Chapter 5 - Limitations, Recommendations & Conclusion

This chapter identifies the study limitations, outlines tentative recommendations and a comprehensive conclusion to the research study.

5.1 Study Limitations

The following are considered potential limitations to this study, and were carefully considered by the researcher throughout:

1. The researcher could be biased, being the coordinator of the programme; and although it was difficult to bracket presuppositions; an attempt was made to explore presuppositions prior to commencing the research.

2. The programme commenced in December 2009, and will be complete in November 2011; therefore the research data were collected prior to the completion of the programme. The programme is non-linear in structure, therefore participants in Unit 3 when data were collected, may or may not have completed Units 1 and 2; which may have impacted the findings.

3. Programme participants have self-selected their engagement with the programme, therefore demonstrating a degree of openness to the content and teaching methodologies. Enabling individuals who are insecure, lacking in confidence, anxious or unsupported to overcome potential barriers to the questioning of values and assumptions may be considered a limitation to this approach. Taylor (2000) suggests that TL theory has much to offer adult educators, but the process of TL is complex and may depend on many factors such as: the readiness of the learner; the personality and learning styles of both the educator and the learner; the curriculum content; the personal philosophy of the educator;

the other learners in the classroom; and the mission of the department and the institution (Magro, 2009).

4. The cost of the programme is €700 for 4 units or €250 for an individual unit, which may have deterred participation. However, this cost was offset by funding secured from the Centre of Nursing and Midwifery Education, Sligo/Leitrim, which enabled all participants to be subsidised. Payment options were flexible and tailored to individual circumstances to make the programme more accessible. A number of participants were either partly or fully funded by their employer.

5. The researcher acknowledges her inexperience as a limitation to the study, and particularly utilising grounded theory for the first time as a novice researcher. There was an abundance of rich data returned, and although exposed to rigorous analysis and coding as outlined in the Methodology, Chapter 3, only snippets of respondent quotes could be included in Chapter 4 – Findings and Discussion. An example of this data is outlined in Appendix XIV - Respondent's Quotes.

6. The researcher also considered a potential paradox in this study, i.e. theoretical saturation, congruent with GT methodology, may require a much longer period of time to complete the research, while on the other hand; transformative learning is an ongoing process, so the dichotomy of approaches presented a possible limitation.

7. Sampling and data collection via the questionnaires could be considered a possible limitation to the study, as the researcher was in the room when the questionnaires were circulated. Nonetheless, every effort was taken to ensure reliability and validity as outlined in the Methodology, Chapter 3.

5.2 Recommendations

The following recommendations have emerged from the discussion of the data findings in this study, and are echoed in the literature by other researchers in the field of spirituality (Puchalski, 2007; Anandarajah, 2008; Bailey *et al.,* 2009; Cooper *et al.,* 2010).

1. **Education and Training** – In line with Puchalski (2007), findings from this present research suggest that it is incumbent on healthcare professionals in today's challenging clinical environments, as palliative care and medicine advancements continue to evolve; to incorporate the spiritual dimension of care. The evident lack of standardisation with respect to clinical and academic preparation for this work is a concern for participants. In the context of hospice palliative care programmes, spiritual care providers may require similar academic orientations as their colleagues from other professions to function optimally within academic interprofessional teams (Cooper *et al.,* 2010). Encompassing spiritual care in a holistic model of care is a way of enhancing our comprehension of the intricacies of human health and well-being. Findings suggest the need for a multidisciplinary and multi-perspective educational initiative to address spiritual care, based on both the art and science components of healthcare. Wilkinson (2000) observed that palliative care nurses of the future will need to play a greater role in the spiritual and personal aspects of caring for patients with increased life trajectories

as palliative nursing in this century endeavours to embrace the body, mind and spirit.

2. **Transformative Learning -** Transformative learning (TL) methodologies have the potential to facilitate, not just enhanced clinical practice, but a transformation in the perception of spiritual care, as demonstrated by the findings in this study. It could be beneficial to incorporate TL principles into educational programmes of the future, to embrace reflective discourse, a mentoring community and opportunities for committed action. TL challenges us not only in how we do things, but also why we do things; and I believe this level of introspection has the potential to transform learning itself. Transformative learning theory continues to be a growing area of study of adult learning and has significant implications for the practice of teaching adults. The growth is so significant that it seems to have replaced andragogy as the dominant educational philosophy of adult education, offering teaching practices grounded in empirical research and supported by sound theoretical assumptions (Taylor, 2008).

