Chapter 2 - Literature Review

2.1 Conducting Literature Review in Grounded Theory

In quantitative research, literature can be drawn on to find relevant prior research in the field under investigation, to identify gaps in the existing body of knowledge; and to discover potential theoretical or conceptual frameworks that could be used to design the research process. In qualitative studies, particularly when the Grounded Theory Method (GTM) is used, researchers are strongly advised to defer the literature abstraction until they have gathered and analysed the initial body of the research data (Glaser & Strauss, 1967; Glaser 1992; 1994).

In using GTM, the motive is to elicit concepts as opposed to testing or repeating them. At the outset of the study, the researcher is cautioned against studying the literature in the chosen field of study. This, according to Glaser, (1992, p.74), could herald researcher bias by giving rise to '*a set of preconceived concepts, categories and properties from other researchers' work*'. Beginning with a literature study could therefore impact the discovery of theory and, therefore potentially overthrow the main axiom of the grounded theory approach (Glaser & Strauss, 1967; Strauss & Corbin, 1990; Glaser, 1992; Charmaz, 2006; Gasson, 2003). This belief is reinforced by Hunter (2000), who argues that addressing a research problem without bias or assumptions will lead to the emanation of a theoretical framework from the raw data. However, it is important to note that Strauss and Corbin (1990) do not completely discourage researchers from reviewing the literature in the subject area prior to data collection. They advocate that some comprehension of the research field will increase '*the theoretical sensitivity of the researcher*' when she is developing theory from the initial data samples.

Charmaz (2006) agrees with Strauss and Corbin, as she also advises the use of a rudimentary theory. With the profusion of available knowledge in the literature, eradicating a rudimentary theory may even result in a lack of research focus (Mavetera & Kroeze, 2009). Therefore literature study can be conducted, once its findings do not influence '*or manifest themselves, in the interviewees' responses*' (Mavetera & Kroeze, 2009, p.23). In this study, the initial superficial literature review focuses on the two areas under scrutiny, i.e. transformative learning and spirituality. The review of literature, together with increasing theoretical sensitivity ensures a more relevant evolution of concepts and categories (Mavetera & Kroeze, 2009). A more in-depth review was conducted following the data collection and analysis. This chapter will present the review of literature on spirituality, including differentiating it from religion, recognising the medical model in end of life care, exploring the role of the multidisciplinary team, realising financial implications, initiating end of life discussions, facilitating end of life care, recognising spiritual distress, conducting spiritual health assessment, minimising barriers to spiritual care, facilitating spiritual healing, utilising transformational learning in end of life care; and training and education in end of life care. The researcher consulted medical, nursing and healthcare textbooks, publications, websites, relevant agencies, professional bodies and reports to illicit current trends in training and education models to facilitate spiritual care at the end of life.

2.2 Understanding Spirituality

Spiritual care at the end of life continues to be inadequately understood, and its delivery remains ambiguous and vague (Millison, 1995; Sinclair *et al.,* 2006). Spirituality is highly subjective, and thus it is difficult to create a one-dimensional definition that would be applicable to all people in all circumstances. There are many definitions of spirituality in the literature that add to the complexity of how to approach this topic (Puchalski, 2007).

The Association of Hospice and Palliative Care Chaplains of the UK (2004) use the following definition:

> ‘*Spirituality concerns all that makes for an individual’s existence as a person with all that implies of our capacity as human beings for self-transcendence, relationship, love, desire and creativity, altruism, self-sacrifice, faith and belief: it is the dynamic of integration towards a person’s unique identity and integrity*’ *(Association of Hospice & Palliative Care Chaplains, 2004).*

While definitions of spirituality vary, Speck (2005) described it as: '*a vital essence of our lives that often enables us to transcend our circumstances and find new meaning and purpose, and that can foster hope*'. In Puchalski’s (2007) work of developing courses for medical schools in spirituality and health, researchers took diverse definitions and attempted to create a definition that encompassed the complexity but allowed for practical application to the clinical setting. This definition states:

> *‘Spirituality is recognised as a factor that contributes to health in many persons. The concept of spirituality is found in all cultures and societies. It is expressed in an individual’s search for ultimate meaning through participation in religion and/or belief in God, family, naturalism, rationalism, humanism, and the arts. All of these factors can influence how patients and healthcare professionals perceive health and illness and how they interact with one another’* (Association of American Medical Colleges, 1999).

Koenig (2007) highlighted two difficulties encountered when defining spirituality. Firstly, atheists may have great meaning, purpose and high personal values in their lives and experience connectivity with others, yet deny being spiritual or religious. Secondly, defining spirituality as psychological well-being, associates it directly with mental health, making interpretation of the relationship between spirituality and health, especially mental health, impossible (Sartori, 2010*a*.). Edwards *et al.* (2010) found that spirituality was individual, unique, and personal, meaning different things to different people and changing through phases of life (Sinclair *et al.,* 2006; Boston & Mount 2006; Bush & Bruni, 2008; Bailey *et al.,* 2009). Spirituality was embedded in everyday and inner life, played out in daily interactions and used as a daily support. It was described as a search or quest for meaning and purpose and wrestling with meaninglessness could also give purpose for life (Sinclair *et al.,* 2006; Boston & Mount 2006; Bush & Bruni, 2008; Bailey *et al.,* 2009).

Considering the lack of agreement as to how spirituality is defined in healthcare, there is nonetheless a growing body of evidence advocating spiritual care (Speck *et al.,* 2004; Sinclair *et al.,* 2006). Spirituality and spiritual care are gaining increasing attention but their potential contribution to palliative care remains unclear. In a meta-study by Edwards *et al.* (2010), data from 178 patients and 116 healthcare providers were synthesised, aiming to bring more comprehensive insight and illumination to this complex area. Studies included covered the UK, USA, Australia, Taiwan, Japan, Ireland and Canada.

