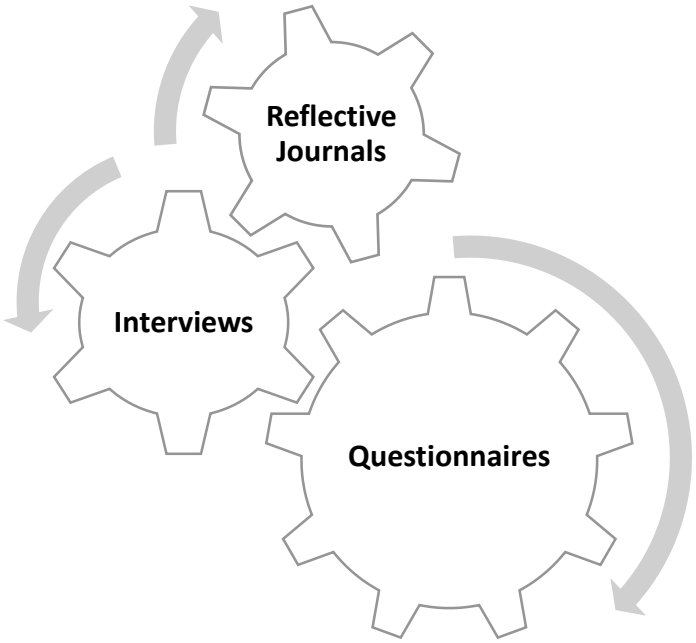
Chapter 4 - Findings and Discussion

4.1 Introduction

This chapter presents and discusses the results from the data analysis of participants on the *Sacred Art of Living and Dying (SALAD) – Healing Anamcara Programme* who took part in the research. The demographic detail of questionnaire respondents will be outlined, followed by detailed findings and discussion from the questionnaires, interviews, researcher's memos and reflective journals. The chapter will be presented under the headings of the three emergent concepts, i.e. perceiving spiritual care, transforming practice settings and integrating learning to life. Following the discussion of the concepts, the overarching theory will be deduced and the chapter will be concluded.

Data were collected via seven reflective journals, forty-seven questionnaires and four interviews, as demonstrated in Figure 5. The findings presented are inclusive of all data sources, including memos kept informally by the researcher.

Figure 5: Data Collection Methods



4.1.1 Questionnaire Data

The following tables outline the demographic details of questionnaire respondents, and figures to support the tables are included in Appendix XIII - Figures of Questionnaire Respondent Demographics.

Table 2: Questionnaire Respondents by Occupation	**No.**
Doctor	2
Nurse	7
Nurse (Hospice)	5
Social Worker	2
Psychotherapist	8
Occupational Therapist	1
Manager	4
Manager (Non-Healthcare)	1
Clerical / Administration	2
Cognitive Behavioural Therapist	1
Education	6
Community Development Worker	1
Spiritual Director	3
Agriculture & Environment Consultant	1
Hairdresser	1
Hospice Volunteer	1
Director of Nursing (Specialist Palliative Care)	1
Total	**47**

Table 3: Questionnaire Respondents by Gender	**No.**
Male	2
Female	45
Total	**47**

Table 4: Questionnaire Respondents by Current Employment	**No.**
Hospital (Acute)	3
Hospital (Community)	3
Hospice	7
Integrated Service Area (ISA – Community)	17
Non-Healthcare	4
Retired	3
Not in Paid Employment	5
University	1
Self-Employed	3
Parish Ministry	1
Total	**47**

Table 5: Questionnaire Respondents Units of SALAD Attended	**No.**
One	5
Two	5
Three	37
Total	**47**

Table 6: Directly Involved in Provision of End of Life Care	**No.**

Yes	21
No	26
Total	**47**

Table 7: Satisfaction with Content	**No.**
Excellent	40
Good	7
Fair	0
Poor	0
Total	**47**

Table 8: Satisfaction with Organisation	**No.**
Excellent	43
Good	4
Fair	0
Poor	0
Total	**47**

Table 9: Satisfaction with Delivery	**No.**
Excellent	43
Good	3
Fair	1
Poor	0
Total	**47**

Table 10: Satisfaction with Participant Focus	**No.**
Excellent	30
Good	15
Fair	1
Poor	1
Total	**47**

Table 11: Satisfaction with Reflection	**No.**
Excellent	28
Good	17
Fair	2
Poor	0
Total	**47**

Table 12: Satisfaction with Relevance	**No.**
Excellent	38
Good	7
Fair	2
Poor	0
Total	**47**

Table 13: Satisfaction with Self-Awareness	**No.**
Excellent	32
Good	11
Fair	4
Poor	0
Total	**47**

Table 14: Satisfaction with Self-Growth	**No.**
Excellent	34
Good	9
Fair	4
Poor	0
Total	**47**

Table 15: Satisfaction with Motivation	**No.**
Excellent	36
Good	8
Fair	3
Poor	0
Total	**47**

Table 16: Satisfaction with Transformation	No.
Excellent	29
Good	15
Fair	3
Poor	0
Total	**47**

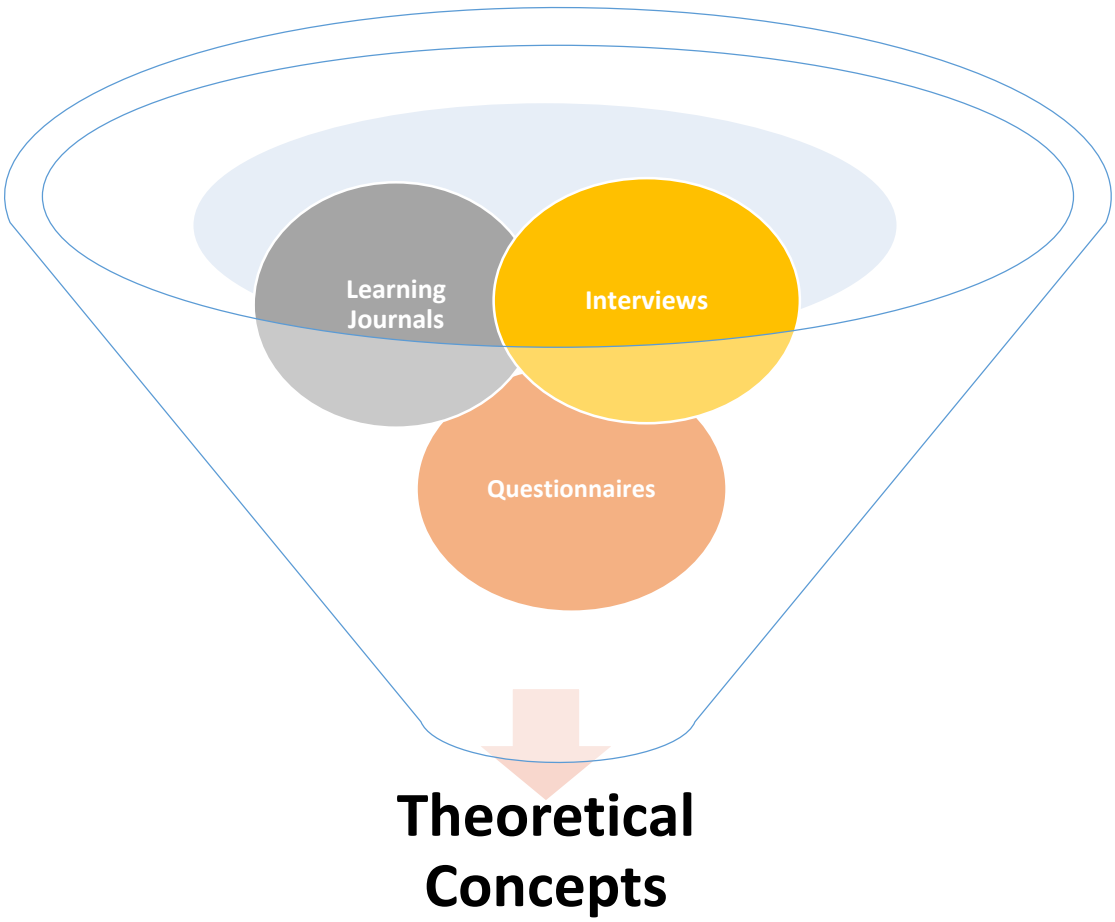
Table 17: Impacted Awareness of Spirituality	No.
Yes	46
No	1
Total	**47**

4.1.2 Grounded Theory Analysis

Congruent with the grounded theory approach, the theory was allowed to emerge from the data. Three methods were utilised (Figure 6: Emergence of Concepts), questionnaires, interviews and reflective journals. The methods used are outlined in Chapter 3 – Methodology. The findings presented are inclusive of all data and they will be discussed in detail in this chapter. Sample quotes are included to amplify the meaning of the relevant findings. Table 18 outlines the key to respondent's direct quotes. The findings and discussion will interlink with Chapter 2 – Literature Review, although the literature was not consulted in detail prior to data analysis, in keeping with the principles of grounded theory, as outlined in Chapter 2 – Literature Review.

