Chapter 1 - Introduction

1.1 Context and Background

End-of-Life includes care provided by multidisciplinary healthcare providers including medical, nursing, clerical, catering, household, portering, physiotherapists, dieticians and pharmacists; and this list is not exhaustive. It includes all aspects of care provided from diagnosis to death, care immediately after death, and the bereavement phase. End-of-life care includes sudden deaths and deaths of children. Care is also inclusive of the bereaved family and friends, and staff who provide end-of-life care. 30,000 people die in Ireland every year, with the majority (75%) dying in hospitals. End of life care is therefore integral to the provision of quality multidisciplinary healthcare (Hospice Friendly Hospitals (HfH) Standards, 2010). Within this context, training and education for multidisciplinary healthcare providers forms the basis for this research study, with a particular emphasis on spirituality in EOL care.

The Quality Standards for End-of-Life Care in Hospitals (HfH, 2010), were launched on 19 May 2010. The underlying message of the standards is that provision of quality EOL care is essential (HfH Standards, 2010). The philosophy includes an emphasis on the holistic model of care, encompassing physical, psychosocial and spiritual dimensions of the person. The document describes a range of standards, with Standard Two (The Staff) advocating that staff participate in relevant training and development to ensure that they are confident, compassionate and competent in their provision of end-of-life care. The HfH Standards encourage reflection on how to address the sacredness of human life by acknowledging the issues and experiences that are an integral part of being a human being (McAleese, 2010).

To facilitate the implementation of staff training, there was a need to offer a programme that developed, increased and internalised recognition of spiritual needs of both patients and care providers. This research will investigate the processes through which Transformative Learning (TL) is integrated into the practice of spiritual care at the end-of-life. Spiritual care provision has moved up the health and social care agenda over recent years in response to a range of local and national initiatives designed to improve and individualise patient experience across all health and social care domains. To achieve this, care providers must be educated and/or trained to a level that can ensure consistent care provision that is holistic in approach and content (Hickey *et al.,* 2008). Research by Hickey *et al.,* (2008), revealed that while 83.7% of respondents stated that they encountered patients with spiritual needs, only 39.9% perceived themselves as competent to respond to this need (ODriscoll, 2001; Hickey *et al.,* 2008). Young and Koopsen (2011, p.175) acknowledge the need to develop educational programmes related to spiritual care, and the growing trend of spiritual importance in the lives of individuals.

Cicely Saunders (2006) introduced the term '*total pain'* to capture the complexity of physical, emotional, and spiritual pain experienced by patients, thus proposing the idea of '*spiritual distress and suffering*' in the palliative care lexicon. Spirituality in end of life care is now integral to healthcare policies, guidelines, training initiatives, and ultimately quality clinical practice (WHO, 2010). There is a widespread acknowledgement by healthcare professionals that spiritual issues may influence the quality of dying, death and bereavement. However, it is less obvious from the literature '*how these needs should be met and by whom*' (Grant *et al.,* 2010, p.659). It is now widely agreed that high-quality treatment and care includes palliative care that focuses on managing pain and other distressing symptoms; providing psychological, social and spiritual support to patients and those close to the patient (General Medical Council, 2010).

Spiritual care is acknowledged to be an important part of end of life care (McClement & Chochinov, 2010). The World Health Organisation's (2010) definition of palliative care includes addressing physical, psychosocial and spiritual needs. It is clear from the evidence in the literature that addressing the spiritual needs of dying patients and their families is an essential part of care, although Pugh (2010) observes that such needs are poorly addressed. The national EOL care strategy for England states that spiritual care and support for both the person and their carers is integral to the end of life care pathway (UK Department of Health, 2008). While EOL care is a profound journey; it is also something with practical repercussions (McAleese, 2010).

Spiritual issues concern us all; Dame Cicely Saunders advocated that we are indivisible physical and spiritual beings (Saunders, 1996). As patients move towards the terminal or end-of-life stage, the impending confrontation with death may prompt a person to engage in spiritual reflection (Speck *et al.,* 2004; Byock, 2006*a*.). Patients have unique needs, life stories and ways of spiritual expression, (Stephenson *et al.,* 2003; Tan *et al.,* 2005), for which individual spiritual care for patients and their significant others is seen as vital (Tan *et al.,* 2005; Shih *et al.,* 2009). Optimal quality palliative care requires attending to the '*multidimensional aspects of patient and family suffering'*, yet professionals report inadequate preparation in this crucial area of care. Deficits in care including unsatisfactory pain and symptom management, carer burnout, poor access to services, communication deficits, and discrepancies in care have emerged in recent studies (Institute of Medicine, 2008; Otis-Green *et al.,* 2009). Spiritual needs are often irregularly addressed (Kramer *et al.,* 2005), and inconsistently delivered (National Quality Forum, 2006; Otis-Green *et al.,* 2009).