One US study describes how the influences of religious beliefs and practices at the EOL are under-investigated. Given nursing's advocacy role and the intimate and personal nature of the dimensions of religiosity and the end of life, exploring the multidimensional interplay of religiosity and EOL care is a significant aspect of the nurse-patient relationship and must be better understood. The question that must be faced is whether nurses' own belief systems impinge on or influence patient care, especially for patients who are at the end of life. When nurses understand their own beliefs and respect the religious practices and needs of patients and their families, it deepens the humanistic dimensions of the nurse-patient relationship (Bjarnason, 2009). However, this research focuses on religion, which the researcher criticises for two reasons; firstly there is a difference between religion and spirituality, and secondly one cannot assume that patients and/or families engage or believe in religious practices.

A recent UK study of 4,000 nurses identified that meeting patient's spiritual needs is extremely important and improves overall quality of nursing care. However, only 5% of respondents felt they achieved this goal (Funning, 2010). Although nurses appear to be aware of spiritual needs, a lack of clear definitions and practical guidance means that they are often uncertain about how these can be addressed as part of clinical care. This is supported by Balboni *et al*., (2007) who, in a study of 230 patients with advanced cancer from diverse ethnic backgrounds, found that 72% felt their spiritual needs were not, or were only minimally supported, by healthcare systems.

There is mounting evidence to show that spirituality and religion play a critical role in how patients cope with illness. In a meta-analysis of more than 1,200 published studies on religion, spirituality and health, substantial evidence was found to support the idea that spiritual and religious beliefs are used to cope with illness and result in positive outcomes (Koenig, 2001). Ultimately, administering good spiritual care has the dual effect of benefiting both patients and caregivers. Staff should understand their own spirituality if they are providing spiritual care. The goal of spiritual care should be to attain a sense of peace, contentment and develop a sense of purpose in life. Patients' state of mind and belief systems may change drastically as a result of their illness and/or deteriorating health (Sartori, 2010*b*.).

However, the role of spirituality is not restricted to end of life care; it is important and beneficial in a variety of clinical contexts including:

- treatment of depression (Wittink, 2009; Bekelman, 2007)
- arthritis (McCauley, 2008);
- chronic pain and fatigue (Baetz & Bowen, 2008);

- mental health (Wilding, 2007);
- medical patients including those with advanced cancer or chronic obstructive pulmonary disease (Steinhauser, 2006);
- hypertension (Gillum & Ingram, 2006);
- heart failure (Griffin, 2007).

Studies have indicated that the majority of patients view religion and spirituality as personally important and experience spiritual needs (Balboni *et al.,* 2007). The most important spiritual needs were identified as:

- respect for privacy, dignity and religious and cultural beliefs;
- taking time to give patients support and reassurance
- showing kindness, concern and cheerfulness when giving care
- allowing patients to discuss anxieties or fears (Funning, 2010).

Other studies have shown that patients in general want spiritual issues addressed, but particularly at the end of life or when facing a serious illness (McCord *et al.,* 2004). Saunders was a staunch advocate of spirituality as essential to the care of hospice patients, and spirituality has always been recognised as an important dimension of the hospice and palliative care model (Puchalski, 2007). Yet, a study by Balboni and colleagues showed that religious and spiritual care in cancer patients was not supported by the patients' religious communities or by the medical system (Balboni *et al.,* 2007). Despite the abatement of ritualistic religion, many people still consider spirituality as '*essential to their sense of self, especially at times of inner turbulence'* (Grant *et al.,* 2010, p.342).

2.3 Differentiating Spirituality and Religion

The term 'spirituality' is often associated with religion and, while they overlap and can interlink, the two are not synonymous. A person may be deeply spiritual but have no affiliation with any particular religion. Spirituality was seen to be a fundamental aspect of nursing and the majority of respondents believed that spiritual care also applied to atheists and agnostics (Balboni *et al.*, 2007). Spirituality is about meaning in life and relationships to others and can be expressed in many ways including music, art, nature, community or family. Religion may influence the development of such relationships or there may be no religious association (Sartori, 2010*a*.). This echoes Bailey *et al.'s* (2009) study, where a majority (75%) of respondents described spirituality as being separate to a belief in religion or transcendence. A significant number (85%) suggested that spirituality and religion are related, although views relating to the strength of the connection varied. For the majority of respondents (95%), the exercise of explaining their understanding of spirituality proved challenging, proposing that the reason for this challenge lay in the uniqueness and complexity of the concept of spirituality (Bailey *et al.,* 2009).

There is a diversity of opinion and lack of consensus on how people view the connection between religion and spirituality. One suggestion is to imagine spirituality as covering human dilemmas and needs; and religion as potentially catering for those dilemmas and providing methods for meeting those needs (Anandarajah, 2008). There appears to be a growing separation of the concepts of spirituality and religion (Tanyi, 2002). Spirituality includes religion, but those who do not identify with an institutional religion or denomination still have spiritual needs, i.e. '*the wish to find meaning in life and the need to feel a genuine connection to others*' (Wasner *et al.,* 2005, p.101).

Spiritual care does not promote religion or spiritual practices or enforce beliefs on patients (D'Souza, 2007); rather, it provides opportunities for patients to express their values and needs, and empowers them to deal with their illness. The spiritual needs of patients and caregivers may conflict and it is important that caregivers have an open mind and tolerance of others' views (Wilding, 2007). However, fears of imposing spirituality and causing distress have not proved founded (Pugh, 2010).

2.4 Recognising the Medical Model in End of Life Care

While science has enabled many significant advances in medicine, it does not have answers for the ultimate questions of life and the questions that many patients face at the end of life:

- What is the reason for suffering?
- Why do people die?
- Why did this illness happen to me?
- Who is God or the Divine?
- What is the value of my life?
- Where can I find hope?
- What is love? (Puchalski, 2007).