Table 18: Key to Respondent Quotes	
Interview 1 Nurse (Hospice Based)	IR1NH
Interview 2 Social Worker	IR2SW
Interview 3 Psychotherapist	IR3P
Interview 4 Educationalist	IR4E
Questionnaires	QR1 - 47
Reflective Journals	RJ1-7

Figure 6: Emergence of Concepts



The three major theoretical concepts, including the sub-categories, which emerged following the data analysis, are as follows:

1. **<u>Perceiving Spiritual Care</u>**
    - Reflecting
        - Connecting through *Circle of Trust* study groups
    - Enhancing self-awareness
    - Differentiating spirituality from religion
    - Trusting the learning environment

2. **Transforming Practice Settings**
    - Contributing to multidisciplinary settings
    - Impacting practice
        - Referring to the medical model
        - Conducting end of life conversations
    - Using spiritual health assessment
    - Acknowledging challenges to spiritual care
    - Identifying need for educational programmes in spiritual care

3. **Integrating Learning to Life**
    - Awakening
    - Transforming
    - Relating with self and others

Each of these concepts and sub-categories will now be discussed in detail.

4.2 Perceiving Spiritual Care

Bradley and Postlethwaite (2003) posited that it is vital for educators to use educational theory in guiding learners toward self-reflective practice. Reflection imbued with theory and turned inward on educators aids in our understanding of not only how learners might act differently after perspective transformation, but also in how learners might think differently during the next clinical scenario (Bradley & Postlethwaite, 2003). Transformative learning (TL) theory with a foundation in reflection has the potential to guide educators in the creation of powerful learning experiences that can transform learner assumptions, values, and beliefs about the world (Parker & Myrick, 2010). TL theory provides educators with the tools to empower learners to challenge their preconceived beliefs, assumptions, and values and socialise them appropriately to thrive in modern day clinical practice, providing scenarios that provide learners with disorientating dilemmas for perspective transformation (Parker & Myrick, 2010).

The goal of professional development is improved practice through change – changes in ways of doing and thinking about one's work. Respondents stated overwhelmingly that their thinking about, and perception of, spiritual care had been transformed by their participation in the programme. This altered perception was enabled by aspects such as reflection, self-awareness exercises, peer learning, small group discussions and transformative learning strategies. It was also facilitated by the programme being multidisciplinary, therefore providing a multi-perspective approach to learning. This section will analyse research findings and discuss the emergence of sub-categories of reflecting, enhancing self-awareness, differentiating between spirituality and religion; and trusting the learning environment (Figure 7: Perceiving Spiritual Care).

Figure 7: Perceiving Spiritual Care

4.2.1 Reflecting

Respondents spoke at length about reflecting and the central role it plays in their learning and transformed perspectives. In his book (2004, p.4), *Becoming a Reflective Practitioner*, Johns states that reflection is when *'the practitioner can gain new insights into self and be empowered to respond more congruently in future situations within a reflexive spiral towards realising one's vision as a lived reality'*. He talks about the idea of a window to look inside at self, to understand thinking (head), feeling (heart) and responding (hand) to situations, and also use a window to look out at practice. There is a beautiful complexity of growth through reflection (Johns, 2004, p.5). I agree with extending 'window' as metaphor, as ODonoghue (1997, p.163) notes the way:

'many people remain trapped at the one window, looking out every day at the same scene in the same way. Real growth is experienced when you draw back from that one window, turn and walk around the inner tower of the soul and see all the different windows that await your gaze. Through these different windows, you can see new vistas of possibility, presence and creativity. Complacency, habit and blindness often prevent you from feeling your life. So much depends on the frame of vision – the window through which we look'.

Quotes from respondents illustrate reflection:

I can't overemphasise the importance of this work and reflecting on oneself to start with…it's as simple as holding up a mirror to oneself (IR1NH)

… I'd forgotten how to be that still and really listen to myself.., to really reflect on how I was feeling… 'pura vida' (how am I within?) (IR2SW)

it (the programme) has helped me to look critically and deeply within myself, and … to date has enriched me as a person (QR33)

Respondents echo dimensions of reflecting in their quotes, by engaging in self-reflection and looking critically at oneself, the result is personally enriching. Although several contested meanings of reflection exist, Brenton (2005) adheres to the tradition of *pragmatist constructivism,* in which reflection refers to helping people examine assumptions in order to construct and deconstruct personal experiences and meanings (Wilson, 2000). This view is supported by Daaleman *et al.,* (2008) who reported that participants who self-reflected and contemplated personal issues, illness and death; viewed reflection as a facilitator of their subsequent spiritual caregiving. Exposure to spiritual situations, even within a classroom setting, that are examined and reflected on constructively and in a safe environment will lead to personal growth and ultimately enhance clinical practice (Hickey *et al.,* 2008). There is substantial

discourse in TL on 'critical' reflection, but I agree with Mezirow (2000, p.126) who states that reflection by definition is not critical, as if adding 'critical' somehow makes it deeper and more profound.

Another dimension of this concept was reflecting on one's own mortality, something I would strongly advocate for those working in end of life care, and indeed applicable to all of us. This is expressed by respondents' reflections:

> *I hope that the people around me at the end of my days …that they will have an understanding of this deep personal work and its significance, it's potential* (IR1NH)

> *I suppose it's something one doesn't really think about until you're in the situation (terminal illness)… it's easy to speculate how I might react, or how I might feel, from the perspective of being a healthy person now* (IR2SW)

Many caregivers testify to increased questioning of their own mortality, and revision of meaning and purpose in their own lives, as a result of repeated exposure to the deaths of others in their care (Vachon & Benor, 2003; Wasner *et al.,* 2005). ODonoghue (2007, p.88), talks about the idea of befriending your own death, as '*from the moment you are born, your death has walked beside you.'*

4.2.1.1 Connecting through *Circle of Trust* Study Groups

The *Circle of Trust* study groups were viewed by respondents as a positive learning experience in which they evaluated their original perception of spiritual care; in a safe learning environment where connecting was the basic social process. *Circles of Trust* are a process designed to maximise learning in the *Sacred Art of Living and Dying Series,* and as the researcher I felt personally privileged to animate one of these study groups. Respondents' narratives convey the dimensions of connecting:

a remarkable process … because sometimes … I go to a course but loose the learning very soon after coming back, so this is a different experience (IR2SW)

allows me a time and space for self-examination and assessment. The sharing facilitates a new awareness and listening (QR1)

Since the units of learning occur every six months, there is a window of time to spend between each unit for learning and reflection that reinforces and builds upon what is gained from the units. In the quotations above, with the deepening of learning fostered in these study groups, participants have the unique opportunity to take the learning from the *Sacred Art of Living and Dying Series* into the work site to impact individual practices. In these study groups, there is a chance to experience a community of trust within one's professional setting, to connect with people and reinforce the learning:

*circles of trust are integral to the programme – they allow for continuity and enhance continued connection to the programme… are very supportive and very helpful in applying some of the techniques in practic*e (QR15)

circles of trust have allowed me the portal to awaken and keep the light burning so to speak (QR16)

The importance of providing a safe space for dialogue to promote TL, through building communities of learning is highlighted. This concept of a safe space espoused by TL is integral to the *Circles of Trust*:

just being able to sit in a circle of trust and speak if you want to about things that matter is awesome (QR46)

4.2.2 Enhancing Self-Awareness

A prerequisite for the integration of spirituality into healthcare is the caring, empathetic attitude and self-awareness of the professionals themselves. As outlined in Chapter 2 – Literature Review, by Puchalski (2007), many spiritual questions are deeply profound, unique to the individual, and unanswerable. However, *'it is often in the appreciation of the questions, rather than the provision of answers, that healing occurs'* (Anandarajah, 2008, p.454), as respondents' state:

> *this programme has impacted very definitely my awareness…. one could not be involved in this programme without asking the deeper soul questions* (IR2SW)

> *I'm now more observant, more aware of me … sometimes it's almost like I'm outside of myself watching myself* (IR4E)

Respondents highlighted the self-awareness aspects of the programme and the emphasis on bringing 'self' to the exercises, or seeing 'self' in the stories and DVD clips presented. It is envisaged that by providing training that promotes the growth of one's personal spirituality, identifying one's own spiritual needs and exploring their own sense of meaning; will ultimately inform their comprehension, competence and confidence in the workplace application of the learning, therefore '*enabling spiritual care provision to become realistically integral to care'* (Hickey *et al.,* 2008, p.398). Self-awareness is articulated by respondents:

> *this degree of introspection is bound to bring up stuff for people, but I think it is so important that we as healthcare professionals take part in, or engage in this kind of self-awareness, otherwise we will… project our own spiritual pain, … onto the patients and their families, either consciously or subconsciously* (IR1NH)

> *I am bubbling with awareness today* (QR2)

It is true we cannot allege to know others without first knowing ourselves (Carrithers, 1992); and the introspection alluded to in the quote above will promote self-awareness for healthcare professionals, which ultimately enhances their clinical practice by alleviating or minimising the risk of projection of self. Spiritual self-awareness is seen as a prerequisite enhancer of spiritual care (Sinclair *et al.,* 2006; Bush & Bruni, 2008; Bailey *et al.,* 2009). This process involves reflective awareness of one's own distress, losses, vulnerability and mortality; cultivating one's own spirituality in order to relate to others (Boston & Mount 2006; Sinclair *et al.,* 2006; Bush & Bruni, 2008; Daaleman *et al.,* 2008). Caregivers note that their spiritual beliefs and practices give them strength to cope, help them find meaning in their caregiving and help them accept the mysteries of life and of death. Also, after the death of the loved one, caregivers' spiritual beliefs may also help with coming to terms with the loss (Puchalski, 2007). The importance of promoting self-awareness was a consistent finding throughout all the coding levels.

