conduct of the British

Psychological Society (2009). Despite careful consideration of the potential ethical issues by the research team, there were several difficulties encountered during the study. The main issues centred on the difficulty in negotiating access to patients and carers and the variation in ethical approval processes across the country. Indeed, the literature acknowledges such gate keeping by clinicians as a recognised barrier to gaining access to patients for palliative care research (Ewing et al., 2004; Steinhauser et al., 2006). Gate keeping can manifest when clinicians filter patients who may be appropriate for a study, based on their own personal interpretations of the study, or on the dying patient's perceived potential willingness to participate, thereby affecting the representativeness of the study findings. Gate keeping may also arise where there is a protective urge toward the vulnerable (White & Hardy, 2008). A full description of the challenges of the ethical application process of this study is available in McLoughlin (2010) (see Appendix A).

5.5.1 Informed consent

Participants recruited to each phase of this study, were required to give their informed consent to participate and great care was taken throughout the study to ensure that participants were as fully informed as possible. In **Phase One**, the researcher wrote to health professionals advising them of the aims of the study and inviting them to complete a questionnaire. Return of the questionnaire implied consent to participate. As part of the postal survey, health professionals were also asked to consider whether they would be interested in taking part in a one-to-one interview at a later date. In order to maintain the confidentiality of their returned questionnaire data, they were asked to complete a reply slip and return under separate cover. Those who were subsequently interviewed were sent an information sheet about the study which provided further detail about the purpose and structure of the interview (see Appendix B). When meeting the health professional, the researcher verbally briefed them about the study and answered any queries they may have had prior to seeking their written informed consent. In **Phase Two,** the methodology to obtain consent differed depending on the whether the participant was a person receiving palliative care, a person living with cancer or a carer. For those who were receiving palliative care services, information about the study was verbally summarised for them, in the first instance, by the Consultant in Palliative Medicine. During this discussion, the Consultant determined whether the person was interested in participating and asked them to give their consent verbally for the researcher to make contact with them. The Consultant then provided the person with an Information Sheet about the study (see Appendix C), completed a "consent to contact" form and contacted the researcher indicating that the patient was interested. Given the nature of the person's condition and prognosis, it was vital that the researcher made contact with the person as soon as possible. Upon arrival, the researcher summarised verbally the purpose of the study, asked if the participants had read the Information Sheet and if they had any further questions or queries. Participants were then asked to provide their written informed consent to participate. At all times, it was made clear that participation was voluntary and that withdrawal at any time (or withdrawal of data) would not affect the services or the relationship they had with the palliative care service. The procedure for cancer patients and carers differed in that these participants made the decision to participate in the study independent of any medical personnel. Upon receiving an expression of interest to participate, the researcher sent by post or email, an Information Sheet about the study and awaited further contact from the interested participant. Upon receipt of further contact, an appointment was made to meet and on arrival, the researcher (as above) summarised the purpose of the study, asked if the information sheet had been read and if they had any further questions or queries. Participants were then asked to provide their written informed consent to participate (Appendix D).

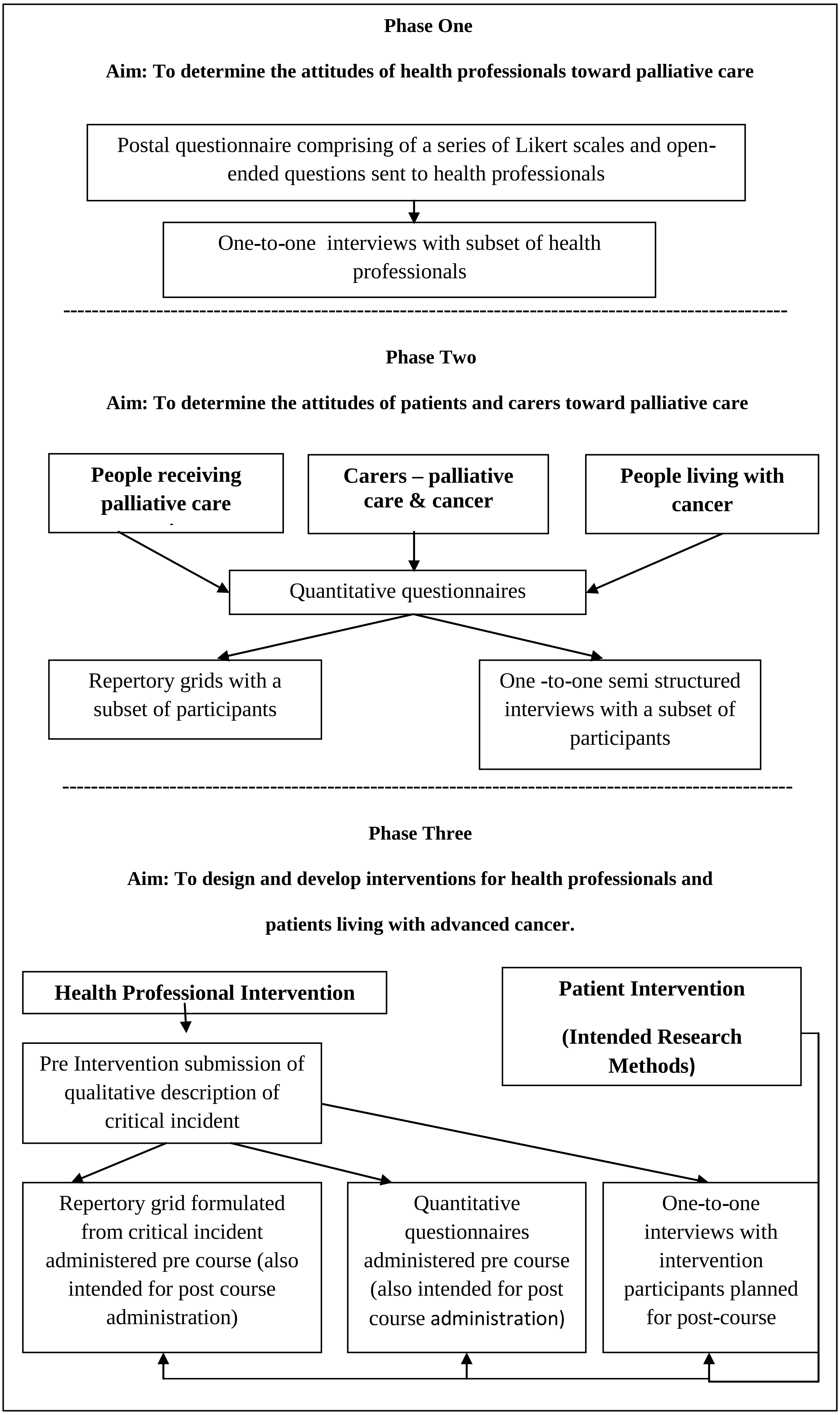

Figure 5.1: Overview of methodologies used by phase

5.5.2 *Researcher sensitivity and welfare*

Upon meeting participants for interview, the researcher advised them that: they could stop the interview at any stage; some of the questions might be difficult for them; and that they were required to answer only the questions with which they felt comfortable. The researcher listened carefully to the language the patient used and substituted some of the words in the questions to match that language; for example, if a patient referred to 'passing away', the researcher would use the same term. For those individuals receiving palliative care services, the researcher checked with the Consultant in Palliative Medicine and nursing staff on duty, prior to meeting the patient, to determine if the patient was deemed to be well enough to be approached for interview on that day. Furthermore questions relating to death and dying were only asked of this group if they had already made reference to dying or death in the early part of the interview.

The researcher monitored the well being of all participants throughout the interview, focusing, in particular on any signs of distress, tiredness or discomfort. On four occasions, when participants became upset, angry or cried, the researcher showed empathy and gave them time to be with their feelings before reminding them that they could withdraw from the study at any time. However, no-one withdrew from the study. Following participation, the participants receiving palliative care services were seen by the Consultant in Palliative Medicine within 12 hours of interview to determine whether the research had raised any issues that they would like to discuss or with which they needed support. Carers and people living with cancer were advised to contact the researcher in the event that they required support after the interview; no post-research contact was made. Participants were later sent a 'thank you' card by post.

Given the nature of the study, the health and welfare of the researcher, when undertaking one-to-one interviews with participants (who were discussing their illness or care experiences and contemplation of death and loss), was considered carefully. Given the potentially distressing nature of the interviews, the researcher kept a reflective diary throughout the data collection phase of the study and had access to the employee assistance service in her place of employment as well as Student Support Services at the University. She also met with a Consultant in Palliative Medicine regularly during the patient data collection phase to discuss any issues arising – only one such issue arose relating to a participant who unexpectedly died very soon after the interview and clarification regarding the patient's condition was given to the researcher. In addition, the researcher corresponded regularly with her research supervisor by email and telephone. The Guidance for Safe Working Practice in Psychological Research (devised by the Department of Psychology, NUI Maynooth) was followed when conducting interviews in locations outside the hospital (see Appendix E).

5.5.3 Other Issues

Other issues of ethical and methodological relevance are discussed below:

5.5.3.1 Identification of appropriate measures

Full consideration was given, when selecting measures, to ensure that they were brief, psychometrically sound, appropriate to the study population and least likely to evoke participant distress or anxiety. Modifications were made to the planned measures outlined in the original funding proposal to ensure that all measures were acceptable to ethics committees, professionals working in palliative medicine and study participants. A pilot of each phase of the study was also conducted and minor adjustments were made based on the feedback received. A full description of the measures used in each phase of the study, is available in subsequent chapters.

5.5.3.2 Reflexivity

"Understanding something about the position, perspective, beliefs and values of the researcher is an issue in all research, but particularly in qualitative research where the researcher is often constructed as the 'human research instrument".

Cohen and Crabtree, (2006)

The role of reflexivity was an important consideration in the qualitative elements of this study. Reflexivity requires the researcher and the reader to be aware that it is impossible to remain outside of the subject matter when conducting qualitative research and that the construction of meaning from data is influenced by the researcher's involvement (Nightingale and Cromby, 1999). There are two types of reflexivity that must be considered. 'Personal reflexivity' refers to the way in which the researcher's own values, beliefs, culture and experiences shape the research outcomes whilst also considering the way in which the research process and findings shape the researcher. 'Epistemological reflexivity', on the other hand, requires the researcher to examine the assumptions made in the course of the research that may have affected the outcome (Willig, 2001).

The importance of keeping a reflexive or reflective journal has been outlined in the literature (Lincoln and Guba, 1985) as a useful tool by which means researchers can record their thoughts and the impact of those thoughts on the construction of meaning. It also enables researchers to process the impact that potentially distressing interviews may have on both them and the participants (Roberts, 2009). In this study, the researcher kept a reflective diary that focused on the research process, design and experience at a personal level for the researcher and also included key points and feelings that were written within 12 hours of each participant interview. The researcher found this useful, particularly in writing up both the qualitative findings and a subsequent paper on the ethical challenges associated with the study (Appendix A). The researcher was also very aware of the importance of her status when meeting participants for the first time and always introduced herself using her title as a student researcher in the palliative care unit, as opposed to her professional title. This required discussion, in advance, with the nursing staff who introduced the researcher to the patient.

5.6 Summary

In summary, this chapter has outlined the main methodological and ethical considerations relevant to the overall study. As indicated earlier, further methodological detail pertaining specifically to each phase of the study, is provided in Chapters Six and Eight.

CHAPTER 6

Method 1: Phase One

This chapter describes the methodology used in Phase One of the study, which was designed to assess attitudes toward palliative care, in a sample of health professionals. This phase consisted of two stages: (1) a postal survey of health professionals; and (2) a small number of one-to-one interviews with a subset of professionals who completed the postal questionnaire.

6.1 Participants and settings

6.1.1 Postal Survey

A purposive sample of 700 health professionals working in, or referring patients to, palliative care, was targeted for purposes of the study. All prospective participants were working in one of three counties (of 26 in Ireland). These three geographical areas were selected because, at the time of the study, the organisation of palliative care services varied across all three regions. Thus, in region A (n=153), the palliative care services were solely provided through community-based nurses without the lead of a consultant in palliative medicine, or a dedicated hospice facility. In contrast, region B (n=382) was selected to provide a view of health professionals who were working in a large county with well developed consultant-led specialist palliative care services, available in both urban and rural locations. Region C (n=165) has a mixed array of services, with a consultant-led department of palliative medicine, but no dedicated hospice facility.

The contact details of all health professionals were identified through senior nursing and health service management in each county and, in some instances, approval was obtained via Freedom of Information Offices within the local Health Service Executive

(HSE) areas. The contact details of General Practitioners (GPs) were identified through the website of the Irish Association of General Practitioners. The questionnaire was distributed by means of direct mailing to work addresses, or via a third party from nursing or health service senior management in the county. For example, hospice staff in region B were mailed a survey form the Chief Executive Officer of the hospice.

All staff working in or referring patients to, palliative care services identified in region A were sent a questionnaire. However, due to the greater number of GPs working in regions B and C, it was decided that a random sample of 1 in 5 region B GPs, and 1 in 3 region C GPs would be contacted to participate in the survey (with appropriate representation from urban and rural locations). This ensured that the study could be conducted within available resources whilst allowing for a sufficient response rate for the results to be considered meaningful. All respondents were asked to return the questionnaire as soon as reasonably practical.

6.1.2 One-to-one interviews

All participants who received the questionnaire were also given an opportunity to indicate their willingness to meet with the researcher to take part in a one-to-one interview to discuss their attitudes toward palliative care in more depth. A total of 11 health professionals (out of 191 in total who returned questionnaires) indicated that they were willing to take part in such an interview, five of whom were subsequently interviewed by the researcher. The remaining six health professionals were not invited for interview as data saturation had been obtained and no new qualitative themes were emerging.

6.2 Measures

6.2.1 Postal survey

The *Health Professional Attitude Questionnaire (HPAQ* – Appendix F) was designed following a comprehensive review of the literature on the attitudes of health professionals toward palliative care and/or care of the dying (Frommelt, 1991; 2003; Strumpf, 1999; Rooda et al., 1999; Bradley et al. 2000; Barclay et al., 2003; Shipman et al., 2003; Addington-Hall and Karlsen, 2005; Groot et al., 2005; and Wessel and Rutledge, 2005). The questionnaire comprised four parts and took approximately 20 minutes to complete.

Part A, a demographics section, was designed to elicit information about the participant's age, gender, race, job title and place of employment, religiosity, experience with personal loss, and experience of working in, referring to and training in palliative care. In Part B, attitudes toward palliative care were explored by presenting 42 statements and asking participants to indicate how strongly they agreed with each statement on a five-point Likert scale: ('strongly agree', 'agree', 'and disagree', 'strongly disagree' and 'unsure'). The statements included in Part B were based on work by Strumpf (1999) (items 1-2 and 4-6), Vejlgaard and Addington-Hall (2005) (items 10-15 and 18-19), as well as the Frommelt *Attitude Toward Care of the Dying Scale* (FATCOD, Part B) (items 20-35) and items 36-42 from Bradley's (2000) quick, reliable and valid assessment instrument used to identify attitudes about care at the end of life among clinicians. Other statements (3, 8, 9, 16 and 17) were added by the researcher to focus specifically on areas associated with palliative care and health promotion**.**

In Part C, participants were asked to rate the importance of a number of aspects of palliative care on a similar scale; items 1-16 of this section are based on those used in a study by Addington-Hall et al. (2005) who adapted them from a previous study of hospice volunteers (Field, 1993; 1997). The final section of the questionnaire (Part D), comprising a number of open-ended bespoke questions, was designed to explore the meaning of terms such as 'hospice' and 'palliative care' and how these were communicated to patients. Further questions explored possible reasons for the non-referral of patients to palliative care, how the service could be improved and the way in which health promotion in palliative care could be explored through further education.

The questionnaire was piloted in January 2006 with ten healthcare professionals working in palliative care services located in a region not included in the larger study. The pilot test resulted in minor changes to the wording of the questions and layout of the questionnaire.

6.2.2 One-to-one interviews

A *Health Professional interview schedule* (Appendix G) comprising 10 open-ended questions, was designed by the researcher to further explore health professionals' attitudes and experience of palliative care, the perceived effect of training on their attitudes toward palliative care, barriers to accessing palliative care services and health promoting palliative care. The questions were selected to supplement and amplify the findings emerging from the HPAQ.

6.3 Procedure

6.3.1 Postal survey

The *HPAQ* was posted to 700 health professionals accompanied by a cover letter explaining the purpose of the study and a contact form for those professionals who wished to be considered for inclusion in a one-to-one interview. Two stamped addressed reply envelopes were included with the questionnaire, one for return of the questionnaire and another for return of the contact form to preserve the anonymity of respondents. Care was taken to maximise potential response rates using the methods outlined in a Cochrane review (Edwards et al., 2003) and within the limited budget available. These included: keeping the questionnaire as brief as possible; signing the cover letter by hand; using postage stamps rather than franking; printing the cover letter on University headed paper; and asking relevant questions first. A reminder follow-up letter was sent to all participants approximately four weeks after the original questionnaire mail shot and this resulted in an additional 23 questionnaires being returned.

6.3.2 One-to-one interviews

Those respondents, who were interested in participating, completed and returned a form outlining their contact details to the researcher. The interviews were then held at a time and place that was convenient for the interviewee; each lasted approximately 30 minutes. All interviews were taped with consent and subsequently transcribed verbatim using a transcription kit.

6.4 Data analysis

6.4.1 Postal questionnaire

The HPAQs were coded and entered into an SPSS (v13.0) file. Answers to open-ended questions were collated and analysed thematically. Descriptive and inferential tests were conducted on the numerical data to include Chi-Squared tests, independent t-tests, correlations and principal component analysis as appropriate.

6.4.2 One-to-one interviews

All of the interview transcripts were subjected to a standard thematic analysis (Hayes, 2000) and were also content analysed in line with the personal construct psychology technique of data analysis (see on).

6.4.2.1 Thematic Analysis

Thematic analysis is used to identify, analyse and report patterns or themes within qualitative data sets. It transforms large amounts of narrative into concisely organised themes that describe the data in detail (Boyatzis, 1998). Thematic analysis is perceived to be the foundation method of qualitative data analysis (Braun and Clarke, 2006) and whilst there has been debate regarding whether it is considered a tool or a method for such analysis (Boyatzis, 1998; Ryan and Bernard, 2000), it has been recognised as a method in its own right (Braun and Clarke, 2006). This method was selected for use in this study as it is considered to be well suited to a number of different epistemological positions. The six-step approach recommended by Braun and Clarke (2006) was followed here (see Table 6.1). One of the transcripts was also independently coded by second researcher and compared with the identified themes in order to check for reliability.

6.4.2.2 Content Analysis (PCP Approach)

A limited content analysis of all six interviews was undertaken in order to determine the constructs that participants used to describe death and dying. All transcripts were reviewed and all constructs associated with death and dying specifically, were classified using the *Manual for Content Analysis of Death Constructs* (Neimeyer, Fontana and Gold, 1984). The Manual provides 25 death-related categories as outlined in later in Chapter Seven to which constructs pertaining to death can be coded. After reviewing the health professional transcripts, it was found that the majority of references were made about the dying process or dying people. However, Neimeyer's instructions regarding the use of the coding manual suggest that it is only possible to use this system to classify constructs *directly* relating to death (as opposed to dying which is what most people discussed). As described later in Chapter Seven (Section B), all health professionals discussed a personal experience of death and also referred to at least one patient who had died in their care. So it was possible to use the manual in the analysis of these. The researcher coded all constructs obtained from the text that were death relevant for each story and categorised them according to the manual. In cases where interviewees had provided more than one patient story, only the first one was utilised for analysis.

Table 6.1: Phases of Thematic Analysis (Braun and Clarke, 2006).

Phase	**Description**
1. Familiarizing yourself with the data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

The findings from Phase One of the study are described in detail in Chapter Seven.

CHAPTER 7

Results 1: Phase One

This chapter presents the results from Phase One of the study and is divided into three sections. In Section A, a descriptive and statistical analysis of the HPAQ data will be presented. This is followed by Section B, comprising mainly a qualitative analysis of Parts C and D of the HPAQ. Finally Section C presents a thematic and content analysis of the interview data.

Analysis of the HPAQ (Section A)

7.1 Response rate

The overall response rate for the postal questionnaire was 27% (191/700); this figure includes seven questionnaires which were returned undelivered, plus three which were returned blank. Thus, the final response rate for purposes of data analysis was 26% (182/700). The number of questionnaires received prior to the posting of the reminder follow-up letter was 168. Table 7.1 compares the profile of respondents and non-respondents by their county of employment and professional background. The figures in the total column indicate that the proportion of replies received for professionals by county, was approximately in proportion in most cases to those in the original mail out.

Due to the fact that the professional backgrounds of all hospice staff that returned questionnaires, were unknown, it was not possible to calculate a response bias for the professions using the titles as listed in Table 7.1. However, when the hospice staff and the allied health professionals (due to the small n value) were removed from the

Table 7.1 Profile of health professionals responding to the postal survey.

	Offaly		**Waterford**		**Cork**		**Location not specified in reply**	**Total (%)**	
	Sent Out	**Replied**	**Sent Out**	**Replied**	**Sent Out**	**Replied**		**Sent Out**	**Received**
General Practitioners	28	7	31	6	65	14	1	**124 (18)**	**28 (15)**
Hospital Consultants / Senior Doctors	31	4	46	4	87	19	3[1]	**164 (23)**	**30 (17)**
Public Health / Community Nurses	65	20	37	12	139	45	2	**241 (34)**	**79 (43)**
Palliative Care / Home Care Nurses	2	2	6	3	4	7[2]	0	**12 (2)**	**12 (7)**
Allied Health Professionals	0	2	3	4	5	3	0	**8 (1)**	**9 (5)**[3]
Palliative Care Consultants / Senior Doctors	N/A	N/A	4	2	2	2	0	**6 (1)**	**4(2)**
Hospital Nurses	27	7	38	1	10	1	0	**75 (11)**	**9 (5)**
Hospice staff[4]	N/A	N/A	N/A	N/A	70	7	0	**70 (10)**	**7 (4)**[5]
Job title not specified in reply	N/A	1	N/A	1	N/A	1	1	**N/A**	**4 (2)**
Total	**153**	**43**	**165**	**33**	**382**	**99**	**7**	**700 (100)**	**182 (26)**
	(22)	**(24)**	**(24)**	**(18)**	**(55)**	**(55)**	**(4)**		

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[1] The Consultants who did not specify their location made a point to note that they did not do so as it could compromise their anonymity since they were the only one of that speciality in an area.

[2] 6 replies were received from this group as the hospice contacted some palliative care nurses directly.

[3] More replies than sent out since some of the AHPs were working in the hospice and are included in the 70 questionnaires sent out from the hospice.

[4] The breakdown of hospice staff by profession is unknown to the research team as questionnaires were mailed to the CEO for delivery to individual staff to preserve staff anonymity. However the group is known to include a mix of doctors, nurses, allied health professionals and palliative care nurses.

[5] This may not be the true figure since some of the respondents may be present in other groups e.g. palliative care nurses / AHPs / doctors.

Table, it was possible to compare the remaining staff by recoding them as either medics or nursing staff (n=622). Thus, 21% (62/294) of doctors replied compared to 30% (100/328) of nurses. A 2x2[6] Chi-Squared analysis confirmed a significant association between job role (i.e. medic versus nurse) and return of the postal questionnaire ($\chi^2(2,N=622) = 7.111$, p=0.008) with nurses significantly more likely to respond to the postal questionnaire. However, the Phi-value was 0.107, showing that the association between the two was relatively weak and, may not, therefore be of any theoretical importance.

7.2 Demographic and background characteristics of respondents

More than three-quarters of respondents were female (78%, 140/182) aged, on average, 44.5 years (SD=9.845) although proportionately more participants were clustered at the higher end of the age range (23-65 years). There were no significant regional differences (i.e. county of origin) between respondents on any of the demographic or background variables outlined in Table 7.2. However, a number of associations were found between the health professionals' role and these variables. For example, significant associations ere found between work location and professional background ($\chi^2(2,N=182) = 93.96$, $p<0.000$), with nurses more likely to work in the community (86%) when compared to doctors (12%) and allied health professionals (11%) whilst doctors more likely to work in hospital settings ($\chi^2(2,N=182) = 33.1$, $p<0.000$). Half of the allied health professionals (AHPs) worked in hospice settings. Whilst no significant associations were found between role and religious affiliation, there was a strong statistically significant difference

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[6] Yates' Correction for Continuity was used to compensate for the overestimate of the ChiSquared value in 1 2x2 table.

between doctors and nurses with respect to their views as to whether or not their religious beliefs strongly influenced their attitudes towards death and dying. Nurses were more likely to report that their beliefs were a strong influence (53%) when compared to doctors (23%) ($\chi^2(2,N=169) = 17.01$, p<0.000).[7]

Table 7.2: Demographic and Background Characteristics of Respondents

Variable	*Category / Measure*	*Number (%)*[8]
Gender (n=182)	Male	40 (22)
	Female	140 (77)
	Not specified	2 (1)
Age (n=182)	Mean	44.6 years
	Standard Deviation	+/- 9.85
	Range	23-65
Race (n=182)	White	178 (98)
	Other	1 (1)
	Not specified	3 (2)
Religion (n=182)	Catholic	162 (89)
	Protestant	8 (4)
	Atheist	4 (2)
	Other	8 (4)
Are your religious beliefs…? (n=182)	a strong influence on your attitude toward death and dying	74 (41)
	a minor influence on your attitude toward death and dying	75 (41)
	of no influence on your attitude toward death and dying	31 (17)
	not specified	2 (1)

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[7] Allied health professionals were not included in this analysis as their low number (N=9) meant that 33.3% of the cells had values less than 5, thereby violating the assumptions of the Chi-Squared test.