'I do not know,' the honest and most genuine answer to the questions presented above; is barely spoken as healthcare professionals scramble to get answers with expensive tests and life-prolonging solutions. It may be that acceptance of mystery, without proof and with dignity, may be the pinnacle of healing for many people—caregivers and patients alike. And this may be where spirituality and health has its strongest partnership—in the acceptance that we need not have all the answers and solutions, all the data and proof, and all the evidence that supports what many call basic excellence in practice: caring for patients with compassion, dignity, and respect (Puchalski, 2007).

The human predilection prefers to keep death at arm's length, but no amount of denial can change the inevitable. The Western perspective on death and dying is the direct result of a medical model that considers death to be the enemy. Our unqualified confidence in science creates the illusion that death is an option (Groves & Klauser, 2009, p.18). The more we are making advancements in science, the more we seem to fear and deny the reality of death (Kubler-Ross, 1969). The challenge is to strike a balance between the rewards of modern medicine and the human and spiritual context of illness. There is belief in our culture *'that every cause of death can be resisted, postponed or avoided*' (Clark, 2002; HfH Standards, 2010, p.13).

Hippocrates (ca. 460 – ca.377 BCE) stated '*it is better to know the patient who has the disease than it is to know the disease which the patient has'* (Ray, 2004). Of course, this is not to suggest that knowledge of the disease is not important. Nonetheless, today's healthcare settings can be cold, clinical and impersonal, making patients feel vulnerable and alienated. Holistic care provision at this juncture is both straightforward and extremely complex. It is therefore incumbent on healthcare professionals to bring their humanity to the provision of care. Elements include empathy, compassion, presence, attentive listening, and the reinforcement of realistic hope, all of which have been documented as vital components of spiritual care (OConnor, 1986). These fundamentals of spiritual care '*do not require doing, but rather being'* (Anandarajah, 2008, p.452). They advocate that healthcare professionals conduct their roles with integrity, humanity, genuineness, compassion and presence.

In all cultures, including Ireland, traditions and rituals exist around death and dying (Grant *et al.,* 2010). However, ancient traditions and rituals emerged from contexts and cultures in stark contrast to today's modern hospital environments, where 48% of people now die in acute hospitals and 23% in long stay facilities in Ireland (HfH, 2010). Although healing professions have affiliations with religious and spiritual heritage (Numbers & Amundsen, 1986), end-of-life care is often delivered in an abstruse scientific environment; which is a '*spiritually barren landscape'*

(Emaneul & Emaneul, 1998, p.27; Daaleman *et al.,* 2008). Halifax (2008, p.10) sums up our culture on death in the excerpt below:

> *'accepting impermanence and our mortality requires loosening the story knot; letting go of our concepts, ideas and expectations around how we think dying ought to be. Our own feelings can be powerful and disturbing as we sit quietly with a dying person, bear witness to the emotional outpouring of grieving relatives, or struggle to be fully present and stable as we face the fear and anger, sadness and confusion, of those whose lives are going through radical change'.*

Medical professionals or caregivers who are uncomfortable with the strong feelings stirred up in them by being with the dying, can distance themselves from the uncertainty of the situation, hide behind their role and treat the dying person as an inanimate object (Halifax, 2008). Pointedly, Kubler-Ross (2009, p.8) asks:

> '*is the reason for this increasingly mechanical, depersonalised approach our own defensiveness? Is this approach our own way to cope with and repress the anxieties that a terminally or critically ill patient evokes in us? Is our concentration on equipment, on blood pressure, our desperate attempt to deny the impending end, which is so frightening and disquieting to us that we displace all our knowledge onto machines, since they are less close to us than the suffering face of another human being, which would remind us once more of our lack of omnipotence, our own limitations and fallibility and, last but not least perhaps, our own mortality?*.'

2.5 Exploring the Role of the Multidisciplinary Team in Spiritual Care

For all patients, regardless of whether they have specific religious needs, spiritual care involves giving time and compassionate attention to them and their families. It may involve simply being with them and listening. When assessing spiritual needs, it is essential to take a genuine interest in the patient as a person, show concern and kindness, have empathy with them, take the time to listen and respect their point of view (Sartori, 2010*a*.). Myers (2009) suggested that spiritual care should be regarded as an important part of nursing care and that this need is more prominent in times of emotional stress, loss, bereavement and death. Articles in a recent meta-study (Edwards *et al.,*2010) started from a pre-supposition that terminal illness may increase awareness, questioning, searching for meaning, spirituality or religiosity (Wright, 2002; Murray *et al.,* 2004; Bush & Bruni, 2008; Bailey *et al.,* 2009; Shih *et al.,* 2009). Patients prefer to have scope and choice to refuse spiritual care, than not to be able to avail of it, and outlined barriers to spiritual care provision relating to hesitance to engage in '*spiritual talk'* and the necessity to address spiritual care outside explicit and specialist religious roles (Yardley *et al.,* 2009). The consequence may be that no one takes responsibility for initiating these discussions and '*the patient and family are left uncertain and confused*' (Barclay & Maher, 2010, p.345).

It is acknowledged that lack of time may limit opportunities to provide spiritual care (Daaleman, 2008). The hospital chaplain can offer support, but there are misconceptions about the role of the chaplain, it is not to evangelise, preach or convert, but a ministry of listening and presence (Sartori, 2010b.). According to one chaplain, if we acknowledge the true holistic approach, spiritual care should be recognised and hopefully provided not only by the chaplain but also the whole healthcare team (Griffin, 2010). Persons functioning in Hospice Palliative Care (HPC) specialist spiritual care roles in Canada are drawn from a diversity of mandates, academic qualifications, and training backgrounds (Cooper *et al.,* 2010).