Recognition of personal vulnerability and the healthcare giver as a '*wounded healer'* helps to overcome any perceived power difference; both patient and healthcare giver have an inner patient and healer (Boston & Mount 2006; Edwards *et al.,* 2010). Spirituality involves a sense of connection with self, leading to well-being, peace and self-acceptance (Sinclair *et al.,* 2006; Boston & Mount 2006). Spirituality is described as the 'inner self', 'essence' or 'core' – what it means to be you – and concerns the spirit and soul, something within, or a 'going within', a journey of self-discovery (Sinclair *et al.,* 2006; Boston & Mount 2006; Bush & Bruni, 2008; Bailey *et al.,* 2009). Quotes from respondents illustrate:

> *the programme has also been a great way of linking in with 'me', 'my soul' – I have always gone home feeling like I have been on retreat* (QR20)

> *I have without question developed a greater depth and breadth of awareness … things I have felt from an intuitive place for years have had words put on them* (QR16)

Self-awareness is enhanced by reflective exercises, applying the learning to one's own life, asking the questions of oneself, putting oneself in the scenarios presented, accessing one's personal losses, vulnerability and spiritual pain.

4.2.3 Differentiating Spirituality from Religion

Respondents spoke about the difficulty in defining spirituality and the importance of differentiating it from religion, a finding which has a copious amount of references in the literature (Wasner *et al.,* 2005; Anandarajah, 2008; Sartori, 2010*a*.). It is important to maintain a distinction between 'spirituality' and 'religion' (Stephenson *et al.,* 2003; Tan *et al.,* 2005). Spirituality is a part of most patients' total existence, a concept that may or may not involve religion, and encompassed more than religion (Hermann, 2001; Tan *et al.,* 2005). Spirituality is described in both religious and humanistic terms and might seek a tangible outlet through religious rituals, but is more than religious expression (Sinclair *et al.,* 2006; Bush & Bruni, 2008). This is reflected by respondents in the following quotes:

> *I used to confuse it (spirituality) with organised religion, which I now see clearly is not at all the same thing* (IR3P)

> *most of us are unable to define it (spirituality) … some think it's the same as religion, which I think minimises the term, I think it's much broader than that* (IR1NH)

> *it's lovely to know that turning someone's bed towards the window to glimpse nature is as spiritual… and maybe sometimes more so than the beads (IR1NH)*

Having explored the difficulty in defining spirituality and differentiating it from the concept of religion, a crucial question is whether or not patients themselves recognise the concept of spirituality as defined by healthcare professionals (Bradshaw, 1996; Walter, 2002; Edwards *et al.,*

2010). What professionals assume to be spiritual care might not correspond with patients' understandings and needs (McSherry *et al.,* 2004; Ross, 2006). It is important to clarify the meaning of spirituality in relation to healthcare in order to enhance communication, practice, education and research.

4.2.4. Trusting the Learning Environment

According to the data, learning was facilitated by creation of a safe space, comfortable learning environment and establishing trust to encourage authentic discussion. Imel (1998) explained that perspective transformation is promoted by creating a trusting, supportive learning environment to facilitate social discourse. Many scholars have contended that learning is most effective if it is embedded in social discourse and a group experience (Glaser, 1991; Whitelaw *et al.,* 2004). Social discourse with groups of learners is required to validate and incorporate learning (Mezirow, 1998). Quotes from respondents illustrate:

> *improves my ability to 'trust'… helps me to listen and 'hear', … feeling deeply connected, feel affirmed in what gives me meaning* (QR43)

> *I really can't explain the sense of connection and trust I felt* (IR1NH)

> *being in a room full of similar, interested people and the energy that creates is quite something, something powerful that inspires everyone present* (IR3P)

Seropian (2003) agreed when arguing that learners learn best when they are able to create meaning from self-analysis and discussion with others (Parker & Myrick, 2010). Cranton (1994) noted that transformation requires considerable discussion with others to confirm new perspectives. The community in which individuals interact is influential in providing powerful norms and cultural influence. Whitelaw *et al.* (2004) argued that authentic contextual problem solving through social discourse exposes learners to cognitive demands similar to those required

to contend with real-life situations. In fostering social discourse, educators can facilitate transformative learning by creating environments that cultivate trusting and caring relationships (Imel, 1998). For perspective transformation to occur, a key component of social discourse and reflection is the development of trust (Imel, 1998).

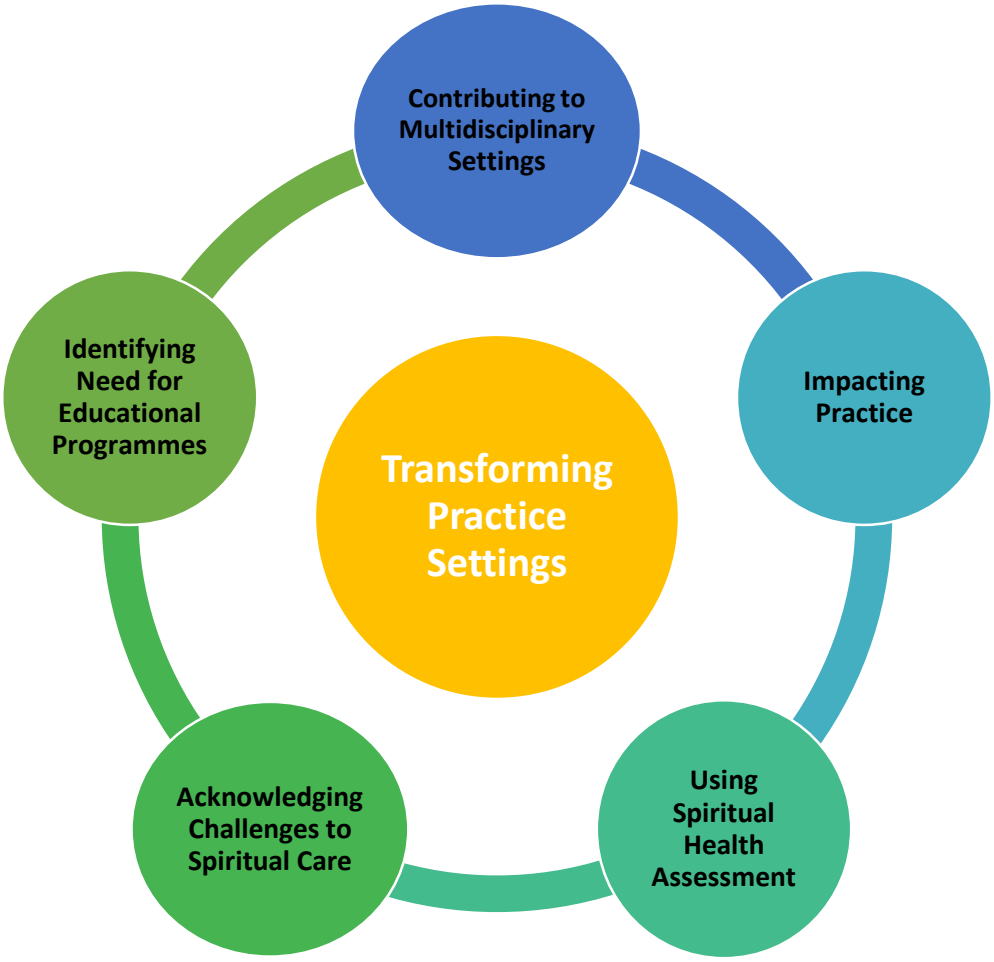
This concludes the discussion on the first major concept, perceiving spiritual care, and how it was transformed by participation in the learning programme. The processes of reflecting, enhancing self-awareness, differentiating spirituality and religion; and trusting the learning environment contributed to transforming perspectives. The importance of being open to transformation is a critical factor in learning, as Halifax (2008, p.2) puts it:

> *'Wisdom, said one Zen teacher, is a ready mind....The true nature of our mind is like a great ocean, boundless, complete and natural just as it is. Most of us choose to live on a small island in the middle of this ocean in order to feel safe and have a familiar reference point.'*

4.3 Transforming Practice Settings

This section will discuss the next major concept which emerged from the data, transforming practice settings (Figure 8: Transforming Practice Settings). Training programmes addressing the spiritual aspect of care need to focus on the perceived gap between theory and practice, ensuring seamless transition to clinical settings (Yardley *et al.,* 2009).