[8] Percentages may not equal 100 due to rounding.

Works in[9]	Community	100 (55)
	Hospital	57 (31)
	Hospice facility	9 (5)
	Practice	22 (12)
	Nursing Home	4 (2)
Provision of care for terminally ill patients… (n=182)	currently	122 (67)
	have done so previously	54 (30)
	have no experience caring for them	6 (3)
Previous experience with loss[10]	I have lost someone close to me within the past year	73 (40)
	immediate family	44 (24)[11]
	significant other	13 (7)
	child	3 (2)
	other	14 (8)
Present experience with loss (n=182)	I am presently anticipating the loss of a loved one	10 (6)
	I presently have a loved one who is terminally ill	8 (4)
	I am not dealing with any impending loss at this time	148 (81)
	No response	16 (9)

7.3 Training in palliative care

Over half of the respondents (57%, 104/182) had received specific training in palliative care. A statistically significant association ($\chi^2(2,N=182) = 26.94$, p=0.001) was found between role of respondent and training; that is, nurses (72%) and allied health professionals (67%) were more likely than doctors to have specific training (32%). The types of training varied and the depth of information provided on training also varied considerably. The training ranged from introductory day release

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[9] It was possible for respondents to work in more than one location therefore the total exceeds 170.

[10] Many participants noted that they had lost someone more than 12 months ago. This study used 12 months as a cut off as in Frommelt (2003).

[11] It was possible for respondents to have lost more than one person therefore total exceeds 66.

workshops to degrees in palliative care and ranged in duration from one day to four years. The training was accessed mainly in Ireland and the UK through hospice or university affiliated courses.

Figure 7.1 shows the specific types of areas of palliative care training received by health professionals throughout their career. Professional role was significantly associated with the type of training which health professionals had received whereby nurses were more likely to have received training in bereavement care ($\chi^2(1,N=169) = 8.341$, p=0.008); syringe drivers ($\chi^2(1,N=169) = 47.315$, p<0.000) and health promotion than medics ($\chi^2(1,N=169) = 8.358$, p=0.001). There were no significant associations (p>0.05) between training received and whether the doctor was a GP or other medical doctor. Due to the low number of AHP respondents, statistical differences were not calculated for this group, although it is interesting to note that 89% of AHPs reported that they had undertaken communication skills training compared to 76% of nurses and 73% of medics. In the area of health promotion, only 44% of AHPs had received training in comparison to 75% of nurses.

7.4 Knowledge of local palliative care services

Respondents were asked to indicate which palliative care services were available in their area (Figure 7.2). For none of the services listed, was there complete consensus amongst professionals in any of the participating regions/counties as to whether the service was available in their area. For example, there is no hospice facility in Offaly

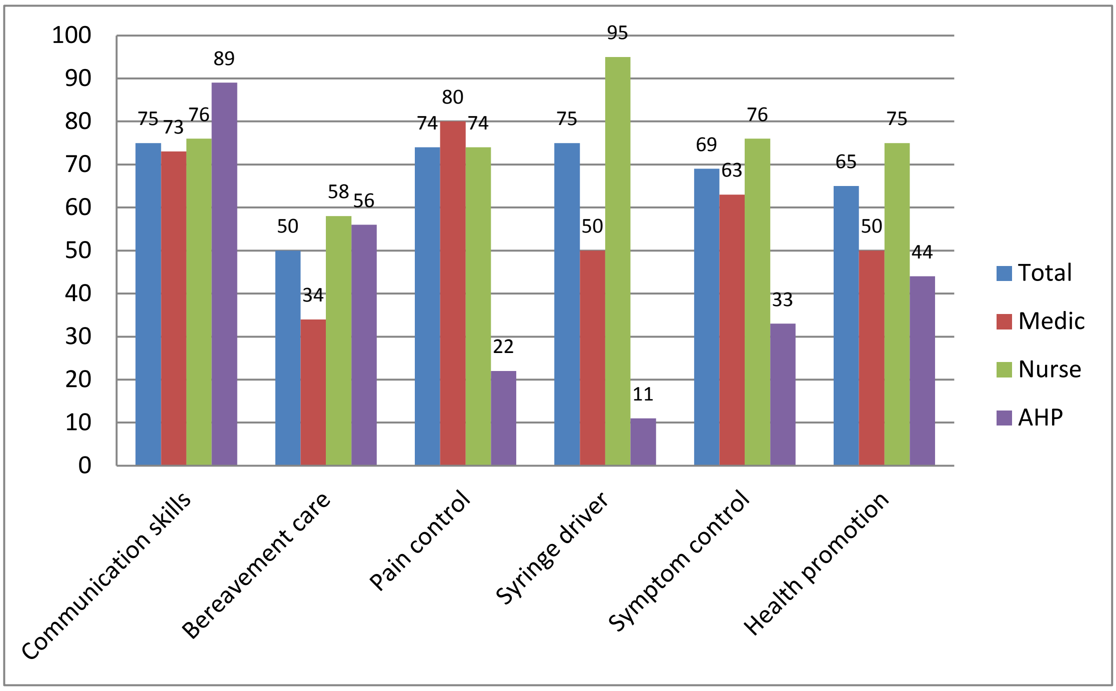

Figure 7.1 Percentages of Health Professionals Who Have Completed Different Types of Training in Palliative Care

or Wexford and yet, 10 and 8 professionals respectively, replied that there was such a facility in those regions. It is possible that they may have understood the term ‘hospice’ to mean more than a building, as there is a fundraising body in Offaly called “Offaly Hospice”, or they may have looked beyond their county area. Where “other” was indicated, professionals discussed the availability of a palliative care advisory service in a nearby acute hospital (Cork), a dedicated palliative care consultant, and beds in oncology wards or local hospitals available for palliative care purposes (all counties). Two health professionals in Cork mentioned the availability of day care for palliative care patients.

7.5 Attitudes toward palliative care

Of the 182 questionnaires returned, 139 respondents correctly completed Part B of the form, indicating their attitude to all 42 statements listed. One respondent did not complete any of this section whilst others failed to complete some of the items listed.

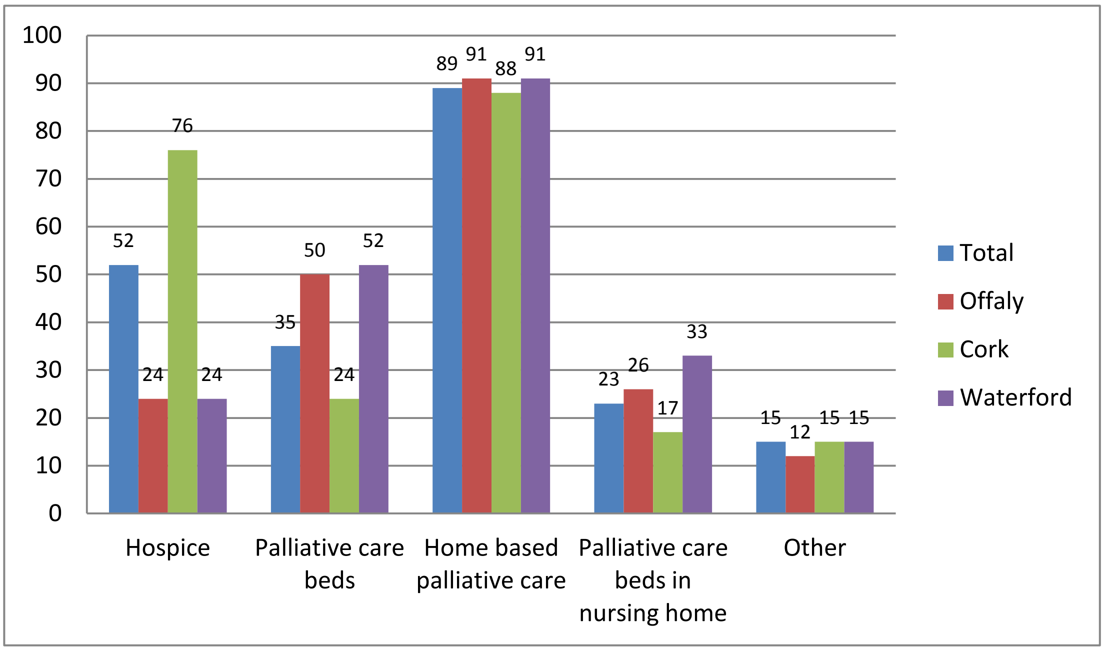

Figure 7.2: Percentage of respondents reporting availability of palliative care services in local area.

The missing data were examined for the 42 participants who did not complete this section fully (excluding at this point the one person who did not complete any of it). From this examination, it was clear that there was no pattern of missing data and almost all items had at least one missing value recorded for them. Upon review of the literature (Tabachnick and Fidell, 2007), it was decided to allocate a missing value based on the mean score for that item of the questionnaire within the professional group to which the respondent belonged (i.e. nurse, medic or allied health professional). Two respondents had not indicated their profession on the questionnaire so for the item they both missed; the overall mean for that item was inserted.

This section of the report presents the findings for the 181 respondents who completed all or most of the items (using the scoring indicated above). The total attitude score of all respondents ranged from 127 – 181 (M=155.26; SD=10.54). Total attitude score was normally distributed (Kolmogorov-Smirnov statistic (181) = 0.057, p= 0.2).

Table 7.3 shows the scores for each item on Part B of the questionnaire with the average mean score and standard deviation for each item. No significant difference was found in mean total attitude score between nurses and doctors[12] (t(167)= -0.056, p=0.96); between males and females (t(178)= -0.519, p=0.61), or between health professionals in different counties (Welsch statistic(2,75.56) = 1.56, p=0.22).

As Table 7.3 highlights, the vast majority of respondents (178/182, 98%) agreed that giving care to dying patients was a worthwhile experience whilst 84% (153/182) agreed that they felt confident caring for a dying person. Whilst 96% (175/182) of respondents agreed that symptom control would be better if a patient was referred to palliative care services, and 80% (147/182) agreed that patients would benefit from palliative care services if they were initiated early in the illness trajectory. Half (90/182) of respondents indicated that many terminally ill patients who need palliative care do not receive it.

The findings from the HPAQ also indicate some difficulty in communicating with patients and families around death, dying and palliative care. For example, whilst 87% (159/182) agreed that it was important for patients to be given honest answers about their condition, only 40% (73/182) of respondents agreed that it was essential

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[12] AHPs not included as small sample size.4.5

Table 7.3: Participants responses to each item on the HPAQ (n and (%).

Attitude toward palliative care items * = negatively scored item.	Strongly agree	Agree	Disagree	Strongly Disagree	Unsure	No response	Mean Score	Std Dev
1. The end of life is a time of great suffering.*	14 (8)	36 (20)	78 (43)	35 (19)	14 (8)	5 (3)	3.48	1.23
2. Little can be done to help someone achieve a sense of peace at the end of life.*	2 (1)	5 (3)	53 (29)	121 (67)	0 (0)	1 (1)	4.58	0.74
3. Health promotion can improve the patient's quality of life at the end of life.	40 (22)	100 (55)	17 (9)	4 (2)	19 (10)	2 (2)	3.86	0.94
4. I am comfortable caring for the dying patient.	57 (31)	96 (53)	17 (9)	7 (4)	4 (2)	1 (1)	3.99	1.03
5. I am not comfortable talking to families about death.*	5 (3)	25 (14)	79 (43)	54 (30)	14 (8)	5 (3)	3.86	1.08
6. Dying patients should be referred to palliative care services.	47 (26)	78 (43)	24 (13)	12 (7)	19 (10)	2 (1)	3.69	1.18
7. I am not comfortable discussing palliative care with patients.*	4 (2)	24 (13)	86 (47)	54 (30)	8 (4)	6 (3)	3.92	1.04
8. A terminally ill cancer patient should be referred to palliative care asap.	66 (36)	74 (41)	23 (13)	7 (4)	11 (6)	1 (1)	3.93	1.13
9. I am not comfortable discussing palliative care with families.*	16 (9)	0 (0)	96 (53)	62 (34)	5 (3)	3 (2)	4.14	0.84
10. Palliative care is a rewarding part of my work.	65 (36)	84 (46)	12 (7)	6 (3)	10 (6)	5 (3)	4.07	0.99
11. Dealing with a dying patient make me more aware of my own feelings of death.	43 (24)	108 (59)	19 (10)	5 (3)	4 (2)	3 (2)	3.92	0.96
12. I often reflect on existential matters (the meaning of life and death).	25 (14)	99 (54)	36 (20)	12 (7)	7 (4)	3 (2)	3.50	1.15
13. I am an active member of a religious community.	7 (4)	69 (38)	57 (31)	42 (23)	3 (2)	4 (2)	2.67	1.30
14. I tend to leave the dying patients to other professionals.	5 (3)	6 (3)	74 (41)	89 (49)	2 (1)	6 (3)	1.66	0.88

Attitude toward palliative care items *** = negatively scored item.**	**Strongly agree**	**Agree**	**Disagree**	**Strongly Disagree**	**Unsure**	**No response**	**Mean Score**	**Std Dev**
15. Doctors play a key role in reducing the suffering of patients with hopelessly advanced disease.	64 (35)	89 (49)	20 (11)	1 (1)	6 (3)	2 (1)	4.08	0.94
16. There is a sense of stigma around palliative care.*	12 (7)	71 (39)	60 (33)	29 (16)	8 (4)	2 (1)	3.13	1.27
17. I believe there is life after death.	31 (17)	77 (42)	10 (6)	8 (4)	52 (29)	4 (2)	3.63	0.98
18. It is primarily the task of nurses to deal with patients' reactions to death.*	11 (6)	35 (19)	78 (43)	38 (21)	16 (9)	4 (2)	3.54	1.19
19. Health professionals find it more satisfying to work with patients expected to improve rather than die.*	5 (3)	81 (45)	55 (30)	24 (13)	15 (8)	2 (1)	3.07	1.18
20. Giving care to the dying person is a worthwhile experience.	91 (50)	87 (48)	1 (1)	1 (1)	1 (1)	0 (1)	4.47	0.60
21. Death is not the worst thing that can happen to a person.	47 (26)	100 (55)	14 (8)	4 (2)	16 (9)	1 (1)	3.95	0.93
22. Caring for the patients' family should continue throughout the period of dying, grief and bereavement.	87 (48)	87 (48)	1 (1)	5 (3)	0 (0)	1 (1)	4.44	0.58
23. I would be upset when the dying person I was caring for gave up hope of getting better.*	4 (2)	29 (16)	107 (59)	29 (16)	11 (6)	1 (1)	3.71	0.99
24. It is difficult to form a relationship with a dying person	9 (5)	9 (5)	96 (52)	65 (36)	2 (1)	1 (1)	4.10	1.01
25. There are times when the dying person welcomes death.*	52 (29)	121 (67)	5 (3)	0 (0)	2 (1)	2 (1)	1.78	0.60
26. When a patient asks "Am I dying?" I think it is best to change the subject to something cheerful.*	7 (4)	1 (1)	75 (41)	92 (51)	4 (2)	3 (2)	4.36	0.88

Attitude toward palliative care items *** = negatively scored item.**	**Strongly agree**	**Agree**	**Disagree**	**Strongly Disagree**	**Unsure**	**No response**	**Mean Score**	**Std Dev**
27. The family should be involved in the physical care of the dying person.*	35 (19)	111 (61)	10 (6)	0 (0)	23 (13)	3 (2)	2.05	0.74
28. I would hope that the person I am caring for dies when I am not present.*	3 (2)	12 (7)	92 (51)	55 (30)	17 (9)	3 (2)	4.03	0.90
29. Families should be concerned about helping their relative make the best of their remaining life.	43 (24)	117 (64)	6 (3)	1 (1)	11 (6)	4 (2)	4.10	0.69
30. The dying patient should not be allowed make decisions about their physical care.*	10 (6)	5 (3)	54 (30)	107 (59)	2 (1)	4 (2)	4.36	1.04
31. It is beneficial for the dying person to verbalise their feelings.	86 (47)	83 (46)	3 (2)	3 (2)	4 (2)	3 (2)	4.38	0.76
32. I would be uncomfortable if I entered the room of a terminally ill person and found them crying.*	9 (5)	31 (17)	79 (43)	56 (31)	3 (2)	4 (2)	3.80	1.19
33. Dying people should be given honest answers about their condition.	62 (34)	97 (53)	7 (4)	1 (1)	14 (8)	1 (1)	4.17	0.77
34. Educating families about death and dying is not a health professionals responsibility*	0 (0)	3 (2)	96 (53)	76 (42)	3 (2)	4 (2)	4.38	0.60
35. Family members who stay close to the dying patient interfere with a health professional’s job with the patient.*	4 (2)	2 (1)	75 (41)	95 (52)	5 (3)	1 (1)	4.41	0.79
36. Most patients want their doctors to determine what care is the best for them.	8 (4)	72 (40)	71 (39)	14 (8)	15 (8)	2 (1)	2.94	1.13
37. I think it is essential for a dying person to be told their prognosis.	9 (5)	64 (35)	56 (31)	7 (4)	43 (24)	3 (2)	3.07	1.01
38. Many terminally ill patients who should receive palliative care do not receive it.*	20 (11)	70 (39)	54 (30)	11 (6)	24 (13)	3 (2)	2.81	1.16

Attitude toward palliative care items *** = negatively scored item.**	**Strongly agree**	**Agree**	**Disagree**	**Strongly Disagree**	**Unsure**	**No response**	**Mean Score**	**Std Dev**
39. Many patients would benefit if palliative care was initiated earlier in the course of their illness.	37 (20)	110 (60)	12 (7)	0 (0)	22 (12)	1 (1)	3.95	0.77
40. When the possibility of palliative care is discussed with the patient and family, they often lose hope.*	2 (1)	68 (37)	80 (44)	12 (7)	18 (10)	2 (1)	3.18	1.05
41. I feel knowledgeable enough to discuss palliative care with patients and families.	36 (20)	96 (53)	32 (18)	6 (3)	11 (6)	1 (1)	3.69	1.08
42. Most of the symptoms of terminally ill patients' such as pain, shortness of breath and nausea are controlled better if they receive palliative care	91 (50)	84 (46)	4 (2)	1 (1)	1 (1)	1 (1)	4.44	0.68

that a dying person should be told their prognosis and 5% (8/182) agreed that if a patient asked them if they were dying, it would be better to change the subject to something more cheerful. One in four respondents indicated that they were either unsure or were uncomfortable about talking to families about death and palliative care (12%); 27% (50/182) indicated that they did not feel knowledgeable enough to discuss palliative care service. 38% (70/182) of respondents noted that when the possibility of palliative care services were mentioned to the patient, they lose hope and 46% (82/182) of respondents agreed that there was a sense of stigma associated with palliative care.

There were no differences in mean total attitude scores by county although it is interesting to note that total mean attitude levels were lowest in Offaly and highest in Cork (Table 7.4).

Table 7.4: Mean Attitude Score of Professionals by County

County of Respondent	**N**	**Mean**	**Std Deviation**
Offaly	42	152.34	12.69
Cork	99	156.26	10.26
Waterford	33	155.24	8.26
Total	174	155.12	10.63

A one-way ANOVA showed that respondents' perception of the extent to which their religious beliefs influenced their attitude to death and dying, did not affect mean total attitude score (F(2,176) =0.865, p=0.423).

7.5.1 Sub - group analyses

The relationship between age of respondents and mean total attitude score was investigated using a Pearson product-moment correlation coefficient. There was a weak, negative correlation between the two variables (r=-0.189, n=168, p=0.014) with more positive attitudes to palliative care associated with younger age. Less than 4% of the variance in attitudinal score can be explained by age. Further sub-group analyses showed that those respondents who had received reported having specific training in palliative care, reported significantly more positive attitudes toward palliative care (M=156.75) than their counterparts (M=153.25) who had received no such training (t(178) =2.20, p=0.028).

7.5.2 Principal component analysis

The 42 items of the attitudinal scale were subjected to Principal Components Analysis (PCA) to reduce the dimensionality of the data set and to identify new meaningful underlying variables that could be succinctly labelled as factors influencing health professionals' attitudes toward palliative care. Prior to performing PCA, the suitability of the data for factor analysis was assessed. Inspection of the correlation matrix revealed the presence of numerous coefficients of 0.3 and above. The Kaiser-Meyer-Olkin value was 0.67, just exceeding the recommended value of 0.6 (Kaiser, 1970, 1974) and the Bartlett's test of Sphercity (Bartlett, 1954) reached statistical significance (p<0.000), supporting the factorability of the correlation matrix. Principal components analysis revealed the presence of 14 components with eigenvalues exceeding one, which explained a total of 63.5% of the variance in attitudinal score. An inspection of the scree plot revealed a break after the 5th component. A parallel analysis was carried out, which showed that five components exceeded the corresponding criterion values for a randomly generated data matrix of the same size (42x181). It was decided from the results of the parallel analysis (Table

7.5) and inspection of the scree plot (Appendix H) to retain five components for further analysis.

Table 7.5: Parallel Analysis Comparisons with actual eigenvalues from the PCA

Component Number	Actual Eigenvalue from PCA	Criterion Value from parallel analysis	Decision
1	5.699	2.0697	accept
2	3.055	1.9383	accept
3	2.482	1.8455	accept
4	2.004	1.7635	accept
5	1.709	1.6956	accept
6	1.610	1.6234	reject

To aid the interpretation of these five components, varimax rotation was performed. The five component solution explained a total of 35.6% of the variance in attitudinal score (see Appendix I for tables highlighting the total variance explained by first five components and rotated component matrix). The interpretations of the five components revealed five key domains that explained health professionals' attitudes toward palliative care.

Component 1 had statements 4, 5, 7, 9, 14 and 41 loading highly onto it (0.5 and above); these relate to the health professional's knowledge of palliative care and the extent to which they felt comfortable discussing death and palliative care with patients and families. Statements 31, 33, 39 and 42 loaded onto Component 2 which related primarily to the honesty about a patient's condition and the benefits of early referral to palliative care services. Component 3 was related to statements 6, 24 and 28 and is concerned with the relationship a health professional can build with a dying patient and their entry into palliative care. Component 4 had high loadings only on items 11 and 12 suggesting the importance of the health professionals' own thoughts on death and dying and the impact that dying patients have on these thoughts. Finally, Component 5 (no loads greater than 0.5) comprised items 15,21,25,36 and 38 (loading at 0.42 – 0.48) which appeared to relate to respondents' ability to reduce the suffering of the patient at the end of life (including referral to palliative care services) and feelings about the imminence of death. These factors are summarised in Figure 7.3.

Part A and B of the HPAQ have provided comprehensive information regarding health professionals' attitudes toward palliative care. Further information about their perception of elements associated with palliative care now follows in Section B.

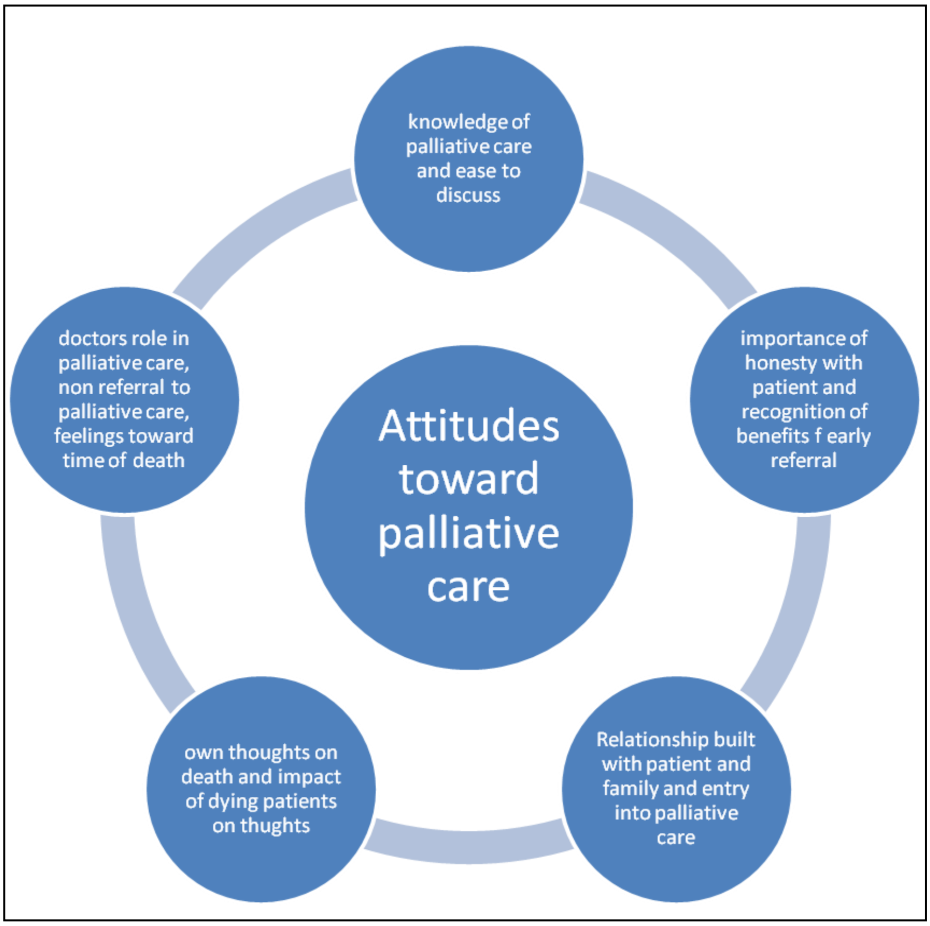


Figure 7.3: Factors influencing health professionals' attitudes toward palliative care as determined by the HPAQ

Analysis of Part C & D of the Health Professional Attitude Questionnaire (HPAQ) – Section B.