Meador (2004) argues that optimal spiritual care is likely to be delivered in the same manner any type of best practice is, i.e. via teamwork and collaboration among multidisciplinary professionals caring for the patient (Grant *et al.,* 2010). It is therefore the obligation of all healthcare professionals to attend to patients' spiritual concerns, issues, and symptoms; but the chaplain is the recognised, credible spiritual care professional and the one that the team refers to for expertise in this area (Puchalski *et al.,* 2006). Acknowledging the intricacies of human suffering, multidisciplinary teams are best placed *'to provide appropriate therapeutic interventions'* (Anandarajah, 2008, p.456).

2.6 Realising the Financial Implications of Spiritual Care

With advances in medicine and health promotion, people now enjoy increased longevity, and given that deteriorating health increases with old age, older people are significant consumers of healthcare and *'the bulk of expenditure on healthcare will be required for the last year of life'* (HfH Standards, 2010, p.12).

As spiritual care becomes accepted as a planned element of the healthcare agenda, there is pressure for it to demonstrate its worth in ways that conform to services increasingly focused on efficiency and effectiveness (Slater, 2007). The same financial pressures stress palliative care services as the rest of healthcare—staff shortages, high turnover rates, the pressure to be strictly evidence based and time effective. Thus, when pressed for time, it can be easier to adjust pain medicines than to take the time to hold someone's pain (at a non-physical level) and listen to deep distress and hopelessness (Puchalski, 2007). Doctors seem to regard death as a failure, therefore in a doomed attempt to stave off the inevitable; typically more money is spent on healthcare during a patient's last year of life than in any other year (Delamothe *et al.,* 2010).

2.7 Initiating End-of-Life Discussions

Patients, their families and clinicians frequently collude to avoid mentioning death or dying, even when the patient's suffering is severe and prognosis is poor (Quill, 2000). While in some ways we are preoccupied and fascinated with death—with frequent reports of sudden, violent, and unexpected deaths portrayed in the media; we are nonetheless hesitant to talk about this absolute destination in terms that identify with our own mortality (Seymour *et al.,* 2010). Even if death is discussed, '*the language used is most often rooted in the discourse of individualism and control of personal destiny*' (Seymour *et al.,* 2010, p.347). A UK survey (2006) states that only 34% of people have talked to their loved ones about end of life issues (ICM, 2006). The most common rationale given by survey participants for this reluctance to talk about death and dying was that '*death seems a long way off*'.

When EOL discussions do take place, they often refrain from words such as or 'dying' 'death'; choosing instead to use euphemisms such as 'time is limited' that are somehow intended to lessen the impact, '*but may also confuse or mislead'* (Berry, 2008; Barclay & Maher, 2010, p.347). Discussions can therefore be postponed until the illness is more advanced and prognosis is more certain, and this deferment can be a common cause of late referrals to palliative care, emergency hospital admissions, and '*inappropriate interventions when crises develop*' (Christakis, 1998, p.76). The literature cites a lack of authenticity about death leading to negative repercussions for the quality of EOL care provided (Seymour *et al.,* 2010). Conversely, studies of the *Gold Standards Framework for Palliative Care* encourage timely end of life discussions in order to initiate care pathways correlated with improvements in care (Dale *et al.,* 2009). In addition to helping patients feel better, function better and experience fewer psychological symptoms (Ray, 2004), critically reflexive end-of-life discussions may also transform the physician (Brenton, 2005). Research has highlighted how physicians who cared for AIDS patients approaching EOL have been moved to write about the personally transforming experience (Selwyn & Forstein, 2003).

End of life conversations are frequently associated with the cessation of active treatment and impending death. However, according to Barclay and Maher (2010), such discontinuation of treatment takes place *'far too late for effective end of life care planning to happen, if it takes place at all'* (Barclay & Maher, 2010, p.345). Healthcare professionals ought to create and support repeated opportunities for patients to discuss end of life care issues, prompted by the patient as to content, pace and timing of such discussions (Barclay & Maher, 2010). However, not all patients will want to discuss EOL related issues, and this must be respected by healthcare providers; but research demonstrates that others may benefit greatly from such open communication (Barclay & Maher, 2010).

2.8 Facilitating Spiritual Care

A number of facilitators of spiritual care were consistent in the literature, namely adequate time, being present, recognising the role of narrative and communication skills. They will now be presented in this section.

2.8.1 A Question of Timing

That we will sooner or later die is a certainty familiar to most adults. However, developing personal meaning around this fate is far more complex. A patient's physical, cognitive and emotional extinction is explicitly wound into the mercy of time. The art of dialogue can shape meaning around a patient's remaining time (Brenton, 2005). For dying patients, making meaning is ranked among the top attributes of *a good death* (Daaleman & VandeCreek, 2000; Block, 2001). Nevertheless, end-of-life discussions, the central forum for constructing meaning, are frequently initiated late, poorly, or not at all (Finucane, 1999).

The concept of 'busyness' merits further reflection, because of the need to reconcile the apparently conflicting demands of doing what needs to be done, while maintaining a caring disposition towards what is being done (McKeown, 2010). The words of Elizabeth Kubler-Ross (1926-2004) in her book, *On Death and Dying*, are worth recalling in this context:

> ‘*when a patient is severely ill…he may cry out for rest, peace, dignity, but he will get infusions, transfusions, a heart machine or a tracheostomy. He may want one single person to stop for one single moment so that he can ask one single question – but he will get a dozen people round the clock, all busily preoccupied with his heart rate, pulse, electrocardiogram or pulmonary functions, his secretions or excretions, but not with him as a human being.*’ (Kubler-Ross, 2009, p.7).

Ample, unconstrained quality time to listen was imperative to the provision of spiritual care while lack of time was a barrier (Sinclair *et al.,* 2006; Boston & Mount 2006; Bush & Bruni, 2008; Bailey *et al.,* 2009; Edwards *et al.,* 2010). Foster and Hawkins (2004) state that patients today spend shorter periods of time in hospital than they did in the past, thereby reducing the opportunity to have time to establish, develop and maintain strong therapeutic relationships. The time available for staff to develop an optimal patient relationship is short and must be used as productively and effectively as possible (Kemp & Wells, 2009). Acute admissions to hospital often meant spiritual needs went unrecognised (Murray *et al.,* 2004). This phenomenon has created a need to work rapidly to engage effectively with patients. In a more recent study, time was reported as a significant and elusive element to the provision of spiritual care (Bailey *et al.,* 2009).