3. **Spiritual Self-Care -** Spiritual self-care can include self-inquiry and self-reflection regarding values and beliefs, questions relating to meaning and purpose; or methods for creating peace and tranquility, such as meditation, yoga or walks. With an increasing impetus on self-care in the management of chronic illness, *'the role of spiritual self-care in health is fertile ground for exploration'* (Anandarajah, 2008, p.456). TL offers a modality to implement such self-reflection and self-awareness as outlined in Chapter 4 – Findings and Discussion.

4. **Acknowledging Diversity** – Transforming spiritual care requires an emphasis on, and inclusion of diversity regarding culture, religion and spirituality; drawing on

ancient models, for example Celtic spirituality, which are inclusive and non-denominational; therefore accommodating difference for both care givers and care recipients (Anandarajah, 2008). Grant *et al,* (2010) advocate reflection on the spiritual needs of the dying and on how these issues can be discerned and responded to appropriately in pluralist societies. The abundance of evidence in recent times promoting the role of spirituality in patient care has evoked '*proposals for a move to a biopsychosocial-spiritual model for health. Making this paradigm shift in today's multicultural societies poses many challenges*' (Anandarajah, 2008, p.457); nonetheless, it is one for all healthcare professionals to embrace.

5. **Management Support** - Lack of time, high number of patients, high turnover, high workload, low staffing, absence of privacy or continuity and loss of the human touch were all factors that impeded spiritual care. Managers and policy makers need to consider these factors, if spiritual care is to be given well and as a component of high-quality holistic care (Edwards *et al.,* 2010). A key objective for hospitals and healthcare facilities is '*the establishment of a culture that enables achieving a 'good death' as a marketable and welcome characteristic*' (Ellershaw *et al.,* 2010, p.4861). However, until spiritual care is given the same credence as other areas of essential training it will not be truly integral to holistic care provision (Hickey *et al.,* 2008).

6. **Future Research** - Future research could build on these findings and illuminate the positive impact of physical, psychosocial, and spiritual health on overall quality of life. Acknowledging the complexities of being a human being, future research regarding holistic care will necessitate an innovative, '*multi-method and multidisciplinary approach, encompassing science, social science, and the*

humanities' (Anandarajah, 2008, p.457). Medicine in general, and also hospice and palliative care, is increasingly moving toward an evidence-based model where accountability in medical decision-making is based on reductionistic scientific evidence. Proponents of spirituality and health, therefore, are attempting to study spirituality in the traditional scientific method in order to obtain the requisite data to show effectiveness and positive outcome. Puchalski (2006) argues that this might not be the best approach to all dimensions of care. Scientific, reductionistic frameworks and analysis may not be the best models in which to understand the observed phenomena that spiritual and religious beliefs are important to people and that those beliefs and practices may impact how patients understand and cope with illness, grief, and loss (Puchalski, 2007). Further empirical investigation could complement this research and provide greater depth to these findings. Investigation of current trends may provide further insights as to the future direction of spiritual care as a component of multidisciplinary clinical practice.

5.3 Conclusion

If hospice and palliative care are to provide the type of care Dame Saunders envisioned then we must integrate spirituality fully into the systems of care for our patients with serious illness and for those who are dying. Death is more than a medical event: it is a spiritual event (Young & Koopsen, 2011, p.175). Perhaps the very mandate that the human person is of value and deserves to have his or her dignity honored and respected is criterion enough to mandate spiritual care as essential to the care of a person with serious illness and those near the end of life, thoughts echoed by Puchalski (2007).

Increasingly the need to provide high quality EOL care as part of the core business of hospitals is being recognised (Ellershaw *et al.,* 2010). Providing high quality care at the

end of life is also an indication of our commitment to the delivery of care in general to all service users, as the components of quality care are standard to all areas of healthcare. '*How we care for the dying must surely be an indicator of how we care for all our sick and vulnerable patients*' (Marie Curie Palliative Care Institute, 2007, p.7). Halifax (2008, p.5) captures the centrality of spiritual care in the following:

> *'One thing that continually concerned me was the marginalisation of people who were dying, the fear and loneliness that dying people experienced, and the shame and guilt that touched physicians, nurses, dying people, and families as the waves of death overtook life. I sensed that spiritual care could reduce fear, stress, the need for certain medications and expensive interventions, lawsuits, and the time doctors and nurses must spend reassuring people, as well as benefit professional and family caregivers, helping them to come to terms with suffering, death, loss, grief and meaning'*.