7.6 Importance of elements associated with palliative care

In part C of the HPAQ, health professionals were asked to indicate how much importance they placed on 18 different aspects of palliative care by using a Likert scale *'very important', 'important enough', 'neither important nor unimportant', 'not important'* or *'unsure.'* All except two respondents (n=180) completed this section of the questionnaire. As highlighted in Figure 7.4, 100% of respondents considered *'the control of pain and other symptoms'* to be a *'very important'* element associated with palliative care. This was the only element upon which there was unanimous agreement amongst respondents. Interestingly only two of the 18 elements, *'assisting with legal concerns of patients and families'* and *'stopping active medical treatment'* were ranked as '*not important'* (albeit it by a very small percentage of participants). These two elements received mixed rating across all five categories with 15% and 19% of respondents respectively indicating that they were *'unsure'* how important these elements were in palliative care. Of particular relevance to this study is the finding that only 55% of health professionals felt that the stage of referral during the patient's illness to palliative care was *'very important'*. It is also interesting to note that a lower percentage of health professionals rated psychosocial issues e.g. management of depression, meeting the religious / spiritual needs of the patient as *'very important'* in comparison to other elements.

Participants were then asked to identify the three *most* important aspects of palliative care from the eighteen elements listed. Data was collated for each element and the three elements that ranked the highest were:

1. '*Care of the whole person and not just their physical needs'* (82%)
2. *'Control of pain and other symptoms'* (47%)
3. *'Respect for the patient's wishes'* (31%)

Interestingly, four elements did not feature in the top three most important for any of the health professionals responding. These were:

'Bereavement support'

'Stopping active medical treatment'

'Assisting with legal concerns of patients and/or families'

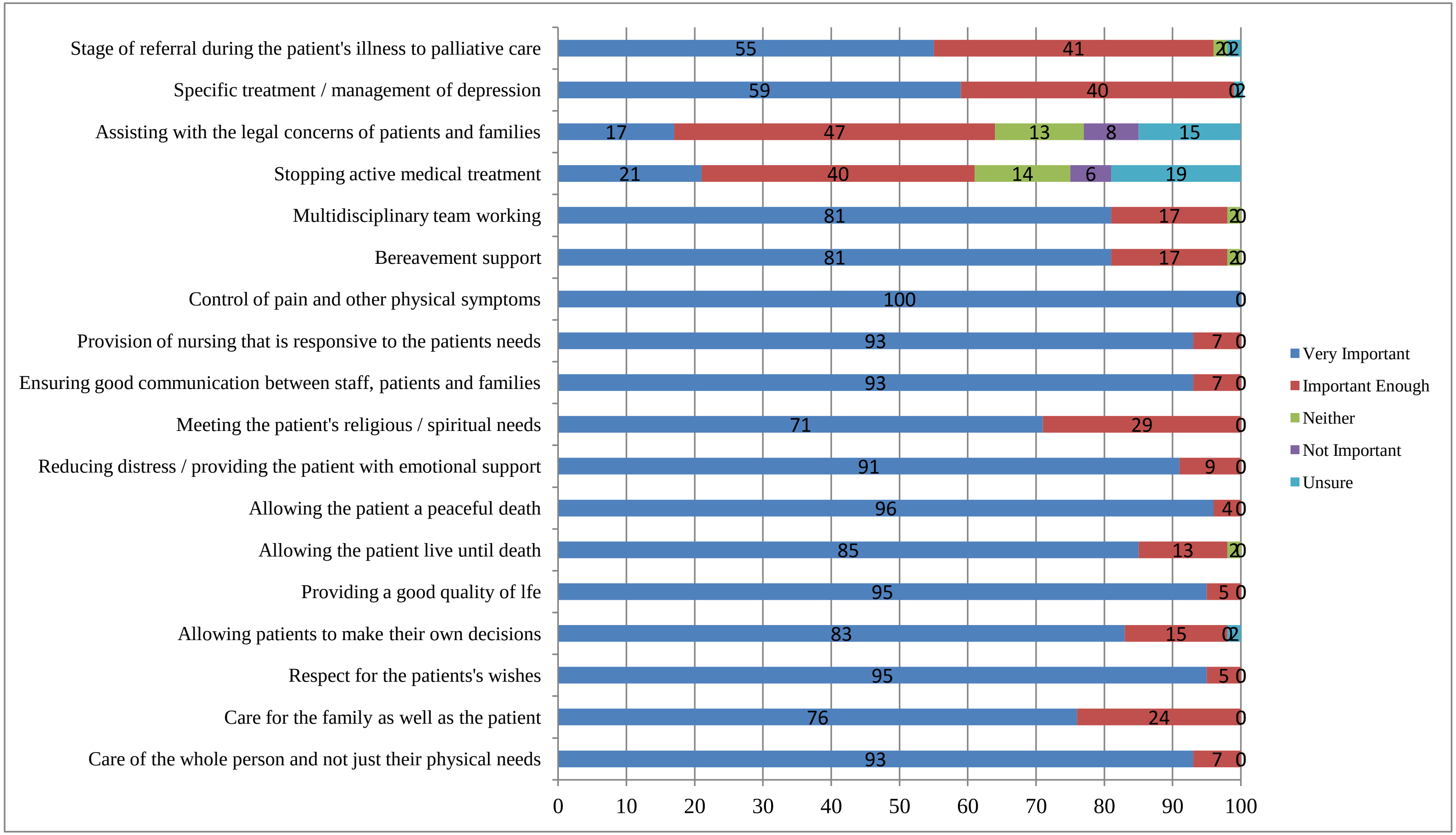
'Specific treatment/management of depression'

Only 6% of respondents listed *'stage of referral during the patient's illness to palliative care'* in their top three most important elements associated with palliative care.

7.7 Understanding of the term

In Part D, a number of qualitative questions were posed to participants. This section was completed in full by 169 respondents. Participants were first asked what the term 'palliative care' meant to them. Approximately 8% of responses to this open-ended question contained specific reference to the World Health Organisation (WHO) definition of palliative care. Where health professionals used their own language to describe the meaning of the term, they often focused on the provision of *"care for the dying or terminally ill patient"*.

Figure 7.4: Ratings of Elements Associated with Palliative Care (%)



Approximately two thirds of health professionals used the word *"incurable"* or referred to a *"lack of cure / recovery"* for the person receiving palliative care services. About one in five respondents referred to the provision of care for the family in their definition.

The aim of palliative care as outlined in health professionals responses, focused on *"ensuring comfort and alleviation of symptoms for patients to meet their physical, emotional, social, spiritual and psychological needs".* The word *"comfort"* was frequently used in the responses obtained. Health professionals were more likely to refer to and discuss the physical and emotional needs in their response than the other areas. Where specific symptoms were named, pain was most frequently referred to. The goal of palliative care was discussed by relatively few respondents. Where it was referred to specifically, *"ensuring maximum quality of life for patients"* and *"enabling a peaceful death"* were cited.

Some health professionals mentioned specific ways of working in palliative care and the standard of care provided, for example *"excellence in multidisciplinary care specific to the patient and the family".* In many responses to the questions, the language lacked concrete content and many respondents spoke of palliative care as being *"holistic"*, *"spiritual"* and *"caring"* whilst others alluded to a concept rather than a concrete branch of medicine/nursing.

Later in Section D, health professionals were asked to outline what they understood by the term 'hospice'. Responses to this question were very much evenly divided between the hospice as a physical space or specialised unit *"a calmer environment, more homely place to manage end of life care"* and the hospice as a philosophy of care *"for the dying regardless of setting".* Interestingly, language used to describe 'hospice' became even more aspirational and lacking in concrete definition than for the term ‘palliative care’. For example, *“a home from home”; “a beautiful, wonderful place”* were sole statements given by two respondents to describe the term ‘hospice’. Whilst ‘hospice’ was described positively by many respondents, a large number, referred to the hospice as being associated with death or dying without any further elaboration and others discussed their unease with the term *“it’s not a word I am happy with”* and referred to the fear and stigma associated with the word that is evoked in patients when mentioned.

7.8 Stage of referral to palliative care services

Participants were asked to outline at what stage of illness they thought a patient should be referred to palliative care services. Whilst some health professionals, acknowledged that referral could only be made *“when the patient is ready to accept palliative care”* and that such decisions to refer patients could only be made *“on a case by case basis”;* the most common responses to this question were along the lines of *“when the patient is terminal and has many symptoms” or “as soon as possible”.* About a quarter of respondents acknowledged that palliative care should be introduced as early as possible for patients and a lesser proportion discussed the referral to palliative care whilst a patient was still receiving active treatment *“to alleviate pain and distress and maximise living with ongoing treatment”*. A minority of respondents to this question specifically stated that they would not refer patients to palliative care services *“too early”.*

7.9 Terms used with patients

Health professionals responding to the questionnaire were asked what other terms (if any) they would use with patients to describe *‘palliative care’* and ‘hospice’. There was a consensus that palliative care was as a specific term rarely used with patients; phrases such as *“homecare nurse”* or *“a team to help you with your pain”* tended to be used instead. Interestingly, many respondents explained *'palliative care'* to patients by referring to '*hospice'* implying that the term '*hospice'* might be better understood by the patient population whilst others outlined that they would never use the word hospice due to the fear it evokes.

7.10 Reasons for non referral to palliative care

Health professionals' responses widely acknowledged that palliative care was often associated with fear, stigma and loss of hope for the patient and family. There was a perceived lack of knowledge regarding palliative care amongst patients and/or families and a general unwillingness to be referred to the service. In relation to specific barriers to palliative care referral, words such as "fear" and "stigma" were commonly used (see Figure 7.5). Some nurses in their response also questioned the relative importance placed by clinicians on palliative care.

7.11 Health promotion programme

The final question in Part D of the HPAQ asked health professionals to consider what aspects a health promotion programme focusing on palliative care would include. This question was not answered by a lot of participants and many of those who did respond, acknowledged that they were unable to identify exactly what would form part of such a programme.

Barriers to Referral to Palliative Care

"Fear of death"; "Stigma of referral"; "Loss of hope"; "Lack of service provision"
"Cannot access services available"

Questioning of relative importance of palliative care

"*Some consultants see palliative care as just an extra bit of TLC"*
"It [palliative care] is perceived as a treatment failure, lack of multidisciplinary team consultation, overzealous oncology"

Figure 7.5: Attitudes toward palliative care

Participants who replied to this question provided very mixed responses. Some focused on recommendations for content for a health professional education programme, similar to an introduction to palliative care that is widely available from hospice education centres and proceeded to list the possible curriculum for this e.g. breathlessness, pain control etc. Others considered the potential usefulness such a programme would provide in establishing and maintaining relationships with the local palliative care team and described programmes that might include the introduction of and information giving by the multidisciplinary staff. A third group, focused on the programme as providing the opportunity for the palliative care service to promote the positive aspects of the service to the public, focusing on quality of life and showcasing the environment on offer in an attempt to balance the negative perception of hospice in society. Finally, some respondents focused on health promotion interventions for patients and families that included the classic interventions associated with mainstream health promoting hospitals interventions e.g. promoting exercise, diet, dental care and relaxation, whilst others focused on interventions for patients that were more specific to their stage of life e.g. management of fatigue, breathlessness. Two respondents discussed the potential for such a programme to include *"reflection on life and death as a natural process".*

Further in-depth analysis of individual health professionals' attitudes toward palliative care now follows in Section C.

Section C

Thematic and content analysis of qualitative health professional interviews

(Section C)

7.12 Profile of health professionals interviewed

Data from five health professional interviews was analysed using thematic analysis (Braun and Clark, 2006). As outlined previously, saturation had been reached at interview number four when comparing the data already obtained from the HPAQ and data emerging from the interviews. Table 7.7 provides a summary of demographic information regarding the participants who were interviewed.

Table 7.7: Demographic Information of Interviewees

Gender	Age	Profession	Region	Previous training in palliative care
Male	52	Consultant	A	Yes
Female	45	Public Health Nurse	A	Yes
Male	35	Acute Hospital Nurse	B	No
Male	60	General Practitioner	B	No
Female	41	Occupational Therapist	C	Yes

7.13 Thematic analysis of health professional interviews

Thematic analysis of the health professional interview data revealed three key themes that describe health professionals' attitudes toward palliative care. The researcher has labelled these as follows (1) Changing Times; (2) This is My Story and (3) It's All About Dying. Within each theme, a number of subthemes were identified as outlined below.

7.13.1 Theme One: Changing Times

The theme 'Changing Times' focuses on health professionals' recognition that attitudes toward palliative care are constantly changing as a result of shifts in (a) palliative care provision; (b) public opinion and (c) professional responsibility. These three categories form the subthemes of Theme One.

7.13.1.1 Palliative care provision

All participants referred to the changing nature of palliative care service provision, in that the manner by which services are delivered had changed and the range of options for people living with life limiting illness had increased considerably in recent years and continued to develop. Health professionals saw these new developments as extremely positive, although regret was expressed by respondents in region A, that service development had been slower there than in other areas *"It's fantastic to see the range of options available in some areas – hospice care, home care, palliative medicine expertise, on tap, in acute hospitals – let's hope we get a bit more of it here and soon" [p1].* Such observations by health professionals in this study highlight the inequity between Health Board areas in Ireland with regard to palliative care service development as outlined in the IHF Baseline Study (2005). Health professionals discussed the move toward the provision of palliative care for all as generally positive but some questioned whether it was reality or merely rhetoric "*I mean at the end of the day, patients will be fine - as long as they have the golden diagnosis of cancer!" [p3].*

The changes in palliative care service development and delivery discussed by health professionals in this study are important to acknowledge, and the pace at which change is occurring is a vital consideration for researchers measuring attitudes toward palliative care at a single point in time. The changing pace of palliative care service development is an area that was not captured by the HPAQ.

7.13.1.2 Public opinion

Health professionals discussed how palliative and hospice care were perceived negatively by patients and their families as outlined in part D of the HPAQ, but there was much acknowledgement that the levels of fear and anxiety *"might not be as bad as they were years ago" [p5].* Some health professionals acknowledged that the stigma associated with palliative care was probably stronger amongst the older age groups in society where the stigma associated with living with cancer as an illness was *"still very much alive and well. They don't want anyone to know they have it you know" [p4].* A number of health professionals referred to various public awareness and fundraising initiatives by the Irish Cancer Society e.g. Daffodil Day and the Irish Hospice Foundation e.g. Coffee Morning and discussed how these may have positively influenced the public perception of cancer, hospice and palliative care: *"The daffodils help to start the conversation and get people to use the word cancer and talk to others about illness and care...the hospice and that" [p2].* One participant discussed at length their perceived rationale for the apparently high levels of support for such fundraising initiatives *"people feel pity for them, the poor, dying people in the lovely, quiet hospice and they see the box and think, I'd better put some money in there, it might insure me against the future" [p1]* The adjectives used to describe hospice in this extract echo the words of many health professionals responding to part D of the HPAQ and also highlights the underlying fear resonating regarding hospice and death in society.

7.13.1.3 Professional role and responsibility

All health professionals referred to the impact that changing times in palliative care and healthcare generally were having on their role and responsibility caring for patients facing the end of life. Most health professionals acknowledged that the development of increased staffing structures in palliative care was positive and the expanding multidisciplinary team in both palliative care and primary care meant that more support was available, particularly for GPs:

"The teams are changing and becoming more dynamic, we have more disciplines working together than ever before. Now I don't have to feel that I am the only one who has to care for this patient...I can send them to physio if they are breathless or call in OT if they need a home assessment. It gives me time to focus on medication management and also reduces the number of visits to the surgery if you ask me" [p4]

Most health professionals perceived themselves to be more supported as a result in the changing levels of staff from different disciplines to work with the patients. This in turn transformed into positive time management benefits for the health professional and had positive implications for the patient. However the public health nursing service appeared to view these developments less positively. In the past palliative care nurses were solely involved with the patient but *"now they only get involved for symptom control only. It works better if they do whole patient care. We work together very well but us PHNs are very busy" [p2].* This tension between public health nursing and clinical nurse specialists in palliative care was also referred to by one of the GPs in a different region, suggesting it is a problem wider than just one individual or area. The words *"but us PHNs are very busy"* may imply that CNSs in palliative care are not and later in the interview, this professional referred negatively to the change in level of speciality in palliative care *"Palliative care is getting to the stage where there are too many specialists and too many advisors...too many chiefs and not enough Indians" [p2].* Whilst this may reflect a power struggle between the two nursing roles or purely individual dynamics in a service, the researcher feels it raises an important question related to the over medicalisation of death in modern society and is one that has been highlighted in the literature.

The debate between specialist and generalist palliative care was discussed and all professionals emphasised the need to be competent in caring for patients at the end of life as part of their role, but acknowledged that where symptoms became complex, patients did require the expertise and skill of palliative care teams. GPs in particular discussed how satisfying it was to work with a patient who had experienced a positive end of life experience, acknowledging that whilst *"it is sad to see someone you have known for years die, it's great to know they died where they wanted to be, with the people they cared about and they weren't in too much pain" [p4].* In contrast a Consultant acknowledged that he *"absolutely hated it"[p1]* when he saw a patient die, particularly a young one, knowing that the treatment he had provided *"did just not work"[p1].* These opposing viewpoints between two different health professional roles again echo the findings in Part B of the HPAQ.

7.13.2 Theme Two: This is My Story

The researcher noted that the use of story-telling by health professionals interviewed was extremely common and subsequently to conducting these interviews, has noted that stories are often used by people when palliative care or hospice becomes the topic of debate. The focus of the stories in the health professionals who were interviewed had two main nuclei (a) the health professionals' personal tale of death, dying, loss or care and/or (b) the story of a patient they had cared for. These are therefore the subthemes for Theme Two.

7.13.2.1 Personal tale

All health professionals who participated in the semi structured interviews, at some point in their interview, referred to their own story of death, dying, loss or care that had touched their life personally. For many, this was the death of a parent and for one health professional, a child. Two of the five professionals used their personal experience purely to highlight a point. For example:

"It must be awful to die in pain – my father died a few years ago, he just dropped dead. It was such a shock but looking back at least we know he didn't really suffer" [p5].

The remainder seemed to dwell on their tale of loss and away from the interview topic, explaining in great detail the circumstances surrounding the death, their feelings at the time and how they felt about it now. One participant discussed their personal loss for over 20 minutes with the researcher and two became quite emotional whilst speaking. The researcher wonders whether health professionals who agreed to participate in the interview did so because of their personal experience related to death, dying, loss and care and if they did, what was it about their experience that motivated them to agree to be interviewed? Their personal tale certainly seemed to have a powerful influence on health professionals practice, understanding and attitude toward palliative care as highlighted below:

"I don't think education influences attitudes toward palliative care, it is shaped by previous experience of those we have cared for who have died. I lost my father in 1999 and now I understand how the dying process works and what it is like to be left behind so that has influenced my practice and changed the way I deal with family members now" [p3].

It should be noted here that this was the only health professional that did not consider education in palliative care to influence attitude and had completed significant levels of palliative care education. The health professionals stories all had relatively positive outcomes and given the impact the stories had on the interview, the researcher questions the effect on practice, understanding and attitude toward palliative care for health professionals whose experience may not be so positive.

7.13.2.2 The patient story

In addition to personal stories, each health professional also voluntarily referred to a patient story, or case study as an example to highlight points being made. Interestingly, seven of the eight patient stories discussed by health professionals were used to indicate a difficult or complex case or an area where systems or services had failed. For example:

"I was visiting Mary for several months and every time I called in she told me she was absolutely fine. After a few weeks, her daughter called me, daily sometimes telling me that her mother was in so much pain...but she just wouldn't admit it to me...crazy"[p4].

In addition to using the case studies as examples to illustrate points and ground them in practice, health professionals often went on to reflect on how they could have done things differently:

"Looking back I should have realised more quickly how depressed he was, the minute I mentioned it to the consultant a referral was made to the mental health team in X" [p3].

Health professionals seemed very comfortable with utilising these patient stories or case studies during the interviews and critically reflecting on them (albeit at a very basic level) and this has lead the researcher to consider how such stories can provide useful points of learning as part of an intervention in Phase Three of the study.

7.13.3 Theme Three: It's All About Dying

The final theme 'It's All About Dying' can be viewed as the superordinate reason health professionals gave for the perceived barriers to palliative care and the fear and stigma associated with the service. Most of the factors identified by the HPAQ earlier in this chapter, as outlined in the PCA model of results were discussed in relation to the barriers to referral to palliative care. However, ultimately, health professionals acknowledged that given the synonymous relationship between palliative care and death, the core reason for non referral and associated fear and stigma toward palliative care is because *"at the end of the day, it's all about dying. It doesn't matter what you call it. It signifies the end" [p1].* Another health professional said:

"People get so hung up on terms, palliative care, hospice, supportive care... the words don't matter. If I referred you to the opthamologist, you'd trot off happily; if I referred you to palliative medicine...it's a different story. I need to work myself up for that one and you need to be prepared" [p4].

This theme is very important in that it indicates that it is not palliative care or hospice that people are frightened of, but what it represents and this supports the call for a major drive to change people's attitudes toward death dying, loss and care (Kellehear, 1999). The second quote highlights the importance of preparing not only the patient for this transition, but the health professional too.

7.14 Health promotion programme

Health professionals were asked what elements they felt a health promotion programme aimed at reducing the fear and stigma associated with palliative care should include. Professionals focused both on interventions for health professionals and patients / public. The focus on the development of a programme for health professionals centred on the provision of communication skills training, knowledge updates and information about service availability. One participant referred to the potential usefulness of creating a reflective space for professionals *"it would be good if there was a bit of time too for us to sit and think about what all this actually means" [p2]* and another discussed the importance of using case studies and patient histories to reinforce learning. For patients and the public, health professionals considered a public awareness campaign *"we have say no to smoking, so why not say yes to palliative care?" [p5]; night classes for carers to learn how to care for people facing the end of life [p3]; the development on an "oncology health squad"* [p2] who would raise awareness of the potential problems that people might encounter and deal with them in an anticipatory, proactive way with the patients, ideally in their own home and support groups for those facing the end of life that include talks by the palliative care team.

7.15 Content analysis

The Manual for Content Analysis of Death Constructs (Neimeyer et al. 1984) provides 25 death related categories to which constructs pertaining to death can be coded. Upon review of the health professional transcripts, the majority of references were made about the dying process or dying people and with reference to Neimeyer's instructions regarding the use of the coding manual, it was only possible to use this system to classify constructs directly relating to death (as opposed to dying which is what most people discussed). However, as outlined in Theme Two, during the interviews, all health professionals discussed a personal experience of death and also referred to at least one patient who had died. The researcher coded the constructs obtained from the text that were death relevant for each story and categorised them according to the manual (see Table 7.8). Where health professionals had provided more than one patient story, only the first one was utilised for analysis.

Table 7.8: Health Professionals Constructs of Death Coded By Category

Category	Personal Story	Patient Story
1a Purposeful	4	
1b Purposeless	1	
2a Positive Evaluation	2	1
2b Negative Evaluation	1	6
3b Negative Emotional State	15	22
4b Low Acceptance		2
5a High Understanding		
5b Low Understanding		
6a High Suffering	2	5
6b Low Suffering	3	
7a High Personal Involvement	5	2
7b Low Personal Involvement		3
8a Long Range Temporal Expectation	2	5
8b Short Range Temporal Expectation	3	
9a High Certainty	2	7
10a Existence	1	
10b Non existence		
11a High Choice		
11b Low Choice		
12a Specific		
12b General		3
13a High Impact	3	3
13bLow Impact		
14a Known Causality	2	5
14b Unknown Causality		

The analysis, whilst limited due to the sample size, raises some interesting differences in the death related constructs used by health professionals telling their own story as opposed to the patient story. Health professionals only utilised constructs relating to the purpose of death when they discussed their own personal story (1a & b); patient death stories tended to be discussed more generally, lacking specificity (12b). Personal deaths discussed were both expected and unexpected/certain (8a&b & 9a) in comparison to patient deaths that were all expected and of a known cause (14a). Health professionals used more negative constructs to evaluate the death in the patient story in comparison to that in their personal tale, construing it as bad (2b) and used constructs suggesting a negative emotional state (referring to both the patient and the health professional (3b)) and high suffering (6a). This confirms the researcher's assumption that the professional was using the patient story as a case study to highlight a learning point or service deficit and also suggests that the emotional impact on the health professional might be equally as high for some professionals as their personal loss (13a).

7.16 Summary of key findings from phase one

This chapter has provided a comprehensive analysis of health professionals' attitudes toward palliative care using a combination of qualitative and quantitative methodologies. Whilst the overall response rate to the postal survey was only 27%, the development of the HPAQ as a tool to assess health professionals' attitudes toward palliative care has been a particularly useful addition to measures available in this area. Respondents attitudes toward palliative care as measured by the HPAQ can be explained by five factors:

- Knowledge of palliative care services and ease to discuss;
- Importance of honesty with patient and recognition of benefits of early referral;
- Relationship built with the patient and family and transition to palliative care;
- Own thoughts on death and impact of dying patients on these thoughts; and
- Health professionals ability to reduce suffering of the patient at the end of life

Further elaboration of this model has been enabled through the thematic analysis of the health professional interview data revealed three additional key themes that describe health professionals attitudes toward palliative care: (1) Changing Times; (2) This is My

Story and (3) It’s All About Dying. Attitudes were not significantly affected by gender, profession, religious beliefs or age; however they more positive for those respondents where palliative care services were more developed at the time of survey. A number of significant differences in scores on individual items of the HPAQ were detected between health professional groups. Encouragingly, there was a positive association between training and attitude toward palliative care.

The vast majority of respondents (178/182, 98%) agreed that giving care to dying patients was a worthwhile experience and 84% (153/182) agreed that they felt confident caring for a dying person (despite only approximately half reporting to have attended any specific training in this area). Whilst 96% (175/182) of respondents agreed that symptom control would be better if a patient was referred to palliative care services and 80% (147/182) agreed that patients would benefit from palliative care services if they were initiated early in the illness trajectory; 50% (90/182) of respondents indicated that many terminally ill patients who need palliative care do not receive it and only 6% of respondents placed the timing of referral to palliative care in their top three factors and only 55% rated this element as ‘very important’.