2.8.2 Being Present

Being present is a consistent theme in the literature, defined as a

> ‘*shared encounter or encounters marked by intentionality or the deliberate ideation and purposeful action of care that went beyond medical treatment, giving attention to emotional, social, and spiritual needs*’ (Daaleman *et al.,* 2008, p.500).

Participants in a recent Irish study Bailey *et al.* (2009, p.46), outline the formation of a ‘*spiritual tapestry that weaves together care and compassion’* with competence and knowledge. Presence, according to Puchalski *et al*. (2006), includes openness, ‘*connection with others, and comfort with uncertainty*’ (Puchalski *et al.,* 2006, p.393). Being present, a tangible sense of ‘being there’

(Wright, 2002), and willingness to ‘share the self,’ are also critical components of spiritual care (Taylor *et al.,* 1994). Spiritual care is about being ‘present’, journeying with or going through the process together and may involve accompanying patients into areas of darkness or pain (Sinclair *et al.,* 2006; Boston & Mount 2006; Bush & Bruni, 2008; Bailey *et al.,* 2009; Edwards *et al.,* 2010).

The basics of spiritual care is that all people, regardless of their physical or mental abilities and regardless of their ability to think clearly or function actively, have an inherent value and dignity that must be honored and respected. Patients want and need more than the technical aspects of medical care; they need love and concern, and this is what spiritual care is grounded on. Therefore, integral to spiritual care is being present to patients in a compassionate and attentive way—present to their suffering, their being, and their journey throughout their illness (Puchalski, 2007).

In a recent Irish study, (Bailey *et al.,* 2009), 75% of respondents articulated that spirituality was a key attribute of nursing care. The importance of making a personal connection was expressed by 55% of participants. 77% of respondents emphasised that ‘being with’ the patient on his or her journey was a significant aspect of spiritual care; which included descriptions of ‘being there’, ‘being with’, ‘giving hope’ and ‘spending time’. Breitbart (2009, p.142), noted that palliative care based on spiritual attentiveness gives the patient and caregiver permission ‘*to give up illusions of therapeutic entitlement to cure’*, whilst concurrently fostering profound care and attention to the person (Grant *et al.,* 2010, p.658). While carers have sought a tool to assist in the provision of spiritual care, patients emphasise that such care is more about being heard, ‘*and about people relating to their essential ‘inner self’ rather than their weakening physical ‘outer self*’’ (Sweeney *et al.,* 2009, p.2863).

2.8.3 Recognising the Role of Narrative

Daaleman *et al.,* (2008, p.408) suggest the need for healthcare professionals to acknowledge the patients' '*unique experience of their illness and their life story'*. Concepts of spirituality are related to stories about the whole of life, giving thanks for life, relationships with self and others, relationships with nature and music, and with God or a higher being, hope, meaning and purpose in life, and the relationship of spirituality and religion (Edwards *et al.,* 2010). Spiritual care is about actively listening to someone's story and involves effective, sensitive communication (Sinclair *et al.,* 2006; Boston & Mount 2006; Bush & Bruni, 2008; Bailey *et al.,* 2009; Edwards *et al.,* 2010). Spiritual care involves a genuine desire to understand, reaching into patients' space, getting to know them (Bailey *et al.,* 2009; Edwards *et al.,* 2010).

In some studies, instead of defining spirituality, patients told life stories reflecting and revealing their spirituality (Hermann, 2001; McGrath, 2003; Shih *et al.,* 2009). There emerged a need for closure, to finish business or 'illness work'. It was important to feel ready to leave without regrets; patients showed regret when they talked of things that remained undone (Shih *et al.,* 2009). There was a need for reconciliation, to forgive and be forgiven in order to find peace before dying (Murray *et al.,* 2004; Shih et al 2009). There was a need for reminiscence and life review; most patients talked about their lives at length, wanted to discuss their past, trying to make sense of why things happened (Stephenson *et al.,* 2003; Murray *et al.,* 2004; Tan *et al.,* 2005).

The use of narratives, including physician's and patients' stories, literature and film, is increasingly popular in medical education. There is, however, a need for an overarching conceptual framework to guide these efforts, which are often dismissed as 'soft' and placed at the margins of medical school curricula (Kumagai, 2008). Transformative learning may be the teaching philosophy to change, or at least challenge, this perception.

2.8.4 Communicating

Research suggests that optimal communication is fundamental to how healthcare providers collect and interpret information, and how this knowledge is subsequently relayed to patients and their loved ones (Daaleman *et al.,* 2008). Patients and families who were satisfied that their spiritual needs were addressed, refer to the sensitivity and understanding demonstrated by caregivers in respecting them and listening to them attentively (Grant *et al.,* 2010). Spiritual care communication also involves physical proximity, touch, massage, or simply just sitting with, holding the patient's hand when there was nothing to say; transcending explicit modes of communication (Bush & Bruni, 2008; Bailey *et al.,* 2009; Edwards *et al.,* 2010).

2.9 Recognising Spiritual Distress

According to the literature, spiritual distress manifested as fear, insecurity and nervousness. Fear of death precipitated anxiety and panic attacks. Fear of the unknown and a sense of uncertainty could be overwhelming (Shih *et al.,* 2009; Edwards *et al.,* 2010). Being able to talk about death and a belief in the afterlife were comforting and protected against fear of death (Tan *et al.,* 2005). Spiritual distress and clinical depression were sometimes difficult to differentiate (Grant *et al.,* 2004). Patients felt angry, cynical and bitter (McGrath, 2003), of not being able to find peace, feeling impatient, irritable and restless, with a sense of frustration and unjustness (McGrath, 2003; Kawa *et al.,* 2003). Some felt guilty, blamed themselves and spoke of feeling punished or judged (Grant *et al.,* 2004). Spiritual distress was sometimes caused by loss or expressed as feelings of loss. Losses could be broadly distinguished as losses of self or relationships or meaning (Edwards *et al.,* 2010).