Figure 8: Transforming Practice Settings



4.3.1 Contributing to Multidisciplinary Settings

The programme participants were from a diversity of work settings, backgrounds and employment status (See Appendix XIII - Figures of Questionnaire Respondent Demographics). Patients who are faced with life-threatening illness are often confronted with an unknown spiritual realm, and an increasing body of evidence shows that this journey often ignites and reawakens the spiritual dimension for people and their significant others; who require support and acknowledgement of their spiritual needs from healthcare professionals (Steinhauser *et al.,* 2000; Hermann, 2001; Walter, 2002). Therefore, as healthcare providers, we are obligated to assume greater responsibility for addressing spiritual issues; which historically may have been left to the chaplain, clergy or religious minister (Association of Professional Chaplains, 2001). However, spiritual care has also been '*effectively and interchangeably provided by multiple members of the care team'* (Daaleman *et al.,* 2008, p.409). The entire palliative care team could have an impact on patients' spiritual expression (Tan *et al.,* 2005). Data demonstrated the applicability of the learning to this diversity of settings; with appropriate quotes to demonstrate:

> *the information presented was applicable to all of us, … no matter what age, profession, background, or religion* (IR1NH)

> *I will espouse the benefits of this programme … which recognises the absolute need for spiritual care to be recognised as vital by all staff in our acute settings* (QR16)

> *I will now be more relaxed around people who are dying, whereas normally I kind of left that kind of close, intimate communication to the doctors and nurses, well particularly the nurse.., but now I can see the importance of all our roles (multidisciplinary team), every single person has something to offer.., from the lady who gives out the cup of tea to the consultant* (IR2SW)

Respondents' quotes capture the complex interaction of physical, social, psychological, and spiritual stresses experienced which make a team approach imperative (McCallin, 2001; Sulmasy, 2002). The National Institute of Clinical Excellence (NICE) guidance on spirituality is clear; that

spiritual care is the responsibility of all health professionals (Yardley *et al.,* 2009). Evidence suggests that all healthcare professionals can deal with initial spiritual care but that those with specialised training and expertise are required to support both colleagues and patients with deeper issues. However, patients are seeking carers with whom they can identify with on a personal level, and communicate with authentically, rather than expertise (Yardley *et al.,* 2009). Spiritual assessment and care is often recognised to be the nurse's role (Bush & Bruni, 2008; Bailey *et al.,* 2009); however, all professionals, including doctors, social workers, psychologists or counsellors, could contribute in a non-hierarchical environment with possible overlap of roles (Bailey *et al.,* 2009; Edwards *et al.,* 2010). Respondent's quotes illustrate the importance of utilising the multidisciplinary team approach to the provision of spiritual care:

> *my work involves a lot of involvement with more a physical and sensory disability –for example with neurological conditions – MS (Multiple Sclerosis); when life for many can lose focus, meaning and hope, already through verbalisation in spiritual pain assessment I have suggested therapies I can use* (QR12)

> *as a psychotherapist, this programme has really highlighted to me what a wonderful 'soul journey' we, and specifically my clients, are on* (QR20)

> *I work with people with acquired brain injury …the work around coma communication was very helpful and powerful* (QR28)

These findings, as illustrated by respondents, are reflected in the literature where one study, (Moreira-Almeida, 2006), showed that religious beliefs have been shown to have a positive influence on mental health outcomes such as suicidal behaviour, well-being and substance misuse; and other studies demonstrated that spiritual needs have an important role in suicide prevention in adolescents (Goldston, 2008); and adolescents with chronic illness (Cotton, 2009), as demonstrated by two respondents:

I work with people who demonstrate/suffer the four types of spiritual pain. I discuss with them how each of the types impacts on their mental health problem. It is particularly useful when working with suicidal clients (QR38)

I work with persons who have very high alcohol and drug dependency and feel this work will support me to support them (QR20)

However, while religion and spirituality has a predominantly positive effect on health, the researcher acknowledges that it can also have negative associations. Weaver and Koenig (2006) identified negative effects such as delays in seeking medical treatment, feelings of excessive guilt, abuse by religious advocates and religious factors often being part of psychosis. Feeling judged, criticised or ostracised by a religious community can also have a negative impact on health (Sartori, 2010a.).

There is an abundance of literature correlating provision of spiritual care with better adjustment in bereavement (Wortmann & Park, 2008; Bailey *et al.,* 2009, Edwards *et al.,* 2010). A sense of spirituality is widely assumed to be beneficial following the death of a loved one, and perhaps this is the reason it is invoked in the bereavement phase, when questions of meaning generally arise (Wortmann & Park, 2008). Sparse studies of bereavement have assessed the impact of spirituality, and the majority reported positive adjustment, and reinforced that attending the spiritual can be a source of comfort, strength and healing. In one such study, (Wortmann & Park, 2008), spiritual support was associated with increased self-worth and less likelihood of depression.

Caring for deceased patients and their relatives can be demanding, complex and emotionally exhausting but it is also a privileged experience. The way in which healthcare professionals convey empathy, compassion and emotional concern may be critical in mediating acute and long

term responses and adjustment to grief. Nurses' ability to manage these extremes and support families relies on interpersonal skills, including access to spiritual care (Hills, 2010). However, given the cardinal role of spirituality, dying and death in the human experience (Bowker, 1991), surprisingly little research has investigated the interaction between spirituality and distressing life events, including bereavement (Wortmann & Park, 2008). A quote from a respondent illustrates:

> *I know with my current caseload, this kind of completion, this attention to spiritual distress… would really be the difference between 'normal' grieving and those who end up not being able to cope … this training gives people the tools to finish and complete whatever is in that category of unfinished business* (IR3P)

Respondents who work in training and education also alluded to the benefits of the programme, and how it will inform their subsequent practice:

> *what I have learned on a personal level about myself and life and living, death and dying, means my approach to teaching will never be the same, because I'm starting from a different place* (QR24)

> *will use in self-awareness and teaching casualty/first aid/CPR students; breathing exercises, meditation, self-care – especially for dealing with themselves after traumatic events* (QR34)

It is clear that research is required to ascertain methods of identifying spiritual needs, and provide appropriate support and interventions at the optimal time in the disease trajectory (Pesut & Thorne, 2007; Smith & Gordon, 2009). Nonetheless, Smith and Gordon (2009) have warned against the inclination towards spiritual care specialists, which could potentially result in deskilling of multidisciplinary spiritual care generalists.

Those not working in healthcare who participated in the *Sacred Art of Living and Dying – Healing Anamcara Programme*, also cited benefits to impact their respective areas of work:

> *though not working in healthcare, the elements of the programme are already being introduced in my workplace. Being present with people, especially those that have had bereavements – don't avoid talking to them about the death and allow them to talk about it and how they are feeling* (QR26)

> *I meet a lot of people daily but I feel as a hairdresser I can do this work in small ways* (QR35)

> *while I'm not in paid employment, I am providing care to my mother who is 93 and dealing with end of life issues, and also … with my brother-in-law who is dying of motor neurone disease and I find the course is invaluable in having conversations with them* (QR17)

It is evident from the findings in this study, as outlined by quotes from respondents, that being a spiritual care generalist promotes optimal care in a diversity of practice settings, both in healthcare and in the broader recognition and delivery of spiritual care.

4.3.2 Impacting Practice

Although spirituality is acknowledged as fundamental to care, it remains vague as to how spiritual needs are actually defined and addressed in clinical practice (Daaleman *et al.,* 2008). Spiritual care permeates all aspects of care, and is seen in the manner in which physical care is provided (Sinclair *et al.,* 2006; Boston & Mount 2006; Bush & Bruni, 2008; Bailey *et al.,* 2009). Spiritual care involves sacrificial, unconditional love and kindness, empathy, compassion, respect, sensitivity, comfort, warm acceptance and gentleness; treating a stranger like family (Sinclair *et al.,* 2006; Bailey *et al.,* 2009; Edwards *et al.,* 2010). Yanez *et al*. (2009) argued that supporting

both spiritual and religious aspects of care is important as they empower patients to find meaning and peace resulting in improved outcomes. Krupski (2006) examined faith and higher meaning/peace in relation to quality of life and found that faith was unrelated to outcomes, whereas having a higher meaning in life correlated to having a higher quality of life. Applicability to practice is articulated by respondents:

> *the learning that has … impacted me most of all…, is the importance of listening to people's stories……it's real companionship, trust, listening and empathy* (IR1NH)

> *it's my intention, or my attentiveness, not what I'm doing per se, but how I'm doing my work, my attitude, my way of being … this is what I must be mindful of… always to remember to keep myself in check* (IR1NH)

> *the impact on my work is profound as I feel I create within the home peacefulness in the presence of loss… a confidence of being with the dying and their families* (QR1)

A patient-centred approach, supporting patients in their worldview, allowing them to set the agenda and make choices is advocated (Grant *et al.,* 2004; Shih *et al.,* 2009). How far we have come from the time when people had only one choice: to fight for life and then quietly die in a confusing and often isolating hospital environment, in the midst of aggressive treatment. More patients are being given the chance to make choices about how to live life while dying (Puchalski, 2007), and this was alluded to by respondents:

> *I've learned to really respect the patient's wishes and choices (IR1NH)*

4.3.2.1 Referring to the Medical Model in End of Life Care

Grave prognoses are so disorienting in nature, that patients often become paralysed by denial, even when they have suspected such information for some time. Upon receiving this knowledge for the first time, a patient's guarded belief that the death is for '*anyone but me*' is challenged

(Kubler-Ross, 1969). Evidence suggests that patients will accept severely painful treatment in return for the unrealistic chance of postponing death (Finucane, 1999). In this regard, every grave prognosis presents a prospective transformative learning opportunity. Physicians and patients, who largely avoid reflection in this setting, deserve a model capable of tackling uncritical assumptions, facilitating meaning and informing optimal coping strategies (Brenton, 2005). If physicians' assumptions around death and dying interrupt their ability to initiate EOL discussions, it may in turn compromise the welfare of patients. When these discussions are avoided, the quality of remaining life for patients can be seriously jeopardised (Larson & Tobin, 2000); as one respondent puts it:

> *it's (spirituality) something I always felt took a back seat to the medical model …. like pain control, symptom management ….physical care that was observable and measureable …. took over or became, as we perceived it, more important than the emotional/spiritual components of care* (IR1NH)

Uncertainty about disease prognosis creates a dilemma for healthcare staff when addressing end of life care, with people often expecting better prognostic certitude than is realistic. Cancer patients have historically had better prognostic accuracy and confidence than those with other life-limiting conditions, because of '*having an identifiable dying trajectory'* (Murray *et al.,* 2005*a*., p.611). This has implications for quality EOL care because '*the difficulty of prognostication results in failure to consider or raise end of life issues until death is very close and the patient too unwell for meaningful conversations*' (Barclay & Maher, 2010, p.4862). According to Kearney, himself a physician in end-of-life care (2007, p.29):

> *'The medical model states that all illnesses of the body have, if one looks hard enough, an underlying cause; if one can find this cause (diagnosis) and proceed to remove, reverse, replace or bypass it (treatment), one can return to the status quo (cure). It is evident that, as models go, the medical model works well. It has led to cures being found for an ever-increasing number of illnesses. It has resulted in an extension in quantity of life and an*

improvement in quality of life for countless sick individuals.... We suppose that it is simply a matter of trying ever harder or of looking ever farther afield for that elusive cure'.