In general health professionals viewed palliative care positively, and the three most important elements of palliative care as rated by respondents were (1) care of the whole person (82%); (2) control of pain and other symptoms (47%) and (3) respect for the patients wishes (31%). However, understanding of palliative care was sometimes questionable since respondents tended to define palliative care and hospice in language that lacked clarity and more than one in four health professionals in indicated that they did not feel knowledgeable enough to discuss palliative care services and many were unaware what services were available locally. The results from the three phases seem to highlight on one hand a lack of understanding regarding the medical rigour of palliative care – focusing on the comfort provided by the approach whilst also placing less emphasis on the importance of psychosocial care as an element of palliative care service provision. There was also a lack of consensus regarding the importance of assisting with the legal concerns of patients and families and stopping active treatment in palliative care.

Communicating with patients and families about palliative care services and the broader area of death and dying has been highlighted as problematic for respondents in this study. The findings from the HPAQ has also indicated some difficulty communicating with patients and families around death, dying and palliative care. For example, whilst 87% (159/182) agreed that it was important for patients to be given honest answers about their condition; only 40% (73/182) of respondents agreed that it was essential that a dying person should be told their prognosis and 5% (8/182) agreed that if a patient asked them if they were dying, it would be better to change the subject to something more cheerful. One in four respondents indicated that they were either unsure or were uncomfortable about talking to families about death and palliative care (12%); with 27% (50/182) indicating that they did not feel knowledgeable enough to discuss palliative care service. 38% (70/182) of respondents noted that when the possibility of palliative care services were mentioned to the patient, they lose hope – possible as a result of the fear and stigma associated with palliative and hospice care.

Interestingly the care of patients at the end of life seems to prompt health professionals to question their own mortality through the reflection on existential issues and critical reflection of personal and professional stories to highlight learning and points of practice. This finding is extremely important for the future development of models of learning that seek to address health professionals attitudes toward palliative care. There was a lack of understanding amongst respondents regarding the purpose of a health promotion programme. Those who did respond to this question approached their response from one of four perspectives (1) providing education to health professionals regarding palliative care; (2) improving the relationship between the palliative care services and other healthcare providers; (3) positively promoting the hospice and (4) focus on the provision of health promotion for patients (focus here on classic approach to health promotion). These findings will be contextualised later in the Discussion Chapter.

CHAPTER 8

Method 2: Phase Two

This chapter describes the methods used in Phase Two of the study to determine the attitudes toward palliative care of a number of participant groups including: (1) those patients receiving specialist palliative care services; (2) people living with cancer; and (3) carers of people in both of these groups. As indicated in Chapter One these groups were included as literature (e.g. Canny, 2002) suggests that patients receiving palliative care describe how their attitudes toward it change between referral to palliative care services and receipt of same. Therefore it would be useful to compare attitudes toward palliative care with people who have not received the service but have the potential to in the future by virtue of their cancer diagnosis. In addition, carers were also included, since palliative care service provision focuses on both the patient and the carer. Whilst it is acknowledged that palliative care services are suitable for patients living with any advanced life-limiting illness, only people with a cancer diagnosis were included in this study since the majority of palliative care service users have a diagnosis of cancer. In addition to exploring attitudes toward palliative care, death anxiety, quality of life and experience of care are compared between the participant groups where appropriate.

This part of the study involved a mixed methods design utilising quantitative measures with all participants plus one-to-one interviews with a smaller subset. Repertory grids were also administered to a small number of participants in order to supplement and amplify the findings from the above.

8.1 Participants and settings

Opportunistic sampling was utilised to recruit a total of 75 participants across the above four groups during 2007-2009; the total sample included 40 patients and 35 carers. A total of 15 participants who were receiving specialist palliative care, were recruited to the study - 10 of whom were identified and recruited via contact with a consultant at a specialist palliative care service in Ireland (see on); the other five were known to the researcher through her family and social contacts and were identified in the course of completing the study. Twenty-five people living with cancer were also recruited to the study, 18 of whom were recruited from a local cancer support group and the remainder of whom responded to an advert in a local newspaper. With respect to the two carer groups, 10 carers of patients receiving palliative care services were recruited to the study by means of one-to-one contact with patients participating in the patient interviews. Lastly, 25 carers of people living with cancer were identified and recruited through the patient population identified by means of advertisements in local newspapers and a local cancer support group. All participants were living in Ireland at the time of the study with the exception of two people receiving palliative care services and their respective carers who were living in the UK but completed their interviews with the researcher who was visiting the UK.

The researcher met all participants in a location of their choice, usually the person's own home. Two participants specifically requested to be interviewed in a local hotel. Most of those receiving palliative care who were interviewed, were residing in a single room in the hospice, where interviews were conducted. Where a patient was in a four-bedded room, the patient and researcher moved to a private interview room on the ward.

8.1.1 Eligibility Criteria

The inclusion criteria for the study agreed by the research team were as follows:

- **All participants had to be aged 18 to 65 years** The lower age limit of 18 ensured that no minors were recruited to the study and the upper age limit of 65 was set since evidence (Hendon and Epting 1989) suggests that once people reach 65, they may construe death and illness as more acceptable and less threatening than those under 65. This may, in turn, impact upon their attitude toward referral to palliative care services.
- **All participants had to have a diagnosis of cancer,** or be **caring for someone with this diagnosis** – Whilst it is acknowledged that palliative care can be provided to patients with a range of conditions, the majority of referrals to specialist palliative care services are made for patients with a diagnosis of cancer. Participants recruited to the palliative group were required to be receiving palliative care services. For those living with cancer, they had to have been diagnosed with cancer at some stage in their life but were not under the care of palliative care services.
- **All participants had to be aware of, and willing to discuss, their condition and prognosis or in the case of carers, those for whom they were providing care** – As this study explored attitudes toward palliative care, it was vital that participants were aware that they, or the person for whom they were caring, were receiving specialist palliative care services and were willing to discuss the illness and future openly with the researcher.
- **All participants had to be considered physically and psychologically well enough to take part in an interview, or series of interviews with the researcher, each lasting approximately 60 minutes** – It is recognised that patients with cancer often tire and fatigue easily so it is important to ensure that

participating in the interview would not be burdensome on the patient or cause their condition to worsen in any way. For palliative patients, this was based on the clinical judgment of the consultant. Upon meeting all palliative care patients and people living with cancer were assessed by the researcher using the *Distress and Impact Thermometer* (Akizuki, 2005) (see on). Participants were required to score above the cut-off to 4 on distress and 3 on impact or less in order to proceed with the study. (NB: No-one scored higher than 3 on either scale).

A number of challenges emerged during the recruitment process including difficulties in negotiating access to patients and families in two health board regions and delays in securing ethical approval (See Chapter five and Appendix A). The numbers recruited to the palliative groups (i.e. patients and carers) were lower than in both cancer groups due to difficulties in securing participants receiving palliative care services. For example, four additional patients receiving palliative care services were approached by a Consultant to take part in the study, but subsequently declined whilst two others who had originally agreed to participate, declined when the researcher arrived, explaining that they were feeling tired. As a result, more one-to-one interviews were conducted with patients receiving palliative care services in order to redress this imbalance across groups.

Unfortunately, the pool of prospective carer participants available to the study was considerably reduced as two other studies involving carers were taking place in the palliative care service used to access patients**,** at the same time as the current research. However, seven one-to-one interviews were held respectively with the people living with cancer and their carers and these were deemed to be sufficient in number to ensure that saturation had been reached, particularly considering that the interview data from all four groups has been analysed as a holistic whole.

8.1.2 Sample recruitment

Recruitment of palliative care groups

The researcher secured the support of two Consultants in palliative medicine to assist with the recruitment of patients and carers from the palliative groups. The Consultants discussed the study with all patients who met the inclusion criteria and those who expressed an interest in taking part were provided with a Patient Information Sheet (Appendix C) and asked to provide their verbal consent for the consultant to contact the researcher with their details. The Consultant subsequently completed a 'consent to contact' form and sent this to the researcher. At the end of the interview, patients were asked if they thought their carer or family member might also like to take part. In the event that a patient expressed that there might be an interest, the researcher left them with a Carer Information Sheet (similar to the patient sheet in Appendix C). Five carers subsequently contacted the researcher to take part in the study. During the course of the study, six people in the researcher's family and social circle entered the palliative stage of illness, five of whom approached the researcher and asked to participate in the study. A family member for each was also recruited to the carer group.

Recruitment of 'living with cancer' groups

An advertisement was devised and submitted to The Midland Tribune Newspaper in order to recruit people living with cancer to the study. This was printed weekly for six weeks and resulted in 10 enquiries. Upon receipt of a telephone call, the researcher discussed the purpose of the study with prospective participants, the eligibility criteria and subsequently sent them an information sheet. All agreed to take part in the research whilst seven of their carers also decided to take part in the one-to-one interviews. Due to the low response rate to the advertisement, the researcher made contact with a local cancer support service. The service leader, a neighbour of the researcher, made arrangements for the researcher to attend a support group meeting. At this meeting, information about the project was given to 35 attendees. 18 of whom subsequently made contact with the researcher along with their carers. All of these participants completed the quantitative measures via post and three people living with cancer and three carers were randomly selected to complete a repertory grid.

8.2 Measures

A summary of measures completed in this phase of the study is highlighted in Figure 8.1.

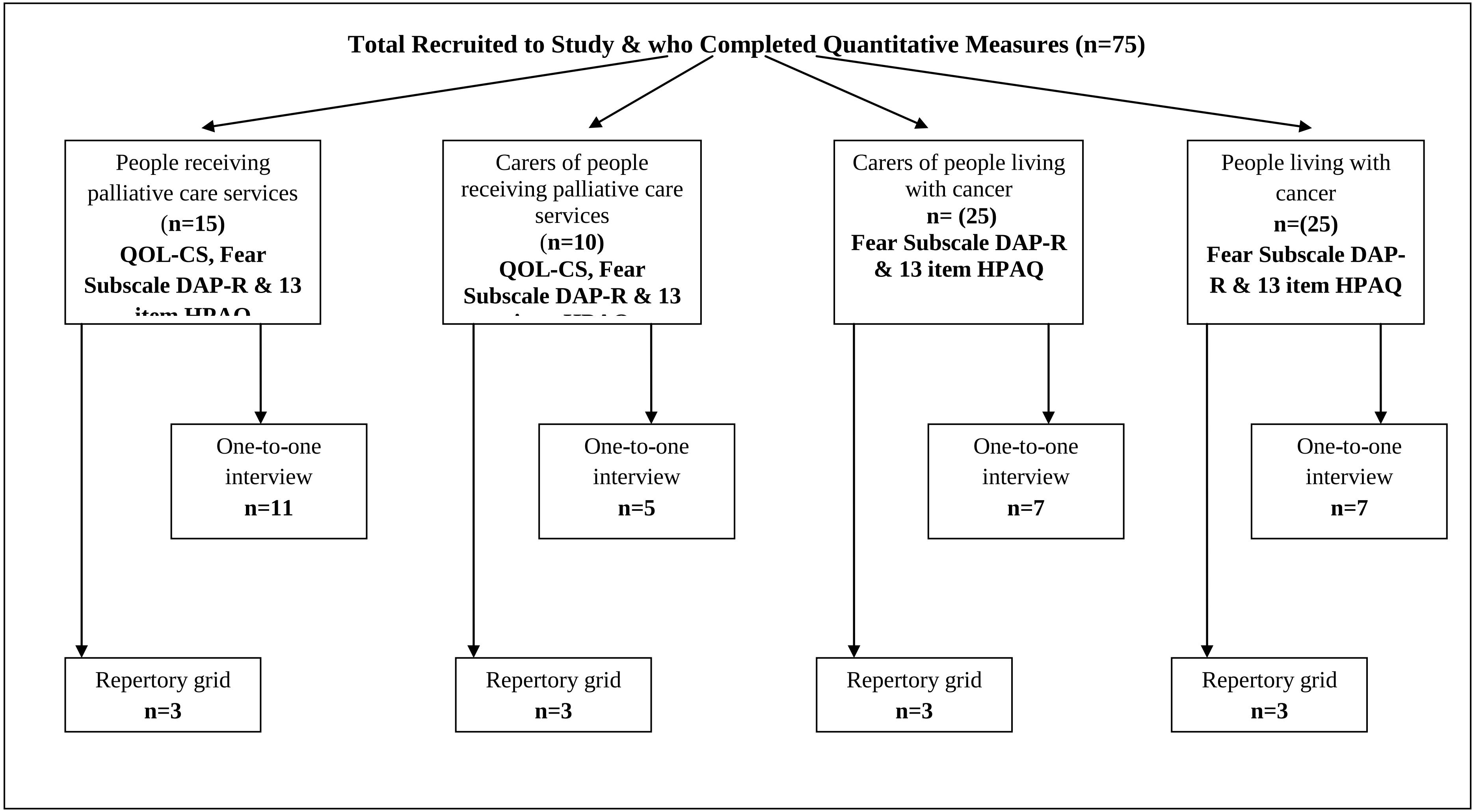


Figure 8.1: Measures Completed by Participants in Phase 2 of the study.

8.2.1 Initial Assessment

In order to comply with the conditions stipulated by the Waterford Regional Hospital research ethics committee**,** all patients involved in the study were required to complete an initial assessment of psychological distress prior to participating in the study. The *Distress and Impact Thermometer* (Akizuki et al. 2005) was selected for its brevity and ability to detect adjustment disorders and major depression. This tool comprises of two sections, the first measuring distress and the second measuring impact**.** The cut off points for detection of adjustment disorders and major depression are 3/4 on 'distress' score and 2/3 on 'impact'. Following discussions with the Consultant in Palliative Medicine, it was agreed to use the higher number in each case as the cut-off point, given that some of the patients in this study were receiving palliative care services and may be more likely to be more distressed and affected by their symptoms than a patient receiving oncological care (for which the test was designed). Akizuki et al., (2005) report the sensitivity and specificity for the DIT as 0.82 and 0.82, respectively and indicate that screening performance of the *Distress and Impact Thermometer (Appendix J)* is comparable but faster to administer than the more widely used *Hospital Anxiety and Depression Scale* when used in oncology settings.

8.2.2 Quantitative Stage

All participants in Phase Two completed the fear subscale of the DAP-R and 13-item HPAQ (n=75). All patient groups also completed the QOL-CS (n=40). A description of each measure is outlined below:

Quality of Life – Cancer Survivor questionnaire

The *Quality of Life-Cancer Survivor* questionnaire (*QoL-CS* Appendix K**)** was developed to measure the QOL of long-term cancer survivors (Ferrell, Dow & Grant,

1995) and was administered here (with the authors' permission) to all patients (n=40) participating in the study. This measure was selected mainly for its brevity and the inclusion of a sub-component assessing fear that was relevant to the focus of the study. It also examines issues of particular concern to long-term cancer survivors, such as fear of a second tumour, recurrence or metastasis, survivorship guilt and the role of spirituality and religion. The *QOL-CS* uses a 41-item visual analogue scale, where participants rate themselves on a scale from zero to ten to indicate their overall quality of life. For some items, zero represents the worst possible quality of life outcome and ten the best; for other items the scale is reversed. The instrument consists of four multi-item scales: physical well-being (eight items); psychological well-being (eighteen items), social well-bring (eight items) and spiritual well-being (seven items). Within the psychological sub-scale are two sub-components assessing fear and distress.

For scoring purposes, all items are ordered (or reverse ordered as necessary) so that zero indicates the lowest or worst possible quality of life outcome and ten indicates the highest or best quality of life outcome for each item. Within each of the four domains and two additional sub-components, item scores are averaged, resulting in a sub-scale score for that domain or sub-component. An overall quality of life score is also calculated by averaging all 41 items. The instrument is reported (Pearce et al., 2008) to have high internal consistency (Cronbachs Alpha = 0.93), good test-retest reliability (r=0.89), evidence of tests for face-validity and content validity (r=0.78 with FACT-G).

Fear Subscale of **Death Attitude Profile - Revised**

The fear subscale of the *Death Attitude Profile–Revised* (*DAP-R,* Appendix L**)** (Wong, Reker, & Gesser, 1994) was administered to all patients and carers (n=75) in this study in order to assess respondents' attitudes toward death. Only the fear subscale of the

DAP-R was used to ensure that participants were not overburdened. This was selected in preference to the more widely used *Death Threat Index (DTI,* Moore and Neimeyer, 1991) because the latter was considered by the palliative care teams to be too complex and time consuming. The *DAP-R* is a 32-item tool comprised of five subscales to determine respondents' feelings of: (a) fear of death—negative thoughts and feelings about death; (b) death avoidance—avoidance of thoughts of death as much as possible; (c) neutral acceptance—death is neither welcomed nor feared; (d) approach acceptance —death is viewed as a passageway to happy afterlife; and (e) escape acceptance—death is viewed as an escape from a painful existence. The mean subscale score is computed by adding the scores on each of the individual items within that scale, from one ('strongly agree') to seven ('strongly disagree') and then dividing by the number of items included in that subscale. In this study only the fear of death subscale questions were asked. To assess reliability of the *DAP-R,* Wong et al. (1994) computed alpha coefficients of internal consistency and four-week test-retest coefficients (n = 90) of stability. The alpha coefficients ranged from a low of 0.65 in neutral acceptance to a high of 0.97 in approach acceptance. The four-week test-retest coefficients of stability ranged from a low of 0.61 in death avoidance to a high of 0.95 in approach acceptance. When taken together, the *DAP-R* has demonstrated acceptable reliability (Dunn et al, 2005) and Neimeyer and van Burnt (1995) indicate that the test also has acceptable internal consistency, good test-retest reliability and appropriate convergent validity Approximate completion time of the fear subscale of the *DAP-R* is approximately 5 minutes.

13-item HPAQ

All patients and carers (n=75) participating in the study were also required to complete 13-items from the *HPAQ* used in Phase One (see Appendix M and Chapter 6). The 13-

items selected were considered to be appropriate for use with these groups since they focused on more general attitudes toward palliative care and were non healthcare professional specific and provided a useful point of comparison with the health professionals surveyed in this study. These items were scored as for the health professional phase of the study (see Chapter 6).

8.2.3 Qualitative Stage

Four semi structured interview schedules (Appendix N) illustrates the palliative care patient schedule) were designed, following a review of the literature, to explore attitudes in each of the four participant groups, toward palliative care and the future as well as perceived quality of life and experiences of illness and care to date. Each schedule comprises 45, mainly open-ended prompt questions that were used as a guide to structure the interview. However, the questions, their pace, format and exact number were adapted to suit the participant as the interview progressed. Furthermore, in order to minimise any potential distress, the researcher listened and reflected back to the participant, the kinds of words and phrases used by them to describe their (or their relative's) condition, treatment, future and death. For example, if they used the word "tumour", the researcher would use "tumour", if they used "cancer", the researcher used the word "cancer". The prompt questions on page 2 of the interview schedule relating to death and fears were used only where participants had referred to the future, death or fear earlier in the interview.

8.2.4 Repertory Grid Interviews

Repertory grid interviews (Kelly, 1995/1991) - providing both qualitative and quantitative data - were conducted with a smaller subset of both patients (n=6) and carers (n=6). The grid (Appendix O) utilised a seven-point rating scale and was designed by the researcher to include: (a) fixed elements representing people, professions/people; and (b) fixed bipolar constructs based on more commonly occurring elements/constructs referred to in the earlier qualitative interviews as determined by the content analysis (see on). Hence, the findings from the qualitative interviews were useful in informing, the development of the rep grids for use in this final part of Phase Two. The grid process required eeach participant to rate each element on each bipolar construct on a scale from one to seven. For example, the participant was asked to rate "myself now" (as one of the elements) on one of the bipolar constructs -"frightened – not frightened" using a scale from one to seven where one is 'frightened' and seven is 'not frightened'. Each rating score was then recorded onto the grid by the researcher.

Whilst it is not possible to determine the validity and/or reliability of the grid used because it was specifically designed for this study, it is interesting to note that the measurement of reliability of results over time for the repertory grid technique is actually of limited interest to personal construct psychologists for theoretical reasons. Given that Kelly's constructivist alternativism viewed man "as a form of motion" (Kelly, 1955), expected to change adaptively at all times, it would be not be unusual for findings to change between tests. Despite this, reliability associated with standard repertory grids has been studied in the area as outlined by Bannister and Mair (1968):

"as a kind of statistical platitude, it can be said that using elements such as people known personally to the subject, with supplied constructs of a conventional type...normal subjects doing repeat grids...tend to yield co-efficients of reliability within the range 0.6-0.8".

The validity of the tool is difficult to measure because the repertory grid technique focused on examining personal construct systems, which may be highly elaborate. However, the face validity of a grid is considered to be high, since it involves the researcher asking participants directly about their world view; the clinical application of grids also supports the validity of the data obtained (Winter 1992).

8.3 Procedure: Data Collection

The researcher met with all participants in person, except for those who were recruited to complete only the quantitative questionnaires from the cancer support group (n=36); this group completed the questionnaires by post and returned them to the researcher. The researcher was flexible throughout all stages of the research in order to facilitate patients and carers who sometimes tired easily. Typically, the interviews were conducted in two stages whereby qualitative information was collected first and quantitative material collated at a later stage. The one-to-one interviews/repertory grids and administration of questionnaires took approximately 45-60 minutes to complete. Where participants completed the questionnaires only, administration time was approximately 15-20 minutes.

Upon meeting the participants the one-to-one interview or repertory grid was completed first. During the interviews, in particular, it was common for participants to become upset and cry. The researcher was naturally empathetic when this occurred, gave the participant time to be with that emotion, offered a tissue and/or a drink of tea or coffee and then asked if they would like to continue or stop the interview. None of the participants indicated that they wanted to cease participation in the study, although arrangements were made for approximately half of the participants, for the researcher to re-visit the following day to conclude data collection due to tiredness, pain or family visits. Follow up support for patients receiving palliative care services was provided by the Consultant in Palliative Medicine who visited participants shortly after interview. In addition, participants in other groups were advised to contact the researcher if they were distressed in anyway after the interview.

All but one of the one-to-one interviews were tape recorded with the consent of the participant. In the case of the participant who did not wish to be recorded, the researcher took detailed notes of the conversation. Following administration of the grid or the interview, participants were asked to complete the quantitative questionnaires. In most cases, the researcher read out the items on each questionnaire and completed the forms on behalf of the participant. Following participation in the study all participants were sent a thank you card in the post.

8.4 Data Analysis

Each quantitative measure was scored and entered into SPSS v13.0 for analysis. Descriptive statistics and independent t-tests were then performed to explore between group differences. All of the transcripts pertaining to the one-to-one interviews were subjected to a standard thematic analysis (see Chapter 6). Data from the thematic analysis were then used to inform the development of the repertory grids.

Individual grids were analysed using Idiogrid (Version 2.4) developed by Grice (2008). This software programme was specifically designed in the tradition of Personal Construct Psychology and the idiographic approach toward personality. Data gathered from repertory grids can be analyzed with a wide array of univariate and multivariate statistical models, including basic descriptive statistics, bivariate statistics, Principal Components Analysis, Singular-Value Decomposition, Profile Analysis, and

Generalized Procrustes Analysis. Most of these analyses are designed to model data gathered from a single person, but other techniques (e.g., Generalized Procrustes Analysis) allow the user to make comparisons across individuals. The latest version of Idiogrid thus offers a comprehensive set of features for the systematic study of data gathered from a single person, from a group of persons, or from separate individuals. Whilst comparable to other software programmes available, Idiogrid has the added advantage of being freely available for use on-line. The following quantitative indices from this analysis were selected for inclusion in the study: (a) the average amount of variance accounted for by the first three components and by the first component of the Principal Component Analysis; (b) the distance between 'self now' and 'ideal self' (an indication of self-esteem), and (c) distance between all other elements and all constructs. The first two of the above indicate what Kelly called cognitive complexity. In other words, a high percentage of variance is indicative of a relatively simple construct system on the dimension of meaning under investigation whilst a low percentage suggests a relatively more complex system. These measures have been selected as they replicate those used in other repertory grid studies e.g. Personal Constructs of Anorexia (Warren and Beumont, 2000).

In addition to the measures described above, which were computed to enable between group grid analysis, a detailed case analysis of two repertory grids provides an in-depth evaluation of two participants constructs of palliative care and visually depicts their construct system on graphical plots. This case study approach is in keeping with the tradition of personal construct analysis that maintains that whilst there may be between group differences detected in construct and element ratings, ultimately the personal construct systems of people are all unique. However space does not permit individual analysis of all 12 grids in this study.

Chapter 9

Results 2: Phase 2

This chapter provides a detailed analysis of the findings of Phase Two of this study and has been divided into three sections accordingly. Section A outlines the key findings from the quantitative analysis of questionnaires with the four groups of participants (n=75). Section B presents a thematic analysis of qualitative interviews with a subset of these participants (n=30) whilst section C details two repertory grid case studies.

Section A

Quantitative Analysis of Questionnaire Data

9.1 Profile of Participants

Table 9.1 outlines the demographic data for participants in each group. Participants were typically aged in their late forties and were predominantly female. A one-way ANOVA indicated no statistically significant difference in the mean age of participants across groups whilst a Chi-Squared test revealed no statistically significant association between group membership and gender. The mean age of carers in this study is similar to those in other studies (e.g. McKay et al., 2011; O'Reilly and McLoughlin, 2011) although the age of participants in the palliative care and cancer patient groups is considerably lower than the service norms. For example the majority of palliative care patients using services in the Mid-West are over 65 years of age. However, a particular requirement for participant eligibility in this study was the need to be under 65 years of age.