Unmet spiritual needs could give rise to spiritual distress, which could worsen physical and emotional symptoms, or present as physical discomfort used to legitimise increased health service utilisation (Grant *et al.,* 2004). Isolated symptomatic treatment, without care for the underlying spiritual distress, would in turn lead to disempowerment, reducing patients' sense of control, and further unmet needs in a vicious circle (Edwards *et al.,* 2010). In providing whole-person or patient-centered care, there is recognition that all of the four dimensions—physical, emotional, social, spiritual—are intertwined, and how a person is doing in one dimension can affect other dimensions as well. Therefore, spiritual distress can impact physical pain and emotional angst (Puchalski, 2007). Patient and healthcare giver studies identified how spiritual distress was mixed with and impinged on physical, psychological, social and financial distress, and was hard to distinguish, even by experienced palliative care providers (Boston & Mount, 2006). Supporting people through expression of fears and concerns may assist them in their search for meaning and purpose and thereby prevent spiritual issues '*escalating into disabling distress'* (Grant *et al.,* 2010, p.659).

Conversely, ongoing spiritual concerns that remain unresolved, can negatively impact *'a person's sense of wellbeing and their ability to cope with pain and suffering'* (Grant *et al.,* 2004, p.375). Spiritual distress has been verified as a potential contributor to depression and end of life hopelessness (Kissane, 2001; Lloyd-Williams, 2003). As healthcare professionals, we are in a profound and privileged position to listen, hear and respond appropriately to patients at the most brittle and vulnerable times in their lives; including the cathartic expression of spiritual concerns (Puchalski, 2004; Grant *et al.,* 2010).

People often find it difficult to define or verbalise their spiritual needs. There is a perceived '*loss of a spiritual language coupled with the tension of traversing two different discourses—medical and spiritual'* which can ultimately result in spiritual distress. This distress can lead to a decreased ability to cope with other symptoms, such as pain, nausea and insomnia (Grant *et al.,* 2010, p.659). In such scenarios, care providers may resort to management of physical symptoms by, for example, prescribing medication (Grant *et al.,* 2010). The UK General Medical Council (GMC, 2009), states that

> '*doctors should be able to diagnose spiritual distress, yet fear of causing offence, of misunderstanding, or of crossing unspoken cultural barriers, along with a lack of training and knowledge, can lead to freezing of action'* (Sheikh *et al.,* 2008; Worth *et al.,* 2009, p184).

2.10 Conducting Spiritual Health Assessment

Some studies advocate the inclusion of a spiritual assessment as an integral part of history-taking that all healthcare professionals do routinely (see Appendix V - Spiritual Health Assessment). This assessment may help initiate discussion pertaining to spiritual values and beliefs and enable healthcare professionals to integrate the information into the subsequent plan of care (Puchalski, 2007). However, there are complexities in assessing spiritual needs as spiritual care incorporates intangible, immeasurable qualities (Boston & Mount 2006; Bailey *et al.,* 2009). Some felt assessment should be open-ended and exploratory, while some questioned whether spirituality could be assessed at all (Sinclair *et al.,* 2006; Boston & Mount 2006; Bailey *et al.,* 2009, Edwards *et al.,* 2010). Holistic assessment should address patients' physical needs and any issues relating to their psychological and spiritual needs (Hayes, 2010). However, Wasner *et al.,* (2005) warn that '*every attempt to measure a highly subjective concept such as spiritual well-being will fall short to some extent'* (p.102).

McCavery (1985) rightly espouses that spiritual assessment and care are subjective and that success revolves around individual relationships and trust. This requirement for personal interaction and personal and professional intuition within the spiritual assessment process, in order to ensure the process is a living and therapeutic interaction, can be negated by the sterility and interrogation that can result as part of form completion (Hickey *et al.,* 2008). By its very nature, caring for an individual's spiritual dimension is complex and cannot easily be measured in quantifiable terms (McSherry & Ross, 2002). In Bailey *et al.'s* (2009) study, participants questioned the practice of assessing and measuring spiritual needs, concerned that in so doing they may reduce the concept to a series of tick boxes and in the process lose the individuality that palliative care seeks to support (Bailey *et al.,* 2009).

2.11 Minimising Barriers to Spiritual Care

Spiritual care is supported by ample time to engage in dialogue, healthcare-giver awareness and reflection, education, training, experience, willingness and team collaboration. In contrast, lack of time; institutional, personal, language, cultural and religious barriers impede spiritual care (Edwards *et al.,* 2010). Barriers identified in the literature include '*the lack of a common language for spirituality, as well as concern regarding boundaries, ethics, and cultural and religious differences'* (Ellis *et al.,* 1999; Koenig, 2004, p.1196).

In practice, spiritual needs should be given equal and sometimes greater precedence than physical needs, but according to Sartori (2010b.) this may not occur for a number of reasons including time constraints, excessive workloads, clashes of beliefs between caregiver and patient, lack of confidence and experience of caregivers, lack of continuity of care and lack of privacy (Daaleman, 2008). Nonetheless, according to Saunders, English pioneer and physician of the modern hospice movement, spiritual care is not an optional extra for the dying (Groves & Klauser, 2009).

2.12 Facilitating Spiritual Healing

Spiritual healing is not a cure or remedy, but '*a movement from the chaos often associated with illness and crisis to a place of groundedness and peace within that chaos'* (Puchalski, 2007, p.38). It is described as a transformation in '*facing death and seeing oneself and others in a new and perhaps deeper light'* (Puchalski, 2007, p.38). Spiritual healing may be viewed as a process of movement on the continuum toward a sense of integrity and wholeness and away from anguish and suffering (Boston & Mount, 2006).