He goes on to say that in the context of end of life care '... *this response engenders an emotional pain that is characterised by feelings of frustration and powerlessness.... These feelings are compounded by hurt pride and an indignant sense of disbelief that a way out, a cure, cannot be found despite all one's courage, ingenuity and best efforts* ' (Kearney, 2007, p.29). The profound suffering that accompanies EOL discussions is said to be *'framed in the clinical encounter by the interplay between the physician's gaze into the patient and the patient's gaze into himself or herself*' (Magid, 2000). Quotes from respondents illustrate this dilemma of grappling with the medical model:

there's more to end of life care than simply calibrating the syringe driver …and although it is very important, … maybe we emphasise those sort of things too much, and neglect the spiritual (IR1NH)

it is so important to preserve this spiritual dimension, particularly in our medicalised world of today (RJ5)

Kuczewski (2007) noticed that spirituality is often perceived as a remote element to the modern scientific, technological, clinical environment. Healthcare professionals have alluded to the unease that can prevail when a patient begins to converse in the spiritual domain. However, '*the notion of a rift between the scientific world and the world of the humanities is not new*' (Robinson *et al.,* 2007, p.25). To address this issue, (Anandarajah, 2008, p.456), recommends paying attention to the health and well-being, including spiritual health, of the caregiver; asserting that self-reflection and self-care are '*essential in the quest to be a healer and scientist'*. One respondent states:

I think we can get so bogged down in the medical end of things… the (syringe) driver, the drugs, the nausea, the constipation, the weight loss and on it goes…, but we can, and did in some cases; I'm sure, forget the soul, the true essence of the person (IR1NH)

The researcher's view is supported by Balboni (2007), who showed that meeting spiritual needs was associated with improved quality of life and suggested that spiritual care could enhance patient well-being at the end of life. Spiritual and religious views can contribute to the decision making process at the EOL and links have been found between religious and spiritual beliefs and the wish for aggressive, high risk end of life measures such as ventilation and cardiopulmonary resuscitation in patients with advanced illness (Phelps, 2009; Balboni, 2007). Phelps (2009) argued clinicians should consider patients' spiritual or religious beliefs when a prognosis of death and treatment plan is discussed, as the process of accepting there is no value in treatment and preparing for death may challenge spiritual beliefs. It may also be appropriate to involve chaplains or other professionals such as psychotherapists, to investigate beliefs and coping mechanisms at the early stages of disease.

4.3.2.2 Conducting End of Life Conversations

Not everyone will want to talk about their end of life care, but appropriate and timely discussions with patients and their families/friends can empower them to live well until they die and have a quality of life despite its diminished timescale (Barclay & Maher, 2010). Evidence supports the positive contribution of open discussions for those who wish to engage; with reports of less anxiety, less depression, reduced active medical treatments; and better bereavement adaptation for those providing care (Wright *et al.,* 2008). However, the researcher acknowledges that healthcare professionals must respect patient choice in relation to engaging in open, authentic discussions; as to impose such conversations would adversely affect trust, communication and relationships, causing significant harm. '*Denial is an important ego defence mechanism that must*

not be broken down' (Barclay & Maher, 2010, p.4863). As one respondent captures this phenomenon:

> *The only danger I see is that maybe I'm ok with that deep level of communication …but to be very careful not to impose it on the patient… to be open to their cues if they don't wish to go there, if they don't want to open up* (IR1NH)

Caregivers can facilitate conversations and offer spiritual care in a manner that uses informed discretion; offering people the opportunity to express themselves and their stories without implied expectations or outcomes (Yardley *et al.,* 2009). The skills required to do this are respect, sensitivity (Maguire *et al.,* 1996), genuineness, openness and empathy; while '*considering atmosphere and environment, explaining motivation, asking questions naturally and giving permission to patients to share without risking judgment'* (Maguire *et al.,* 1996, p.80; Sherman & Kim, 2005), i.e. good communication skills. Respondents spoke of attentive listening, having difficult conversations and the impact of the programme on their ability to communicate effectively:

> *I think I talk less now (with patients & families) and listen and feel more, it's about presence and attentive listening … the course has given me a new vitality and enthusiasm for my work as a result of being in tune with how important and privileged I am to be with people at the end-of-life… I will listen to them and learn from them* (IR2SW)

> *I have learned how to have difficult conversations…about death and dying, and even mentioning those words, rather than talking around it... It's a bit like the elephant in the room scenario.., now it's acknowledged… I'm more confident and competent… answering the difficult questions, the ones I've always hated been asked, … "have I got long left to live?", "am I going to die?", "what should I tell my family?", "who's going to look after things when I'm gone?" now I see them (questions) as an opportunity to open up meaningful communication* (IR2SW)

Welcoming end of life complexities, as outlined by the respondent above, is congruent with conventional wisdom that authentic communication and openness about death and dying is considered the optimum for everyone. As healthcare professionals we are accountable for the provision of quality end of life care including the obligation *'to offer timely, sensitive, patient-led conversations about the end of life'* (Barclay & Maher, 2010, p.4863). Quotes from respondents to illustrate:

> *it gives me great hope and reassurance…that even when things seem hopeless and the news is bad and there is no cure …there is no miracle, still there's a lot of spiritual, psychological and emotional healing that can occur, and to think for a moment of being part of facilitating that process is just awesome (IR1NH)*

> *this is something that will nourish and enable me to support my clients, their families and my own family in times of stress/pain and emotional trauma* (QR28)

4.3.3 Using Spiritual Health Assessment

In a recent study, (Yardley *et al.,* 2009), participants (patients) were open to the completion of a Spiritual Health Assessment (SHA), suggesting that it would be a welcome practice if administered with a caring, empathetic attitude. They emphasised the importance of sensitivity, and being comfortable with ambiguity when asked questions relating to spiritual care by healthcare professionals, who need to find '*natural ways of engaging with patients',* and demonstrate active listening and empathy (Yardley *et al.,* 2009, p.604). Respondents identified the potential relevance of the spiritual health assessment (See Appendix V - Spiritual Health Assessment), as illustrated by the following quotes:

> *I am using the spiritual health assessment now as part of my routine assessment of new patients referred to the service* (IR1NH)

> *what I would ideally like to see…is some sort of spiritual assessment when someone is referred to palliative care services, in the same way that we assess everything else… taking one's 'spiritual pulse' as it were… something to go on…, some method of documenting and naming it… making other professionals take it seriously* (IR1NH)

It is also important to illicit patient's views on conducting spiritual health assessment. Patients in Yardley *et al.'s* study, (2009), felt that identifying spiritual needs could be facilitated by caregivers broaching the subject, asking tentative questions initially and engaging in more detailed conversations over time. Respondents were adamant that spiritual assessment was not to become a 'tick box' exercise, but rather an adaptable tool giving them the freedom to set the content and agenda of conversations (Yardley *et al.,* 2009). The World Health Organisation's (2002) statement on palliative care uses the term '*impeccable assessment*' of physical, psychological, social and spiritual needs. Yet, even in an ideal situation where optimum spiritual care can be provided, there is no guarantee that a patient's spiritual needs will be fully satisfied or indeed that such is the patient's desire (Randall & Downie, 2006; McEvoy & Duffy, 2008). Perhaps this is because the spiritual is not bound to conform to natural laws, unlike the body, as Ross (1997) suggests, '*to do so would be to deny its very nature'* – a view supported by Randall and Downie (2006).

4.3.4 Acknowledging Challenges to Spiritual Care

Respondents alluded to challenges in implementing spiritual care in their respective settings, encompassing both personal and professional issues. Spiritual care could be personally challenging with an emotional cost, resulting in 'compassion fatigue'. Some staff struggled when their own suffering was acute, or lacked confidence and felt inadequate and ill prepared, with personal uncertainty about the meaning of spiritual care (Boston & Mount 2006; Sinclair *et al.,* 2006). However, it is clear from both the data and the literature that adequate preparation and

training are central components to implementing spiritual care and addressing potential challenges in multidisciplinary settings, as illustrated by respondent's quotes:

> *the challenge is now to incorporate the two… the spiritual dimension with ordinary life… one has to live in the real world too* (IR1NH)
>
> *the challenge will be to remember all this amidst the busyness of clinical work* (IR2SW)
>
> *I'm also very aware and conscious that it will be difficult, very challenging to even attempt to bring this to a medicalised setting …but I intend to be bold in my endeavours to do so* (IR2SW)
>
> *I find some aspects challenging from a personal point of view, can't not face my own issues in relation to how I am* (QR44)

To have the time to listen and get to know patients, to develop relationships, enabled sensitivity to individual needs and helped facilitate spiritual discussions (Tan *et al.,* 2005). Timely care is important: patients believe that if professionals are sensitive, they should know when and where to discuss spiritual concerns (Shih *et al.,* 2009). Time is therefore; both a facilitator and an impediment to effective spiritual care (Daaleman *et al.,* 2008).