For those at the end of life, emotional and spiritual needs are often exacerbated, intensifying the perception of pain and other distressing symptoms. Surveys suggest that addressing spiritual needs is associated with better health outcomes, (Townsend *et al.,* 2002), including improved coping skills, quality of life, and less angst, distress and depression, (Post *et al.,* 2000; Mueller *et al.,* 2001; Wasner *et al.,* 2005) even during terminal illness (McClain *et al.,* 2003). Mounting evidence for the constructive role of spirituality in health and wellbeing proposes '*opportunities for innovation in providing relief and comfort*' (Koenig, 2004; McCord *et al.,* 2004; Williams, 2006; Anandarajah, 2008). The palliative care model aims to enhance both psychosocial and physical wellbeing regardless of the illness or disease trajectory (Department of Health and Children, 2001). Oates (2004) suggests that the aim of spiritual care is to reduce the individual's anxiety about death through identification of purpose and meaning of life.

1.2 Sacred Art of Living and Dying, Healing Anamcara Programme

A programme is currently being offered to multidisciplinary personnel in Sligo, based on the principles of transformative learning (TL), (see Appendix I – *Sacred Art of Living and Dying (SALAD) – Healing Anamcara Programme* Flyer), including participants who have travelled from Australia, the US and France. The programme is grounded in rich international history as well as contemporary clinical research. Participants explore the universal patterns of spiritual suffering and time-tested ways to relieve them. The programme is run over two years, four units consisting of two-day workshops, each followed by five *Circle of Trust* study groups. The workshops are facilitated by Professor Richard Groves, (2009), whose doctoral thesis focused on diagnosing and addressing spiritual pain from a variety of cultural and psycho-spiritual perspectives (see Figure 1 and Appendix I - *Sacred Art of Living and Dying (SALAD) – Healing Anamcara Programme*). The programme offers a holistic model of education and healing that draws from the great wisdom traditions while respecting contemporary science and psychology. Teaching methodologies incorporate clinically-proven practices that respect the total person regardless of age, culture, gender and spiritual tradition, creating a learning model that addresses suffering and loss in transformative and life-giving ways; utilising the philosophical underpinnings of TL.

1.2.1 Circles of Trust Study Groups

Circles of Trust study groups meet once a month and are comprised of an 'animator' and maximum of eight participants, based on the work of Palmer (2007). Each group is assigned a group facilitator called an animator (one who brings '*anima*' or spirit). The animators receive training in the circles of trust processes before the program begins. Using circle of trust practices, including the touchstones (see Appendix II – Circle of Trust Touchstones); the group reads and discusses the recommended books in addition to other relevant materials. Opportunities to reflect on what each person is learning during the units are accommodated, in addition to how they see the intersections between the teachings and their practice. Drawing on the work of Dr. Parker Palmer, (Palmer, 1998; 2004; 2007), the study group process is not about covering the material or every idea in each chapter or unit, but rather creating a space in which participants use the readings and teaching from the units to listen to themselves, and to reflect on their practices with others. In the circles, open and honest questions are encouraged (see Appendix III - *Circle of Trust* – Guidelines for Open, Honest Questions). Rather than agreeing, disagreeing or debating, participants simply offer responses to evocative questions about how the material intersects with their lives and their experiences; therefore utilising the TL philosophy.

Figure 1: Sacred Art of Living and Dying - Healing Anamcara Programme

Unit 1 Understanding Spiritual Pain	• Circle of Trust Study Group x 5
Unit 2 Diagnosing Spiritual Pain	• Circle of Trust Study Group x 5
Unit 3 Healing Spiritual Pain	• Circle of Trust Study Group x 5
Unit 4 Transforming Spiritual Pain	• Circle of Trust Study Group x 5

1.2.2 Aim of Training Programme

The aim of the programme is to empower participants to recognise the different aspects of suffering experienced by the dying and their families/friends, and to respond appropriately. Participants learn techniques of compassionate and attentive listening, and how to recognise and respond to the possible causes of emotional and spiritual suffering. Practical exercises are incorporated to enable participants to work effectively with cognitively impaired patients, or those in altered states of consciousness. Non-denominational spiritual practices such as art and music therapies and meditation are utilised; to enable participants to integrate and use the benefits of spiritual care both for themselves and in their professional roles; '*calming the mind and deepening compassion*' (Wasner *et al.,* 2005).