Table 9.1 Demographic Characteristics of Respondents

	All Participants	**Patients Receiving Palliative Care**	**Carers of Patients Receiving Palliative Care**	**People Living With Cancer**	**Carers of People Living With Cancer**
Mean Age in Years (SD) & age range	49.4 (9.64) 32-64 years	52.5 (5.61) 40-64 years	47.9 (9.2) 30-64 years	49.0 (8.7) 35-64 years	48.6 (9.1) 34-65 years
Gender	29 males (39%) 46 females (61%)	7 males (47%) 8 females (53%)	2 males (20%) 8 females (80%)	9 males (36%) 16 females (64%)	11 males (44%) 14 females (66%)
Total Participants	75	15	10	25	25

9.2 Attitudes Toward Palliative Care

The average participant score on the HPAQ was 41.8 (SD+/-3.61). The maximum possible score was 65 and in this study participant scores ranged from 34 to 52 indicating that attitudes toward palliative care were relatively positive overall with some scope for improvement. There were no differences detected in attitudes with respect to either gender or age. A one-way between-groups analysis of variance was conducted to explore the impact of group membership (i.e. patients receiving palliative care; carers of patients receiving palliative care; people living with cancer and their carers) on attitudes toward palliative care as measured by the 13-item HPAQ. There was a statistically significant difference ($p<0.05$) in mean attitude scores for the four groups ($F(3,71)=3.5$, $p=0.019$), although the magnitude of the differences in mean scores across groups was small (eta squared= 0.12). Post-hoc comparisons using the Tukey HSD test indicated that the mean attitude scores of patients receiving palliative care (Mn=43.8, SD=4.37) was significantly higher than for persons living with cancer (Mn=40.68, SD=2.94) and their carers (Mn=40.56, SD=3.61). This suggests that patients receiving palliative care services are more positive about palliative care then people living with cancer and their carers. The attitude scores of carers of patients receiving palliative care (Mn=42.3, SD=2.36) did not differ significantly from any of the other groups.

9.3 Fear of Death

The mean fear of death score for participants in this study was 4.17 (SD 0.77). Fear of death scores ranged from 2.43 to a maximum of 6.0 (the highest score on this tool). Male respondents in this study had a significantly higher mean fear of death score than females (t(73)=3.35, $p<0.001$). However, no relationship between age and fear of death score was detected. A one-way between-groups analysis of variance was conducted to explore the impact of group membership on fear of death as measured by the fear subscale of the DAP-R. There was no statistically significant difference in this respect between the four groups (F(3, 71)=0.19, p=0.996).

9.4 Quality of Life

Only patients receiving palliative care services (n=15) and people living with cancer (n=25) completed the QoL-CS as a measure of quality of life. QoL scores ranged from 140 to 253, with participants mean score of 212.2 (SD=37.03) and there were no age or gender differences detected with respect to total QoL scores or subscale scores with the exception of spiritual wellbeing where males (Mn= 5.22) obtained significantly higher scores, on average, than females (Mn= 4.27) (t(38)=2.066, $p<0.046$). An independent t-test revealed that people living with cancer had significantly better QoL score than their palliative care group counterparts as revealed by the total measure (t=-17.406, df=38, p<0.000) as well as significantly higher scores (p<0.05) on all subscales of the questionnaire (see Figure 9.1). Interestingly, patients receiving palliative care services obtained significantly lower scores (Mn=4.28) on the distress subscale than those people living with cancer (Mn= 4.8) (t(38)=-2.028, p<0.05). Many of the items on this scale refer to the participant's distress at the time of diagnosis and treatment and this difference may indicate that these kinds of issues may not have been processed or addressed as effectively for those living with cancer. Alternatively, it may simply that the palliative care patients have moved further along the illness spectrum and come to better accept their diagnosis and its implications. This will be discussed further in Chapter 11.

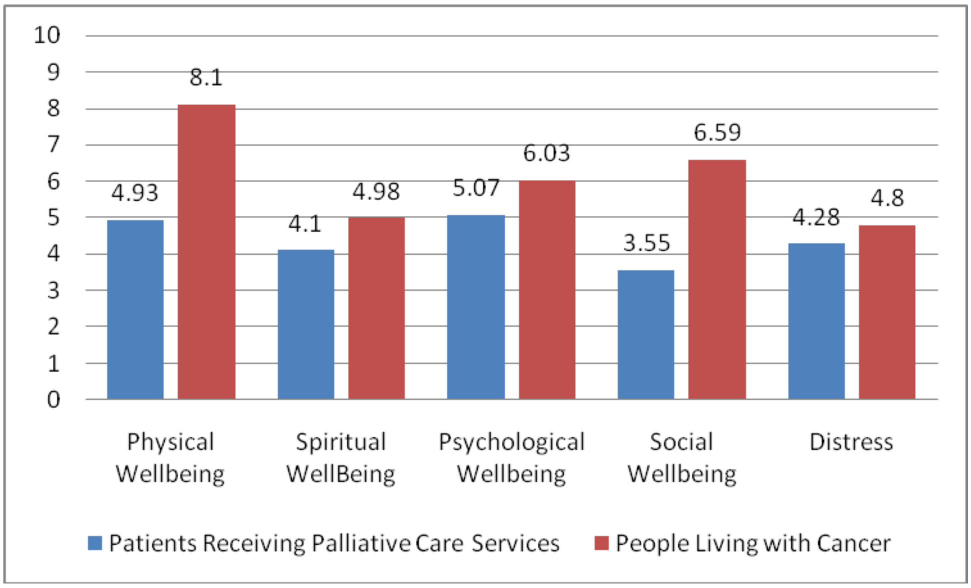


Figure 9.1: Comparison of QoL-CS Subscale Scores Between Patients Receiving Palliative Care Services and People Living with Cancer.

Section B

Thematic analysis of qualitative interviews

Data from the 30 one-to-one interviews were analysed using thematic analysis (Braun and Clark, 2006) in order to better understand and compare the attitudes, views and experiences of the four participant groups. In addition, where participants had referred to death specifically, death-related constructs were content analysed using the Manual for Content Analysis of Death Constructs (Neimeyer et al., 1984) as outlined previously in Chapter Eight

.

9.5 Profile of Interviewees

The demographic and background characteristics of interviewees are outlined in Table 9.2. The groups were generally well balanced with respect to gender although proportionately more carers were female (as might be expected). The other background characteristics of both carer groups were broadly comparable. The same was true of the patient groups although those receiving palliative care services were slightly older, on average, than participants living with cancer. Half of the people in the ‘living with cancer’ group identified the breast as the primary site of the tumour, compared to 18% of those in the palliative care group.

Table 9.2: Demographic and Background Characteristics of Respondents

	People receiving palliative care services (n=11)	**People living with cancer (n=10)**	**Carers/family members of people receiving palliative care services (n=7)**	**Carers/family members of people living with cancer (n=7)**
Gender	6 males 5 females	5 males 5 females	1 male 6 females	2 males 5 females
Mean Age (SD)	57.3 (4.94) 50-64 years	51.0 (9.76) 35-64 years	50.1 (8.71) 39-60 years	48.4 (9.64) 32-61 years
Marital Status	6 married 2 single 3 separated / divorced	7 married 1 single 2 separated / divorced	5 married 1 single 1 separated / divorced	7 married
Family	2 no children 9 between 1 and 4 children	2 no children 8 between 1 and 7 children	2 no children 5 between 1 and 4 children	1 no children 6 between 1 and 7 children
Religion	11 Roman Catholic	10 Roman Catholic 1 Church of Ireland	7 Roman Catholic	6 Roman Catholic 1 Atheist
Primary Site of Cancer	Bowel =3 Breast= 2 Cervix= 2 Lung= 2 Prostate= 1 Throat= 1	Colon = 2 Breast = 5 Skin = 1 Kidney = 2	N/A	N/A

9.6 Thematic Analysis

The thematic analysis of the interview data from the four groups revealed four key themes and associated subthemes that described patients' and carers' attitudes toward palliative care. Within each theme, different perspectives were taken by each of the groups as outlined below. All names are fictitious and group membership is indicated as follows: [pc] = palliative care patient; [cp] = cancer patient; [cpc] – carer of palliative patient; and [cc] = carer of someone living with cancer. Each theme will now be described in detail.

9.6.1 Theme One: 'This is My Story'

Participants' attitudes toward palliative care appeared to be strongly influenced by their life story and experiences. The participant's story of their life journey through health and illness, told from a personal or carer perspective, dominated the content and flow of at least half of all interviews. Patient groups often commenced the interview talking about either their illness specifically and their navigation from diagnosis to remission or palliative care (depending on what group they were in), or they spoke more generally about their identity and life. Carers tended to focus more immediately on the illness and the life of the person for whom they were caring, suggesting that their story was secondary to that of their loved one. Whilst that may be due to the structure of the opening questions, it became apparent, that with the exception of one participant, each wanted to share with the researcher their identity and life story and explore how cancer had impacted upon them. From the researcher's perspective, these stories were vitally important as they identified the terminology used by participants to describe their illness and, in turn, provided the researcher with an appropriate vocabulary within which to phrase future questions.

Two sub-themes were identified here, that focus on the impact of the illness 'journey' and the power of the experience of death dying, loss and care in times of health, on attitudes toward palliative care.

9.6.1.1 Subtheme A: 'In Sickness'

For those people who were receiving palliative care services and their carers, the most influential factor that shaped their attitude toward palliative care, was the process of being referred to, and accepting, palliative care intervention as part of their illness story. Both participant groups appeared to have a greater understanding of palliative care and more positive attitudes toward it, than those who were living with, or caring for someone with, cancer who had no prior experience of this service.

Each participant was asked what the term 'palliative care' meant to them. Whilst some patients receiving palliative care services were a little unsure of the actual term, following explanation by the researcher, they were able to equate it with *"this place" [pc1]*, referring to the physical building of the specialist palliative care inpatient unit whilst others spoke of *"hospice"* [pc2] immediately without prompting. Some participants did not discuss palliative care as a concrete place or service, but rather as an approach to care. All participants in the palliative care patient and carer groups, following prompting, were able to discuss their frame of meaning of the term palliative care and everyone described it in generally positive terms e.g. *"it means so much help"* [pc4] and many focused on the patient centred benefits of palliative care *"looking after the patient" [cpc1].* In contrast, people living with cancer and their carers were generally more negative and unsure of palliative care and some actually seemed quite taken aback when the researcher explained what it was, whilst appearing unsure as to exactly how palliative care might have any association with their illness story: *“Oh, that...the hospice you mean, where the unlucky buggers end up”* [cc1]. *“To be honest, I haven’t thought too much about that kind of thing, I focus on the positive side, treatment options and follow up scans, you know. Wouldn’t know anything about, what did you call it again? Yeah, palliative care”* [cp1].

The carers of patients receiving palliative care services also appeared more positive about the service than their counterparts who were providing support for their relatives who were living with cancer. Hence, their illness story focused on the benefits of palliative care for the patient and only one carer discussed the service as having any obvious benefit for carers or family members. Interestingly people receiving palliative care services and their carers often stood back and reflected on how the reality of palliative care services - now that they had become part of their illness story - were very different from what they had perceived them to be. They recalled the fear that the term ‘palliative care’ had evoked at the outset and their shock upon referral to the service but then went on to describe how they now perceive palliative care very differently:

“I thought, that’s it, it really is bad now. I am on my last legs“ [pc5].

“It (referring to the day she was told about the transition to palliative care) was horrendous” [p4].

“Once you get in, you realise you should’ve been here a long time ago” [p2]

“It’s like heaven on earth in here!” [cpc3]

The retrospective observations of this group mirrored the attitudes that cancer patients and their carers seemed to hold at the time of interview, as they focused on palliative care from within their illness story: *"Palliative care services, I am sure, are only really intended for those who have days to live. I do know of a fellow who was in a hospice for months, but he would be the exception, the case where the doctors made a mistake. Let's hope we never see Paul in one of those hey?" [cc6].*

9.6.1.2 Subtheme B: 'And in Health'

The 'And' in the title of this next subtheme is quite significant in that participants' attitudes toward palliative care appeared to be shaped mainly by their own personal experience of palliative care where it has been encountered within their illness story. However, the role of previous experience relating to death, dying, loss and palliative care, in times of health, also appeared to be important, although perhaps less so than the personal experience of the service (hence the use of 'and').

Participants were asked if they had ever had any previous experience of someone close to them dying or using palliative care services. The majority of respondents had previous experience of the death of someone close, usually of a parent and tended to relay spontaneously to the researcher, the circumstances surrounding the person's death, This often included a brief judgement regarding the quality of the person's death, as shown by the following comment:

*"Mummy was 94 when she went [*died*]. It was Christmas eve and everyone was together playing cards downstairs, she was playing up to 7pm, the fire was on, the*

music playing and she went to bed, and that was it, died peacefully in her sleep – just the way it should be." [pc11].

Participants often referred back to the death description of this person later in the interview when the researcher asked what they considered a 'good death' to be and compared it to their constructs of a good death. It was notable that half of all participants described a 'good death' as being one where they died in their sleep and without any pain. For patients and carers receiving palliative care, their personal experience of death, dying, loss or care often seemed to bring the person comfort, or gave meaning and purpose to the palliative stages of their own illness. One man, who was caring for his wife, reflected on losing his son ten years previously to cancer:

"This whole disaster brings only one glimmer of hope for Anne that she might be reunited with Mark [her son] one day soon and I think that's the only thing that's keeping us sane." [cpc7].

Two cancer patients and two carers chose not to speak of a personal loss in terms of a loved one or family member, but focused their previous experience of palliative care and death on stories about cancer patients whom they had met through the treatment stages, who had subsequently died. They spoke with particularly poignant sadness about these people and seemed very concerned that it could have been them or their loved one. Hence the participants in the cancer groups appeared to be distancing themselves from that person's death occurring as and it when it did – in contrast to those in the palliative care group who almost seemed to be considering the degree to which their ‘personal experience of death’ story matched their constructs of a ‘good death’.

Only four participants had any previous experience of palliative care services as part of their life story before illness. For three of these participants, the experience had been positive and they acknowledged that this in turn had influenced their perspective toward the service:

“I’ve seen for myself, first-hand what relief my dad got from the hospice team and I know that if I ever need that level of care, I would be in the best place possible” [cp8].

“I would recommend palliative care to everyone who needs it. Their care for my sister was impeccable” [cpc7].

9.6.2 Theme Two: ‘Leave It To The Experts’

This second overarching theme focuses on the way in which patients perceived health professionals working in palliative care, oncology and healthcare generally to be experts (or not as the case may be) and explores how perceptions of expertise differ between professions, individuals and time points. Two key sub-themes were identified here to encompass two important factors noted by patients and carers when referring specifically to expertise in oncology and palliative care services: (a) trust and (b) communication skills.

9.6.2.1 Subtheme A: 'The importance of developing trust'

Most participants trusted the health professionals whom they met and tended to leave decision making to them:

> *"I said to Dr Smith, look, you're the expert now, you know what you are doing. I trust you 100%, so whatever you have to do" [pc1].*

> *"Dr Jones explained things. She was very forthcoming. There was no mystery with her about anything. I felt really at ease, I followed all her instructions." [pc2]*

The great majority of health professionals to whom participants referred during the interviews, were perceived to be experts in their associated field and were held in high regard by participants and were therefore trusted. For some, this perception of expert practice was based on previous direct contact with them or on their reputation, often built up in the form of anecdotal stories from other patients:

"We knew once we were seen by Professor Fraser, that we were safe. We met a woman in the waiting room - she told us he had saved her life too". [cp6]

Oncology staff (doctors in particular) were viewed extremely positively by all respondents and with an energy and enthusiasm by people living with cancer and their carers that was often palpable. At times, these professionals seemed almost heroic: *"He was amazing, no matter what the ailment was that Patrick went with, it disappeared within a day"* [cc5]. This positivity, whilst still present both in patients receiving palliative care and their carers, was not as tangible. Their energy centred, instead, on describing the palliative care teams in warm and fond terms: *"Words fail me, they are truly gorgeous people here…" [pc5].*

There were also some instances where participants felt that they could not entirely trust particular health professionals. For patients and carers who discussed a delayed initial diagnosis of cancer, the GP was often referred to in less positive terms and there was some concern and anger that this professional, as the primary point of contact had *"wasted so much bloody valuable time telling Petra to go wheat free when she had bowel cancer - BOWEL cancer imagine!" [cpc6].* Another patient, having acknowledged that the staff were *"angels"* [pc1] was very angry that his information needs were not being met and felt that this may have been attributed to the fact that some of the staff working in the palliative care team were very young and less experienced than others. As a result, the patient found it difficult to form a relationship with these members of staff and lacked trust in their abilities:

"I need a mature person someone in their 30s who isn't just full of promises. Someone who understands an old man and a young man and finds a middle ground" [pc1].

In the above instances, there was generally considerable anger and resentment surrounding experiences and explanations of events.

9.6.2.1 Subtheme B: 'The role of effective communication'

All participants referred to the importance of good communication and to particular health professionals with reference to their communication style. However, there was a specific focus on the ability of staff working in palliative care services to communicate particularly well amongst respondents with experience of palliative care services. This 'expert' ability to communicate was recognised and welcomed by patients, who seemed to be comparing their style with other professionals whom they had met along their journey. Patients often drew significant comfort and strength from the words spoken to them by staff working in palliative care:

"People are very considerate. A home care nurse visited me and she said that 'no-one matters except you now', others don't matter, this is about me. I found this hard, I am a giver and not a taker, but I had no choice anymore, but she was right" [pc2].

Many of those patients who were receiving palliative care services noted that staff seemed to have more time to spend with patients and wanted to get to them *"as a whole person." [pc10]* The importance of staff maintaining a balanced demeanour in both oncology and palliative care services on a day-to-day basis was also considered very important by patients who often appreciatively discussed staff who were *"so normal. Not all happy-happy…just normal" [pc2]* or who displayed a good sense of humour despite their working environment:

"I mean everyone here is dying so if you have got a headache or a sore toe, stay at home and be miserable, don't come in here sharing your bad moods. We have enough of our own; we want a laugh and a joke…not your problems" [pc4].

Interestingly, the communication style of one particular consultant was noted by a number of patients in both groups and especially with regard to breaking bad news. There appeared to be a *"rumour going around ward x" [cp4]* that the Consultant usually brought patients to a private room and asked them if they had *"thought of going home and looking after themselves" [pc5]* instead of going through treatment. It was noted that those participants who referred to this particular professional, often quoted a similar form of words suggesting that the consultant may have formulated a package of words that they considered appropriate for breaking bad news.

The carers of patients receiving palliative care services focused more on how the communication with them as carers/family members differed within palliative care services when compared to oncology services: the former involved more consultation and a greater emphasis placed on the family: *"Here [*palliative care*] it's like we're all on the team – they even bring us to meetings". [cpc6].* Interestingly, one of the more pressing concerns for patients receiving palliative care services at the time of interview, related to the manner in which their family members would cope following their death. Care of the family is a key consideration of palliative care, but the degree to which palliative care is meeting the concerns of patients in this regard, requires further exploration.

9.6.3 Theme Three: 'The Fear of a Building'

Whilst there was mixed knowledge amongst respondents regarding the definition of palliative care, all respondents had a perception of the meaning of hospice and for some, the term 'palliative care' was defined directly as *"hospice."* Respondents tended to refer to the hospice as a place or building, whilst others spoke of daffodil nurses and home care nurses who arrived at the door with a *"big black bag and a syringe driver" [cc3].*

All of the interviewees expressed fear in relation to the hospice; for some, it was a personal fear and for those who were patients in the hospice at the time of interview, these personal fears were discussed retrospectively and many commented on how these had now dissipated. Patients receiving palliative care services acknowledged the fear that had been evoked in family and friends, by the transition to the hospice and a typical response of fear and sorrow to news of the referral: *"When people call and you say that you are going to (hospice), there is silence"* [pc11]. However, their experience of the service had changed these initial views as succinctly highlighted by one participant:

"She thought I was done for. She came to visit me...she left this place with a completely different view as to what this place is about. People need to see this place. Anyone who sees me leaves with a different image of this place". [pc9]

Many participants spoke of the need for a greater awareness amongst the public about hospice and palliative care: *"People have a bad idea of the hospice - they think it is a nice place if you are dying...and it is, but you can avail of the nice place while you are living too!" [pc5].* Whilst the fears of hospice had dissipated amongst patients receiving palliative care services, some carers remained apprehensive and concerned that referral to the hospice might *"lead the person to lose hope" [cpc4]* and questioned whether the continuation of curative treatment might be a better option. Carers also spoke of the difficulty explaining to others that their loved one was in the hospice *"the way they look at you and nod but don't say anything" [cpc1]*. Two carers spoke of their concerns regarding syringe drivers in particular:

"Once they start those pumps with morphine, that's it, it's a matter of days – when I see them with them I know they mean business" [cpc2]

However, it should be noted that this concern was expressed immediately after a controversial interview given by a celebrity regarding hospice and palliative care and did not feature generally in earlier interviews with patients and carers receiving palliative care services. However it is very important to refer to this since the media portrayal of hospice and palliative care can often be negative and affect attitudes and behaviours considerably. The fear regarding syringe drivers and morphine use in the hospice setting was very real for people living with cancer and their carers. Interestingly, some carers of people living with cancer also discussed the hospice building in great depth:

"*When you arrive there is a sign 'Mortuary, straight ahead' and then there are the shiny floors...it's lovely and clean and all that but the floors are so shiny. There's a restaurant under the ground and you'd walk up the long tunnel to get your lunch and it's so far away that you wonder if you'll make it back before you mum is dead – a friend of mine referred to it as the 'tunnel of death'. Don't get me wrong, it's a nice place and that. (Shudders)". [cc5]*

"Every time I go past that place I close my eyes and bless myself. God only knows what they are doing to people in there. God only knows." [cc4]

Despite these fears and negative associations with the hospice as a building, there was also a lot of positivity about local hospices and the concept of hospice care. Many respondents commented on the *"good work"* that the hospice did and discussed how they often gave money to support various initiatives. Many patients receiving palliative care services also viewed the hospice building as a refuge were they could *"just be myself and cry all day if I want to"* [pc6] thereby emphasising the importance of the physical building as a space to which patients can retreat and get a break from their roles within family and society.

9.6.4 The Paradox of Life and Death

The final key theme identified from the analysis related to the paradox of life and death. A unique finding amongst the data obtained from the patients receiving palliative care services and their carers, was that over half of those interviewed, often referred to life and death - within their frame of meaning of palliative care - , in a paradoxical way:

"I would have thought with palliative care, it is coming nearer, towards death, near the end... But now I see it as caring, especially early on, not just when you are dying". [pc2].

Others contrasted their initial perception of palliative care *"about emotions and providing comfort" [cpc 4]* with their experience of the *"medical side of palliative care".* The manner in which respondents who were involved with palliative care services define palliative care / hospice as a balance between life and death, is in stark contrast between those in the cancer groups who focus purely on the relationship between hospice and death. Many patients and their carers receiving palliative care described the improvements in quality of life that they had witnessed since arriving to the service.

Section C

Analysis of Repertory Grids

9.7 Case studies

Twelve repertory grids were completed by twelve participants in phase two of this study. Two individual repertory grids were subsequently selected at random for detailed case study analysis, reflecting each of the two patient groups of participants in Phase Two of the study. Both case studies are presented below and a comparison between the two is also provided. Later in this section a between group analysis of all twelve grids has been conducted. The decision to select two grids for a comparative case study analysis, reflects the quantitative findings reported earlier in section A. These suggest that the differences in attitudes toward palliative care were greatest between the patient in receipt of palliative care and those living with cancer. This requires a more in-depth analysis that can be facilitated through comparisons of repertory grids.

9.7.1 Case Study One – A Person Receiving Palliative Care

Mary, a 54 year old woman with advanced breast cancer had been receiving palliative care services for the three months prior to interview and had been living with cancer for six years. She was married with one adult daughter.

Eighty-six per cent of the total amount of variance in this gird was associated with the first three components of the principal component analysis (Appendix P). Component One (56%) was associated with constructs ‘sad’; ‘angry’; ‘frightened’; ‘in pain’; ‘dead’ and ‘poor communication skills’. Construed in these terms were the elements ‘a person receiving palliative care’; ‘self now’; ‘self in the future’; ‘a dying person’ and ‘next of kin now’ (referred to as husband herein). The elements ‘ideal self’; ‘self before I was sick’ and the health professionals were construed in terms of the opposite poles of these constructs. Component Two (20%) was associated with the construct ‘expert’. The elements ‘ideal self’; ‘palliative care consultant’ and ‘oncologist’ were construed as ‘expert’ whilst the elements ‘self before I was sick’ and ‘husband before I was sick’ were construed as ‘novice’. Component Three (11%) was associated with the construct ‘untrustworthy’. Construed as ‘untrustworthy’ were Mary’s husband now and in the future and the GP. Figures 9.2 and 9.3presents this information figuratively for Component 1 mapped against Component 2 (Figure 9.2) and Component 2 mapped against Component 3 (Figure 9.3).