Puchalski (2007) proposes that healthcare professionals are stressed with time constraints, receive inadequate training in spirituality and end of life communication aptitudes, and desist from reflection on their own spiritual needs to such an extent that they are not competent to address this realm of care with their patients. Caring for dying people forces one to face questions that have no answers, to help people make decisions for which there are no absolutes, and to open oneself up to emotions and suffering associated with death and loss. This is not an easy task and, in some ways, focusing on the scientific, medical model can be '*more comfortable and known territory*' (Puchalski, 2007, p.39). A key issue identified by the research is the

challenge of dealing with the emotional turmoil associated with patients' suffering; and learning how to be present and compassionate '*while maintaining the delicate boundary that keeps the carers from being burned out by their work*' (Vachon & Benor, 2003, p.177; Wasner *et al.,* 2005).

4.3.5 Identifying Need for Educational Programmes in Spiritual Care

Healthcare professionals often have deficient preparation for responding to patients who are struggling to find meaning and purpose in life. Power and Sharp (1988) demonstrate that inadequate training, and lack of competence to respond to emotional and spiritual issues can be a significant stressor for hospice nurses (Power & Sharp, 1988). Conversely, having both professional and personal life experience with illness and death was thought beneficial in providing spiritual care (Boston & Mount 2006; Daaleman *et al.,* 2008; Bailey *et al.,* 2009). Respondents recognise this deficit in current spiritual care training:

> *spiritual pain is something I haven't felt confident about, it's very complex to deal with … but hopefully that is changing with this kind of training* (IR3P)

> *I really think it should be incorporated into every palliative care programme … and included in mandatory training for hospice staff, or those caring for the dying* (IR1NH)

However, in practice, a dichotomy has been revealed between the expectations of education and the reality of practice (Narayanasamy, 2002). The literature cited a lack of training, (Grant *et al.,* 2004) and called for more training in listening skills, awareness of individual needs and different cultural beliefs to benefit and enhance care empathy (Tan *et al.,* 2005; Shih *et al.,* 2009). Healthcare givers need willingness to ask about spiritual beliefs and to listen, rather than expert knowledge, (Murray *et al.,* 2004), and could give good spiritual care unintentionally through relationships and with some creativity (Hermann, 2001; Grant *et al.,* 2004). This is reflected by respondents' quotes:

> *we should all take time out to do this kind of thing on a regular basis… to refresh oneself and start again with renewed competence and energy* (IR2SW)

> *although my background is in nursing, and later on in psychotherapy, none of the training in either of those professions gave me much insight into what spirituality is all about… it's hard to believe … two caring professions deeply centred on people skills, communication and interaction… and yet I'm not sure I still fully understand the concept of spirituality, despite years of training and experience.., or maybe we can never really confine it* (IR3P)

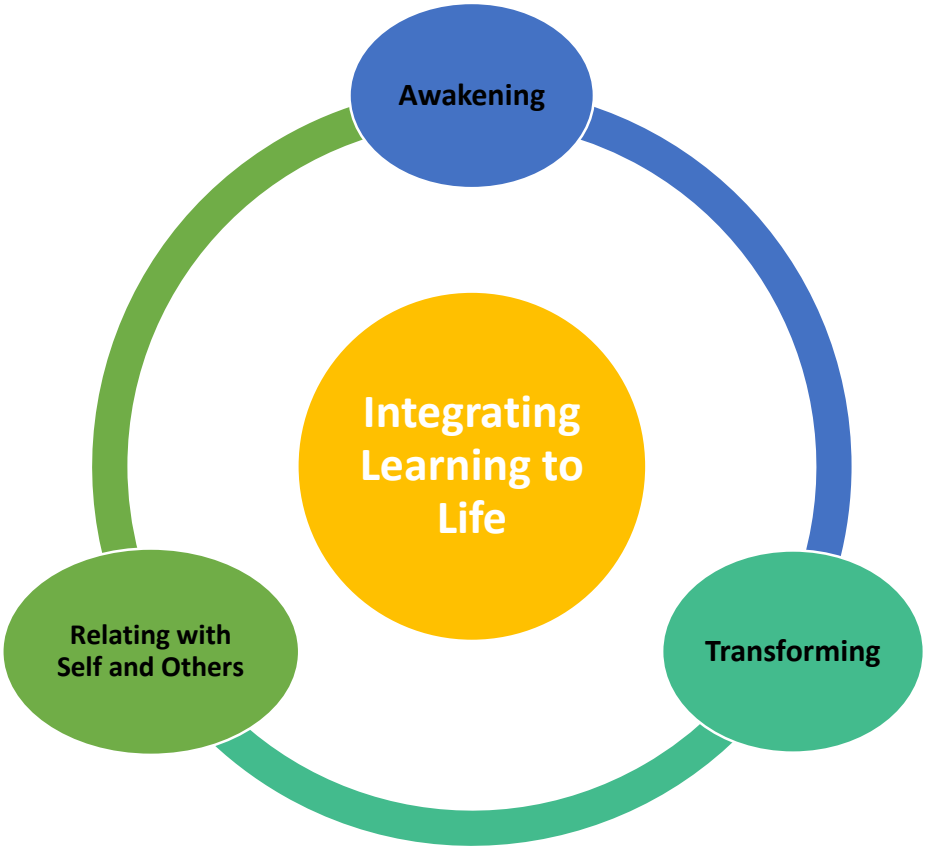
However, education in itself was not a pre-determinant of good spiritual care. Rather, caring is an art requiring creativity and caregivers who were relational, willing, human, reflective and spiritually self-aware (Edwards *et al.,* 2010). Where education and training is given, it is suggested it be in a small-group format, with case discussions and opportunity for self-reflection (Morita *et al.,* 2007; Edwards *et al.,* 2010), all of which are central to the programme in this study.

This concludes the section on the second major concept to emerge from the data, transforming practice settings, and discussed contributing to multidisciplinary settings, impacting practice, using spiritual health assessment, acknowledging challenges to the provision of spiritual care and identifying the need for educational programmes in this area.

4.4 Integrating Learning to Life

This section will discuss the final major concept which emerged from the data, integrating the learning to life (Figure 9: Integrating Learning to Life), and how the programme contributes to personal as well as professional development. This concept is central to the underpinning philosophy of the programme, i.e. transformative learning. Although there are some blurred boundaries between findings in this concept and those in *4.2 Perceiving Spiritual Care,* the findings were sufficient to warrant a separate major concept specifically focused on the integration of learning to life situations.

Figure 9: Integrating Learning to Life



Spirituality comes from the word spirit, which means breath or breathing. Spirituality is the very essence of who we all are as human beings—it is the source of our life, our being (Puchalski, 2007). It is impossible to fulfil any healthcare role without firstly attending to one's own spirit (Murray *et al.,* 2003). Following spiritual care training, participants in Wasner *et al.'s* (2005) study showed considerable enhancement in both compassion for self and for the dying. Furthermore, '*attitudes improved, satisfaction with work increased, and work-related stress decreased*' (Wasner *et al.,* 2005, p.102). Respondents' quotes illustrate this application of learning to the 'self', integrating the personal and professional:

> *I really want to integrate it into all aspects of my life, not just acquiring a new set of work skills … it's applicable to everything I do … and how I am as a person; which cannot be different in different contexts, it is integrated as part of who I am* (IR1NH)

> *deeply enriching, nourishing and healing - 'real' teaching on the meaning of life of being human and human experience and what is real rather than transitory, illusionary, meaningless. I feel it has enriched my living* (QR29)

> *initially I thought the course was purely to help me with my work, but in actuality it has had a deeper impact on me personally* (QR40)

> *it has made me take a long, hard look inwards, at myself, it has meant that whatever I took from it…whatever I learn will stay with me… because the insights are internalised now (IR1NH)*

> *I've learned a lot professionally and personally, and I don't know if you can separate the two in the end… it'll be a part of my life the same way as getting up in the morning and having my breakfast … I know that it has changed the way that I look at myself* (IR4E)

> *I am an American and this course has helped me integrate my life in Ireland* (QR34)

Palmer (2007, p.4) reflects on this notion of self, and the integration of personal and professional attributes, where he states that *'seldom, if ever, do we ask the "who" question—who is the self that teaches?*' Spirituality is characterised by certain identifiable values in regard to self, others, nature, life and whatever one considers to be the Ultimate; it is that which gives one purpose, meaning, and hope and provides a vital connection (Sumner, 1998).