Healing can occur if healthcare professionals provide the opportunity and resources for patients to verbalise their despair, hopes, fears, and issues of meaning, connection, and dignity, and if they provide resources for patients to resolve these issues and come to some understanding of who they are in the midst of their dying. These resources might be referral to a chaplain, pastoral counselor, or spiritual director, encouraging the patients to journal or write about their feelings and experiences, or providing religious readings, sacraments, or rituals to the patient if desired by the patient and/or family (Puchalski, 2007).

2.13 Training and Education in End-of-Life Care

The literature suggests that there is a dearth in EOL care training and education, with many professionals feeling inadequately prepared for this core clinical activity; both during their initial training and on a post graduate or in-service level (Ellershaw *et al.,* 2010). Nurse educators have identified that historically nurses have not been prepared to care for dying patients. Research has also identified that nursing students have anxieties about death, dying and caring for dying patients (Mallory, 2003). Evidence suggests that acknowledgement of professional ambiguity regarding spirituality and spiritual care has not led to the expected review and development of training (Vivat, 2008). Results of this US study indicate that education can have a positive effect on nursing students' attitudes toward care of the dying. Nursing students in the intervention group had a significant positive increase in their attitudes towards EOL care following the intervention, using experiential and TL theory (Vivat, 2008).

Today, the majority of medical schools teach courses on spirituality and health because of the recognition that spirituality is fundamental to healthcare, to the patients' stories, and to the impact on healthcare decision making and coping (Puchalski, 2007). However, formal spiritual care training and education were rare and were noted by some to impede spiritual care (Sinclair *et al.,* 2006; Bush & Bruni, 2008). While training staff to recognise spiritual issues and the needs of religious groups was viewed as important (Wright, 2002); those with less education, such as domestic staff, might sometimes be best at giving spiritual care (Wright, 2002; Harrington, 2006). Marr *et al*. (2007) claim that spirituality is a major domain of palliative medicine training; yet no data exist on how it is taught, nor is there consensus about the content and methods of such education. The authors suggest this statement equally applies to all similar education for other professionals and that promoting access to this type of education remains difficult (Hickey *et al.,* 2008).

It is evident that patients value integration of their spiritual needs by healthcare professionals, especially in times of serious illness (Ehman *et al.,* 1999). Sadly however, it is believed that '*60% to 80% of the time these needs for greater spiritual care go unrecognised, unmet, or only minimally addressed'* (Balboni *et al.,* 2007, p.558; Feudtner *et al.,* 2003). For many, this new discourse of '*greater relational and moral engagement with patients and families, including demands to integrate spiritual care, can be fraught with resistance, trepidation, and ill-preparedness'* (Browning, 2003; Robinson *et al.,* 2007, p.25). Kuczewski (2007) suggests healthcare providers must receive adequate training, support and practice, to act as spiritual care generalists (Robinson *et al.,* 2007).

Conversations between physicians and their patients concerning terminal conditions are undoubtedly an uneasy process. These conversations are referred in one study as 'death-talks' (Moon, 2008). 'Death-talks' are social engagements among meaning-making human beings, and such encounters comprise complex grief dynamics as well as opportunities for personal insight. Towards preparing for and improving upon such sensitive and crucial talks, physicians must become growingly informed of their own existential standpoints in order to exude a more authentic presence. Transformative learning is a theory of adult learning offering a rationale for physicians to exercise critically reflexive learning towards formulating a more meaningful medical and human care for those who are dying and their grieving relations (Moon, 2008).

While there is a surfeit of literature on spirituality, the evidence indicates that spiritual issues are not adequately addressed in clinical practice; yet, studies by Grey (1994); and McSherry (2000), showed that the majority of patients felt their spirituality positively contributed to their ability to cope. The respondents also felt that anyone involved in direct or indirect care delivery should hold recognition of the importance of each person's spirituality in relation to service delivery and their own personal development (Hickey *et al.,* 2008). There is increased recognition of the importance of raising awareness of the spiritual dimension of patient care and introducing programmes that support this (Drijfhout and Baldry, 2007).

Baldacchino (2011) studied the perceived impact on staff having completed a study unit on spiritual care, and suggests that the paucity of literature demonstrates some benefits perceived by the learners namely, clarification of the concepts of spirituality and spiritual care, self-awareness of personal spirituality and their current clinical practice which neglects the spiritual dimension. Recommendations were proposed to integrate the spiritual dimension in education and patient care (Baldacchino, 2011). In healthcare we see people at the best and worst times of their lives, at a time when the greatest questions of life are asked. However, for staff dealing with matters of spirituality or faith, it can be a daunting or unsettling experience (Kemp & Wells, 2009).

2.14 Utilising Transformative Learning in End-of-Life Care

From conducting the literature review, it seems most research on transformative learning (TL) and end of life (EOL) care are at undergraduate level, and focusing on homogenous groups of healthcare professionals, either student nurses or medical students. Cranton and King (2003) noted that the basic concept at the heart of TL is that learners develop their understanding of the world through experiences (Parker & Myrick, 2010). Mezirow is considered the creator and predominant scholar regarding the theory of transformative learning (Imel, 1998; Whitelaw *et al.,* 2004). Mezirow's TL theory has developed into '*a comprehensive and complex description of how learners construe, validate, and reformulate the meaning of their experience'* (Cranton, 1994, p.22).