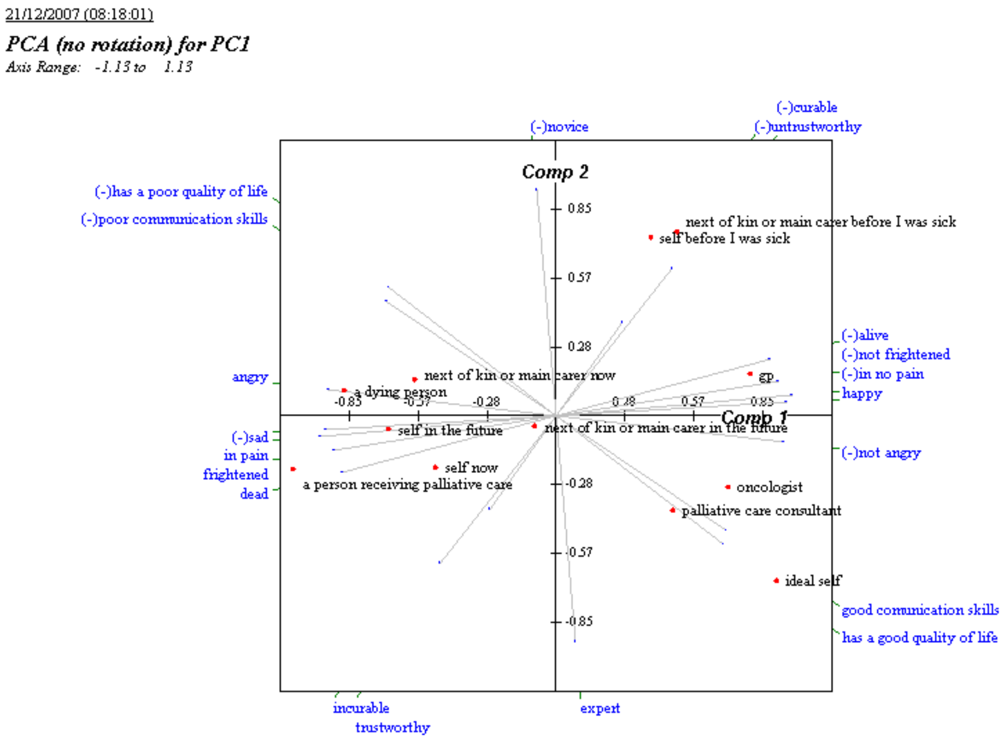


Figure 9.2 Principal Component One x Principal Component Two (Mary)

Ordination is a measure of the ordinal position and meaningfulness of constructs in a repertory grid (Landfield and Cannell, 1988). Thus, a high ordination score for a given construct indicates that it is superordinate or more meaningful when compared to other constructs in the grid.

The constructs with the highest ordination score in this grid were related to communication skills (42.0); anger (36.0) and quality of life (36.0) in comparison to an average ordination score for all constructs of 27.5. An ordination score was also calculated for the elements in the grid. The average ordination score for elements was 24.75. The elements with the highest ordination score in Mary's grid were 'myself in the future' and 'a dying person', both with a score of 30, suggesting that these are the most meaningful elements in the grid for Mary.

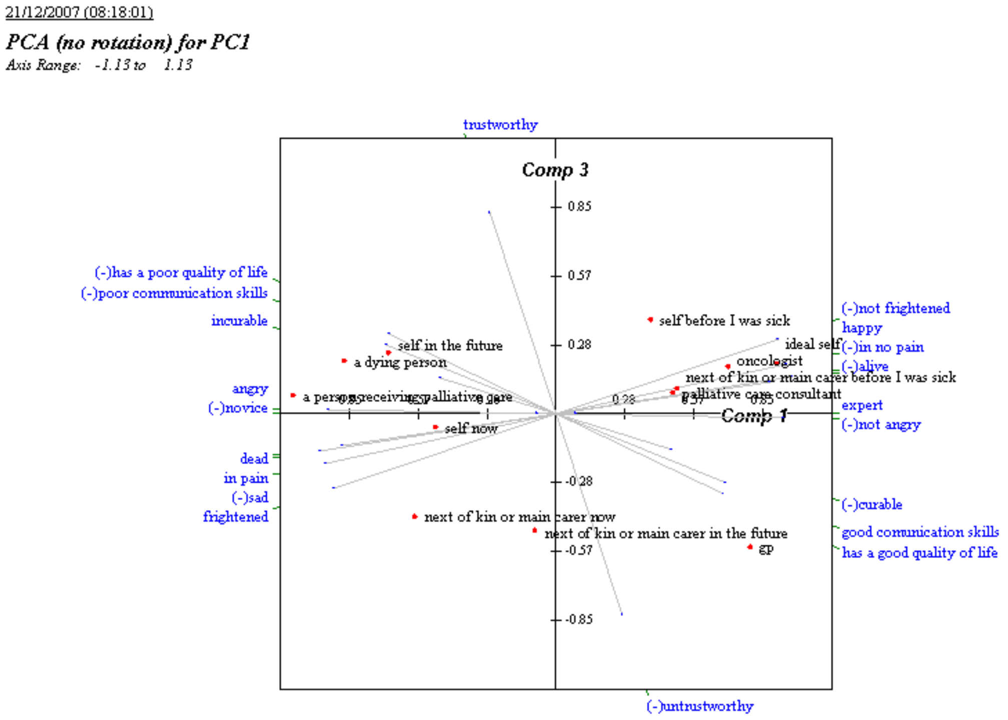


Figure 9.3 Principal Component One x Principal Component Three (Mary)

Mary construed herself, at the time of interview, as most similar to a person receiving palliative care (0.68) and a dying person (0.64) which is in stark contrast, as might be expected, to the manner in which she construed her ideal self or indeed herself before she was sick**.** Interestingly, Mary construes a person receiving palliative care more negatively on Component One than a person dying, suggesting that she may anticipate a small degree of resolution of feelings of sadness between where she perceives herself now and by the time she dies as measured by Component One; this could be a result of anticipated meaning making of her illness and death, or a perception that some issues would be resolved or perhaps feelings not experienced as intensely, as death approaches. Mary associates herself in the future strongly with a person who is receiving palliative care (0.92) and a person who is dying (0.87) suggesting that she may accept that her life is limited and will require palliative care until the time of death. The closest person listed in the elements to Mary in real life terms is probably her husband and she construes herself at the time of interview to be similar to him whilst recognising that he has changed too since her illness. The distance between Mary now and her ideal self was 96.19 degrees; this can be interpreted as a measure of her self-esteem and suggests that Mary had quite low self-esteem at the time of interview.

With regard to Component Two and the construct ‘expert’, Mary perceives her expertise to have developed over time and anticipates it to develop further as illness progresses into the future and considers her ideal self to be an expert with greater levels of expertise than any of the health professionals in the grid. This may suggest a desire to know more than them in an ideal situation and potentially to seek to cure the illness she is living with. Interestingly Mary perceived the palliative care consultant to have slightly more expertise than the oncologist, suggesting that she recognises that, at this point in her illness, the most knowledgeable and experienced person to care for her is the Consultant in Palliative Care. The only real difference between herself and her husband at the time of interview relates to expertise, in that Mary construes herself to have more expertise than her husband which is probably expected given that she is the person living with her illness, treatment pathway and now palliative care.

Component Three, relating to trustworthiness indicates that Mary construes her GP and husband now and in the future as the most untrustworthy of the elements supplied. Given that she did not construe her husband as untrustworthy prior to her illness; this suggests that this shift may be a result of her cancer and entry into palliative care. Perhaps Mary anticipates or may have experienced a situation where the truth about her illness has not been forthcoming from her husband and/or GP and may suspect collusion between them. Alternatively, with regard to her GP, she may lack trust in him/her as a result of issues relating to the diagnosis of her illness (similar to some participants in their qualitative interviews).

9.7.2 Case Study Two – A Person Living with Cancer

Jim, a 57 year old man was diagnosed with colon cancer in 2005. He was given the "all clear" in 2008 and attends for annual checkups.

Eighty per cent of the total amount of variance in this grid was associated with the first two components of the principal component analysis (Appendix P). Whilst this percentage was lower than Mary's, suggesting that Jim's construct system of palliative care is more complex than Mary's (Warren and Beumont, 2000), it must be noted that only two components were extracted for Jim compared to three for Mary; this in turn suggests that she has a greater number of dimensions of meaning for the topic under consideration. Component One in Jim's grid (67%) was associated with constructs 'dead; 'angry'; 'frightened'; 'has a poor quality of life'; 'sad'; 'in pain' and 'incurable'. Construed in these terms were the elements 'a person receiving palliative care' and 'a dying person'. Component Two (13%) was associated with the construct 'novice'. Construed as 'novice' were most elements in the grid with the exception of 'ideal self' and the health professionals listed. Figure 9.4 presents this information figuratively for Component 1 mapped against Component 2. The composition of Components 1 and 2 for Mary and Jim was very similar, the main difference being that quality of life loaded significantly on Jim's first component, suggesting that that construct might be more important for Jim than Mary.

The constructs with the highest ordination score in this grid were related to expert-novice (42.0) and good communication skills-poor communication skills (30.0) in comparison to an average ordination score for all constructs of 22.10, suggesting that these constructs were most meaningful for Jim. An ordination score was also calculated for the elements in the grid. The average ordination score for elements was 28.50. The element with the highest ordination score in Jim's grid was 'myself in the future' with a score of 42 (compared to the average score of 28.50 for all elements) suggesting that this was the most meaningful element to Jim. Jim's ordination of elements is comparable to Mary's although Mary also had "a dying person' with a high score, again confirming Mary's construing of herself in the future as some who will be dying.

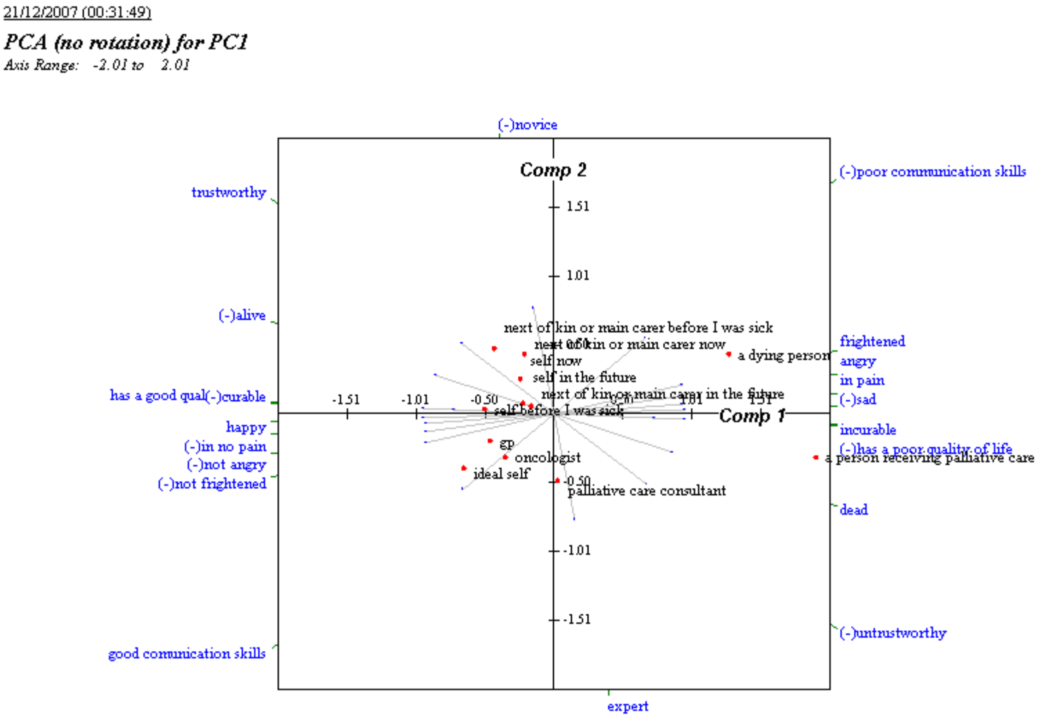


Figure 9.4 Principal Component 1 vs Principal Component 2 (Jim)

Most of the elements in Jim’s grid were construed as similar with regard to Component 1 where the elements were rated on the more positive poles of the constructs associated with this component. However Jim construed two elements as vastly different to the other elements – ‘person receiving palliative care’ and ‘a dying person’ were both construed according to the negative poles of the constructs associated with Component One. For example, ‘incurable’, ‘poor quality of life’ and ‘dead’ were placed at a considerable distance from the rest suggesting that Jim does not perceive himself (now, in the past or in the future) to be in anyway similar to these elements. As described previously, this contrasts sharply with Mary’s grid.

Interestingly the palliative care consultant has been placed quite centrally to component one by Jim, whilst the oncologist and GP are situated more toward the positive poles of the associated constructs. This may suggest that Jim construes the palliative care consultant to be less positive which could, in turn, suggest that the consultant might be negatively affected by their working role with the dying. The distance between Jim now and his ideal self was 34.05 degrees suggesting that Jim has much higher self-esteem than Mary.

A Slaters Analysis (principal component analysis) was conducted to compare the two grids. The general degree of correlation between Jim and Mary’s grid is 0.58, suggesting that they do not correlate significantly. This may reflect individual differences between Mary and Jim regardless of their stage of illness, and/ or may reflect the fact that Mary is at the palliative stage of illness and Jim is currently in remission. Therefore a between group analysis of all grids was undertaken to determine which rationale might be more appropriate to explain this difference.

9.8 A Comparison of Group Repertory Grid Scores

Each grid was analysed and the mean score for each group across the three grids was calculated (Table 9.3). Since sample sizes here are small, inferential statistics were not possible. However the data below indicate that there were potentially interesting differences between the four groups particularly in relation to the distances between elements calculated in degrees.

Patients receiving palliative care services construed themselves as more similar to the elements ‘a person receiving palliative care’ (60) and ‘a dying person’ (56) than those in the other groups. In comparison to the ‘self now’ for those receiving palliative care, patients construed that over time they would become even closer to the rating used to describe the ‘dying person’ (34 vs. 33). In contrast cancer patients construed themselves as very distant to people dying (106) with little difference in mean distance between themselves at the time of interview and in the future.

Interestingly, carers in both groups saw themselves in the future becoming a little closer to a dying person than they construed themselves to be at the time of interview, this could suggest that they anticipate that the loss of the person they are caring for or perhaps the aging process may impact upon them negatively.

Table 9.3: Comparison of Rep Grid Measures by Group

	Palliative Patients (n=3)	**Carers of Palliative (n=3)**	**Cancer Patients (n-=3)**	**Cancer Carers (n=3)**
	Mean Score			
Variance (% 3 components)	88%	84%	90%	88%
Variance (% 1 component)	62%	60%	65%	59%
Dying person – person in palliative care distance	30	42	51	54
Self now – ideal self distance	99	112	36	50
Self in future – self now distance	62	70	20	35
Self in future – dying person	33	99	107	121
Self in future – person receiving palliative care	38	89	130	133
Self now – person receiving palliative care	60	82	136	128
Self now – dying person	56	103	106	125

With regard to self esteem, carers of people receiving palliative care services appeared to have the lowest level of self esteem (112) and cancer patients the highest (36). This confirms the findings from the earlier interviews whereby it was suggested that palliative care service providers may need to focus more on carers than they do currently whilst also suggesting that cancer patients who are in remission, may have increased levels of self-esteem as a result of their successful "battle" with cancer. These findings point toward some interesting between group differences that may warrant further investigation.

9.9 Summary

In summary, this chapter has provided a comprehensive analysis of patients receiving palliative care services, people living with cancer and their carers' attitudes, experience and constructs of palliative care. The findings highlight significant differences in attitudes toward palliative care between people who are receiving palliative care services and other groups with the latter reporting more negative attitudes and views. The analysis of personal constructs of palliative care also suggest that such between group differences are potentially very “real” and the challenge therefore remains for palliative care services to be perceived more positively by those who do not directly require access to them in the short term. The findings suggest that there is considerable fear and stigma associated with palliative and hospice care, and that current service users may be open and willing to engage with members of the public / communities / families and friends to address these fears within a health promoting palliative care approach.

CHAPTER 10

Phase Three: Development of Interventions

Phase Three of the study involved the design and development of an educational intervention for: (a) health professionals; and (b) people living with advanced cancer. These were informed, in large part, by the findings from Phases One and Two described earlier in this thesis. As indicated in Chapter Five, this final phase of the study proved difficult to progress. Therefore, for clarity, the methodology described here, also reflects earlier work that had to be changed at a later date, due to factors beyond the researcher's control. Thus, there were two versions of the health professional intervention – an original version followed by a later revised version which incorporated some elements of the original, but which was designed for a different mode of delivery. Further details are provided below.

The intervention designed for people living with advanced cancer was developed to draft stage only, due to lack of buy-in from oncology and palliative care services within the timeframe of this study. However, it is described here as a potentially useful product of the study that might subsequently be utilised as part of service development within an agreed health promoting approach to palliative care. Again, further details are provided in this chapter.

10.1 The Original Health Professional Intervention

10.1.1 Development and Evolution

Ethical approval to proceed with the health professional intervention was granted in spring 2010 by the Mid Western Regional Hospital Scientific Ethics Committee. The findings from Phase One of this study indicate that the attitudes of health professionals toward palliative care are shaped by five key factors including health professionals' knowledge of palliative care services, their ability to communicate with the patient and family and the degree to which they reflect upon existential issues (see Chapter Seven). The original educational intervention for health professionals (Appendix Q), developed as part of Phase Three of this study, was therefore designed taking these factors into account. Central to the design of the intervention is a health promoting palliative care approach as advocated by Kellehear (1999) and previously described in Chapter Four. Therefore, the educational intervention designed as part of this study, is consistent with the concept of health/death education within Kellehear's health promoting framework; the main aim was to focus on all of the above and to attempt, in particular to reduce fear and stigma through the medium of an adapted approach to critical reflection (Fook and Gardener, 2007), This approach aims to engage participants in open and honest discussion about death and dying and the potential benefits of palliative care. A face-to-face, one-day workshop was initially considered to provide the most appropriate medium for intervention delivery.

The aim of the workshop, entitled *"Making Time for Death, Dying and Palliative Care",* was to explore participants' attitudes and beliefs toward death, dying and specialist palliative care in a small facilitated group environment. A working group was established first in order to determine the structure of the day (see Appendix Q for workshop overview). This comprised the researcher and a number of other employees of Milford Care Centre, Limerick, including the Head of Therapies and Social Care, a Principal Social Worker and a Pastoral Care Worker. The workshop centred on an analysis of critical incidents submitted in advance by workshop participants (see below for more information regarding critical incidents and critical reflection). The use of this methodology was based on the findings in Phase One of this study whereby health professionals tended to focus on personal and professional stories that often had negative outcomes, in order to illustrate their values and attitudes toward death, dying, loss and care. The potential benefits of integrating a health promoting palliative care framework with critical reflection have also been advocated in the literature (Fook and Kellehear, 2010).

A didactic element was also provided as part of the workshop to enable participants to consider and understand the aim and purpose of palliative care and to obtain further information regarding palliative care service availability and options. A session within the proposed workshop was dedicated to reflection on one's own mortality using a guided visualisation process previously utilised as part of a 12-week bereavement support programme delivered by Milford Care Centre. A communication skills session was also included as part of the workshop, in view of the findings from Phase One of this study and from the literature outlined in Chapter Three, both of which highlight the central importance of communication between the health professional and patient/family at the point of transition to palliative care services.

A participant's handbook was developed to outline the structure and purpose of the workshop to prospective participants whilst also highlighting clearly, the research component of the course (see Appendix Q). Participants, who wanted to proceed with their involvement, having read the course handbook, were asked to complete and return a course application form and consent form. The workshop was available to any qualified healthcare professionals who were in a position to refer cancer patients to specialist palliative care services, or who may have had a role in discussing future transition to specialist palliative care with cancer patients and their families. Prospective applicants were advised that if they had experienced a significant personal bereavement during the previous 12 months, that they should not take part in the course due to the potential emotional impact of some of the issues raised therein. In addition, participants were required to speak in front of a group about professional (and possibly personal) experiences whilst also spending time reflecting on their own mortality. Thus, in order to maximise the learning, it was important that participants felt comfortable in sharing their thoughts with others.

As indicated earlier, it was originally intended that the workshop would be undertaken and evaluated as a pilot and as part of a larger research study, although this was subsequently not possible. This was particularly disappointing, since the workshop developed was quite unique in its approach and provided a potential practice model to add to the conceptualisation of the use of critical reflection within a health promoting approach to palliative care as advocated by Fook and Kellehear (2010). The proposed model for workshop delivery was quite unique particularly in an Irish context in that other one-day workshops on offer often focus solely on reflection on one’s own mortality (e.g. one day Working with Death and Dying offered as part of the Living Well Dying Well programme), or on education specifically around palliative care. However, the workshop proposed as part of this study was much broader in its scope and aimed to cover a number of key factors that were considered important in shaping the attitudes of health professionals toward palliative care.

10.1.2 Theoretical Perspective/Framework

As outlined briefly above, the course was loosely based on a model of critical reflection (Fook and Gardener, 2007) and was designed within a health promoting palliative care (Kellehear, 1999) and adult learning framework**.** A critical reflection framework was considered appropriate because it involves exploring the underlying assumptions that humans make about the situations they experience. This can be useful for health professionals as it allows them to explore fundamental assumptions they make about their practice and provides a space to enable a re-working of these. Professor Fook was invited to deliver a two day workshop at a hospice in region D during summer 2009 in order that all course facilitators could become fully informed about this model of critical reflection. Eight staff from the hospice, four of whom were to facilitate the proposed intervention, attended this event.

10.2 Revised Health Professional Intervention

Due to the lack of uptake of the workshop-based intervention described above, and due to subsequent ethical restrictions, the research team decided to re-format the course for online delivery. Further details are provided below.

10.2.1 Development

The revised e-learning course of the same name (‘*Making Time for Death, Dying and Palliative Care*’) was developed with the intention of being made available to any qualified healthcare professional who was in a position to refer cancer patients to specialist palliative care services, or who may have had a role in discussing future transition to specialist palliative care with cancer patients and their families. The same constraints also applied here in the same way as above; that is, prospective applicants were advised that if they had experienced a significant personal bereavement during the previous 12 months, that they should not take part in the course due the potential emotional impact of some of the issues raised therein. As the course requires access to the internet, it was also vital that prospective participants had online access and a personal, secure, email address

The e-learning course was based in Moodle, a virtual electronic learning environment hosted on the e-learning site of the hospice in region D. The course was password-protected and accessible via the URL http://www.e-life.ie upon provision of a username and password from the researcher. The basic appearance of the site was designed by the researcher whilst the design concepts were translated into the virtual environment by the Moodle hosting company who was contracted by the hospice to build the site to deliver a range of programmes for its education service. The course was then developed solely by the researcher who acted as the course creator and administrator. Prior to this, the researcher completed an eight-week e-learning MoodleBite course and 2.5 days of classroom-based Moodle training in order to develop the necessary skills to set up the course.

The course format comprised of similar elements to the workshop described above. Thus, participants were asked to submit a critical incident as part of a forum discussion and where any didactic input regarding the nature of palliative care and palliative care service availability were required, an Adobe E-learning presentation utilising audio voiceover was presented. The course facilitators then posed a number of questions using the forums in Moodle to engage participants in discussion and critical analysis. Communication skills input was provided through the use of analysis of role played communication skills scenarios developed as part of the HfH education training programme “Final Journeys”. Permission was granted to the researcher to utilise these filmed scenarios on the Moodle site. The reflection on one’s own mortality was altered for the purposes of e-learning, requiring participants to consider and discuss on the forum, their first experiences with death, dying and loss and to reflect on the extent to which these experiences had impacted upon their attitude toward death, dying, loss and care.

10.2.2 Ethical Issues

Originally, ethical approval was granted (by the Mid-Western Regional Scientific ethics committee) for the one-day workshop in spring 2010. A subsequent submission was made to the same Ethics Committee to indicate that the proposed form of delivery had now been changed. However, in this instance (August 2010), ethical approval for the evaluation of the e-learning course was not granted by the committee since it was considered that participants who would be enrolling on the course, should not be required to also enrol in the evaluation/research component of the course. However, the procedure for enrolment had not changed from the original version of the course described above and it was made clear that participation in all aspects of the course was entirely voluntary. At this point, it was clear that a further submission to the ethics committee would be required and could take a further three months to process. Therefore, the research supervisor advised that, in the interests of not delaying the study any more, the evaluation element should be removed and undertaken at a later date. As a result, it was not possible to evaluate the e-learning course as part of the work presented here.

10.3 Proposed Intervention for People Living with Cancer

“Living with Dying”, a six-week, pilot group education programme, for people living with advanced cancer was designed in 2009 (Appendix R) and in parallel to the health professional workshop. The programme was again developed within a health promoting palliative care framework (Kellehear, 1999) and incorporated both health and death education. In order to secure ethical approval to deliver the intervention to patients in region D, the Scientific Regional Ethics Committee requires that submissions for ethical approval involving patient participation are supported by the Consultant with responsibility for the group of patients involved. Unfortunately, over the course of nine months of negotiation with the oncology and palliative care services in the region, it was not possible to agree a format with which everyone was satisfied and, as a result, the application for ethical approval could not be made and the developed intervention could not proceed as intended (as outlined earlier in Chapter 5). The section below outlines the planned intervention and its evaluation in order to indicate the considerable planning and work that has been invested in this component of the study.

10.3.1 Programme objectives and target population

The “Living with Dying” pilot programme was designed for people living with advanced cancer, who may be facing the end of life, but who were not in receipt of specialist palliative care services. The programme was open to people living in region D, aged between 18 and 65 years of age and with a good level of spoken English. The intended learning outcomes of the programme were:

1. To understand the meaning of palliative care, the services available and how services can be accessed;
2. To explore and become familiar with common reactions to referral to palliative care services from a patient and family perspective based on the lived experience of others (e.g. through invited speakers, narrative text, patient video);
3. To receive health and death education and information, relative to their condition, in a safe, supportive, facilitated group environment;
4. To explore physical, dietary/nutrition, mobility/activity, social, emotional and spiritual needs and to identify areas that might be of concern in the future with health professionals working in specialist palliative care;
5. To discover the potential benefits of various therapies (e.g. music, complementary, art and horticulture);
6. To find a space within which to feel comfortable contemplating the end of life and discuss care of people in the final days of life;
7. To form social supports with other group members and/or other agencies as a result of the information delivered;
8. To become familiar with the hospice environment and services available;
9. To learn about problem solving strategies to deal with issues as they arise in the future
10. To foster a sense of hope throughout all stages of life.