4.4.1 Awakening

Data referred to an awakening taking place for the respondents. Spiritual care recognises our shared humanity, affirms and nurtures; giving patients and healthcare givers permission to be themselves (Sinclair *et al.,* 2006; Boston & Mount 2006; Bush & Bruni, 2008; Bailey *et al.,* 2009; Edwards *et al.,* 2010). Spiritual care recognises the value of each person as a whole (Sinclair *et al.,* 2006; Boston & Mount 2006; Bush & Bruni, 2008; Edwards *et al.,* 2010). It sees the person behind the pathology, with a respect for the dignity, uniqueness and nobility of human life spirit (Sinclair *et al.,* 2006; Daaleman *et al.,* 2008). Respondents allude to this concept of awakening:

> *I feel I have travelled to arrive where I started, but knowing the place for the first time … in a sense I feel like I have come home. So many threads and experiences of my life have been merged to a new togetherness, a new awakening* (QR12)

> *the self-awareness, self-growth dimension of the programme is foundational to any good caring model… it will have a major impact in my work, and my life … the anamcara philosophy has awakened in me a new life* (IR2SW)

> *it's quite incredible to think I've brought so many clients to this sort of realisation, this sort of 'light bulb' moment, and only now can I say I've got there myself* (IR3P)

These quotes demonstrate an acknowledgment of profound awakening and self-growth for the respondents as a result of their engagement with the educational programme.

4.4.2 Transforming

Because the programme is based on the philosophy of transformative learning, transformation was a likely outcome; however the researcher did not take this for granted. Both Dewey (1916) and Freire (1974) viewed education as a medium for social change that involves personal evolution and development. Learning has the potential for personal evolution and transformation to push the adult learner to the level of an autonomous and empowered thinker (Imel, 1998; Mezirow, 1995). The findings emphasise personal and professional transformation throughout the data. Transformation was referred to as getting to know oneself, change in direction or perspectives, and a desire to explore new dimensions in life. Respondents referred to change, personal development and gaining insight into themselves, their thinking and their roles. However, it is important to note that respondents were questioning the boundaries between TL's level of introspection and psychotherapy. One respondent's quote captures this dichotomy of opinion:

> *I would be concerned if people were to become fixated with spiritual care… it's not personal therapy… this being seen as a substitute for psychotherapy or counselling… I think it is important to acknowledge the boundaries* (IR3P)

Evidence for this legitimate concern is apparent in the literature (Paley, 2008; Anandarajah, 2008; Bailey *et al.,* 2009). Paley (2008) discusses the fundamental question: '*Where does spiritual care end and psychological care begin*?' The findings of a recent Irish study revealed that spirituality and psychological care are synonymous and both are an essential component of holistic nursing (Bailey *et al.,* 2009), yet it failed to differentiate between the two. Anandarajah, (2008, p.453) points out that spiritual care does not necessitate '*emotional entanglement'* and there is clear differentiation *'between being engaged vs. enmeshed'*. Mezirow (2000) offers some advice on the difference between psychotherapeutic interventions and transformative learning, where he states that critical reflection in the context of psychotherapy focuses on assumptions regarding

feelings pertaining to interpersonal relationships; whereas in adult education its focus is on an infinitely wider range of concepts and their accompanying cognitive, affective and conative dimensions. This distinction is important in differentiating between these two professional fields (Mezirow, 2000, p.23).

Effective participation in TL requires emotional maturity, characterised by awareness, empathy and control (Mezirow, 2000). It is also reliant on an educator's ability to recognise subtle cues indicating emotional preparedness, as Taylor (2007) describes awareness of learners' readiness to change; recognising learners at the edge of their knowing, in the *'transitional zone*'. Open-mindedness is also essential for TL, which is according to Bruner, *'a willingness to construe knowledge and values from multiple perspectives without loss of commitment to one's own values'*. Solidarity, empathy and trust are requisite to the learners' commitment to a transformative learning group (Mezirow, 2000). Respondents identify transformative aspects:

> *for the first time in my life I am getting to know who I really am* (QR5/RJ1)
>
> *this kind of programme is a beginning…a chance, an opportunity… a catalyst for new beginnings, for giving someone a different and a healthier perspective, on life, and ultimately on death … I am almost a different person in some respects* (IR1NH)
>
> *I don't think it would be possible to be involved in this programme without profound change taking place in the individual* (IR2SW)
>
> *if I hadn't done it (the programme) now I would have missed a huge opportunity … for self-development* (IR4E)
>
> *this programme is 'transformative' as it changes my thinking and facilitates me to integrate all areas of my life and examine a whole variety of belief systems and begins to answer the questions 'who am I?' and 'what sustains me?* (QR43)

Respondents acknowledge that this level of personal work and introspection regarding one's own personal spiritual journey may be beneficial to care providers who want to get to know their deeper selves in order to enhance their spiritual and psychological health; and consequently affirms their capacity and ability to accompany others on that journey, a view is supported by Vachon (2001).

4.4.3 Relating with Self and Others

A general concept emerged, both from the literature and the data; that spirituality was inherently relational, including relationships with self, others, nature and God (Wright, 2002; Murray *et al.,* 2004; Shih *et al.,* 2009). In the nursing as well as social work literature, spirituality is understood in terms of relationship, and specifically the loving and caring relationship formed with patients and others (Govier, 2000). Relationships form an integral part of spirituality as they are a spiritual need, cause spiritual distress when broken are the way spiritual care is given (Edwards *et al.,* 2010). It is argued that relationship evolved over time with the patient and family enables issues of hope, suffering and loss to be tended to (Larkin, 2010). Spiritual care is not a task or intervention, but is expressed in the way care, including physical care, is given in relationships (Grant *et al.,* 2004; Shih *et al.,* 2009), as one respondent puts it:

> *I now converse about these issues in a very real and meaningful way, more so than before, with the people in my life, as well as in work … it makes it easier to relate at a deeper level* (IR1NH)

This finding concurs with research which showed that patients want nurses who could be seen as part of the family, and doctors who were willing to have meaningful relationships with them; rather than to give spiritual advice or to have knowledge of different religions or theology (Marie Curie Palliative Care Institute, 2007; Edwards *et al.,* 2010). Good rapport and affirmative, valuing, trusting, personal relationships with healthcare givers who were able to '*step beyond rigid*

professional boundaries' facilitated patients' spiritual expression and enabled them to respond to their own spiritual needs (Shih *et al.,* 2009; Edwards *et al.,* 2010). Life was described as a journey, which patients wanted to face together with a guide and companion (McGrath, 2003; Grant *et al.,* 2004; Shih *et al.,* 2009). Healthcare staff often have the opportunity for such conversations, and can establish deep, though often underutilised relationships with patients and their significant others (Robinson *et al.,* 2007). Spiritual care involves building trusting, intimate, meaningful healthcare giver–patient relationships (Sinclair *et al.,* 2006; Boston & Mount 2006; Bush & Bruni, 2008; Bailey *et al.,* 2009; Edwards *et al.,* 2010). This idea of relationship is echoed by respondents:

> *I communicate differently with my family, friends and my children in a new way… because of insights gained* (IR1NH)
>
> *Mum has Alzheimer's – better able to be with her…better presence to family and self* (QR10)
>
> *I feel I know all this, and yet in a funny way it's as if I am hearing it for the first time.., finally a language for what my soul knows deep down… for me, my family, my work, my community, my world* (IR3P)

This finding is echoed in the literature where spirituality was related to relationship with self; the discovery and retention of one's intrinsic identity, the 'authentic self' (Chao *et al.,* 2002; Grant *et al.,* 2004; Tan *et al.,* 2005). Healthcare providers are an integral part of the client's healing journey. '*The energy and intent they bring to their relationship with the client is essential to this journey'* (Young & Koopsen, 2011, p.162). Patients want to retain a sense of self-worth, value, wholeness and understanding (Murray *et al.,* 2004; Shih *et al.,* 2009). Spirituality is related to being able to reach self-acceptance, self-reconciliation and peace (Hermann, 2001; McGrath, 2003; Murray *et al.,* 2004; Shih *et al.,* 2009). Respondents recognise this concept of self-acceptance, relatedness and peace:

it's a new way of being but what makes it easier to stick with it is I know in my gut…it just feels right (IR4E)

it's great to be able to come to a group and just be as you are, no falseness, no pretense (QR35)

being able to provide the opportunity for open, authentic, communication (IR1NH)

Intimate, fulfilling, meaningful relationships are at the heart of spirituality and often the most important aspect of patients' spiritual expression (Hermann, 2001; McGrath, 2003; Murray *et al.,* 2004; Shih *et al.,* 2009). Spirituality is about a relationship or personal connection with others; including family, friends, colleagues, patients and the community, involving intimacy, commitment, sacrifice, caring, peace and love (Sinclair *et al.,* 2006; Boston & Mount 2006; Bush & Bruni, 2008; Bailey *et al.,* 2009; Edwards *et al.,* 2010). A common denominator to all expressions of spirituality among those facing end of life is a search for meaning. Spiritual healing and peace is frequently about affirming and completing '*relationships with self, with family, with community, and with the 'other'—whether that is a deity, unseen spirits, nature, humanity, or the unknown'* (Grant *et al.,* 2010, p.659).