Spirituality in healthcare should form a space in every patient's journey, a vital component to their wellbeing. Getting it right produces a stronger bond between staff and patients and keeps patients at the heart of what we do. Getting it wrong can damage that relationship permanently (Kemp & Wells, 2009). By recognising, respecting and responding to patient's leads, we can empower them '*to provide us with the language of spirituality that best suits them*' (Anandarajah, 2008, p.457). It is clear that in the care-giving relationship, it is not only the patient's spirituality that is important but also that of the professional caregiver. The definition focuses on spirituality as essential to who people are, what constitutes meaning, and how they relate to one another (Puchalski, 2007). Spirituality is therefore an integral aspect of being human. It is, at its core, about respecting the innate dignity, value and inherent goodness of all human beings. Spirituality is caring and relational by its very essence, and thus forms the crux of the altruistic model professional caregivers are entrusted to.

There is a paucity of Irish published research focusing on this phenomenon in palliative care; therefore, this study provides a worthwhile addition to the discourse on the topic. Although limitations were identified in the study, the researcher attempted to minimise these affects. In view of the changing demographics of healthcare, and the current imperatives, '*many new service configurations are likely to be tried. In the meantime, we must strive to ensure that a good death is the expectation rather than the exception in all settings*' (Ellershaw *et al.,* 2010, p.4861).

Puchalski (2007) challenges all healthcare professionals to reflect on what gives our personal and professional lives meaning. All of us walk the line between certitude and mystery in all our dealings with our patients. All of us have the potential to help our patients tap into their own resources of strength, hope, and meaning. The education system needs to have more uniform training in interdisciplinary spiritual care. These are the issues that will propel the field of spirituality and palliative care into the next level where it can become more fully integrated into our educational programmes as well as healthcare in general (Puchalski, 2007). The educational process in this study based on transformative learning, provides a useful framework for the teaching of spirituality in the broader healthcare context, applicable to patient care, research, education, policy development; and ultimately transforming spiritual care. Participants evaluated the course positively both in terms of personal and professional learning acquired. Comments alluded to the high quality resources used; participative, interactive and reflexive teaching methods; and benefits of having a multidisciplinary learning coalition. They overwhelmingly stated that they would '*highly recommend*' the programme to others, both in healthcare settings and external agencies. Participants reported increased confidence, competence and compassion as practitioners in diverse settings. The exciting part of TL theoretical perspectives is that it has the potential to offer a more diverse interpretation of learning and have significant implications for practice.

In conclusion, death is not the ultimate tragedy in life. Cousins (1989) states, '*the ultimate tragedy is depersonalisation – dying in an alien and sterile area, separated from the spiritual nourishment that comes from being able to reach out to a loving hand; separated from a desire to experience the things that make life worth living, separated from hope*' (Ciaramicoli & Ketcham, 2000). As healthcare professionals, we should strive for optimal end of life spiritual care, as outlined in this research by transforming spiritual care; as Kubler-Ross (2009, p.225) suggests:

> *'those who have the strength and the love to sit with a dying patient in the silence that goes beyond words will know that this moment is neither frightening nor painful, but a peaceful cessation of the functioning of the body. Watching a peaceful death of a human being reminds us of a falling star; one of a million lights in a vast sky that flares up for a brief moment only to disappear into the endless night forever'*.

"For Death." (ODonoghue, 2007)

From the moment you were born,
Your death has walked beside you.
Though it seldom shows its face,
You still feel its empty touch
When fear invades your life,
Or what you love is lost
Or inner damage is incurred.

Yet when destiny draws you
In to these spaces of poverty,
And your heart stays generous
Until some door opens into the light,
You are quietly befriending your death;
So that you will have no need to fear
When your time comes to turn and leave.

That the silent presence of your death
Would call your life to attention,
Wake up to how scare your time is
And to the urgency to become free
And equal to the call of your destiny.

That you would gather yourself
And decide carefully
How you now can live
The life you would love
To look back on
From your deathbed.

References

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Appendices

Available on request

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