Participants practice skill and competency development through facilitated group work, role play, and experiential discussions. Teaching methodologies include lectures, discussion of scenarios, personal death awareness reflections, reading recommended texts, and case studies. The *Sacred Art of Living – Healing Anamcara Programme* provides diverse resources including PowerPoint slides, lecture notes, CDs, DVDs, and additional reading resources. The programme encourages personal journaling, imagery, and use of the arts to promote reflective practice and foster learning. A harp therapist provides music, and a labyrinth is utilised to promote self-reflection. Exercises, including narratives and rituals from a diversity of traditions, are incorporated in the programme at the beginning and conclusion of each day. Personal death awareness exercises encourage reflection on one's own mortality, in an attempt to improve understanding and provision of quality palliative care.

1.2.3 Transformative Learning

Mezirow (1978; 1994) believed that perspective transformation occurred through a rational process that begins with an experience of the disorientating dilemma followed by self-examination and assessment of assumptions, connection with others who are experiencing similar transformations, discovery of new ways of interpreting meaning, the creation and trial of a new plan of action, and the building of confidence toward reintegration into the world reinforced with a new perspective (Cranton, 1994; Imel, 1998; Mezirow, 1995). This process leads to knowledge acquisition during which individuals critically examine their beliefs, assumptions, and values surrounding a particular situation (Whitelaw *et al.,* 2004). Similar to the principles of constructivist pedagogy (Cohen, 1999; Gillani, 2003; Yilmaz, 2008), learners seek to restore homeostasis in their thinking but in doing so transform their frames of reference and how they create meaning in relation to the world and those around them (Parker & Myrick, 2010). With an understanding of transformative learning theory, educators can maximise the flexibility and alterability of clinical scenarios to empower learners to become autonomous thinkers who are able to contend with the complexities of today's healthcare environment (Parker & Myrick, 2010).

1.3 Research Aim

Research is a process of systematic inquiry that is designed to collect, analyse, interpret, and use data to understand, describe, predict or control an educational or psychological phenomenon; or to empower individuals in such contexts (Mertens, 1998). The aim of this research is to explore the processes of transformative learning as an educational framework to inform end-of-life spiritual care.

1.4 Research Statement

The research statement in this dissertation is: 'Integrating the processes of Transformative Learning to Multidisciplinary Education in End-of-Life Spiritual Care'. Hart (2006) outlines features of a good topic, which concur with those described by Bradley (2010b.), data availability; access to the data; time available; availability of resources; and symmetry of potential outcomes. The data were widely available and accessible to the researcher, who is coordinating design and delivery of the programme. This topic builds and develops capabilities, skills and knowledge that the researcher already has.

1.5 Research Objectives

The objectives of the research are to:

- explore the processes of transformative learning (TL) as an educational framework to promote the advancement of quality end-of-life spiritual care for patients, families and healthcare professionals
- integrate learning to multidisciplinary practice settings
- explore and learn from recent, relevant and international evidence based practice with regard to optimal end-of-life spiritual care

1.6 Scope of the Research

The research was conducted with participants attending the *Sacred Art of Living – Healing Anamcara Programme* in Sligo, inclusive of multidisciplinary perspectives; i.e. nurses, doctors, social workers, psychotherapists, occupational therapists, clerical staff, managers, spiritual directors; and personnel from other non-healthcare areas with a role in end of life care, for example, agencies such as acquired brain injury and the life boat association. Staff who participated in the research were inclusive of diverse backgrounds; including acute services, community, public health, hospice, mental health and intellectual disability services. Data were collected from November 2010 to February 2011, utilising questionnaires, one-to-one unstructured interviews, memos and reflective journals. The population, sampling and methods will be discussed in detail in Chapter 3 – Methodology.

1.7 Plan of Development

The researcher developed a Gantt chart (see Appendix IV – Gantt Chart) to chart the research plan from the outset. Having explored the subject, purpose, scope of the research and the plan of development in this Chapter 1 - Introduction; Chapter 2 will present the relevant Literature Review; Chapter 3 - Methodology, including ethical considerations, sampling, data collection and analysis; Chapter 4 - Findings and Discussion, including rich data to support the interpretation and discussion of the findings; and finally, Chapter 5 – Limitations, Recommendations and Conclusion.