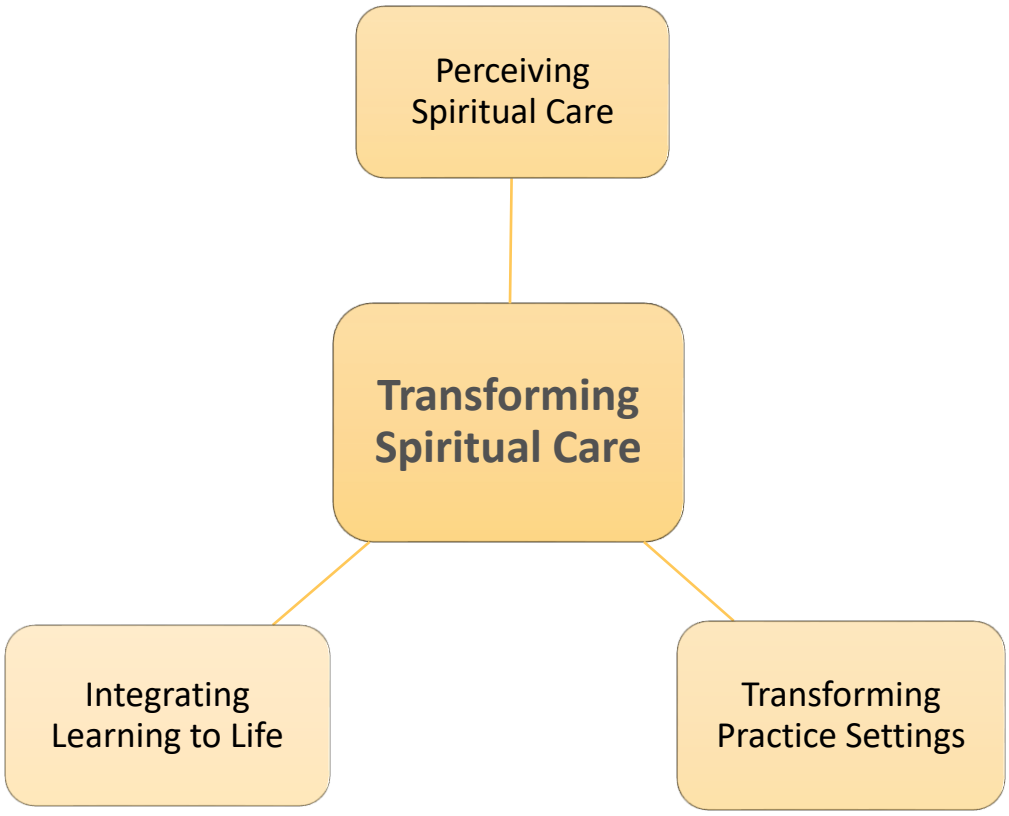
4.5 Emergent Theory and Conclusion

Having presented and discussed the findings from the study, the overarching theory that emerged was one of '***Transforming Spiritual Care***' (Figure 10: Emergent Theory). Participants expressed how they perceived spiritual care in a new way, applied their learning to practice settings, whilst at the same time integrated the learning to their lives. The processual concepts of the emergent theory suggest that this was achieved by using a Transformative Learning framework and applying the learning to all aspects of the practitioner's life, rather than merely confining it to work scenarios. The resultant theory thus conceptualises practices as not just

transforming practice, but transforming perspectives on how practitioners think about their role, and how they integrate transformed perspectives into their lives.

Learning in the transformative approach results in action from insights and new understandings (Askew & Carnell, 1998, p.92). The learning is internalised and guides participants to challenge assumptions, to reflect and be self-aware. We make meaning by using different dimensions of awareness and understanding (Mezirow, 2000). Therefore it is essential that education programmes strive to emphasise contextual understanding, reflection on existing assumptions, and validate meaning by assessing reasons (Mezirow, 2000). In this research, the transformation of spiritual care was facilitated by utilising a TL philosophy in the design and delivery of the education programme. This approach facilitated participants in internalising the learning, and transforming their thinking, meaning, and ultimately their practice, in a diversity of roles and settings.

Figure 10: Emergent Theory



The theory of '***Transforming Spiritual Care'*** is an ongoing process, congruent with the philosophy of transformational learning. This is reflected throughout the research findings and discussion. For example, the process of *Perceiving Spiritual Care* evolves through a range of processual actions such as reflecting; enhancing self-awareness; differentiating between spirituality and religion; and trusting the learning environment. *Transforming Practice Setting*s is depicted through contributing to multidisciplinary settings; impacting practice; using spiritual health assessment; acknowledging challenges to spiritual care; and identifying the need for educational programmes in spiritual care. *Integrating Learning to Life* emerges through the concepts of awakening; transforming; and relating to self and others. A psycho-developmental view of transformative learning is one where learning and growth are continuous, progressive and incremental throughout the lifespan of the learner. Fundamental to this view of transformation is a change in how we construct meaning, rather than being confined to behavioural change or simply the accumulation of knowledge. This is evident from the findings in this study, where

participants are integrating learning to life, enhancing self-awareness; therefore not just transforming practice. It also involves an ontological shift for the individual. As Clark (1993, p.47) states, transformative learning '*produces far-reaching changes in the learner than does learning in general, and these changes have a significant impact on the learner's subsequent experiences. In short, transformative learning shapes people; they're different afterward, in ways both they and others can recognise*'. Respondents reflect this process of transformation and awakening in the findings, with an emphasis on change and transformation of themselves as a prerequisite to transforming their work. They are reflecting on both on themselves and their practice, communicating in new ways, adjusting their perceptions and applying the learning to life in general.

Participating in the *Sacred Art of Living and Dying – Healing Anamcara Education Programme* prompted participants to ask themselves the same questions about the meaning and purpose of life that their dying patients were reflecting on; cultivating and enhancing a sense of spirituality; a similar finding to that found in Sinclair (2011). This transformed perspective was often described as an inner awakening, fostering an acceptance of the unknown and a new way of seeing the world. Findings in a recent study by OShea *et al*. (2011), confirmed that spiritual education had a positive effect on nurses' perspectives toward providing spiritual care. In addition, a positive correlation was identified between the nurses' perception of their own spirituality and their perception toward providing care. Embodied within this theory of '***Transforming Spiritual Care'*** are the components of perceiving spiritual care, subsequently impacting practice and integrating the learning to life. The concepts are therefore interrelated and dependent on each other; perceiving spiritual care being a precursor to transforming care provision. Transformative learning theory explains this continuous process of learning by constructing *'new and revised interpretations of the meaning of an experience in the world'* (Taylor, 2008, p.1002). Expertise in spiritual care can be acquired through reflexive thought, specialist education and ongoing practice with patients (McBrien, 2010). With increased expertise, healthcare professionals can help patients to experience spiritual transformation in

times of crisis and, ultimately, enable them to transcend their difficulties. The findings in this research will therefore contribute to quality end of life spiritual care for patients, families and caregivers.

'Transforming Spiritual Care' articulates the practitioners' acknowledgement of the role of relationships, personal influences and experiences, and alternative ways of knowing in transformative learning (Taylor, 2008). Moreover, this is a dominant theme in the findings, relating to self and others (Cranton, 1996; Mezirow, 1997; Dirkx, 2006; Taylor, 2008). Transformative learning incorporates the notion that learning results in a change in the meaning of experience, and consequently a different approach to our experiences, and perception of ourselves (Askew & Carnell, 1998, p.92). Holistic approaches to care emphasise the crucial role of relationships in promoting transformative learning (Cranton, 2006; Mezirow, 1997; Dirkx, 2006; Palmer, 2007; Taylor, 2008). Dirkx (2006, p.46) suggests it is '*about inviting 'the whole person' into the classroom environment, the person in fullness of being: as an affective, intuitive, thinking, physical, spiritual self*'. In a study by Wasner *et al.,* (2005), significant and sustained improvements were found in compassion for oneself, subsequent care for patients and their families, satisfaction with work, reduction in work-related stress, and attitude towards colleagues following training in spiritual care. The results demonstrate that appropriate training in spiritual care can positively influence the well-being and attitudes of the participants (Wasner *et al.,* 2005). The programme being researched demonstrates similar findings for participants; who alluded to having a transformed perception of spiritual care, the importance of self-care, applying the learning with greater enthusiasm, recognising their role in spiritual care and enhancing their self-awareness.

While current training solutions to improve end of life discussions place emphasis on communication skills (Larson & Tobin, 2000; Von Gunten *et al.,* 2000), they fall short in developing constructive coping strategies and personal meaning (Brenton, 2005). Leaders of the

medical community have called for research on '*the science of prognosis and the art of its disclosure'* (Lamont, 2003). Central to the art of disclosure is further research on transformative learning (Brenton, 2005). The contribution to practice that the findings from this research offers is a renewed perception of spiritual care, making a positive difference to multi-faceted practice settings and consequently enhancing end of life care for patients and their families. The findings from this research contextualise the striking extent to which reflection is required in end of life care to facilitate co-inquiry and mutual transformation. As Dewey (1938) noted, without proper reflection on our underlying values and beliefs about teaching and learning, we leave the education of our learners to the whim of every educational trend that comes our way. It is therefore incumbent on educators to continuously critique the curriculum and the educational practices that contribute to learner socialisation and their knowledge development, attitudes and skills. It is important that we critically analyse our educational practices and reflect not only on *how* they work, but also *why* they work (Cranton, 1996). Spirituality cannot be learned solely from books or in a classroom; knowledge and understanding develop through experiences of caring for patients along with personal life experience (Sartori, 2010*b*.), and it is in tapping into this life experience on the *SALAD* programme, and in the *Circle of Trust* study groups, that participants have transformed their perceptions, their practice and ultimately spiritual care.

This concludes the findings and discussion. Chapter 5 follows, outlining the limitations, recommendations and conclusion to the research study.