It was anticipated that applications to the "Living with Dying" programme would be made by the prospective participant directly. It was intended to advertise the programme in local newspapers, on the radio, via GP surgeries, Cancer Support Networks and Regional Cancer Centres. Prospective participants, who expressed an interest, would then have been invited to an information session (group and one-to-one sessions offered) about the programme and the research. As this was intended as a pilot programme, with a research element, it was considered important that participants were physically and psychologically well enough to participate and the consent of the patient's GP would have been sought by the researcher prior to the offer of a place on the programme.

10.3.2 Course format and content

The course was being offered free of charge to a maximum of eight participants, using the education centre of the hospice in region D as the venue. Where in excess of eight people applied for the programme, a waiting list would have been established for future courses and those on the waiting list would, in the interim, have been invited to take part in the control group phase of the research study. The course was designed to run weekly over six weeks - two weeks less than the Australian model of a similar programme with advanced cancer patients (La Trobe 2000-2) - in order to reduce participant burden. The course was designed to include six three-hour sessions (with a break after two hours).

It is important to note that the content of the course was intended to be participant-led based on their consideration of needs as explored in session One. However, from a review of similar courses with carers (e.g. Hudson, 2009), it was anticipated that sessions might be loosely themed as outlined below. Further more detailed session plans would have been made available regarding the exact breakdown of each session following agreement in principle for the delivery of the programme by members of the multidisciplinary team who were invited to participate.

Session 1: Introductions and tuning into your needs.

In the opening session, participants and facilitators will meet each other for the first time as a group. They will introduce each other and facilitators will identify some ground rules for working as a group. This session will give an opportunity for participants to tell their own story of their illness. Participants will be invited to consider what their needs are at this time and what they might be in the future. This will shape the structure of future sessions. Facilitators will recognise the different stages that participants might be at in their illness and will advise them to take what they consider to be relevant from each session, storing the remainder for use at a future time is required. An overview of available healthcare services will also be given.

Session 2: Understanding your changing body.

In this session, the group will be asked to identify ways in which they feel their bodies have changed and to discuss how they have adapted to these changes. They will be asked to consider what might be of concern to them in the future regarding their physical health.   Members of the specialist palliative care team will come to the group to discuss areas such as: (1) coping with pain and recognising common symptoms (nausea, breathlessness, fatigue); (2) diet and nutrition (constipation) and (3) maintaining mobility and activity (aids and appliances).

Session 3: Social issues and caring for relationships with family/friends.

During the third session, the group will be asked to consider the social and family networks they have available to them and to consider who might be available to help with specific areas of their life moving forward. Some fictitious case studies will be used to enable the group to explore social and family issues without delving too deeply at a personal level. A member of the social work team will be invited to discuss the role of the social worker, benefits and entitlements and outline services available for the participant and their family that might be useful now, or in the future. The session will also cover practical issues (e.g. how to make a will) and will include a guided relaxation component.

Session 4: Tuning into your emotional and spiritual side

The fourth session will allow the group an opportunity to explore their emotional reactions to advanced illness and spirituality with a member of the pastoral care team. They will also be given the opportunity to experience the benefits of therapies (e.g. horticulture, music, art and complementary therapy) in individual or group format as applicable to the needs of the group. The session will end with a guided relaxation.

Session 5: Contemplating life and death.

In this session, the group will contemplate life and the end of life by reflecting on a song, poem and personal story relayed via a DVD. They will be asked to consider what the concerns are that are outlined in the pieces and how, if faced with similar concerns at the end of life, they might cope with them. The documentary '*Going Home*' (Donnelly, 2007) will also be shown and discussed. The pastoral care team will be invited to join in with this session to address any questions that participants may have.

Session 6: Palliative Care and keeping hope alive

During the final session, the group will discuss how they feel about palliative care and hospice and consider common reactions to referral to palliative care. Members of the homecare team, hospice and day care nursing staff will come and talk about the services offered. They will explore the topic of hope and identify strategies for keeping hope alive throughout life. A tour of the hospice will also be offered.

In conclusion, it is hoped that the content of both of the above programmes, either in full or in part, may prove useful in the future, in advancing education in palliative care for both health professionals and patients or, at the very least, serve as a basis upon which to deliver such education as part of an innovative hospice health promoting strategy. The difficulties encountered in the implementation of this final phase of the research are discussed in more detail in the next chapter.

CHAPTER 11

Discussion

As indicated earlier in this thesis, relatively little is known about attitudes toward palliative care. In addition, the development of health promoting palliative care as an approach to potentially change attitudes, and ultimately practice and behaviour, is relatively new internationally, and untested in Ireland. This study set out to address these gaps in knowledge by conducting a comprehensive analysis of attitudes toward, and experiences of, palliative care amongst five participant groups, with a view to informing the design and development of a health promoting intervention for health professionals and people living with cancer respectively. The study, which was conducted in three phases and which incorporated mixed methodologies, included the perspectives of a wide range of health professionals, patients receiving palliative care services, people living with cancer and the carers of the last two groups. This chapter discusses the key findings of the study, some of which have already been disseminated (McLoughlin, 2010; McLoughlin and McGilloway, in submission) and outlines implications for policy and practice, particularly with respect to the future development of health promoting palliative care in Ireland.

11.1 The research context

In this section, the findings regarding attitudes toward palliative care, will be contextualised and compared to international literature in the first instance. Secondly, the intervention programmes designed during Phase Three of this study will be compared with the limited programmes available internationally. Finally, in view of the ethical issues and methodological debates that arose during the study, the experience of the researcher will be contextualised and compared to experiences of others working in this field.

11.1.1 The attitudes of health professionals toward palliative care

This research highlights, for the first time, the attitudes of Irish health professionals toward palliative care, whilst also adding to the relatively small pool of literature in this area. The findings are broadly consistent with those reported elsewhere. For example, Addington-Hall and Karlsen (2005) found that 'care of the whole person', 'pain and symptom control', 'quality of life' and 'dying peacefully' to be of central importance in palliative care to health professionals and volunteers working in UK hospice settings. These findings are echoed here in the extent to which Irish health professionals also emphasise the importance of 'maintaining respect for the patient's wishes'. Groot et al., (2005) classified the barriers associated with accessing palliative care services into three types: (1) personal barriers relating to knowledge, skills and emotions; (2) relational barriers concerning communication and collaboration; and (3) organisational barriers related to the organisation of care and compartmentalisation in healthcare. These types of barriers are all echoed in the findings reported in this study. In addition, Raudonis (2003) and Hanratty et al., (2006) described the health professionals' fear and a sense of failure as further barriers to the referral of patients to palliative care services. These issues have also been illuminated in this study and, therefore, have obvious relevance for health professionals working in Ireland.

The response rate to the postal questionnaire in this study was substantially lower than in other studies despite considerable efforts to maximise the overall response rate. For example, other similar studies of hospital doctors and GPs have obtained response rates of 60% to 69%. (Schneider et al., 2006; Shipman et al., 2001) Arguably, the lower response rate obtained in the present study, might suggest lower levels of interest in, and/or possibly a certain level of discomfort in dealing with, palliative care amongst health professionals in Ireland, but only further research can illuminate the real reasons underpinning this finding.

The findings from the one-to-one interviews with health professionals indicate that palliative care services and health services, in general, are in a state of flux and as a result, the roles and responsibilities of health professionals in the care of the dying, is also shifting. The inequity, both in the availability of palliative care services and in admission criteria, was also noted; whilst the postal survey findings suggest a need to increase awareness amongst Irish health professionals of the availability of their local palliative care services. This is possibly one of the reasons underlying the typically low levels of, or delay in, referral to palliative care within Ireland.

However, whilst there were some differences in overall attitudes between professionals working in areas where services are well developed, these were not statistically significant. This would suggest that other more important and potentially complex factors are at play in the decision to refer patients (or not) to these services. The composite findings from this study indicate that consideration must also be given to health professionals' level of training in palliative care, knowledge of palliative care services, their ability to communicate around issues associated with death, dying, loss and care, their attitude toward palliative care and the degree to which they reflect on existential matters when trying to understand what prompts an early, successful transition to palliative care services. These factors are discussed below.

This study highlights a lack of training in palliative care amongst a substantial proportion of health professionals working in Ireland; this is of some concern given that almost all participants indicated that they were currently caring for, or had previously cared for, a terminally ill patient. The need for increased development and delivery of palliative education has been widely documented in other studies (e.g. Low et al., 2006). Additionally, the findings in the present study suggest that participation in many forms of palliative education may have a positive effect on health professionals' overall attitudes toward palliative care (Mallory, 2003; Frommelt, 2003). The principal component analysis – conducted in only one other study (Bradley et al., 2000) - builds upon the relationship between knowledge and communication by suggesting that one may depend on the other to influence attitudes toward palliative care.

The findings from the qualitative interviews highlight the important influence of personal and professional experience on attitudes toward palliative care and the use of personal and professional stories in the accounts of health professionals was extremely common. This suggests that utilising and processing individual personal and professional stories might serve as a powerful educational tool to enable health professionals to explore their own attitudes toward, and experience of, death, dying, loss and care. Indeed, the use of stories and case studies is common in palliative and gerontology education provision (Kirkpatrick and Brown, 2004) and the use of reflection is also encouraged (Duke, 2000).

Interestingly, the health professional participants in this study often used ‘negative outcome’ stories to reference points made in their interviews regarding palliative care. This may suggest that the use of critical reflection (Fook and Gardener, 2007) in palliative education could prove particularly useful. Indeed, Fook and Kellehear (2010) suggest that critical reflection is a useful method for learning about practice experience in palliative care and is particularly useful in that it includes an emotional element thereby allowing health professionals an opportunity to process emotionally rich critical incidents that may have personal and/or professional origins. They argue that critical reflection is:

> *“One important and innovative means for supporting and encouraging health promotion approaches among practitioners who share a wider vision of social support in palliative care”.* *(Fook and Kellehear, 2010)*

The findings also point toward a lack of awareness of palliative care service availability; this is consistent with other international studies which have shown a similar lack of awareness amongst health professionals in countries such as the UK (Burt et al., 2006) and New Zealand (New Zealand Ministry for Health, 2001). The findings also support the evidence from elsewhere, to suggest that ‘fear’ and ‘stigma’ are words commonly associated with palliative care (Canny et al., 2002), thereby supporting the central hypothesis of this study. Health professionals recognised fear and stigma as important barriers to the referral of patients to palliative care services. Whilst this fear is recognised as residing in the patient and/or family, it may also belong to the health professional and it is possible that this fear may not be of palliative care *per se,* but of what it represents.

The complex relationship between the health professionals' own attitudes and thoughts around death and dying and the impact the patient might have on these beliefs, is highlighted by component four of the Principal Component Analysis. Where fear exists for the health professional around death and dying on a personal level, this may also impact upon referral of patients to palliative care; this is something that requires further research. In Ireland, 60% of the 30,000 people who die each year do so in hospitals and in 2005, the Irish Hospice Foundation embarked on a €10 million euro, 'Hospice Friendly Hospitals' programme that aimed to change the culture of dying in hospitals within Ireland. Arguably, if this programme is to be successful and, if specialist palliative care services are to be developed and made widely available, then concerted efforts must be made to tackle this fear and stigma at all levels.

The qualitative interviews conducted in this study, highlight the importance of public opinion on attitudes toward palliative care. Whilst the health professionals recognised that there has been a positive shift in opinion toward palliative care in recent years, there was still considerable fear and stigma associated with services, particularly amongst older people. . This finding provides additional evidence to support the work of international and national awareness raising campaigns, such as *Dying Matters* in the UK and the work of the *Forum on End of Life* in Ireland that aim to change public attitudes and behaviours toward death, dying, loss and care. There is also considerable evidence to suggest that public opinion can be influenced strongly by the media (e.g. Woodthorpe, 2010) and during the course of this study, there was a high profile media story in Ireland, whereby a respected member of the media died from cancer in a hospice and spoke openly in her final weeks of life about her experience of care and attitude toward death and illness. Following her death, her partner went on to discuss the hospice and the use of morphine in extremely negative terms:

"We already have euthanasia in this country. It is called hospice care. The crude description of it would be that the hospice people are licensed to kill. On the double effect principle, they will give you enough morphine to give you an easeful death, pain-free. But the effect of the morphine is to speed up your death. And we try not to look at it in this country." (Nell McCafferty, 2008)

The impact of these television and radio interviews sparked considerable debate amongst the palliative care community in Ireland and many hospices indicated that referrals for approximately one month following the interview were reduced, whilst considerable fear and anxiety amongst service users was also reported (Horan, 2008). This raises questions about the extent to which the palliative care community in Ireland is willing and able to respond effectively to such negative media coverage and to engage proactively in media campaigns in order to positively influence attitudes toward palliative care.

Communication was an important and recurring theme resonating, at a number of levels, within the findings. At a service provision level, there appeared to be an uncertainty about the availability of palliative care services; at an interdisciplinary level, a misunderstanding or pre-conception of roles was apparent; whilst at a patient–practitioner level, the findings suggest a complex interplay between the knowledge of the clinician of palliative care, their ability to form a relationship with

the patient and their ability to then communicate honestly about their condition. Indeed, it may not be the case that, the better the health professional knows the patient, the more likely they are to refer to palliative care. For example, Fallowfield et al (2003) have discussed the complexities of a relationship whereby, the better the doctor knows the patient, the more likely the doctor is to overestimate the patient's chances of survival. Consequently, there is a tendency for doctors
"to hope against hope that things are better than they really are and this is more pronounced when the doctor has built up a relationship with the patient." (p301, Fallowfield et al., 2003). This may explain, at least in part, why doctors persist with treatments rather than discuss referral to palliative care.

Effective communication with patients and families is considered a core competency within palliative education frameworks (De Vlieger et al., 2002). The requirement for enhanced communication is also a key feature of the Irish Association of Palliative Care strategy, as well as the recommendations of the Irish Hospice Foundation Round Table Education Discussion paper (IHF, 2006) about the future of palliative education in Ireland. The effects of increased awareness and training on patient–practitioner communication and population-wide attitudes, requires assessment over in time and may build on recognised models of communication skills training (Vlieger et al., 2002; Fallowfield, 2003; De Wilkinson et al., 2003; McLoughlin et al., 2010).

One potential theory for the general unwillingness of health professionals, patients and families to talk about death, dying, loss and care, centres on the notion that such matters are considered to be socially taboo (Gorer, 1955; Aries, 1974). However, this argument is not without its critics (Lofland, 1978; Kellehear, 1984; Walter 1994). For instance, Kellehear argues that the practice of not discussing death is due to the fact that such discussions are emotionally upsetting and thus, it becomes *"sound interprofessional practice"* to avoid this as a subject of conversation. This, in turn, may encourage denial, but does not necessarily stem from it. Zimmermann and Roden (2004) assert that there will probably always be a tension between the increasing need for health professionals to speak about death and the natural difficulty in doing so.

The description of palliative care in generally aspirational language in this study, as opposed to something more concrete, is a source of some concern, whilst the perception that referral to palliative care can signify a failure on the part of the health professional, raises questions about the beliefs and understanding surrounding palliative care. Indeed, Hanratty et al. (2006) noted that health professionals, whilst displaying an understanding of the wider concept of palliative care, often have *"a relatively poor grasp of the role of the specialist in palliative medicine"* whilst specialists in palliative care have previously noted that they have not been particularly effective at marketing or explaining to others their role (Hanratty et al, 2006). The findings reported here, also highlight that there may be a lack of appreciation of the importance of early referral of patients to palliative care services. This may be best understood by the qualitative findings which suggest that palliative care is synonymous with death and may be perceived, therefore, to be suitable only for patients who are actively or imminently dying. These findings are important cues to action because such beliefs may impact upon a patient's referral to palliative care. Indeed, health promoting palliative care may provide a useful framework for the development of a social marketing approach to matters associated with death, dying, loss and care (Fook and Kellehear, 2010).

This study, unlike a few others, did not find a significant difference between different professional groups, in their overall attitudes toward palliative care (Vejlgaard and Addington-Hall, 2005), although some differences were detected with regard to specific attitudinal statements. Of particular interest here, was the finding that doctors were more likely than nurses, to agree that it is primarily the role of nurses to deal with patients' reactions toward death. This suggests some consistency with previous work which concluded that there is a strong perception amongst doctors that palliative care is *"the province of nurses rather than doctors"* (Hanratty et al. 2006). Interestingly, doctors in the current study perceived themselves to have a key role in reducing suffering, but were less positive about the psychosocial issues surrounding palliative care. Indeed, the health professionals in this study generally saw these as less important factors associated with palliative care as in other studies. Such attitudes, beliefs and self perceptions may serve as potential barriers to the provision of holistic end of life care at levels 1 and 2 as stipulated in the NACPC (2001) report and which 82% of health professionals in this study rated as highly important.

The collective findings from this study suggest the need to take account of eight factors or variables which best describe the attitudes of health professionals toward palliative care and which ought to be addressed when developing an educational intervention for health professionals (Figure 12.1)**.** These factors suggest a need to: (1) raise awareness of hospice and palliative care service availability and admission criteria; (2) examine palliative care and hospice philosophy and purpose; (3) explain the potential benefits of early referral to palliative care services; (4) deconstruct personal and professional stories of death, dying, loss and care; (5) provide strategies for communication skills development; and (6) increase an understanding of health promoting palliative care. In addition, it is vital that two key external factors are monitored – public opinion and service provision development. Both of these have the potential to rapidly alter attitudes toward palliative care services. Therefore, it is essential that palliative care services continue to: (1) campaign for equality of access and service provision regardless of geographical location; (2) continues to inform definitions of levels of palliative care service provision across health care settings; and (3) maintains a high profile responding to media issues associated with death, dying, loss and care. These findings were used to inform the development of the health professional intervention in Phase Three of the study.

11.1.2 The attitudes toward, and constructs of, palliative care amongst patients and carers

Phase Two of this study addressed a major gap in the literature by providing valuable insights into the attitudes toward, and constructs of, palliative care, amongst patients and carers. To date, most of the international literature in this area (e.g. Connor et al., 2005; Miyashita et al., 2008) has focused on the attitudes toward, and experiences of, hospice and palliative care services amongst current or bereaved service users as well as the meaning of a 'good death' (e.g. Steinhauser et al., 2000). There has been very little emphasis on attitudes toward palliative care in its broadest sense whilst, likewise, the constructivist literature has focused heavily on constructs of death and dying (e.g. Kreiger et al., 1974) to the exclusion of constructs of palliative care *per* *se.* Therefore, this study adds to the psychological and health services literature regarding the manner in which patients, carers and health professionals view issues associated with death, dying, loss and care.

The findings from this study indicate that there was no difference in attitudes toward palliative care by gender or age, in either the patient or carer group. This is interesting because arguably, as a person ages, their previous experience with death, dying, loss and care may impact upon their attitudes. However, it is notable that all participants in this study were under 65 years of age and the average age of participants was surprisingly young. It is possible, therefore, that the impact of age might be less apparent than in older age groups, as hypothesised by Hendon and Epting (1989). Whilst participants' *past* experience of death, dying, loss and care did not significantly influence attitudes toward palliative care as assessed by the quantitative measures used in this study, it was crucial in the qualitative data (see below). Of more importance, however, from the quantitative findings reported in Chapter nine, is the actual experience of patient involvement in palliative care services which leading to more positive attitudes toward palliative care. Whilst the effect size may have been small, this finding provides quantitative support for previous qualitative findings reported elsewhere (Canny et al., 2002). Interestingly, service use did not have a measurable impact on the attitudes of carers toward palliative care in this study, but the qualitative interviews highlighted patient and carer positivity toward, and perceived benefits of, palliative care**.**

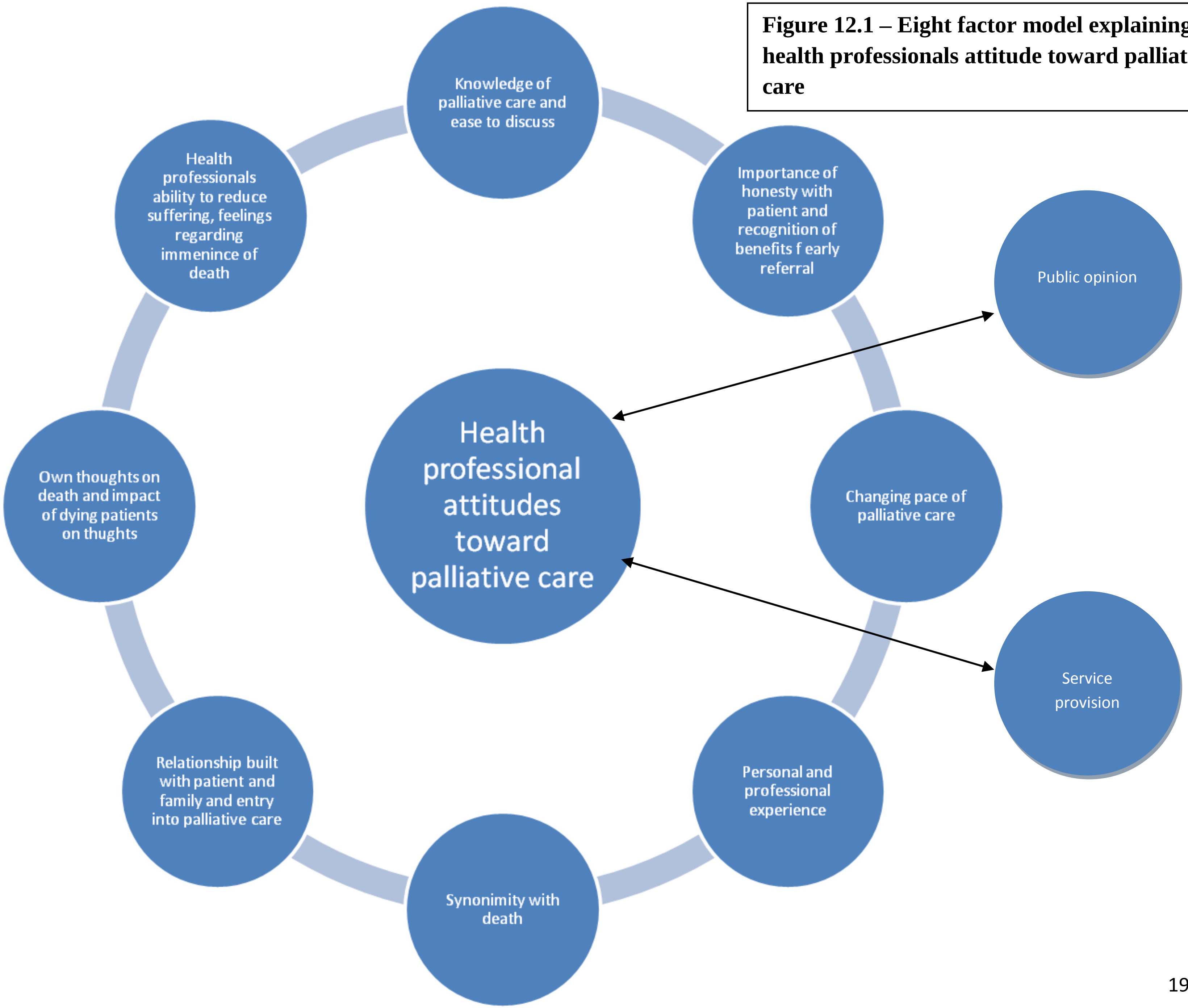


Figure 12.1 – Eight factor model explaining health professionals attitude toward palliative care

These findings suggest that, whilst past experience and association with palliative care services as a carer, or relative of someone at the end of life, are generally positive influences on overall attitudes toward palliative care, it is ultimately the experience of service receipt that appears to change attitudes in any meaningful way. This highlights the importance of utilising the direct service user voice in any social marketing campaigns to change attitudes toward palliative care whilst also questioning the validity of utilising the experiences of carers in satisfaction surveys as a patient proxy measure.

Four key themes and four sub-themes were identified from the thematic analysis of the interviews with patients and carers in this study, all of which are broadly comparable to the 11 themes used to describe the lived existence of palliative care service users in a study conducted in New Zealand (McKinlay, 2001). McKinlay (2010) refers to palliative care patients living within a circle of *"care."* Indeed the general terms used to describe palliative care by service users in this study often focused on "care" suggesting that patients might actually palpably sense the care they are receiving.

The themes identified in the current study, in line with the earlier findings from Phase One, show that the attitudes of patients and carers toward palliative care, appear to be strongly influenced by their life story and experiences of health, death, dying, loss and care. Considerable emphasis was placed on health professional expertise with particular reference to the importance of trust and communication between patient and practitioner, regardless of discipline. The fear and stigma associated with palliative care and, in particular, the hospice environment, amongst non-palliative care groups, was almost palpable, but was mediated somewhat by the perception that the hospice did good work and improved the quality of life of those who experienced the services. Finally, the paradox of life and death was central to participants' narrative in that palliative care service users tended to define palliative care/the hospice as a balance between life and death; this provides a stark contrast with those participants in the cancer groups who focused solely on the relationship between hospice and death.

Lawton (1998) maintains that most people would rather die at home than in a sanitised and impersonal environment and refers to the argument by Mellor (1993) that hospices sequester dying patients due to the taboo nature of death and dying in western society. Lawton focuses on the disease process taking place within and upon the patient's body, in order to understand why some patients are contained or held within the bounded spaces of hospices, whereas others are not. She argues that:

"…contemporary hospices set a particular type of bodily deterioration, demise, and decay apart from mainstream society and suggests that hospices enable certain ideas about 'living', personhood and the hygienic, sanitised, somatically bounded body to be symbolically enforced and maintained" (Lawton, 1998 p123).