The key for Mezirow is that people faced with disorientating dilemmas use reflection to alter their frames of reference, thereby altering the way they interpret and interact with others (Cranton, 1996; Mezirow, 1998; Whitelaw *et al.,* 2004). There is more to transformative learning than a cognitive rational process of reflection; the soul of the learner must be nurtured in order to reach deeper levels of change and development (Dirkx, 2006). This is also supported by Dirkx (2000; 2006, p.127), who suggests that a holistic approach recognises '*the role of feelings, other ways of knowing (intuition, somatic), and the role of relationships'*, inviting the whole person into the classroom. Marrocco (2009), in his review of Cranton's book, *Understanding and Promoting Transformative Learning: A Guide for Educators of Adults (2006)* refers to the role of imagination and spirituality in transformation.

Transformative learning (TL) theory derives from the premise that today's adult learner needs to develop the ability to become an independent autonomous thinker (Imel, 1998; Mezirow, 1997). Engaging learners in their own self-regulated learning is imperative for education in the 21st century according to Brown *et al.,* (2009), in their global study of 946 nurse educators. Transformative learning has become very popular and widely used in both nursing and medical education. There have been a number of recent studies in nursing (Smith-Stoner & Hand, 2008; Parker & Myrick, 2010; Ruth-Sahd *et al.,* 2010; Matthew-Maich *et al.,* 2010; Faulk *et al.,* 2010; Story & Butts, 2010); and in medicine (Moon, 2008; Kumagai, 2008; OConnell, 2010; Wittich *et al.,* 2010; Mueller *et al.,* 2010).

Cranton (2006) suggests that to enhance our personal and professional development, we need to do what we ask our learners to do – question our assumptions and thereby open ourselves to transformation, and she makes frequent references to works by Parker Palmer (1998; 2004). Both Cranton and Palmer invite us, as educators, to 'allow the soul speak', to become increasingly authentic in our vocation and increasingly effective as facilitators of transformation in those with whom we continue to learn (Marrocco, 2009). Palmer's book, *A Hidden Wholeness*, (2007) forms the basis for the '*Circle of Trust'* study groups in the *SALAD* programme being researched.

A number of international studies, which will now be discussed, have been done using aspects of transformative learning in end-of-life care and healthcare in general (Hesselink *et al.,* 2010; McAllister *et al.,* 2007; Matthew-Maich *et al.*, 2010); but to date there are no such studies undertaken or published in Ireland. By subscribing to a TL framework, caregivers may be better equipped to keep their own values in check, while allowing the values of diverse patients to permeate and enrich the personal meaning of each prognosis. A TL framework invites an exploration of cultural differences and allows deeply engrained values, such as spiritual commitment to inform personal meaning (Brenton, 2005). TL theory invites us to consider the power of patient belief systems through critical reflection and cultivate a spirit of co-inquiry into guarded assumptions regarding death.

A study in The Netherlands, (Hesselink *et al.,* 2010), suggests that more attention can and should be paid to education on end-of-life (EOL) care in the medical curriculum. In New Zealand, MacLeod *et al.* (2003), assert that the nature of medical care provision at the end of life and, in particular, the way in which caring is learned remain problematic for medical educators and the profession. The students in this study produced a portfolio assignment, including personal reflections on experience, utilising a phenomenological methodology. The way in which many of the participants approach EOL care has been altered through a transformative educational experience that encouraged them to draw on their own experiences and skills. An Australian study argues the benefits of TL and outline specific skills in transformative education to address some common problems faced by clinical educators and nursing students in the time-constrained, complex and specialised field of clinical learning (McAllister *et al.,* 2007). They advocate '*moving beyond unwittingly serving the status quo*' toward consciously contributing to change.

A national survey was conducted in Japan to examine how programmes to teach end-of-life care to medical students influence their death attitude (Hirakawa *et al.,* 2007). Overall, 1,510 students (67.4%) from 16 medical schools participated by completing a questionnaire. Results suggested that improving end-of-life care education is needed to mould the attitude of medical students to death. However, the study did not suggest educational methods to facilitate improving EOL education. The need for educators to continue to investigate and systematically evaluate outcomes associated with EOL education initiatives is echoed by a US study (Schlairet, 2009). Schlairet suggests persistent deficiencies in EOL nursing care practice and the education to support that care.

In a recent international evidence-based publication, Matthew-Maich *et al.* (2010), suggest that transformation theory offers an explanatory theory and specific strategies (critical reflection and critical discourse) to explore attitudes, beliefs and behaviours; so that they are understood, validated and can better guide actions. TL strategies can facilitate insight into experiences, finding shared meanings among groups of people, and understanding/validating beliefs, attitudes and feelings so they can more consciously guide future actions. The authors go as far as stating that TL may be the missing link to make research utilisation initiatives more effective in rendering and sustaining nursing practice change, thus enhancing client care and well-being.

In a Finnish study, (Liimatainen *et al.,* 2001), student nurses at undergraduate level utilised TL theory to develop reflective learning in the context of health counselling and health promotion. The data consisted of stimulated recall interviews with 16 students conducted once a year between 1998 and 2000. The interviews were videotaped, and questions were open-ended and based on John's (1994) model of structured reflection. Data were analysed using categorisation and thematic analysis. However, this is a small sample size at undergraduate level and the results may not be transferrable to a multidisciplinary team.

2.15 Conclusion

This concludes the literature review, which focused on both the concepts in the research statement, i.e. spirituality and transformative learning; and investigating how the processes of TL could be integrated into EOL spiritual care training and education. Given that there is an abundance of literature, nonetheless there was a paucity of studies encompassing both TL and spirituality in end of life care. The major themes arising were: understanding spirituality; differentiating it from the concept of religion; recognising the medical model in EOL care, exploring the role of the multidisciplinary team; realising the financial implications of spiritual care; initiating EOL conversations; facilitating spiritual care, recognising potential barriers and spiritual distress; conducting spiritual health assessment; facilitating spiritual healing, and finally training and education in EOL spiritual care and how TL could be utilised to inform EOL care training programmes. Chapter 3 – Methodology will follow, outlining the methods of data collection and analysis, in addition to ethical considerations.