Indeed, some of the participants in this study alluded to hospice cleanliness and their generally negative perceptions of hospice activity may be coloured by their previous personal experience of what Lawton refers to *"as the dirty dying".* Such perceptions naturally impact upon the fear and stigma associated with hospice and palliative care.

Fear of death is considered universal (Marshall, 1980) and whilst this study found no significant differences in fear of death between the patient and carer groups, the study indicated that males had higher levels of such fear. This finding is inconsistent with the small pool of literature which suggests that woman are more likely than men to report fear of death (Pollak, 1980), or that no such gender differences are apparent (Cicirelli, 2001). Indeed, Neimeyer (1994) indicates that studies identifying higher levels of death anxiety amongst men are rare. The current study findings, whilst perhaps counterintuitive, suggest that further research exploring gender differences in the Irish population, is required.

As expected and in line with international evidence, the quality of life of the patients receiving palliative care services in this study, was significantly lower than that of those people living with cancer who were primarily in remission. Evidence suggests that if the people living with cancer who participated in this study were facing immediate referral to palliative care services, their quality of life might be expected to be slightly lower (Temel el al., 2010). However, it is interesting to note that the patients who were living with cancer also displayed significantly higher levels of distress. As outlined previously in Chapter 9**,** this may indicate that the issues regarding distress at, and since, the time of diagnosis and treatment are no longer relevant for palliative care patients who have shifted along the illness spectrum. Alternatively, these issues may still be affecting those living with cancer and may not have been adequately processed or addressed. A study by Cleeland et al. (2000) proposes that cancer patients are burdened by symptoms related to the disease itself, or the toxicities of treatment. Unrelieved symptoms are a major detriment to patients' quality of life and ability to function and despite the distress that symptoms can cause, comprehensive symptom assessment is rarely a part of routine cancer care (Chang et al., 2000). Health care professionals often wait until patients spontaneously complain of symptoms before formally assessing them and they may be afraid to complain of symptoms for a variety of reasons. For example, patients may believe that complaining of symptoms distracts the doctor’s attention from taking care of the cancer, defeats their attempts to be “good” patients, involves a new set of medications with unknown side effects, or is an admission that their disease is growing worse. By contrast, “impeccable assessment” (WHO, 2002) in palliative care is core (i.e. assessment of symptoms across physical, psychosocial, emotional, spiritual domains), and the finding in this study that people living with cancer are more distressed, may reveal differences in symptom assessment for the reasons indicated by Cleeland et al. (2000); these essentially relate to difficulties in communication between patient and practitioner.

The findings from the quality of life assessment in this study also highlight lower levels of spiritual and social well being amongst patients in receipt of palliative care when compared to other domains. Indeed, this is an area where assessment and intervention in palliative care can often be difficult (O'Reilly, 2010) and there is a tendency for health professionals to focus too much on the physical assessment of symptoms (Wilkinson, 1999). Thus, these patients tend to perceive low levels of social support and engagement thereby highlighting a need for social models of care to be developed in line with health promoting palliative care principles For example,, the 'Home Hospice' model (Home Hospice, 2009) enables patients and their families access to a community mentor who works with them to identify their social needs and any appropriate people living in their community or social/family networks who may be available and willing to meet these needs (e.g. collecting children from school, painting the hall in advance of a Wake). These actions may reduce the stress and strain on patients and families living with advanced illness whilst providing an opportunity for members of the community to engage and experience death, dying, loss and care; this, in turn, may empower them when faced with similar issues in their own life.

Interestingly, the males in this study reported significantly higher levels of spiritual wellbeing than females. However, most studies report the opposite effect (e.g. Miller and Hoffman, 1995; Dorahy et al., 1998; Roothman et al., 2003; Cecero et al., 2006; Gauthier et al., 2006. This may be due to methodological differences in the measurement of this construct across studies, or the use of different samples (e.g. utilisation of different measures). Arguably, this may also be due to cultural factors but future research is required to examine this more closely.

The repertory grid case-study approach that was used in this study to explore the personal constructs of palliative care, highlighted some interesting differences in the construct systems of a patient receiving palliative care and a person living with cancer. The stark contrast between the negative poles of constructs used to rate palliative care by the person living with cancer, when compared to the current service user, again emphasises the shift in attitudes that seems to arise when in receipt of palliative care services. The case study comparison, together with the subsequent analysis of the quantitative between-group data, suggest a need for further more in-depth research on between group differences in constructs of palliative care. The individual case studies reported here, support and amplify the findings emanating from the qualitative and quantitative phases of this study by emphasising the importance of communication as a key construct of palliative care and exploring perceived quality of life by individuals at key points in the illness 'journey'.

For the patient receiving palliative care services, there appeared to be an acceptance that they would in the future be a dying person since these elements were centrally important in that grid, whereas the person living with cancer placed a considerable distance between these two elements. This may warrant a future longitudinal study to explore at what point in the illness trajectory, a person's construct system shifts to make this change. The grid data also highlighted the negative manner in which patients receiving palliative care are often perceived. They showed further that, although palliative medicine consultants are perceived as experts, they are viewed less positively in terms of other constructs, such as ‘happiness’, thereby indicating that patients may perceive their job to impact negatively on their personality or emotions. This contrasts to many palliative care patients in this study who commented on how important it was that palliative care staff were happy, ‘normal’ and used humour in their work. Interestingly, a study by Ramirez et al. (1995) found greater symptoms of burnout in oncologists when compared to palliative care physicians.

Central to the aims of this study is the exploration of the potential for the concepts of health promoting palliative care to change attitudes (and ultimately behaviour) toward death, dying, loss and palliative care in particular. The participants in this study were asked specifically about health promotion in palliative care and the findings revealed mixed views amongst patients and carers regarding its potential utility. Interestingly, patients receiving palliative care felt that they had a positive role in demystifying palliative care services for their friends and family, suggesting, therefore, that they may be quite willing to assume a role in health promoting initiatives (e.g. telling their story to others to educate and inform). Others focused on the need to develop programmes for carers and patients to inform them about the changes as their illness progressed. Some people had a limited understanding of health promoting palliative care, some of whom believed it to be associated with complementary therapy. This suggests the need for a greater awareness of this concept amongst both health professionals and the general public. Indeed the conceptualisation of palliative care and health promotion is often “blurred” (Rosenberg 2007).

Clearly the findings from the comprehensive analysis of patient and carer attitudes toward palliative care in this study, highlight a need to develop an intervention for people living with cancer, in order to address the fear and stigma associated with hospice and palliative care. Arguably, this might best be situated within an overall health promoting palliative care strategy as an educational component. The results suggest that such an educational intervention should aim to: (1) provide information about palliative care services; (2) utilise the patient ‘voice’ and ‘story’; (3) focus on the health promoting benefits of palliative care; and (4) demystify hospice, palliative care and the dying process. These findings were used to inform Phase Three of this study which is discussed in more detail below.

11.2 Design and development of health promoting interventions

It was anticipated that the design and development of two interventions for health professionals and people living with cancer would contribute to the much-needed changes in the ‘death-defying’ culture that would appear to be predominant in Ireland. For example, Van Doorslaer and Keegan (2001) in their study of contemporary Irish attitudes towards death, dying and bereavement, suggest a need for open, honest debate as *“the way forward, a healthy ‘modern’ way of coping with the implications of death, dying and being left in grief”*. Whilst Kellehear (1984) has argued against the ‘denial of death’ thesis *per se,* he suggests that the development of health promoting palliative care interventions that include health and death education, are vital to enable society to engage in issues associated with death, dying, loss and care and to ultimately change behaviours and practice.

Unfortunately, for the reasons outlined earlier, it was not possible to implement and evaluate either of the interventions that were developed, within the time frame of this study. Nonetheless, the two courses that were developed, were designed to address the fear and stigma associated with palliative care utilising group education, critical reflection and participant-lead agendas to engage with issues associated with death, dying, loss and care that were found to be important in Phases One and Two of this study. Each intervention may be delivered on a stand-alone basis in the future and/or as part of other larger more generic courses. The process of design and development also generated considerable learning whilst also raising questions that may prompt further investigation. These are further discussed below.

The health professional intervention was originally designed as a one-day workshop for health professionals who had the ability to refer to palliative care services. The face-to-face workshop was granted ethical approval and the researcher worked with specialist staff in palliative care services, to design the free programme based on the findings generated during Phases One and Two of the study. Central to the programme was the use of Fook and Gardener's (2007) model of critical reflection whereby participants utilise a critical incident to deconstruct their assumptions of palliative care. Lack of participant registration was the main impediment to the delivery and evaluation of the programme. The programme team concluded that this may highlight a general unwillingness amongst health professionals to reflect on their own mortality in a public setting. Further research is required to identify the precise reasons for the lack of participation and to examine ways in which some elements of the course might best be delivered.

In an attempt to address the initial difficulties in participant recruitment, it was agreed to develop an e-learning programme and to adapt the content for online delivery. Whilst the programme is now available (www.e-life.ie), ethical approval was not granted for the evaluation of the programme for the reasons outlined earlier in Chapters 5 and 10. This again raises interesting questions regarding the manner by which ethics committees perceive education regarding issues and research associated with death, dying, loss and care, and their perception of the risks and benefits associated with e-learning formats for such issues. Whilst the use of e-learning approaches to education in general and, specifically, around issues associated with death, dying, loss and care is relatively new, several studies suggest that this medium is indeed useful, and can be effectively applied to learning around such issues. Indeed, e-learning falls within the realm of distance learning and there has been considerable success in the development of, and uptake on, courses such as the European Certificate in Essential Palliative Care (McLoughlin, 2009), the ICGP short course in palliative care and Open University programmes. In Ireland, there is currently a shift toward the development of blended learning education programmes at higher diploma level in palliative nursing to accommodate students' needs to learn in a flexible and accessible manner. It may be considered that e-learning might prove more suitable for fact-based learning, as opposed to providing a format for engagement that can sometimes be heavily value-based, discursive or indeed experiential, as is the case for many death education/palliative care programmes. However, there is potential for some of the barriers associated with face-to-face education in this area to be addressed. For example, the use of critical reflection assumes a willingness to be open and to verbalise and challenge assumptions (both personal and those of others). This can be challenging for those who dislike public speaking, or are concerned about confidentiality. Therefore, the use of e-learning provides an opportunity to engage in these issues openly in a forum-based discussion whilst maintaining some of the anonymity that some participants may find useful. Arguably, it may be difficult to fully engage in, and explore, some of the issues arising in a subject such as palliative care in an e-learning format and certainly, the power and influence of non-verbal communication in such interactions is lost.

Nonetheless, the use of e-learning to supplement distance learning in palliative care has recently been considered by Callinan and McLoughlin (2011) in the Irish context., Whilst the format and medium of e-learning is acceptable to learners and perceived as valuable, there is concern that full engagement on discussion-based forums is limited. Thus, strategies to ensure participation in programmes such as that designed for this study, are essential. From an ethical perspective, the use of e-learning programmes to address issues such as death, dying, loss and care, can present several challenges. Particularly important is the provision of support to those who find the content emotionally difficult. It is therefore vital that participants who engage in online learning in this area, are made fully aware of: (a) the potential content and themes that might arise; (b) consent to participation; (c) meet any inclusion criteria (e.g. no recent bereavement); and (d) are fully aware of any research that might be related to their participation.

An intervention was also developed in this study for people living with cancer, based on the findings of Phase Two of this study and drawing on the work at La Trobe (2000-2). As previously described, there was a lack of buy-in by the oncology teams (and to a lesser extent palliative medicine) to deliver and evaluate the intervention. A number of reasons were cited by the oncology team including: (1) a desire not to frighten or reduce patients' hope by telling them about the course; (2) cultural differences between Australia - where the other studies were conducted - and Ireland, in that most patients in Ireland with cancer do not want to discuss death and dying and it is rarely discussed openly in consultations; (3) the course was too long; (4) that the course should not be held in a hospice; and (5) that the intervention was part of a research study and was not a mainstream service development**.**

Thus, there are important potentially generalisable lessons from this study for the implementation of these kinds of courses elsewhere in the world. Further research should also be undertaken to: (1) explore possible cultural differences in the ‘narrative’ of patient-practitioner consultations in Australia, Ireland and other countries; (2) to assess patients living with cancer to determine the extent to which they would be interested in attending such a course (this was proposed as part of this study, but the oncology team advised against it). The uneasiness, with which the oncology services viewed the patient intervention, raises questions about their own perceptions of palliative care, their acceptance of death and dying as part of life and their ease at which they converse with patients and their families around such matters. Again, these are important lessons for the development of similar interventions elsewhere.

11.3 Ethical Issues

The process of completing this research was time consuming and fraught with ethical and other methodological difficulties (see Appendices for full paper). A review of the literature indicates that these kinds of challenges were not unique to this study (de Raeve, 1994; Jordhoy et al., 1999). The ethical aspects of this study were very carefully considered and scrutinised in order to ensure that all aspects of this study were appropriate from an ethical perspective. However, under Article 19 of the Human Declaration of Human Rights:

“Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers” (United Nations,1948).

Arguably, as researchers and health professionals, perhaps we ought to give patients the opportunity to exercise this right. Perhaps we should allow patients a choice. Perhaps we should detach our perception of the truth regarding the appropriateness of others taking part in a research study and allow the dying patient "*to speak, to be a voice for the voiceless"* (Monroe, 2003). One possible means by which this might be achieved, involves the development of national patient, carer, and public forums in palliative care, as proposed by the *All Ireland Institute for Hospice and Palliative Care*. These could, in turn, enable researchers to engage in dialogue with service users in order to assess the appropriateness of proposed research designs. It might also be useful for ethics committees to have access to such forums in the future, in order to hear the service user perspective and to assess the extent to which researcher procedures are appropriate and safe. It may also be useful to develop evidence-based guidelines for ethics committees to assist them in their decision making around research in palliative care.

Casarett (2000) welcomes the Institutional Review Board recommendations (http://www.nih.gov/grants/oprr/irb) that each ethics committee in the United States should have at least one member experienced in the care of people at the end of life. It also calls for further considerations to ensure that the person is familiar with palliative care research and the nature of palliative care, including the often frank discussions about death and dying that occur in this discipline between health professionals and patients. Whilst it can be argued that such frank discussion is not commonplace in Ireland (McKay et al., 2011; O'Reilly and McLoughlin, 2011), these recommendations could, nonetheless, be considered by Irish ethics committees and due consideration given to the potential for ethical approval obtained in one HSE area, to be applicable in other HSE areas without question or the need for another submission.

The difficulties associated with gaining ethical approval and subsequent access to patients in Phase Two of this study and the issues highlighted above with regard to the development and evaluation of the patient intervention, suggest that there is considerable "gate-keeping" within the field of palliative care and oncology in general. This is certainly not unique to this study (McLoughlin, 2010). However, in order for society to engage in issues associated with death, dying, loss and care in an informed manner, it is vital that appropriate access is provided to ensure that research and evaluation in the field of death, dying, loss and care is allowed to flourish with due regard and consideration of ethical issues associated with the topic.

11.4 Strengths and Limitations of the Study

This study, as with most others, was limited in a number of ways although some of these may be usefully transformed into research questions for the future. First of all, despite the researcher's best efforts, the response rate to the postal survey was poor in comparison with other international studies of a comparable nature with a similar population. As outlined earlier, this may reflect cultural differences, or may indicate something more fundamentally different about the attitudes of Irish health professionals toward palliative care. Therefore, it is possible that there was some element of response bias in that perhaps only those health professionals who were more positive or interested in palliative care, responded to the survey.

Likewise, those patients who were invited to participate in the one-to-one interviews, were selected by the Consultant who may have chosen people on the basis of a perceived likelihood to participate, or their more positive attitudes. Thus, this may have led to some degree of sampling bias. Another possible and related limitation, which has been highlighted by a number of other authors in the field, is the effect of self-selection on the representativeness of the samples (Cook & Bosley, 1995). This is particularly relevant for health professional, cancer and carer groups and it is important to consider how those who participate in these studies, differ from those who do not. Unfortunately, it was not possible to obtain information in this study on non-responders.

Whilst the response rate to the postal survey questionnaire might be considered low, it is important to also consider the relatively large number of participants who engaged in the qualitative aspects of the research. This is a key strength of this study and in comparison to other studies of this nature (e.g. McKinlay, 2010), provided an opportunity to engage with and analyse rich data from a wide range of perspectives. These perspectives included the patient voice directly, which again is quite unique given that many studies in this area focus solely on the responses of current or bereaved carers. Kubler-Ross urges us to hear the patient voice and this study has enabled the patient voice in two key patient groups to be communicated and understood.

This study also provides the first comprehensive analysis of the attitudes of Irish health professionals, patients and carers toward palliative care and, unlike previous work internationally, it focuses on multiple perspectives (i.e. as opposed to one group only, usually health professionals). In addition, the study involved the application of mixed methods across three separate but inter-related phases, which collectively addressed important gaps in the literature, whilst also leading to the development of a number of useful end-products/deliverables for future utilisation in the field. These include: (1) the Health Professional Attitude Questionnaire (HPAQ); (2) the development of a workshop and evaluation for health professionals; (3) the development of an e-learning package for health professionals; and (4) a draft development plan for an intervention for people living with cancer. Furthermore, the development of an 8-variable comprehensive framework to describe health professionals' attitudes toward palliative care and associated action points arising from the framework, add considerably to models that have been developed in the past (e.g. Bradley 2000) and provides a roadmap for action in the future development of this area. However, as indicated earlier in Chapter 5, it is important to consider is the often conflicting evidence regarding the link between attitudes, as determined in this study, and future behaviour. The methodologies utilised in this study explored explicit attitudes toward palliative care and it is acknowledged that implicit attitudes toward palliative care, death and dying, could indeed be somewhat different. Whilst this is a limitation of this study, it was important for the purposes of this research to utilise methods that were deemed to be appropriate and convenient to the research sample. Further research could incorporate, where feasible, the use of laboratory based technologies, such as the IRAP, to explore whether there is indeed a difference in explicit and implicit attitudes of groups of respondents to these issues.

A key element of Phase Two of this study involved the use of the repertory grid technique, derived from Personal Construct Psychology which has proven to be a useful tool in therapy, business, human resources and educational research. This tool has only been used in palliative care research in one other, now dated, study (Hendon and Epting, 1989). This is a potentially powerful instrument to evaluate core constructs that arguably may be less transient than attitudes. Therefore, the focus in the current study, on both attitudes and constructs is unique and also very important as a basis upon which to consider how behaviour around death, dying, loss and care may change and is of interest and relevance to modern psychology. In addition, it is anticipated that the use of the repertory grid may prove to be a useful technique in palliative care research in the future. It may also be possible to apply this tool in a therapeutic manner with patients who may be considered to require psychosocial intervention within palliative care, since it provides an insight into the manner by which illness and people in the patient's construct system, are construed. For example, as part of routine psychological assessment, repertory grids could be utilised to explore the unique personal constructs of illness and family dynamics with the patient, with a view to using the grid to inform treatment and intervention. Palliative care has been slow to utilise the skills and tools offered by modern psychology and this study has offered the field useful insights into how methods, such as the repertory grid, may be of value in practice.

Despite the ethical challenges that arose in the conduct of this study, most participants found their participation to be a positive and helpful experience. This is consistent with previous work (e.g. Brabin & Berah, 1995; Seamark et al., 2000) which illustrates the potentially therapeutic benefits of taking part in this kind of research. Furthermore, as Roberts (2008) indicates, this may reflect the skills and qualities of the researcher who, in the current study, attempted to show compassion, empathy, understanding and flexibility throughout the study. The researcher was also particularly skilled at making participants feel at ease and at seeking a common ground to 'warm up' conversations. Hynson et al. (2006) focussed on similar attributes, all of which were harnessed here, including: an ability to show understanding, but not claim to have any particular insight; a capacity to contend with powerful expressions of emotion; an ability to pace the interviews; and keeping in mind the informal, conversational and non-clinical nature of the interview.

The development of the HPAQ was a useful end product of the study and adds to current tools available in the field in that it combines attitudes toward death, dying, loss and palliative care in one instrument. The formulation of the tool and subsequent adaptation of the HPAQ for non-healthcare professionals in this study, suggests that the instrument is versatile and can be used across settings and groups. No specific tool is, as yet, available to assess patient and/or carers attitudes toward palliative care and the adapted HPAQ used in this study, could address this deficit. This also presents an opportunity to test the validity and reliability of this new instrument in the future. The above may also provide a useful basis on which to develop a specific tool aimed at assessing patient and/or carer attitudes toward palliative care (none of which currently exists).

In general, the tools and measures used in this study appeared to be effective and acceptable to the study population. However it is recommended in future studies that the fear subscale of the QoL-CS is not administered to palliative care populations, since many of the items within this subscale referred to a fear of cancer re-occurrence or future treatments; these were not appropriate for the palliative care group. In order to ensure that participants were not over burdened, only the fear subscale of the DAP-R was used. Whilst this did not detect any difference in fear of death of participants, an opportunity presents for a future study to include the death acceptance scale as well. Likewise, to reduce participant burden, the repertory grid technique used in this study focused on the rating of researcher-provided constructs and elements. It is acknowledged that this is not ideal since it does not allow the researcher to tap into the participant’s own construct system and a participant’s understanding of a construct could also be significantly different from the construct the researcher intended it to be (Fransella 2003); again this offers potential for future research.

Finally, it must be acknowledged that in addition to the many strengths and outputs arising from this research study, the study has also served as a stepping stone for the development of health promoting palliative care in Ireland. As a result of the findings herein and the focus of this study, significant developments have taken place, particularly since 2007, which can be directly attributed to the conduct of this study and the findings that have emerged therein. For example, the hospice within which this study was based, is now piloting Ireland's first 'Compassionate Communities' model and is leading the development of health promoting palliative care in Ireland.

11.5 Recommendations for future research

As outlined throughout this chapter, this study has highlighted a number of potential avenues for future research. These are summarised below:

- Conduct a second postal survey of health professionals in 2016 to determine if anything has changed with regard to attitudes toward palliative care over the ten-year period.
- Undertake a psychometric study of the validity and reliability of the HPAQ with a range of other samples.
- Carry out a qualitative investigation to identify the reasons underpinning the unusually low response rate of Irish health professionals to the postal survey
- Design, develop and evaluate a media awareness-raising campaign focusing on the positive health promoting aspects of hospice and palliative care.
- Implement and evaluate the health professional and patient interventions designed and developed for this study.
- Undertake a comparative analysis of narrative differences between oncologists and patients regarding death, dying, loss and care in Ireland and elsewhere (including Australia).
- Conduct a study to examine the potential gender effects on spiritual well being and fear of death in Ireland.
- Explore in more depth, personal constructs toward palliative care utilising participant- derived repertory grids.

- Identify by means of a national/cross-national survey, the potential uptake of a health promoting intervention for people living with cancer.
- Undertake future qualitative research to explore the reasons why health professionals choose to attend, or not to attend, courses that enable them to focus on their own mortality.
- Carry out a longitudinal study to assess patterns or changes in attitudes / constructs of death, dying, loss and care over time in particular groups.
- Examine the differences between implicit and explicit attitudes toward palliative care, death, dying and loss utilising laboratory based techniques (e.g. the IRAP).

11.6 Conclusion

This study has highlighted for the first time, the attitudes of Irish health professionals, patients and carers, toward palliative care and the findings represent a valuable addition to a very limited body of international evidence. The fear and stigma associated with palliative care services have been described from a range of perspectives and a greater understanding of attitudes toward palliative care between and within groups has been developed. This, in turn, has led to the development of potentially useful health professional and patient interventions which were designed using a health promoting palliative care framework. The study has also demonstrated the many challenges involved in undertaking research with patients in palliative care services and has provided evidence that might be useful in informing the manner by which palliative care research studies are normally given ethical approval (or not) in Ireland. In addition, the researcher's involvement in this research study has led to a number of local, national and international developments.

It is clear from this study that attitudes toward palliative care need to change in order for palliative care services to be able to achieve their ultimate health promoting goal, which is to improve the quality of life of patients and carers at the end of life. Palliative care service providers are therefore clearly faced with a challenge to contribute to, and lead, the drive to redefine death, dying, loss and care as a social change priority. Perhaps palliative care service providers can achieve this through partnership with public health colleagues and social scientists to change the social mindset whereby death, dying, loss and care are not considered as personal problems or the responsibilities of health professionals. This, in turn, may lead to a situation whereby society considers these issues as a natural part of life and engages in behaviour to confront them without fear or stigma.

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List of Appendices

Appendix A – Peer Reviewed Publication – McLoughlin, K. (2010). Dying to talk: unsettling assumptions toward research with patients at the end of life. Palliative and Supportive Care, 8, 371-375.

Appendix B – Health professional information sheet

Appendix C – Example of patient information sheet

Appendix D – Example of consent form

Appendix E – Guidance for Safe Working Practice in Psychological Research

Appendix F – HPAQ

Appendix G – Health Professional Semi Structured Interview Schedule

Appendix H – Scree Plot (Phase One)

Appendix I - Total variance explained by first five components

Appendix J – Distress / Impact Thermometer

Appendix K – QoL-CS

Appendix L – DAP-R – Fear Subscale

Appendix M – 13 Item HPAQ

Appendix N – Semi structured interview schedule (Phase Two – patients)

Appendix O – Rep Grid

Appendix P – Rep Grid PCAs

Appendix Q - Making Time for Death, Dying and Palliative Care Course Information Guide for Participants – Developed for Phase Three of this Study

Appendix R - Living with Dying, A Six Week, Pilot, Group Education Programme for People Living With Cancer – Developed for Phase Three of This Study.